THE UNIVERSITY OF CHICAGO

INJURY TO THE BRAIN, ASSAULT ON THE SELF: IDENTITY RE-CONSTRUCTION IN THE AFTERMATH OF STROKE AND TRAUMATIC BRAIN INJURY

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Keira Cries in OT

Hi! I see your light's on? the nurse, June, said.

Y'all busy? I need to be changed, Keira replied.

I have a patient who needs some insulin. Can you wait a few minutes?

Of course Keira was willing to wait a few minutes. She was an excellent patient, cooperative and accommodating, understanding that nurses and patient care techs (PCTs) were pulled in a dozen directions each morning. Breakfast trays arrived, and some patients required supervision or assistance when eating. Medications had to be distributed, and patients needed to be dressed and readied for therapy.

Keira was a Black woman, a post-stroke patient. She was what staff euphemistically described as a "bariatric" patient. Some staff members who were less experienced with physical therapy techniques were hesitant to work with her, unsure how to safely assist her with transfers. Keira herself often seemed tentative, concerned her body was a liability or an inconvenience and that a young, skinny physical therapist might not be able to support her if she fell. Or she worried she was imposing on staff by asking for help with dressing or incontinence care. Many patients felt that way—embarrassed and apologetic about requiring assistance with personal care—but Keira was especially vocal in her thanks and leery of burdening anyone.

Keira was known for her sunny, optimistic demeanor. When June, a soft-spoken White nurse, arrived to help Keira get ready for her first therapy of the day, Keira was humming along to gospel music, a well-thumbed Bible on her nightstand.

A voice sang from Keira's phone:

The enemy came up against your health
The enemy came up against your finance
You will win, win

June gave Keira her morning medications and rubbed lidocaine cream into Keira's sore hand.

You're getting some movement back in that hand, June remarked.

Yep! I've gotta move it, if I'm going to walk, Keira said.

When Keira and June were finished getting Keira dressed, Keira asked to sit up on the edge of her bed until her occupational therapy (OT) session began.

I'm not so comfortable, but I can get the PCT! Did she help you yesterday? June asked.

No, Keira said.

Or you can get up with the walker and then you can pivot to the chair? How do I deflate the bed? Do you start in a sitting position? June seemed uncertain how to proceed, but together they worked out a plan to get Keira up.

June enthused, *Oh! Amazing! Look at you! Wow! Keira, you're not going to need me anymore. That's great. You look amazing. You couldn't do that, a week ago.*

I couldn't do nothing, a week ago, Keira said.

That's great motivation! The OT is going to be so psyched you did it all on your own.

As if on cue, the occupational therapist (OT) arrived to start Keira's session. The plan was to demonstrate Keira's current method of transferring to the toilet, for June and the PCT, so they would be comfortable assisting Keira to the bathroom, and she wouldn't have to use a bedpan anymore. The OT framed the exercise in a celebratory way: showing off Keira's latest gains to the nursing staff.

The transfer went smoothly, and the OT left Keira alone in the bathroom. An abrupt noise emanated from behind the closed door. Cheerful, cooperative, friendly Keira was sobbing.

I don't want to be like this! I wasn't like this! I could do all of this before, Keira cried.

The OT joined her in the bathroom, attempting to comfort her. *Take a deep breath. We're doing this now because you can. You couldn't do this last week. That's how much progress you've already made! I know it's difficult and everything's changed a bit.*

I just don't understand why this happened to me. I'm a good person. I'm a good person! I don't understand, Keira sobbed. *Oh my god! I've got to start all over again.*

We don't have to—we aren't in a rush. We can practice the transfer later, the OT said.

No, it's not that. It's—things you learned when you were a baby, I have to learn all over again. I have support and people to take care of me. But it's not fair to them. I don't want to be a burden on them.

I'm going to be optimistic, the OT said. *These skills have gotten so much better since you got here. And you'll continue to improve.*

I'm just tired. I don't understand why.

Totally valid. I can't even begin to understand. Moments like this are bound to happen. It's scary and frustrating. You've persevered in such a good way. You're so strong! Let it out. I would be the same way, the OT comforted.

It's so much. It's SO much.

Anything in particular in the last 24 hours that brought this up? the OT asked.

I've just—I've always done all this. And I have to start all over.

Don't think of it like, "I've been doing this, and I have to start all over." Your body is healing. You don't know why it happened. All you can do is look at what you can do now. Which is a lot! But you've still got a way to go.

Keira's sobs started to recede. *I'm going to be okay*, she said, eventually.

You ARE going to be okay, Keira. It's hard for you to see, so I'm going to tell you. You're doing really well.

Sorry, Keira said, chagrinned at her outburst.

Don't be. You're going through a ton. Totally normal to feel this way. You're a super strong lady!

When Keira finished composing herself, the OT asked if Keira wanted to practice the transfer now, and Keira said she was ready.

Let's show 'em what you got, girlfriend! the OT said.

Everyone feel comfortable with that? the OT asked the nurse and PCT. She walked them through the finer points: the shower chair was too sticky for Keira to slide across, so they were using the commode chair. When the demonstration was finished, they left Keira to use the toilet in private.

You ok? You need my help, you just holler, the OT said. Outside the door, she drafted an email to the floor psychologist, looping psych in on Keira's emotional state.

Keira called for assistance. *Sorry*, she said.

No, that's okay! Honestly, Keira, you're getting awfully close to doing this on your own, the OT assured her.

As they exited the bathroom, the OT let the PCT know Keira had a bowel movement, so nursing could chart it.

I'm sorry, Keira said.

Don't apologize! It's a good thing, the OT assured her.

Well, that was such a success! And honestly that was what I had planned for this session, and we still have thirty minutes left. Do you want to do some mat exercises in the gym? the OT asked.

“You’re zipping around in that chair, missy!” the OT said, as Keira maneuvered her electric wheelchair out the door.

The OT later told me she’d heard from other therapists that Keira had broken down in session before. June and the PCT were entirely blindsided. Keira always seemed so upbeat. They hadn’t expected such a display of abjection.

Introduction

Patients like Keira experienced profound change, in a short period of time—many of them were healthy and independent one day and hospitalized the next. Most of them had no experience navigating chronic illness or disability, and they were unprepared to confront the realities of taking on a disability identity and engaging with the social world as a disabled person. They experienced a range of complex reactions, from horror and grief to unshakable confidence they would recover completely and get "back to normal." As Keira demonstrated, it could be difficult to sustain motivation and engage enthusiastically with the rehabilitation process while coming to grips with the many ways one's mind and body had changed.

Stroke and traumatic brain injury (TBI) patients also confronted the unsettling reality that damage to the brain could have an impact on every single component of what we think of as our Selves: our physical ability to move and care for ourselves and others; our mental faculties and capacity to remember our lives and loved ones; our ability to make decisions and engage in "appropriate" social interactions; our mood, emotional self-regulation, and more. Changes in each of these areas had complex, interconnected effects on key aspects of patients' identities. If you could no longer control your temper, what happened to your relationships? What if your outbursts frightened your spouse and children? If you could no longer drive or walk or transfer to the toilet, what happened to your sense of independence, privacy, and self-determination? What if you were a gregarious person with a job that required a high level of verbal skill, and you suffered a stroke with aphasia that reduced your ability to communicate? What if you experienced unrelenting fatigue and brain fog that made it harder to engage in the activities that were most meaningful to you? Stroke and TBI patients grappled with these sorts of questions and tried to find ways to preserve their sense of Self, insulate their most salient identity characteristics from damage, and/or adapt and find meaning in a new version of the Self.

Project Overview

Neurological conditions are increasingly conceived of as physiological disorders, with changes in function linked to specific alterations in the physical brain (Pitts-Taylor 2016). What happens, however, when a change in the brain causes a change in what is commonly understood to be the mind or even the Self? In this study, I investigated how patients suffering from stroke and TBI understood the distinctions between the mind, the brain, and the Self. How did patients coping with neurological changes conceptualize the continuity and/or discontinuity of the Self?

In order to pursue these research questions, I conducted observations at an inpatient post-acute neurorehabilitation facility and two affiliated outpatient "day rehab" clinics.[1] For five months, I collected ethnographic data, shadowing doctors, nursing staff, therapy staff, and others, and spending time around the facilities with patients and their loved ones. I also conducted open-ended interviews with stroke and TBI patients, patients' significant others, and staff members.

Across all sites, I interviewed fifty patients, twenty-six family members, and sixty-three staff members, for a total of 139 interview subjects. While the experiences and insights of staff and family were fascinating and will provide fruitful ground for future work, I chose to center the patients and focus on illuminating their subjective experiences and their construction of meaning around the brain-mind distinction and identity.

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[1] To preserve the anonymity of my subjects, I'll refer to these sites only as "inpatient rehab," "North day rehab," and "South day rehab."

As I describe in greater detail in the Methods Appendix, I expanded my sampling framework to incorporate an equal sample of outpatients. I always intended to spend time at the day rehabs to see what happened to patients after inpatient, but it quickly became clear that the outpatient perspective was critically important to my research question. When I talked to inpatient staff and inpatients themselves and asked questions about professional and relational roles and identities, I often got responses like the following:

> I think my colleagues on the outpatient side probably get a better sense of that. And, you know, when folks are in the acute care hospital, it's all about crisis mode and problem solving. When they get [to post-acute inpatient rehab], they can step away from that a little bit, but it's still very goal oriented. (staff, inpatient)

Interviewing an equal sample of outpatients and inpatients allowed me to examine issues that often took center stage only at the outpatient level. And by focusing on congruent populations on the inpatient and outpatient sides, I gained a useful proxy for longitudinal data and was able to examine how patients' priorities, plans, and self-perceptions changed as they proceeded through the stages of rehabilitation and were further out from their initial injury.

By definition, the patients I followed were severely enough injured to require inpatient rehabilitation. As many staff members pointed out, if you had a mini-stroke (like a transient ischemic attack, or TIA) or a mild concussion, you didn't end up at post-acute inpatient rehab. The patients in my study varied in severity, but they were all seriously injured enough to require long-term therapy. One physician explained that there was a continuum between mild concussion and severe TBI. It wasn't always perfectly clear where the dividing line between severe concussion and mild TBI lay, but a general rule of thumb was that if a patient lost consciousness for only seconds to minutes, it was a concussion, and if a patient lost consciousness for hours to days or weeks, it was a TBI. The patients in my study were certainly not concussion patients, although they varied in the severity of their TBIs.

Site Description

The inpatient facility (and broader organization) was a recognized leader in the field of rehabilitative medicine. The inpatient rehab was a joint clinical and research building. They emphasized translational medicine and encouraged collaboration between clinicians and researchers. It was also a teaching hospital, so residents, medical students, and therapists in training cycled through the wards.

The trajectory of patients, post-injury, was (generally) as follows:

Acute hospital

Following stroke or TBI, patients were admitted to a variety of acute care hospitals. In some cases, they spent a few days there before they were medically stable enough to discharge to inpatient rehab. In other cases, particularly for TBI patients, they spent weeks or months at an acute hospital (or in a long-term acute facility) before they were ready to begin intensive rehab.

Inpatient Rehab

Patients came to inpatient rehab when they were capable of participating in therapies but still had medical needs that required round-the-clock professional monitoring. Patients in this setting were in therapy six days a week, for a minimum of three hours a day. The inpatient stay was supposed to set the plan of care and provide an initial, high impact burst of therapy. In some cases, a patient's medical status declined, and they were sent back to acute care for treatment. When they were stable again, they often returned to inpatient rehab.

Inpatients were expected to make rapid therapy gains; staff were looking essentially for daily improvement. When staff (and insurance providers) decided patients were no longer benefiting from inpatient therapy—either because they could not participate, their recovery had plateaued, or they had improved enough to move on to day rehab—patients were discharged.

Patients remained at inpatient rehab for three weeks, on average,[2] although a few patients stayed for months.

The inpatient facility was state of the art, attracting highly qualified staff and providing cutting-edge equipment. All patients had private rooms, which was not only convenient for infection control but also invaluable for patients who were agitated or sensitive to stimuli. Due to their neurological condition, many patients were sensitive to noise, light, and/or hectic activity, so it was incredibly useful to have a greater degree of control over their environment. In many ways, this site represented a best-case scenario for rehab, but (as described in the Methods Appendix) it drew a cross-section of patients from a wide variety of demographics.

There were three “brain floors.” The first treated primarily stroke patients; on the whole, these patients were lower “acuity,” less medically complex, and/or severely injured. The second floor was predominantly a stroke floor, but it also admitted less severe TBI patients. In almost all cases, locked-in patients were admitted to the second floor,[3] where rooms were set up and staff were trained to accommodate their particular needs. The third floor took the more acute TBI cases.

When I began my research, I was describing my project to some nurses on the first floor. *Go to the third floor if you want to get hit or spit on*, one of them told me. The third floor had a reputation for housing disoriented and highly agitated patients. In some cases, the patients on the third floor were still in the grip of post-traumatic amnesia (PTA) and its accompanying agitation.

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[2] Several staff members reported that length of stay had decreased over the past few decades. As one staff member explained:

> Back in the day, many years ago, people would be admitted to this program and stay for eight months in a rehab program. Now we get them for three to four weeks. So it's a very different structure. And healthcare has changed. And the need to get people in and out has changed. That's certainly altered the way that we approach rehabilitation. (staff, inpatient)

[3] Locked-in Syndrome (LIS) is a rare condition caused by damage to the brain stem. Patients remain conscious and aware of their surroundings (and in most cases cognitively unchanged), but they are unable to verbally communicate or move.

Consequently, patients on the third floor represented a vast behavioral spectrum: on one end, you had disorders of consciousness (DOC) patients who were minimally conscious; on the other end, you had patients who were physically mobile but highly confused and even combative.

For this reason, the third floor was set up with additional precautions. Although all three floors were locked and had security measures to prevent elopement, the third floor also had cameras in some of the rooms to monitor patients who required constant supervision. Most importantly, staff on the third floor had specialized experience and training. Physicians, nursing staff, and therapists were all skilled in behavioral management. In this thesis, I didn't have the opportunity to discuss this subject at length, but in future work, I plan to discuss interactional and institutional methods by which staff gain patient cooperation.

Inpatient staff comprised a vast cast of characters, from nutritionists and respiratory therapists to orthotists and art therapists. I tried to get as broad a picture as possible by interviewing multiple staff including a chaplain, a bioethicist, an interpreter, and a patient educator, among others. Patients and family most commonly interacted with medical staff, nursing staff, therapy staff, and if necessary, psychology staff and social workers. Medical staff included attending physicians, residents, fellows, and medical students.

Nursing staff included floor nurses and patient care techs (PCTs). While floor nurses could (and ideally, did) do anything the PCTs did, PCTs could not perform some of the nurse functions, like administering medications. In general, PCTs did the lion's share of the physical care work (e.g., dressing, feeding, toileting and incontinence care, hygiene, and transferring) and patient supervision (e.g., keeping a constant eye on agitated or confused patients). The floor nurses were a somewhat racially and ethnically heterogeneous group, but the majority were White women. Nearly all of the PCTs were Black women. They also wore color-coded scrubs, so there was a sharp visual distinction between the two halves of the nursing workforce. At the time of my research, numerous factors—including staffing pressures caused by COVID-19—had fomented conflict among the nursing staff. I plan to write about the pressures and complexities of the nursing role in neurorehabilitation in forthcoming work.

Many staff members told me the work of inpatient rehab revolved around the therapists. Everyone else's job was to make sure the patients were healthy and prepared for their therapy sessions each day. The primary therapy disciplines were physical therapy (PT), occupational therapy (OT), and speech therapy. The therapists themselves were referred to as PTs, OTs, and SLPs (speech and language pathologists). The therapists were primarily young, White women, with very few exceptions.[4] Therapists explained that, roughly, PT dealt with legs and walking, OT dealt with arms and activities of daily living (ADLs), and SLPs dealt with everything from the neck up (not only speaking but also swallowing and cognition). Therapists pointed out that occupational therapy and speech were misleadingly named. Many patients initially bridled when therapists introduced themselves (e.g., *I don't need speech; I can speak fine)*, so therapists had to explain why they were involved (e.g., *Speech therapy also deals with skills like memory*).

Cognition was primarily the purview of Speech. It was part of every therapy, to some extent, but PTs confronted cognition mostly in passing (e.g., pointing out when a patient's injury caused lack of judgment that put them at physical risk). OTs focused on "functional cognition," like remembering and sequencing the steps needed to perform a task like dressing or sorting medications.

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[4] At one point, the therapists were talking about a newly hired male therapist, and one of them joked, *A boy!? Should we get blue balloons?*

Day Rehab

Some patients went on to skilled nursing facilities (SNFs)[5] or received in-home therapies, following inpatient discharge and did not continue to day rehab.[6] Other day rehab patients weren't coming straight from inpatient rehab. Some patients arrived at day rehab directly from the acute hospital or after having spent time in SNFs or long-term acute care (LTACs). Day rehab was an outpatient program, open only on weekdays. Most patients came to the facility two or three days a week, although some came more frequently. Some patients were at day rehab for a half day each time; some stayed longer. Day rehab was a longer-term program, and depending on insurance coverage and staff's progress assessments, patients continued with day rehab for anywhere from three to twelve months. As long as patients were still making gains and required therapy in two of the three disciplines (physical, occupational, and speech therapy), they could remain at day rehab.

To provide contrast, I spent time at two of the day rehab sites: "North" day rehab and "South" day rehab. I describe the demographic differences between the two sites in greater detail in the Methods Appendix and in Chapter Three (The Transition Home). I chose the sites because North was located in a relatively affluent, predominantly White suburb, and South was located in a lower-SES, disproportionately Black and Hispanic area. Patients were assigned to day rehab locations based on their home addresses. The two sites had notable differences in the composition of their patient populations and the family and community resources patients could access.

The primary therapy disciplines (PT, OT, and Speech) were all present at day rehab, but there were also a few vocational therapists who focused on helping patients through the return-to-work transition. There were doctors and nurses at day rehab, but relatively few. Each site had one

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[5] Staff universally pronounced SNF as "Sniff," not "S-N-F," so while it would be technically correct to write "an SNF," I will use "a SNF," in keeping with the prevailing pronunciation.

[6] See Chapter Three: The Transition Home.

or two nurses, on any given day, and a doctor and/or nurse practitioner several days a week. The doctor had appointments with each patient at roughly monthly intervals to continue monitoring their health.

Long-term Outpatient

Confusingly enough, the next stage was simply referred to as "outpatient," even though day rehab was also conducted on an outpatient basis. For the sake of clarity, I will refer to "outpatient" as long-term outpatient, to specify that I mean the stage that comes after day rehab. If patients still needed ongoing therapy in one discipline but not others (e.g., needed ongoing speech therapy but had plateaued or met their goals in physical and occupational therapies), patients could continue on to long-term outpatient therapy.

Patients might attend sessions once or twice a week, for several months or until their insurance coverage ran out. In some cases, when insurance caps reset for the year, patients could come back and continue therapy, but staff clarified that therapy was not intended to be a lifetime proposition. The idea was to teach patients the skills to continue their exercises on their own at home, although in some cases, patients could come back for another spate of sessions if their situation changed (e.g., they improved or declined) and it was deemed they could benefit from instruction on how to adapt to their present needs.

For the purposes of this study, I focused on inpatient rehab and day rehab. I interviewed a handful of long-term outpatient staff and spent several days observing long-term outpatient therapy sessions to get a sense of what the next step looked like. But I observed greater differences between inpatient and day rehab than between day rehab and long-term outpatient, so while long-term outpatients may be a key area for future study, I have reason to believe that, across my dimensions of interest, the critical changes and conflicts occurred (or at least began to take shape) during inpatient and day rehab.

Chapter Outline

Vignettes

The short vignettes between chapters allow us to take an extended look at the particularities of individual patients' cases. These interludes provide context and highlight the themes explored in the chapters. I cover at least one PT, OT, and speech session to give the reader a sense of what the therapies entail.

Chapter One: Goals over Time, Goals in Conflict

My primary interest is in patient subjectivity and the phenomenology of identity formation as opposed to the institutional/organizational processes of setting goals and evaluating patients' progress against codified benchmarks. This chapter focuses on goal setting and benchmarking as they relate to how patients perceive the changes that have occurred and who patients hope (and expect) to be in the future.

This chapter asks: What do patients prioritize as inpatients and why? What do patients prioritize as outpatients and why? What changes between inpatient and outpatient contribute to a shift in patients' focus? How do patients, staff, and family members negotiate conflicting objectives and competing perspectives on what is important, realistic, and achievable?

Chapter Two: Managing Expectations

Staff are tasked with the complex interactional and ethical challenge of providing patients honest information about prognosis without destroying their hope for recovery and undermining their motivation.

This chapter asks: What factors create unrealistic expectations for recovery? How accurately do staff believe they can predict recovery outcomes and how much do they share with patients? What strategies do staff use to manage expectations when they feel patients and families expect improbable or impossible outcomes?

Chapter Three: The Transition Home

Chapter Three provides contextual information about how patients, family, and staff navigate the inpatient discharge process and what comes afterward. It explains logistics that laypeople may be unfamiliar with.

This chapter asks: What factors decide whether a patient goes home vs. to a skilled nursing facility? For patients who go home, what determines whether they go on to day rehab or receive "home health" instead? What issues complicate the discharge process and transition home? What measures are in place to avoid common pitfalls and help patients and family troubleshoot?

Chapter Four: Shifting Relationships

Chapter Four focuses on changes in the social roles patients inhabit and the impact of shifting dynamics on patients' relational identities and closest social ties.

This chapter asks: How do patients and caregivers negotiate altered relational dynamics, particularly around issues of dependency? What changes occur for patients with young children, patients with adult children, and patients with partners or spouses, specifically? How do patients begin to reintegrate into their extended networks?

Chapter Five: Re-Constructing Identity

Chapter Five takes on some of the central questions of this thesis. This chapter focuses on the patient's self-understanding as it relates to their diagnosis and prognosis. It explores how patients reconcile that information with who they believe they fundamentally are, who they feel themselves to be in the moment (with respect to their current physical, emotional, and cognitive states), and who they hope to be in the future. It also touches on how patients' interactions with staff members and significant others impact patients' assessments of how others perceive them. (A changed person? a diminished person? a recovering person? the same person but with different capacities?)

This chapter asks: How does sense of Self change over time, from inpatient to outpatient? How do patients adopt or reject a disability identity in interactions with other patients and with models of disability? To whom does the patient compare their progress? Who is held up by staff as an example to other patients? With whom does the patient feel able to commiserate? What are patients coping with around salient identity characteristics such as social self-presentation, health and youth, intelligence, and professional role and identity?

Chapter Six: Brain, Body, and Mind

Chapter Six zooms in on how patients conceptualize the brain, mind, and Self and how these concepts emerge as patients confront the changes in their bodies and minds. I examine bodily change, behavioral change, emotional change, and cognitive change, in turn. Each section discusses the phenomenology of alteration to and alienation from central facets of Self.

This chapter asks: How do patients experience and conceptualize bodily, behavioral, emotional, and cognitive symptoms as changes in the brain and/or changes in the Self?

Chapter Seven: Understanding and Finding Meaning

Chapter Seven discusses how patients understand what happened to them in both a medical and ontological sense. It covers how patients learn and understand (or fail to learn and understand) about the biomedical event of stroke or TBI and its causes. It also discusses how patients try to derive meaning from the experience by asking why their life has taken this course and what it means for them, going forward.

This chapter asks: How do patients learn about and understand (or fail to understand) what happened to them, in a biomedical sense? How do patients experience shame and guilt surrounding risky behavior (for TBI) and health risk factors (for stroke)? How do patients derive meaning from the experience of injury and recovery?

Motivating Questions

The central aim of this research was to examine how stroke and TBI patients understand and articulate the distinctions (if any) between the functions/dysfunctions of their brains and characteristics central to the Self. In a broader sense, this research will explore the impact of biomedical frameworks on cultural concepts of the brain, the mind, and the Self. I will elaborate on how the following factors differ before and after injury: the patient's characterization of their Self and their capacities; how the patient believes they were and are perceived by others; and the centrality of particular traits, capacities, and role positions to the patient's sense of self. I will also examine any rhetorical and conceptual distinctions the patient may draw between the physiological/biological and the metaphysical (e.g., mind, Self, or "soul"). Finally, I hope to gain further insight into the patient's perception of what is constant and what is ephemeral or changeable in themselves, their bodies, minds, and brains.

Notes to the Reader

All names used are pseudonyms.

While I identify the race of patients, I often don't identify the race of staff. This choice was not because I assume the race of staff is irrelevant. The social characteristics both parties carry into encounters and the ways these sets of experiences and identities interact are incredibly important. But unfortunately, in many cases, groups were racially homogeneous except for one or two people (e.g., all the inpatient physical therapists were White except for one Asian woman), so to identify race would be to preserve the anonymity of the White staff and identify only the people of color. Similarly, there were only a handful of stroke and TBI attending physicians, so to describe any one of them in detail would be to identify them, if not to the casual reader, then certainly to their colleagues.

Text drawn from interviews (in block quotes or quotation marks) are direct quotations. Text and scenes taken from fieldnotes were reconstructed to the best of my ability. They are as close to the original dialogue as possible given the limitations of contemporaneous notetaking. If I was confident I recorded a phrase exactly, it appears in quotation marks. Otherwise, dialogue taken from fieldnotes appears in italics.

To avoid the clunkiness of repeating "he or she" (and reifying the gender binary), I use singular "they," throughout.

Also, for simplicity's sake, I frequently refer to "patients, family, and staff." I intend "family" in a broad sense, including partners, biological and non-biological relatives, and chosen family and friends.

In descriptions of scenes during rounds, I use the descriptors "doctor" and "resident" to refer to the attending physician and the medical resident. Both are doctors, but to streamline the text and make it clear who was speaking, I refer to them as "doctors" and "residents."

I often use “brain injury” as a catchall term to include both stroke and TBI. Both involve insult to the brain, whether traumatic or non-traumatic. Often, the distinction between stroke and TBI was practically, and even diagnostically, blurred. For instance, a hemorrhagic stroke and a TBI causing subdural hematoma were both, in effect, bleeding in the brain. And in some cases, staff weren’t entirely certain what caused a patient’s injury: a fall causing a brain bleed or a brain bleed causing a fall.

Literature Review

Constructing Categories, Defining "Normal"

Diseases and disorders are often framed as biological entities that exist in the natural world independent of human intervention, waiting to be unearthed and characterized by researchers and clinicians (Aronowitz 1998). However, social construction theorists argue that medico-scientific knowledge is heavily shaped by the social context in which it is codified and applied. For brain disorders, the creation of diagnostic classifications hinges on drawing distinctions between normal and abnormal cognition, behavior, perception, and affect. (e.g., What is a standard degree of stress or worry and what rises to the level of anxiety disorder?) Tracing the influence of shifting social norms on the boundaries of diagnostic categories illuminates the ways in which medical science is not purely "value-neutral, timeless, or objective" (Metzl 2009, 157).[7] Although radical anti-psychiatry theorists such as Szasz (1961) contend that nearly all mental disorders are entirely produced in social interactions and have no underlying biochemical component, theories of social construction can easily accommodate both a biological substrate to illness and the influence of human interactions, cultural frameworks, and political and social institutions on clinical theory and practice (Horwitz 2002; Lakoff 2005; Aronowitz 1998; Metzl 2009).

For diagnostic categories to be workable, clinicians must be able to make distinctions along a behavioral spectrum. For instance, what falls within the bounds of fastidiousness and scrupulous attention to detail and what should be considered disruptive or excessive vigilance (Zerubavel 2015, 81)? How do clinicians and laypeople distinguish between behaviorally and experientially

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[7] It is crucial to note that in arguing that scientific facts arise from interaction between natural and social worlds, the social construction model does not suggest that disorders are figments of the imagination or deny the often painful and unsettling phenomenological reality and social consequences of brain disorders, for those who experience them.

similar (but categorically different) conditions, such as grieving vs. depression? Even when categories of disorders are underpinned by well-founded theories of disease etiology, the clinical definition may not be clear cut: for instance, the qualitative difference between Alzheimer's and "normal" age-related memory loss is not always readily apparent, particularly in early stages, and a definitive diagnosis can only be made when the characteristic plaques and tangles are identified post-mortem (Beard 2016).

Social definitions of what constitutes a "problem" shift over time; for example, as the threshold of what the public regards as a tolerable degree of discomfort has lowered, social historians have observed a "progressive medicalization of physical distress in which uncomfortable body states and isolated symptoms are reclassified as diseases" (Conrad 2007, 6). Researchers and clinicians are also called upon to adjudicate new medical claims and to determine whether the suffering and beliefs of desperate would-be patients who are lobbying for the recognition of a medically contested illness category (e.g., Chronic Fatigue Syndrome, Chronic Lyme Disease, etc.) represent a true biomedical disorder or a shared delusion. The success of a particular advocacy campaign rests, to a considerable extent, on the degree of economic and social capital available to the advocates in question and their historical relationship with the medical establishment (Epstein 1996, 12 and 259). The social identities the sufferers carry often have a decisive influence on whether a particular set of truth claims are legitimized, dismissed as quackery and hysteria, or attributed to cultural pathology or individual malingering (Aronowitz 1998; Schweik 2009; Brown et al. 2011).

Many mental health practitioners resist the reductionistic version of the neurobiological model (Lakoff 2005, 119). Proponents of the "entanglement theory of dementia," for instance, argue that genetics and epigenetics, life events, environmental and social factors, age-related neuroanatomical and neurochemical changes, and cultural models of normative aging and cognition all interact to create the phenomenological experience and clinical object identified as dementia (Lock 2013, 5). Critics of neuroreductionism caution that underplaying the role of sociocultural, interpersonal, and intrapsychic factors in shaping human cognition and behavior risks reifying social norms and naturalizing inequalities (Pitts-Taylor 2016, 5; Luhrmann 2008, 250). When one discounts the brain's ability to change over time in response to environmental constraints, social cues, and personal biographical factors, it becomes possible to view any perceived intergroup differences as "hardwired" or "natural" (Fine 2010, 134–35; Pitts-Taylor 2016, 17).

Despite cautionary critiques of neuroreductionism, the rise of the neurobiological framework has had a transformative effect on the imagination of the Self in the modern, Western world, with growing support for a concept of mind that is indistinguishable from and reducible to the anatomy of the brain, the activities of neurotransmitters, and the movement of electrochemical impulses. The mind, brain, and Self are closely identified, with the mind viewed as an emanation of the brain and the terms "mind" and "brain" often used interchangeably in common parlance (Lakoff 2005, 106; Nochi 2000, 1801). Within this framework, neuroimaging becomes a form of self-portraiture, and with sufficient scientific advancement, it would theoretically be possible to pinpoint the neurobiological source of every behavioral, affective, or cognitive aberration (Beard 2016, 38; Lock 2013, 127).

This neurodeterminist model is complicated, however, by influential research on neuroplasticity, which suggests that the brain changes over time in response to its environment. Where once neuroplasticity was thought to be limited to particular functions of the brain (such as learning and encoding memories) or to specific life phases or circumstances (primarily development in childhood and adolescence and, to some extent, recovery from damage), it is now believed that the human brain is neither set on an inexorable course from infancy nor carved in stone at the onset of adulthood. The human brain is in a constant state of "becoming," receiving and sending feedback and adapting to its environment (Pitts-Taylor 2016, 12). Despite prominent research on neuroplasticity, however, the image of a concrete brain increasingly eclipses the concept of the shifting and reactive mind, in biomedical discourse. Environmental and interpersonal factors are commonly framed as potential triggers or stressors that might spring a biogenetic trap or set in motion a predetermined neurobiological process (Mills 2014, 32).

The degree to which the biomedical model or the psychodynamic model dominates a particular institutional environment depends on a variety of factors, including cultural context, institutional constraints, and physicians' personal ideologies. In the United States, health insurance policies influence not only which treatments are available to which patients but also how diagnostic labels are applied. Insurance policies often require doctors and intake coordinators to arrive at and apply a specific diagnosis before billing requests can be processed (Meyers 2013, 91), and managed care plans notoriously limit access to more expensive services, such as psychotherapy (Kirk and Kutchins 1992, 226).

The more streamlined treatment system is not without its benefits. For instance, Lakoff (2005, 65) argues that the medicalization of psychiatric care has been "to the advantage both of the doctor, who makes more money with shorter sessions, and the patient who gets to look at a specific disorder and hear, 'you have this,' as opposed to spending months exploring his or her mental landscape." Depending on the patient, the diagnosis, and the context in which the diagnosis is applied, a solid diagnosis may be received as a comforting and welcome relief from doubt and an opportunity to put a recognizable face on a disconcerting set of nebulous experiences (Angell et al. 2008, 88; Beard 2016, 124). In other cases, however, the process of labeling can be experienced as a "radically dehumanizing and devaluing transformation from being a person to being an illness" (Angell et al. 2008, 79).

Globalization of Western Models and The Pharmaceutical Self

Any discussion of diagnostic categories and mental health must address cross-cultural differences in "community definitions of normal and abnormal behavior, variations in diagnostic usage, and cultural attitudes toward treatment and institutionalization" (Scheper-Hughes 2001, 62). For instance, an experience that would be regarded by biomedicine as a potential symptom of psychosis (e.g., hearing voices) might alternatively be interpreted through a spiritual lens and received as a mark of otherworldly power or religious calling (Scheper-Hughes 2001, 302), but when biomedicine is upheld as the epistemological gold standard, other modes of understanding (spiritual, social, or psychological) are relegated to subordinate or, at best, adjunct status. Biomedical treatment focuses on correcting individual bodily disorder and tends to deemphasize "framing distress as 'disorders of relationships' and the role of healing as aiming to restore lost harmony between that person and their community" (Mills 2014, 27). For instance, what biomedicine would identify as neurodegeneration might alternately (or additionally) be characterized as a failure of the family and community to make adequate provision for the care of an elderly person (Cohen 1999, 303).

Biomedicine's claims rest on a belief in the universal brain: regardless of differing models of the mind or interpretations of behavior across cultures, the underlying neuroanatomy and neurochemistry are regarded as invariant. If one accepts that a given disorder is a thing-in-itself that arises from the natural world and can be accurately characterized and categorically distinguished from other diagnostic entities, then the same set of brain disorders must exist everywhere, regardless of local variations in expression or interpretation (Mills 2014, 25, 32). Belief in the fundamental truth and universality of the biopsychiatric model of brain disorder underpins a "rhetoric of backwardness" that understands local practices as failing, to varying degrees and in varying respects, to rise to the medical standard of Western biomedicine (Davis 2012, 58).

As previously noted, pharmaceutical companies have a financial as well as ideological interest in promoting the primacy of biopsychiatric diagnostic categories and treatment modalities. For instance, a company marketing an antidepressant might have to convince local populations both of the validity of the diagnostic category and that the collection of symptoms associated with depression are best dealt with by seeking a prescription from a doctor (Conrad 2007, 144–45; Mills 2014, 69). Following Fanon and Foucault, it is possible to argue that medical ideologies and categories are shaped by political, socioeconomic, and racial power relations and still acknowledge the lived realities and suffering of people in distress (Metzl 2009, 14–15).

Increasingly, medicine is framed as a set of tools and techniques for perfecting the Self and for enhancing not only physical but mental performance. Particularly in America, consumers are enjoined to turn to neuroscientific and psychopharmacological technologies to stave off future potential decline and to optimize current alertness, focus, mood, and so on (Pitts-Taylor 2016, 3), shifting the goal from correcting abnormality to achieving "hypernormality" (Jenkins 2011, 9). With the emergence of the "therapeutics of prevention," a patient whose test results meet certain established benchmarks can be diagnosed with a medical condition and treated with medication in the absence of any phenomenological experience of illness (e.g., a patient with mild to moderate hypertension or high cholesterol likely will not complain of any associated symptoms) (Aronowitz 1998, 37; Conrad 2007, 142; Greene 2007, 79). Under this framework, the pool of potential patients expands, increasing the number of patients who are told to incorporate a particular diagnosis into their identities and a new drug into their daily regimens, creating a liminal population of "at risk" patients (e.g., prediabetics) who are instructed to remain vigilant and/or take preventative measures (Mills 2014, 147; Greene 2007, 113).

The therapeutics of prevention go hand in hand with "the daily integration of oral medications into outpatient life" and the taking on of a medication (whether for hypertension, diabetes, or sub-clinical mild cognitive impairment) as a "lifetime partner" (Greene 2007, 112–13). However, when the chronic disease being treated is a mental disorder, the application of pharmaceutical technologies of the Self may necessitate the emergence of a new subjectivity—a "pharmaceutical being" (Biehl 2005, 199)—as shaped by the interaction between an individual's neurochemistry and drugs designed to alter it (Mills 2014, 17; Jenkins 2011, 10). From a purely logistical standpoint, doctors might prescribe psychopharmaceuticals with the hope that an obstreperous patient will become more compliant both with the proposed treatment protocol and with clinic routines and staff.

Even if doctors do not believe a particular medication will have an effect on the underlying cause of the illness (by redressing a "chemical imbalance," for instance), clinicians may prescribe medication that will alleviate cognitive or behavioral symptoms that are troubling the patient or are getting in the way of other treatment strategies; this prescribing philosophy relies on psychopharmaceuticals' effects on the mind without a clear underlying explanation of what has gone awry in the brain and how exactly the pharmaceuticals are intervening. Despite the disciplinary tension between psychodynamic and psychopharmaceutical models of psychiatric treatment, Lakoff (2005, 83–84; 132) reports that some practitioners regard psychopharmaceuticals as a means of rendering patients capable of the self-insight and communication capability necessary to engage productively in psychodynamic treatment—a framing in which psychopharmaceuticals are not targeted at treating the underlying condition but are tools that enable the patient to eventually participate in a different form of treatment. Medication can repair "patient subjectivity" or "restore reason and agency" when the brain has been overtaken by disorder (Lakoff 2005, 83). However, psychopharmaceuticals can also muddy the diagnostic waters, particularly for long-term users of psychiatric medication with complex psychiatric histories; in these cases, it is "difficult … to separate the signs and symptoms of the psychiatric illness being treated from the effects of the medications" (Biehl 2005, 194).

Insurers and administrators are not the only stakeholders who turn to psychopharmaceuticals as quicker and cheaper alternative to psychodynamic methods: patients are increasingly framed as consumers, and patient-consumers are susceptible to the allure of a quick technological solution: a pill that can enhance their lives and Selves. Direct-to-consumer advertising has contributed to a growing tendency to regard the Self as optimizable, a "cosmetic psychopharmacology" ethos that promises to make you "better than well," enhance your overall performance (sharpen focus, increase productivity, regulate unwanted emotions, etc.), and even shape your personality into a more desirable version of itself (Conrad 2007, 71, 129). This marketing effort both draws on and actively reconstructs social norms regarding what it means to live a good life or be a good worker, partner, or parent (Pitts-Taylor 2016, 120). American laws surrounding pharmaceutical marketing have exposed the public to marketing as "education," and drug companies not only seek to keep the public up to date on new pharmaceuticals but also to raise awareness of the variety of disorders, problems, and personal insufficiencies that their products purport to address (Greene 2007, 49).

For patient-consumers to seek out medication, they must first accept the validity of the disease category or problem for which the drug is marketed (e.g., they regard depression as a legitimate clinical disorder, ideally with a biological etiology amenable to drug treatment), identify with the phenomenological description of the disorder (e.g., they recognize their own experience in the description of depression symptoms and begin to identify as a depressed person), and believe that the particular drug being described is an effective treatment for the disorder in question.

However, the decision to take medication that is designed to act upon the brain is particularly fraught, raising concerns that chemically altering the brain will refashion the Self. In the case of medications that, from the patient's perspective, cause undesirable effects (e.g., fogginess, lethargy, dampening of emotional range, etc.) the unwanted alterations may be weighed against the independence that medication compliance may permit, particularly if "stabilization" on medication can prevent future institutionalization (Davis 2012, 44). Ultimately, perceptions about the relative costs and benefits of medication vary considerably from patients to care workers and from case to case, depending on the effects of the medication in question and on the degree and type of disruption the underlying disorder has created. Davis (2012, 220) describes the ethical quandary thus:

> From a procedural point of view, the decision by patients to take neuroleptic medication, for example, can be ethically valorized so long as that decision is undertaken voluntarily, even if it amounts substantively to patients' submission to treatment that may expose them to severe side effects, while drastically altering their sense of self and thereby their future basis for decision making.

Although pharmacological treatment can be incredibly effective and can support highly positive outcomes, the question remains: to what degree can informed consent be given when a patient's decision-making apparatus is currently in disarray?

Workplace Context and Professional Socialization: Learning to Apply Labels

How diagnostic labels are applied can be influenced by the social identities that patients carry into the clinic and how demographic characteristics and associated stereotypes influence whose testimony is regarded as credible; those whose symptoms are cause for concern and those that are "normal" for their demographic group; those whose problems are medicalized and addressed with care; and, those symptoms that are regarded as evidence of potential criminality or personal weakness. Patients' social identities represent only half of the equation, however; healthcare workers enter clinical interactions with their own set of identities (which in turn elicit particular responses from patients), their own life experiences, and their own professional socialization. To further complicate matters, diagnostic interactions take place within clinical contexts with complex moral/ideological, bureaucratic, and social structures.

Healthcare workers, particularly nurses and doctors, are socialized over the course of many years of training. While there are some overarching commonalities, the field of medicine does not have a monolithic culture, and the process of professional socialization is particular to the medical specialty, the training institution, and the historical context. Medical specialties and training programs choose who they admit, but prospective trainees also self-sort, gravitating toward the practice area and ideological bent for which they have the greatest affinity. Even within subspecialties, different clinics may take divergent approaches to diagnosis and treatment; for instance, Beard (2016) contrasted two Alzheimer's clinics, one that emphasized neurological testing and a brain-oriented model of explaining and treating Alzheimer's, whereas the other clinic

> focused squarely on the mind, was far less involved in the taxonomy of memory loss or the certainty of the diagnosis itself. Rather it focused on studies regarding healthy aging, sleep patterns, caregiver health, and clinical assessments, as well as follow-up care and meeting the psychosocial needs of a clientele who were likely to be given a diagnosis with serious emotional, financial, and social ramifications. (Beard 2016, 70)

Although I will primarily discuss MDs, clinical psychologists, and nurses, a panoply of healthcare professionals is involved in treating mental disorders, from imaging technicians to social workers, and not all healthcare professionals operate with a bioscientific lens or center treatment on the physiological and socioemotional needs of the patient. Hospital chaplains, for instance, often claim a broader jurisdiction than administering specific rites when called upon or tending to the ritual and spiritual requirements of one particular religious group; they emphasize the necessity of attending to all interested patients' spiritual and ontological needs as part of a complete treatment strategy (Cadge 2012, 103). While various clinical and paraclinical professionals may be involved in treating brain disorders, it is primarily MDs and clinical psychologists who are empowered to affix diagnostic labels.

Society invests a great deal of authority in doctors, and as medical knowledge and technologies become increasingly complex and specialized, we are more reliant than ever on trust: even the most highly skilled cardiologist must defer to the professional capabilities of a neurosurgeon to diagnose and treat a brain lesion (Becker et al. 1961, 5). Doctors' expertise is not simply a pool of information or a set of skills but is in fact a social performance, a claim to authority that rests not only on doctors' interactional proficiency but also on the institutional context that bolsters their claims and imbues them with bureaucratic and symbolic status (Brodwin 2013, 48). Healthcare workers must command respect for institutional protocols and inspire trust in the biomedical enterprise.

The clinic is also a "moralized workplace" in that healthcare professionals express an ethic of "responsibility and care," a circumstance that raises the daily workplace stakes as any inefficiency, blunder, or unavoidable obstacle that impacts patients' wellbeing "threatens clinicians' preferred self-image as well as their technical skills" (Brodwin 2013, ii). Workers are often called upon to reconcile moral dilemmas, such as conflicts between respecting patient autonomy versus employing more coercive measures in order to secure a more favorable health outcome. Workers' moral frameworks develop as they pass through training and as they're socialized into the institutional cultures of different workplaces, but they are not entirely beholden to the prevailing moral order: "Insiders actually find ways to criticize standard practices and assumptions, often by reference to high-order virtues and universal imperatives … how they wrench themselves free, if only for a moment, from the near-at-hand warrants for action and the local moral worlds…." (Brodwin 2013, 16). Ethics are both situated in everyday practice and contemplated with reference to broader values and ideals, but clinical workers routinely confront ethical decisions, small and large.

Healthcare workers in mind/brain specialties must also cope with the routinization of disaster—with navigating a workplace that is the site of other people's life-altering catastrophes and going about your daily round while people around you are being diagnosed with brain cancer or being told their loved one has sustained serious neurotrauma (Chambliss 1996, 39–41). Care providers are simultaneously witnesses to human suffering and office workers acting within the constraints of their resources and roles, and when patients turn to workers as lifelines, it can be difficult for workers to separate their instinct to empathize and invest fully in each individual case with the necessity of recognizing the limits of their abilities to effect change. Brodwin (2013, ii) describes workers in one psychiatric clinic as "[struggling] to make sense of [their] dual role as witness to clients' mortality as well as insignificant cog in the municipal machinery that processes the disenfranchised."

Healthcare workers employ a variety of distancing strategies to make this uncomfortable overlap of professional responsibility and personal investment tenable (Chambliss 1996, 67; Bosk

1979), including engaging in gallows humor (Wear et al. 2006) and employing technical verbiage that allows them to operate at a professional remove and separate the clinical register from the personal (Becker et al. 1961, 272). Institutional structures provide an additional foundation for these distancing strategies by codifying responses to common ethical quandaries, creating routines and strategies around difficult or distasteful tasks, and "shaping the patient into an object" (Chambliss 1996, 151). Interactional norms may overlay clinical routine in a way that normalizes patient objectification and promotes professional distance (e.g., when nurses completing the requisite patient handoff at shift change exchange information about a patient while standing in the patient's room and talking about him or her, all the while referring to the patient in the third person). Institutional policies and workplace hierarchies also provide convenient mechanisms for displacing blame and diffusing responsibility (e.g., when a nurse cites hospital regulations or "doctor's orders" when a patient complains about a source of discomfort or inconvenience) (Chambliss 1996, 174–75). Ultimately, however, despite strategies and structures that routinize and normalize the extraordinary stressors of the clinical workplace, healthcare workers may still struggle to apportion blame and cope with responsibility for negative patient outcomes (Bosk 1979) while striving to live up to their ethical commitments and the dictates of human compassion in the face of daily obstacles.

Professional socialization helps workers manage not only the rigors of the moralized workplace and the routinization of crisis but also the inherent awkwardness of breaching social norms. Within the "sterile and uniform context" of the clinic, workers may struggle to convey a sense of care and concern or to put patients at ease when, for instance, scheduling policies dictate that a doctor has to launch into an inherently difficult conversation with limited preamble because he or she has only a narrow window in which to deliver an Alzheimer's diagnosis and discuss treatment strategies (Beard 2016, 94). Clinical evaluations violate norms of reciprocity and joint production: it is fundamentally awkward to barrage a nervous patient with questions and offer no information about yourself in turn, and it goes against basic socialization to watch as a person twists in the wind, struggling to come up with a forgotten word, without jumping in to fill the silence and put your interactional partner at ease (Beard 2016, 101). One psychiatrist described becoming an effective therapist as learning to "undo your socialization":

> I had to learn not to do that, not to nod so much, not to agree instinctively but to step back, to say, "You're asking that question, and it's important. Why are you asking? What's behind it?" It's really a perverse act, because you are taught socially to cooperate, and as a psychiatrist you learn to resist, to introduce some discomfort in order to create the space for them to discover something. (Luhrmann 2001, 111)

In the midst of these discomfiting departures from interactional convention, staff members such as hospital chaplains may deliberately push back against the potentially alienating effects of clinical distance, by "[providing] space for patients to tell stories, express concerns, and seek out empathy and recognition of shared humanity" (Cadge 2012, 125).

Clinical responsibilities are often structured along clear hierarchical lines, with MDs and clinical psychologists reserving the power to apply a diagnosis and decide upon a treatment plan (with MDs responsible for prescribing medication). However, it is often case workers and/or nurses who spend the majority of time with patients and who most intimately observe them. Brodwin (2013, 48) noted that, when diagnosis and treatment plans were discussed during case presentations, case managers and psychiatrists "[relied] on different warrants for knowledge," with psychiatrists' authority stemming from their medical training and specialized pharmaceutical knowledge and case managers laying claim to "substantially longer interactions with particular clients and much deeper knowledge of clients' life world – their roommates, neighborhoods, usual moods, pastimes, hopes, social connections, and family histories." Caseworkers also tend to have more longitudinal relationships with patients, negotiating chronically mentally ill patients' interactions with and access to the healthcare system for months or years (Brodwin 2013, 66).

In inpatient facilities, nurses and orderlies generally take on the more physically demanding tasks, such as washing patients or dressing wounds and sores (Twigg et al. 2011, 182) while witnessing patients' suffering at close quarters, in real time. Doctors, on the other hand, generally hear summaries of patient progress and complaints during daily rounds (Chambliss 1996, 64–65). For some care workers, building a relationship with the patient is not only a central aim but also a principal therapeutic technique (Cadge 2012); nurses and other non-physicians often invest a great deal of time fielding questions from patients and family members, helping patients access services and deal with bureaucratic hurdles, educating patients about self-care techniques, and lending a sympathetic ear as patients voice frustrations or fears (Chambliss 1996, 65).

Responsibility for the "dirty work" of caregiving (both in the sense of tasks that are undesirable and physically or emotionally draining and in the sense of work that requires interacting with bodies and contaminating bodily substances) differentially falls to specific demographic groups, including women, people of color, people of low socioeconomic status, and immigrant workers (Twigg et al. 2011, 172, 178). In many respects, the healthcare labor market is highly segmented, with high status, highly paid occupations (e.g., doctors, pharmacists, etc.) at the top and low-status, low-wage hospital orderly or home health care labor that requires relatively little training and attracts workers with few alternatives at the bottom. Hochschild reports the following demographic breakdown among paid care workers:

> About 90 percent of long-term care workers in the United States were middle-aged females. More than half were nonwhite and about 20 percent were foreign-born. U.S. Census data show that of all hospital aides in the United States in 2000, 17 percent were foreign-born or noncitizens, as were 13 percent of home care aides (2012, 256).

Historically, flows of global migration have supplied low-wage care labor to the American market, from the turn-of-the-century Irish wet nurse to the immigrant nannies and home nurses of the present day (Hochschild 2012, 251). Less highly credentialed positions in healthcare and eldercare tend to be physically and emotionally demanding and poorly remunerated, factors that may account for the preponderance of minority and immigrant women in the field (Hicks-Bartlett 2000, 43–44).

The influence of stereotypes surrounding nativity and ethnicity on the segmented emotional labor market is evident in the way Hochschild's subjects talk about perceived capacities for caregiving. One woman opined: "Compared to Nolan [my mother's Nepalese caregiver], I have a much more jumpy, get-it-done yesterday personality; it's what made me a good manager. Patience, relaxation, empathy—these have almost been bred out of me.… It sounds strange, but I had to go looking elsewhere for the qualities of a great care worker" (Hochschild 2012, 177). Just as traditional gender ideologies serve to rationalize and reinforce women's concentration in caregiving positions, reductive and essentialist beliefs about foreign cultures are invoked to justify the overrepresentation of minority and immigrant workers among low-wage healthcare labor. An implicit distinction is drawn between hard-charging, success-oriented American culture and the mythologized "simpler life" and family/community-oriented values of minority and immigrant populations, presumably endowed with a culturally conditioned respect for the elderly and gifted with a knack for nurturing (Hochschild 2012, 154–55).

Becoming Labeled

The way diagnostic labels are deployed is shaped by the professional socialization of medical personnel, exchanges between patients and staff, and individual actors' beliefs and biases. These interactions between patient narratives and clinical interpreters are also influenced by the environments in which they occur, and the clinical setting is shaped by structural forces, including differential availability of healthcare resources based on socioeconomic status and geographic region (Wentzell 2011, 225).

Just as we do not become gendered until we interact with the social world (Butler 1990), it is through a social process that people come to assume a medical label. A tumor or trauma may damage the brain or a patient may experience distressing symptoms, but it is in the context of medical interaction that the specificity of a human body or human experience comes to be fitted into a generalizable medical framework (Lakoff 2005, 33). Once applied, these labels have considerable social power to shape the individual life course, interpersonal relationships, social identities, and sense of Self (Estroff 2004). Lakoff (2005, 132) pointed out the deeply personal implications of seemingly technical clinical distinctions: “The boundaries between schizophrenia and schizoaffective disorder may not always be clear. What matters is not the name itself but what the label will imply in terms of medication, social services, employability. Think about it: if she were your child, which diagnosis would you rather she receive?”

The labeling process does not take place in one room, on one occasion: diagnosis occurs in stages, and patients may enter the clinical encounter with prior expectations that have been set by media, by previous clinical interactions, or by discussions with family and friends. Patients and caregivers may come into the clinic with preconceived definitions of “the problem” at hand (Beard 2016, 9). In the early stages of a disorder, a patient may begin gathering information about a suspected diagnosis, evaluating whether the symptom pattern corresponds to his/her experience, and on this basis, starting to integrate the diagnostic label into his/her identity. The form this investigative process and consequent narrative reconstruction takes varies depending on the person’s degree of familiarity with medical discourse (Monks and Frankenberg 1995, 111, 129).

Prior to receiving even a preliminary diagnosis, patients may interact with several different staff members, undergo a variety of diagnostic tests, recount their own medical history and complaints, or hear their troubles detailed by caregivers. In the process of rendering a diagnostic verdict, the physician(s) must transform multiple streams of potentially contradictory information, including an idiosyncratic life history and personal perceptions and experiences, into a medical object, a case history (Beard 2016, 83). Throughout the diagnostic process, both patient and medical staff work in dual registers, regarding the patient as an experiencing subject and simultaneously viewing the patient's body, mind, and history as facets of a medicoscientific object (Radley 2010).

Many patients, particularly those with chronic mental health conditions, present at the clinic with an extensive medical history and their own "biochemical career," or pharmaceutical history (Biehl 2005, 194). Given the efficiency imperatives enforced by structural conditions such as billing practices and insurance reimbursements, medical staff aim to elicit relevant information as comprehensively and efficiently as possible, even when confronted with complex histories and/or patients who are ill-equipped to produce a cogent and concise narrative. Where possible, clinicians often attempt to supplement the fuzziness of qualitative variables such as doctors' "clinical impression" of a patient with more "objective" metrics, such as neurological testing (Beard 2016, 62).

Deinstitutionalization has exacerbated this data collection obstacle by removing patients from the clinical gaze, for most of their lives, and necessitating that patients act as the primary reporters of their progress, setbacks, challenges, and triumphs (Davis 2012, 59), unless family or community members are available to serve as informants and corroborate the information furnished by the doctor's clinical impression, any available neuropsychological testing, and the patient's account. Often, financial and institutional constraints preclude long-term, inpatient observation, but even if such detailed evidence were available, it is arguable that observation almost inevitably produces aberration: Who among us does not act differently if observed or would not exhibit some degree of idiosyncrasy if watched for long enough (Chambliss 1996, 148)? Pharmacological treatment models and managed care administrative practices demand "diagnostic and conceptual precision," but even at the best of times, diagnoses emerge through an uncertain process of self-report and incomplete observation (Meyers 2013, 94). It becomes even harder to collect robust data when the primary witness's testimony has been compromised by problems with cognition or communication, (Aronowitz 1998, 7).

In seeking treatment, patients must endeavor to "turn [their] suffering into testimony" in a way that will lead to a diagnosis and some form of care (Frank 1995, 18). Creating a streamlined narrative, distilled to its diagnostically relevant details, is a hurdle in many medical interactions. It is all the more challenging to construct a disciplined narrative when dealing with a chronic illness "chaos story" in which protracted suffering without a clear explanatory framework results in turbulent emotions, a disordered narrative, and a storyteller with "no distance from her life and no reflective grasp on it" (Frank 1995, 98). In the context of a case presentation and differential diagnosis, these chaos stories must be processed into orderly patient histories that "fit neatly into a linear plot with a predictable ending" (Beard 2016, 64). These narrative presentations often conform to a local idiom of illness experience, and once the doctor recognizes the narrative tropes presented by a particular patient, the doctor can "create" the illness by associating the presented symptoms with a codified disorder, anchoring personal experience in shared meaning and transforming biographical specificity into a case history that fits existing schema (Meyers 2013, 12; Beard 2016, 56).

In diagnosing brain disorders, doctors may encounter a broad range of narrators: articulate patients who are able to present an accurate and complete history (to the extent that any subjective representation can be viewed as the unalloyed truth); patients with severe memory deficits who confabulate and fill in narrative holes with fantasies; patients who are too emotionally distraught, affectless, or absent to render an account of any kind; and so on through the infinite variety of human expression and experience. Patient narratives should not be construed as "authentic" or unalloyed truth, nor should they be epistemologically subordinated to clinical observations and tests with greater claims to empiricism (Bury 2001, 281). Ultimately, a medical diagnosis arises from a complex interaction between the patient's subjective experience and clinicians' attempts to reconcile the patient's account with other forms of evidence (informants' reports, test results, etc.) and to map that narrative onto an existing diagnostic category.

The setting in which a patient's initial contact with the healthcare system occurs also influences diagnostic practice (e.g., did the patient arrive at the ER after a violent encounter; was the patient remanded to court-appointed drug and alcohol treatment; did the patient visit the student care center seeking treatment for depression). Mental healthcare is often complicated by physical health or addiction comorbidities, and the manner and location of patient presentation has an impact on the prioritization of one diagnosis or treatment method over another. Where and how a patient "presents" influences which diagnosis is regarded as the primary concern or the condition underlying the others; the location and context in which a patient presents dictates, for instance, whether the patient is regarded as a drug addict or as a mental health patient experiencing severe depression and self-medicating by abusing illegal drugs and whether the patient is placed in a drug treatment or mental health facility or, less fortunately, is shunted into the legal system (Meyers 2013, 91, 104). The context of initial presentation interacts with the perceived social status of the person seeking treatment as well as the beliefs the patient carries into the interaction and his/her degree of trust or mistrust of biomedicine and medical personnel (Beard 2016, 56; 87). A patient narrative may be received as more or less credible depending on the social identities of the patient and the doctor in question (e.g., a white, highly educated, upper middle-class patient may be reflexively perceived as a trustworthy reporter by a doctor with similar social characteristics). Just as racial, gender, and socioeconomic ideologies influence the creation of diagnostic categories, the social characteristics people carry into clinical encounters influence how diagnostic categories are applied.

Accepting or Rejecting Labels

Having discussed the social, ideological, and structural forces that shape diagnostic categories and influence how and to whom diagnostic categories are applied, I turn now to how individuals respond to the labeling process, how patients assimilate a clinical label into their identities or reject it, and how they cope with the experience of the labeled self. At what point does one *become* a patient—when the first signs of illness manifest? When you recognize a change in your own body or mind and begin to mark it as a threat or disturbance? When a clinician observes and records these signs and symptoms and begins to associate them with a diagnostic entity?

The advent of technologies such as neuroimaging and genetic screening further complicates these questions because it is now possible to find evidence of abnormality on a brain scan or identify genetic markers of risk before any troubling changes are felt or observed. One may inhabit a pre-patient liminal state in which shadowy harbingers of disorder have been announced, but it is not yet known whether you are a patient-in-waiting with a “preclinical” form of disorder or whether you may never become symptomatic at all (Lock 2013, 128, 174). Depending on the inheritance pattern of a given genetic disorder, a positive test result may represent anything from a slightly elevated risk to a status passage, in and of itself (e.g., in the case of Huntington's Disease, where learning that you carry a particular gene collapses all potential futures into the certainty that you will one day suffer from Huntington's) (Lock 2013, 178). Somewhat counterintuitively, between 5 and 25 percent of people who are at risk of Huntington's or who are carrying an at-risk fetus decline genetic testing, and Lock (2013, 177, 179) posits that, when knowing one's future does not afford any chance of proactively avoiding the negative outcome, people may choose ignorance as a means of preserving an unblemished identity and remaining someone for whom the future holds an array of possibilities. Alternately, people may seek to avoid trading fear of a potential future death sentence for a ticking clock and anxiety about exactly when and how the inevitable symptoms will begin to manifest.

The increased availability of genetic testing contributes to a new form of biosociality in which people who test positive for a particular genetic marker join an expanding group of the pre-diagnosed or diseased-in-waiting and are encouraged to identify as potential sufferers (Lock 2013, 179). Imperfect folk understandings of genetics, probability, and risk complicate this identification, however. For instance, Lock reports that some study participants interpreted genetic risk on the basis of beliefs about which side of the family's genes were "stronger" or which child was more at risk of inheriting a parents' illness based on perceived physical or temperamental resemblance (Lock 2013, 195). Our incomplete knowledge of patterns of genetic inheritance and associations between genetic markers and complex traits interacts with muddled popular understandings of genetic science to foster considerable ambiguity. Despite this lack of clarity, seeking out appropriate genetic knowledge has become part of our moral landscape, characterized as "a form of future-orientation, which patients and families were to apply to themselves by monitoring their own mood and behavior" (Lakoff 2005, 31). Under this framework, responsible patient-citizens carry an obligation to know their risk and act accordingly (e.g., by watching for signs of illness onset, taking preventative measures, or even forgoing reproduction to avoid passing on genetic risk to children) (Lock 2013, 190).

Moving on from the world of risk assessment and pre-symptomatic, “pre-clinical” phases of illness, we turn now to diagnostic labels as they are more generally applied. Diagnoses represent a common idiom that allow medical practitioners to conveniently distil the particularities of individual cases in order to more effectively communicate and create generalizable treatment strategies. Within modern American mental healthcare, diagnoses also serve a functional institutional purpose, organizing the messiness and ambiguities of lived experience into administrative categories that correspond to insurance billing codes (Meyers 2013, 92), and mental healthcare workers may even acknowledge the conceptual distance between the “lived reality of the patient” and the medical record (Donald 2001, 434). While in some sense, a diagnostic label transforms a patient from experiencing subject to medical object, a patient in the grip of a mental health crisis or in the aftermath of a stroke or traumatic brain injury may lack the “insight” into his or her condition to either acknowledge or accept the diagnostic label.

In other cases, however, patients begin to identify with a diagnostic category before they even start the process of seeking an official diagnosis. A patient and/or his or her family members may notice signs of neurodegeneration, for instance, and these suspicions about the underlying cause of the symptoms may prompt a visit to a dementia specialist (Beard 2016, 89). In the early stages of a disorder, a patient may begin gathering information about a suspected diagnosis, evaluating whether the symptom pattern corresponds to his/her experience, and on this basis, start to integrate the diagnostic label into his/her identity. The form this investigative process and the consequent narrative reconstruction takes varies depending on the person’s degree of familiarity with medical discourse (Monks and Frankenberg 1995, 111, 129). As part of the rise of bioscientific explanatory models in modern American society, people are more likely to seek out medical explanations for life experiences or events and self-diagnose physical or mental disorders (Conrad 2007, 59), and an increasing tendency to medicalize under-performance has encouraged people to self-apply neurological or psychological diagnoses to perceived deficits. Re-examining personal history and identifying with a disorder such as Asperger's or adult ADHD has the potential to reframe one's life narrative, such that "underachievement" or "social awkwardness" can be reconceived as symptoms of an underlying disorder rather than moral or personal defects (Conrad 2007, 64–65).

Conversely, we can "ignore or reject identities" that conflict with our perceptions or beliefs about who we are and how we experience the world (Watson 2002, 511). For instance, a patient who experiences mania or hypomania may relish the feelings of invincibility, euphoria, and heightened cognition that can accompany a manic episode and may be resistant to the idea that these desirable sensations stem from a pathology (Lakoff 2005, 109). Similarly, patients who lack insight into their condition may be difficult to persuade that anything is amiss: for instance, a patient who believes in the reality of his/her hallucinations or delusions may not accept the validity of a diagnosis or the necessity of treatment, particularly if the patient does not experience the symptoms as unnerving or alarming (Brodwin 2013, 64).

However, when patients do experience their symptoms as disconcerting or confusing, a diagnosis may be received as a comforting and welcome explanatory framework—a relief from doubt or a recognizable face to put on a nebulous foe (Angell et al. 2008, 88; Beard 2016, 124). A diagnosis can also ameliorate feelings of guilt or stigma in cases where the patient's behavior has previously been attributed to irascibility or laziness (Beard 2016, 124–25). Patients and family members alike may be comforted by the concept of a biological disorder—a brain disease that is morally indistinguishable from pathology in any other bodily organ. Family members may be particularly relieved at the reprieve from stigma when a "no fault" medical explanation is provided for a loved one's socially inappropriate behavior. However, the "brain disorder" framing may also be construed negatively, as a fundamental and permanent dysfunction with no hope of remedy (Angell et al. 2008, 92).

In some cases, a particular diagnosis carries such negative connotations that doctors and/or loved ones may avoid revealing the diagnosis to the patient, or if applying a specific diagnosis is not necessary for treatment, doctors may avoid a definitive label altogether. When a physician suspects Alzheimer's, for instance, he or she might (accurately) tell the patient that there is no conclusive way of verifying that the patient definitely has Alzheimer's (as opposed to another form of dementia), so that the patient does not have to receive a diagnosis of a disorder widely regarded as the "funeral that never ends" (Lock 2013, 63). In cases where multiple labels could potentially apply and the treatment is essentially the same, physicians may take into consideration what a particular diagnosis will mean for the patient, choosing to avoid the diagnosis with more negative connotations or a less favorable prognosis (e.g., diagnosing bipolar disorder rather than schizophrenia because it is less stigmatized, more easily "controlled," and less likely to lead to long-term institutionalization) (Lakoff 2005, 116).

Ultimately, a patient's initial perception of a diagnosis' meaning and its implications for his/her social identity and sense of Self may hinge on the way the diagnosing mental healthcare professional frames the condition and its prognosis in the initial clinical encounter. In Beard's (2016, 89) study of Alzheimer's patients, she found that "reactions to diagnosis also cover a wide spectrum from shock to sadness, fear, and relief. The experience of being diagnosed, however, is intimately linked to the tone used, the information given, and the hope for the future conveyed by the specific clinician rendering the diagnosis." Even pragmatic attempts to prepare a patient for the logistical challenges ahead (e.g., discussing future plans for giving up driving or for finding assisted living options), may unintentionally frame a diagnosis as an assault on a patient's sense of Self and core values.

There is an inherent temporal element to the labeling process. Even if the patient suspected or sought out a particular diagnosis, the application of an official diagnosis creates a "before" Self and an "after" Self. In some cases, the rupture is more acute than others (e.g., when diagnosis follows a trauma or a breakdown), and incidents such as one's first hospitalization for a chronic mental disorder may serve as narrative turning points that prompt a reassessment of identity (Angell et al. 2008, 91). Diagnosis amounts to a "status passage" that acts to "[ascribe the] identity of patient" to the diagnosed individual (Beard 2016, 94). In the case of a diagnosis such as Alzheimer's, this status passage can be experienced as a "degradation ceremony," in which cherished identities such as Valued Worker or Independent and Capable Adult are taken away and replaced with an undesirable new status as an object of care and pity. Even people who underwent cognitive evaluation but were ultimately *not* diagnosed with any form of dementia found the testing experience to be impersonal, uncomfortable, and stressful and were humiliated by the implication that their cognitive faculties were in doubt (Beard 2016, 16, 104). Although patients or their loved ones may have been noticing cognitive changes for a while before the testing and diagnosis and may even have anticipated the diagnosis itself, it is the social event of diagnosis rather than the underlying biopsychological alterations that effects the transition from "forgetful" to pathological (Beard 2016, 18). It is a confluence of structural, interactional, and social processes in the clinic and beyond that ultimately "deprives the demented elder of selfhood" (Cohen 1999, 7). The specific label applied sets expectations for future prognosis and performance (Lakoff 116), and whether a condition is considered chronic, degenerative, or recoverable has a decisive impact on a patient's sense of Self.

Patients often must grapple with the distinction between *cure* and *healing*, as defined by Canguilhem, with *cure* representing a return to a previous state—to an externally defined norm, the achievement of which can only be validated by outside observation. For many brain disorder patients, initial diagnosis prompts a longing for *cure*—a desire to inhabit a body and brain that is medically and socially normative and to be returned to the category of health. *Healing*, on the other hand is "fundamentally subjective and individual" and does not seek to "restore a previously existing order" or "return to an old norm" (Meyers 2013, 9). For patients who have sustained brain trauma, for instance, the concept of *cure* is seductive, but a *healing* model is more realistic. Patients who are diagnosed with chronic or degenerative conditions are precluded from envisioning a future of total restoration and normative health, and the process of reconciling oneself to a future of chronic or degenerative illness can be painful and protracted. Murphy (2001, 90), for instance, describes how his self-image and perception of his future shifted in the aftermath of his diagnosis with an inoperable spinal cord tumor that caused increasing physical disability.

> This sense of damage to the self … grew upon me in my first months in a wheelchair, and it hit me hardest when I returned to the university … by then, I could no longer hold on to the myth that I was using a wheelchair during convalescence. I had to face the unpalatable fact that I was wedded permanently to it; it had become an indispensable extension of my body.

While a chronic condition may be a lifelong presence, patients can reasonably expect periods of relative quiescence when their condition is "controlled" and stability is maintained, but degenerative illness requires a series of reconciliations with a shifting identity (e.g., from a person who uses a wheelchair during convalescence to person who relies on a wheelchair in certain scenarios to a person who is entirely dependent on a wheelchair).

Upon diagnosis, a patient embarks upon a “moral career” and “must *learn* how to become a patient in keeping with their diagnosis” (Beard 2016, 137–38), a process of socialization that may incorporate learning to use an assistive device or adapting to a new medication regimen. An insulin-dependent diabetic, for instance, must learn not only to manage the intensive new dietary, testing, and medication regimen but must also become comfortable with the idea of insulin and its attendant daily routines as a lifetime partner (Greene 2007, 87). In the case of assistive technology, such as a walker or wheelchair, the partnership also entails learning to manage the identity of Person with Visible Disability.

While a person who begins taking medication for a chronic psychiatric condition will not necessarily bear visible signs of a stigmatized identity, adapting to the new medication requires not only managing disclosure (i.e., deciding when or if to reveal one’s diagnosis to social partners) but also coming to terms with a neurochemical “partnership”—with taking a drug intended to alter not one’s blood glucose levels but one’s mood, cognition, or perception of reality. Inpatient treatment facilities, support groups, and other forms of patient networks can be critical sites of acculturation where which the newly diagnosed learn techniques for managing stigma and constructing or reconstructing a desired identity and are socialized into the values, narrative frames, and discourses of, for instance, disability culture or drug addiction recovery culture (Devlinger et al. 2007, 1951; Meyers 2013, 62).

Diagnostic Labeling and Stigma

Before proceeding to a discussion of the implications that diagnostic labels have on a patient’s social relationships and sense of Self, it is necessary to delve more deeply into the concept of stigma. Within a given social context, social consensus defines a range of behaviors and traits: those that are regarded as normal and acceptable, those that are within the realm of tolerable deviance, and those that are socially proscribed and stigmatized. Several factors influence the social response to a particular instance of eccentric behavior, including the social characteristics of the audience, the social characteristics of the eccentric actor, and the environmental context in which the action occurs. A trait that might be stigmatized in one setting may be valued in another (e.g., dark skin in an overwhelmingly white space vs. dark skin at a UNIA rally) (Monk 2015, 415–16). Behavior that might be deemed highly inappropriate in certain settings might be afforded license under particular conditions (e.g., during a holiday known for public displays of drunken revelry), and people are more likely to excuse and rationalize the behaviors of members of their own social groups or societal elites. Scheper-Hughes (2001, 160) details how social convention may create carveouts for acceptable forms of deviant behavior and/or acceptable deviants.

> So do villagers today make allowances for public displays under the influence of spirits, which they would never stand for in a sober man ("Pay Steve no mind; tis only the drink that's upon him"). A certain amount of mental illness and "abnormal" behavior (by village standards) is tolerated when disguised in the cloak of alcohol…. Since alcoholism is, to a degree, an accepted part of masculine role behavior (especially among bachelors), it is not recognized as "abnormal." The common Irish defenses of denial and "scapegoating" also serve to protect village alcoholics from recognition and public shame. Just as what might be referred to as a "community myth" perpetuates within Ballybran the comfortable notion that only Maighread among us is really "crazy," so too, the village at large attempted to deny alcoholism as a widespread mental and social problem by acknowledging the existence of only *one* village alcoholic—the despised water-bailiff.

Under these rules, drunkenness provides a convenient means of deflecting stigma, and scapegoating permits the community to maintain a distinction between in-group members who misbehave within acceptable limits and the people who are "truly" deviant and whose positioning beyond the social pale provides a clear point of contrast for everyone else.

In some cases of mental disorder, the particular intersection of the social characteristics of the sufferer and the disorder in question may initially fly under the stigma radar: for instance, an affluent, white anorexic woman may initially receive positive feedback for her weight loss and slender frame, up until her body begins to fall outside the realm of cultural ideals of fashionable and attractive thinness and crosses the boundary to "unhealthy" or alarming gauntness (Mclorg and Taub 2009). People with brain disorders may discomfit interactional partners not only by diverging from appearance norms but also by failing to conform to established social roles or to maintain an appropriate "front" (Goffman 1959, 26-27). When people are confronted by differences that disrupt typical social scripts and present interactional challenges (e.g., when I see a familiar colleague in a wheelchair for the first time, should I ignore the difference or inquire about his health? Should I bend down to talk to him so that it doesn't feel like I'm hovering over him?), they often resolve the dilemma by either ignoring the difference or ignoring the person (Murphy 2001, 91; Goffman 1963, 18).

This avoidance is not simply a panicked reaction to being thrown off script or confronted with deviance; from an early age, we are taught what we should pay attention to what is inconsequential and unworthy of notice and what should be studiously disattended (e.g., telling a child never to stare at someone who is behaving strangely or whose body is visibly non-normative), and this attentional socialization tends to reinforce stigma and social ostracism (Zerubavel 2015, 59, 63). Evidence suggests, however, that social exposure can reduce stigma and diminish public fear of people with mental illness, although the cognitive mechanisms behind this effect are unclear (Estroff 2004, 495). Murphy theorizes that the visibly disabled serve as unwanted reminders of human frailty (i.e., that every body will someday betray its owner through slow decline or sudden cessation or diminution of function), and that rather than accept the randomness of human misfortune, people are inclined to believe, either implicitly or explicitly, that disabling accidents and medical events represent some sort of karmic retribution or moral desert (Murphy 2001, 93, 334).

Davis (2004) argues that people with mental disorders are often subject to “moral stigma” as defined by Erving Goffman. Moral stigma is applied to people who are thought to “hold a degree of control over their stigmatizing attribute(s)” (Davis 2004, 436)—people with physical disabilities may be stigmatized, but they are generally not subject to *moral* stigma, unless they are thought to have, in some way, caused or contributed to their impairments (e.g., drunk drivers). Despite the increased dominance of biomedical frameworks that suggest that mental disorders have neurological or biochemical origins, moral stigma is still frequently applied to the mentally ill: they may be seen as lacking in moral fiber (i.e., unwilling to put in the standard amount of effort to cope with life’s problems) or as fundamentally unpleasant or malevolent people.

In the case of certain brain disorders, the stigma may not always be readily apparent (e.g., a case of schizophrenia that is well managed with medication) or may not be noticeable without close interaction (e.g., some forms of brain trauma or neurodegeneration). Goffman draws a distinction between *discredited* (deviance that is readily apparent at a distance or in social interaction) and *discreditable* (deviance that is *not* immediately discoverable but would produce stigma were it to become legible), and people managing discreditable stigma may choose either self-revelation in order to control the manner and means in which the information is presented or a presentation of self that carefully avoids revealing the hidden discreditable aspect of self (Goffman 1959, 12; Goffman 1963, 100). Unfortunately, Goffman (1959) suggests that a person whose hidden deviance has been revealed may be additionally socially penalized for having “fooled” his or her social partners or claimed status to which he or she was not entitled.

“Paradoxically, the more closely the imposter’s performance approximates the real thing, the more intensely we may be threatened, for a competent performance by someone who proves to be an imposter may weaken in our minds the moral connection between legitimate authorization to play a part and the capacity to play it” (59). However, “passing” too effectively may produce undesirable social effects, *even if the discreditable stigma is not revealed*, as in the case of people with invisible disabilities who provoke ire or contempt when they use disability accommodations to which they are presumed to be unentitled or in the case of physically robust people with cognitive impairments who may not be offered necessary assistance (Beard 2016, 100).

Living with stigma requires a concerted and often exhausting effort at self-presentation, as a person managing stigma “[has] to be self-conscious and calculating about the impression he is making, to a degree and in areas of conduct which he assumes others are not” (Goffman 1963, 14). A stigmatized person may or may not be the target of dramatic displays of social opprobrium or overt acts of discrimination, but “everyday discrimination,” or exposure to constant, pervasive social bias as opposed to singular traumatic events, represents a significant and unrelenting cognitive and emotional tax (Monk 2015, 400). Stigma also carries with it a loss of anonymity and a tendency for others to feel entitled to impose on or encroach on the privacy of a stigmatized person—for instance, by offering unsolicited help or “positive” comments that are patronizing and unwelcome (Schweik 2009, 208).

Mackelprang and Salsgiver (1999) and others have outlined the prevalent models of disability in modern American culture. Disabled people may be regarded as objects of pity or as opportunities to ritually enact beneficence and demonstrate moral character through conspicuous charity (Longmore 1997). Alternately, people with disabilities may fashion themselves as models of perseverance and fortitude, not only refusing to give in to self-pity or despair but striving to achieve feats that will demonstrate their triumph over disability and all it represents (Mackelprang and Salsgiver 1999).

Among the roles available to people with disabilities is the "sick role," characterized by Parsons (1958) as one of dependence and disempowerment. Crucially, the patience and forbearance afforded the occupant of the "sick role" is conditional and is reliant on being a "good" patient, working as hard as possible to get well and continuing to make steady progress (Parsons 1958). This aspect of the "sick role" not only sets an impossible standard for people with degenerative conditions or permanent impairments but also places the focus on "repair" rather than self-acceptance. Mackelprang and Salsgiver (1999) argue that the medical model of disability gives rise to a project of "perfecting the imperfect": if disability is understood to be a morally neutral deviation from a biological norm, then medical treatment must be applied to bring people with disabilities into greater accord with the established standard. In some cases, however, "perfection" is unachievable. "When cure was not possible, persons with disabilities could at least be trained to become functional enough to behave acceptably in social situations" (Mackelprang and Salsgiver 1999, 84).

One means of combating stigma and status loss is to reframe one's identity to highlight capacities that remain intact. However, even if individuals are able to reframe their identities to foreground their capacities rather than their disabilities, they may still experience identity threats in the form of social ostracism or stigma (Rabin and Rabin 1982). Stigmatized people are also at risk of internalizing the negative beliefs or impressions that other people convey (e.g., by feeling guilt or shame when occupying public space, despite knowing that they have a right to exist in the public sphere) (Murphy 2001, 92). Disability literature has extensively covered the impact of social relations on individual identity among the physically impaired. People confronting disabilities of various types often share a similar experience: the assumption of a negative self-identity due to the association of disability with incapacity, invalidation, and disempowerment (Shakespeare 1996). According to Rothman (2010, 219), "stereotypes and biases that are often internalized by people with disabilities, [affect] self-esteem, self-determination, relationships with others (including social work professionals), and the integration of people with disabilities into society."

As Mead (1934, 138) articulates, a stigmatized person "becomes an object to himself only by taking the attitudes of other individuals toward himself within a social environment or context of experience and behavior in which both he and they are involved." Beliefs about how other people see us influence our self-perception and affect our life chances. Murphy (2001, 113) echoes this point and encapsulates a central tenet of the disability rights movement.

> Whatever the physically impaired person may think of himself, he is attributed a negative identity by society, and much of his social life is a struggle against this imposed image. It is for this reason that we can say that stigmatization is less a by-product of disability than its substance. The greatest impediment to a person's taking full part in his society are not his physical flaws, but rather the tissue of myths, fears, and misunderstandings that society attaches to them.

Disability is effectively constructed by a society that stigmatizes and refuses to accommodate the full range of human physical and mental variation.

Disability stigma is such that disabled observers have noted a tendency within the disabled community to perpetuate an implicit social hierarchy based on ability, with more severe and visible disorders at the bottom (Goffman 1963, 107; Murphy 2001, 132). As always, the intersection of disability with social categories such as race, gender, and socioeconomic status has considerable impact on individuals' experiences and life chances and the effect is felt in innumerable ways, including by intensifying or mitigating the effects of stigma, affecting the ways in which interactional partners implicitly attribute "blame" for a disabling condition, and influencing willingness to seek help and the resources available.

Markers of socioeconomic or professional status can complicate or attenuate the effects of stigma; “insider” or elite status may insulate someone from being regarded as marginal or socially contaminated (Murphy 2001, 171), creating expectations that a person will be “high-functioning.” In cases of traumatic brain injury, for instance, perceptions about pre-injury levels of cognitive and social functioning shape recovery goals, and progress in rehabilitation may be assessed relative to preconceived notions of potential that are influenced by socioeconomic biases. Furthermore, the intersection of poverty and disability has historically been regarded as menacing insofar as the poor, disabled person represents “an ideological threat to the capitalist ethos of hard work and self-reliance and sturdy bodies as instruments of production, and a eugenic threat to the genes of the nation … [and] a criminal threat to the social and economic life of the community” (Schweik 2009, 213). Shades of these prejudices inflect the current debate surrounding healthcare access as a fundamental right and routine political grandstanding surrounding claims of disability benefit fraud. Poor people and particularly poor people of color are especially likely to be blamed, in some form or another, for a disabling injury, substance abuse disorder, or other mental health condition. Rich (2009, 17), a medical doctor, elaborated on how his own experience of racism, as a Black man, did not prevent him from engaging in racialized victim blaming.

> My colleagues and, to be honest, most everyone else I knew, we all carried around inside us an unspoken assumption. When a young Black man rolled into the emergency room with a gunshot wound, we all assumed that it wasn’t just bad luck. He didn’t just get shot; he got himself shot…. They were desperate to stop this flow of injury and death, but there was a hovering nihilism that “these people” were who they were and nothing could be done about it.

Even as healthcare workers labor tirelessly to save lives and care for patients, prejudice both subtle and overt clouds interpretations of which patients are innocent of wrongdoing and deserving of sympathy and solicitude and which patients are victims of their own misdeeds and poor decision-making.

It has been suggested that “in the hierarchical world of disability, those perceived as having mental disabilities have the most difficulties, as they are perceived as potentially dangerous to others” (Charlton 2000). Numerous researchers have documented the ubiquity of unfavorable representations of mental illness in the media (e.g., Hyler et al. 1991; Wahl 1995; Lawson and Fouts 2004), and people with disorders of the brain are regularly portrayed as ranging from socially maladroit, insensitive, or unnerving to outright dangerous and violently malicious. Media representations both reflect and reinforce the stigmatization of the mentally ill, and negative media depictions have been shown to have a deleterious effect on mentally ill individuals’ self-perceptions (Stuart 2006). While the Mad Pride Movement has made considerable headway in attempting to encourage positive self-identification with labels such as “mad” (Lewis 2013), self-stigmatization is still prevalent among people with brain disorders (Angell et al. 2005).

Brain injury may cause personality changes, loss of executive functions, loss of memories, and myriad other symptoms that may have a deep and lasting impact on an individual’s sense of self and identity. Brain injury patients express concerns about stigmatization, concerned that “society may suppose that people with traumatic brain injury have lost the essential character or dispositions that constituted them before the accident” (Nochi 1998). Consequently, brain injury patients employ presentation strategies to manage a discredited identity, or a discreditable identity if their injuries permit them to conceal their impairments in certain social contexts (Goffman 1963; Nochi 1998). Researchers have studied the effects of certain factors, such as “sick” or “recovery” roles (Barclay 2012) or perceived self-efficacy (Cicerone 2007), on rehabilitation outcomes and measures of life satisfaction in brain injury patients; Nochi has begun to explore brain injury patients’ self-narratives (Nochi 2000) and methods of dealing with stigma and the labeled self (Nochi 1998).

While some amount of research into the impact of brain injury on identity has already been conducted, the study of how medical practitioners, caregivers, and especially patients theorize and experience the distinction between the brain and the mind in the aftermath of brain injury represents a fruitful area for future inquiry. Taking into account models of identity re-formation and stigma management that focus on physical disability, what can we learn about the specific case of brain injury, and what can it tell us about medical and social perceptions of the brain-mind distinction? How do brain injury patients distinguish damage to the brain from damage to the Self, and how do patients and practitioners mobilize these distinctions to mitigate the effects of identity threat?

Becoming a Medical Object

Although disability-related stigma can exist prior to and independent of receiving a medical diagnosis, the process of clinical evaluation, diagnosis, and treatment has a distinctive impact on the stigmatized individual. As previously discussed, diagnosis often represents a negative status passage (e.g., by transforming "forgetfulness" or "absentmindedness" into the frightening and degrading specter of Alzheimer's), but in some cases, diagnosis can actually serve to ameliorate stigma (e.g., by providing an exculpatory biomedical explanatory model that reframes "misbehavior" or "disruptiveness" as a morally neutral neurological condition, such as Tourette's or ADHD). In conjunction with the social and epistemic impact of the specific diagnostic label, the process of labeling can itself be experienced as a "radically dehumanizing and devaluing transformation from being a person to being an illness" (Angell et al. 2008, 79).

In the section on the moralized workplace and the professional socialization of healthcare workers, I discussed the necessity of distancing strategies that enable workers to operate under conditions of constant stress and exposure to human suffering. Healthcare workers maintain a form of double bookkeeping: the patient as disease process and the patient as suffering human being (Beard 2016, 82). Medical professionals may engage in symbolic acts that re-personalize patients (e.g., by decorating the bassinets of premature babies being kept in isolation or by preserving the privacy and modesty of patients who are unconscious or unaware of their surroundings), but it is difficult for patients to avoid some sense of dehumanization when they have become the object of someone else's professional expertise or a challenge in someone else's workday (Chambliss 1996, 124–25). People with brain disorders are particularly at risk of feeling like (and actively being regarded as) somehow less than human, "devoid of feelings, sensitivities, and basic rights," being talked *about* rather than *to*, and being perceived as unreliable narrators of their own experiences (Angell et al. 2008, 76).

Institutionalization, whether in a nursing home, hospital, mental health facility, or similar environment, often carries with it a loss of privacy, autonomy, and dignity, with residents generally ceding at least some measure of control over how they dress, with whom they share space, their options for entertainment and mental and social stimulation, and when and how they eat, sleep, and groom themselves (Gawande 2014, 73). Patients may not be trusted with certain objects or permitted to undertake various activities on their own. Depending on the type of facility and the patient's particular condition, his or her actions and body will be under various forms of surveillance, and medical personnel may wash, examine, and otherwise handle the patient. Osborn (1998, 196) vividly describes the intrusiveness and physical indignities to which the institutionalized body may be subjected:

> Six doctors – only one of whom needs to see your chest incision—crowd around your bed while your breasts are exposed. A resident tells you how lucky you should feel because you didn't die in the accident with your beloved husband. You stare at the bedpan and call-light—both just out of reach—while you soil your sheets. The procedure that they never explained to you except to say it would feel like a little pinch feels like a root canal without

> Novocain. The lab tech who needed three tries to draw your blood ten minutes ago is back for more because the intern forgot to order a specific test.

In cases of brain disorder, the physical impositions are compounded by an arguably even more intrusive form of surveillance: it is not just the patient's heart rate, meal choices, or urine retention being observed and charted; it is his or her thoughts, behaviors, and interactions that are chronicled and analyzed for signs of aberration (Chambliss 1996, 147).

Living with, and particularly being diagnosed with, a mental disorder can also be experienced as entering a phase of living death. The experience of "social death" is distressingly common (Lock 2013, 91), and "those who suffer from prolonged terminal illnesses, who are very old, and who are believed to experience a loss of personhood as a result of their condition are often relegated to the status of inanimate objects" and regarded as "socially obsolete" or thought of in the past tense (Beard 2016, 173). People who have experienced brain trauma or disorder may feel as though people around them are cataloguing their deficits, lamenting the loss of "who they were," and treating their present condition as a pale imitation of their "former" Selves. Patients may also feel patronized or infantilized and may find, to their frustration, that a cognitive deficit in one area overshadows all their other capabilities. One dementia patient poignantly summed up this experience of being socially demoted and treated as a diminished version of oneself:

> I realize that I forget things and that I'm not always completely with it, but I feel like I still have enough intelligence, you know, *to be a person, and not just someone you pat on the head as you go by* … I guess maybe I'm a bossy person by nature, but I really resent being bossed around and being told how I should do something when I know I know how to do it. It's devastating, and *it takes away your sense of self.*… It is important to me because I feel like I'm still a person and my wants and desires should at least be considered before decisions are made. (Beard 2016, 147)

Following a diagnosis with a neurodegenerative condition, people may feel they are being prematurely mourned, that loved ones are speaking of them as walking tragedies or eulogizing their future "loss." In cases of people in the grip of catatonia, late-stage dementia, or other conditions that can cause profound withdrawal, unresponsiveness, and flattening of affect, interactants may begin to treat the patient as essentially inanimate, as a "vegetable." This tendency to equate the mind with the Self, and consequently to regard cognitive deterioration as a loss of Self, contributes to the treatment of patients with brain disorders as tragedies that have been visited upon their families and friends. In this framing, the patients' loved ones are the true "victims," since the patient is regarded as already essentially gone, leaving caregivers to deal with his or her disordered remains (Cohen 1999, 50).

Patients' experiences of dehumanization and loss of privacy, autonomy, and esteem raise questions of how we understand the distinction between the brain, the mind, and the Self, and what characteristics we regard as essentially "human." Mead posited that, "The body is not a self, as such; it becomes a self only when it has developed a mind, in the context of social experience" (Mead 1934, 50). Can humanity be boiled down to attributes such as cognition, emotion, self-awareness, empathy, agency, and will? Beyond humanity in a broad sense, what does it mean to be specifically *you*—do you remain yourself in the absence of continuity of perception, memory, and a distinctive set of traits? What do we regard as fundamental to our being, and how do we experience its loss?

Loss of Self

Individual autonomy has long been a central value in America's cultural landscape with notions of "rugged individualism" and "personal responsibility" intimately intertwined with concepts of personhood. As Beard (2016, 205) aptly summarizes, "In a hypercognitive society, where people envision the fundamental essence of themselves as located solely in the brain, this conflation between personhood and the mind/brain reflects and reinforces constructions of diseases as threatening a person's core being in the world." The biomedical turn in psychiatry sought to reframe mental illness as a biological disorder, comparable to diseases of the kidney, lung, etc. However, in contemporary understanding, the mind, brain, and Self are bound together, with the mind viewed as an emanation of the brain and the terms “mind” and “brain” often used interchangeably, in common parlance, so disorder of the brain becomes difficult to separate from disorder of the Self (Lakoff 2005, 106; Nochi 2000, 1801).

It is important to note that the biomedical framing of mental illness is crucial to destigmatization efforts: if mental illness is brain disease, no different in principle than disease of any other organ, then mental illness should not confer a moral stigma. Unfortunately, if the consequence of brain disease is that a person’s cognition and emotions are altered, potentially permanently, and if the disease can be alleviated only with medical and possibly pharmacological intervention, then the implication remains that control over the Self has been lost, to some extent (Luhrmann 2001, 285). The effects may be physical as well as cognitive, but the cognitive impact of brain injury represents a particularly fascinating case because cognitive impairment could be perceived as an assault not only to the body but also to the Self.

If the brain, as the putative seat of consciousness (Place 1956), is injured, the damage to one’s identity may be far-reaching. Of course, at the most basic of levels, the brain controls autonomic function, movement, balance, sensory perception, etc., so injury to the brain can do anything from altering a person’s gait to shutting down a person’s ability to breathe independently. However, it is the functions of the brain related to reason, emotion, and memory that are most closely associated with our conception of the mind and the Self. The close identification of cognition with the Self is at the root of the perception that neurodegenerative disorders such as dementia slowly erode or annihilate the Self (Beard 2016, 88). Mead theorized that the hallmark of human intelligence—what separates cognition from instinct—is the ability to pause and formulate a deliberate response before reacting to a stimulus (Mead 1934, 99). If reasoned, considered response is the fundament of humanity, then a malfunctioning brain can undermine one's claim not only to social status but to human dignity. Brain disorder patients often struggle to conceal their cognitive changes and manage the impression that they are "stupid" or lazy (Nochi 1998, 676). Evidence of loss of cognitive ability can be experienced as extraordinarily humiliating, striking at the core of one's self-esteem (Beard 2016, 124).

Perhaps even more destabilizing than the perception that one's cognitive faculties are failing is the horror of being unable to trust the evidence of one's own senses. People who experience delusions, hallucinations, or other disorders of perception may lack insight into their mental state, but in many cases, they remain cognizant of the discrepancy between their perceptions and objective reality, effectively forcing them to grapple with the knowledge that they are no longer reliable narrators of their own experience. Confronting the fact that one's awareness of the surrounding world may be shaky or incomplete is disorienting enough, but disorders of the brain may disrupt not only consciousness but also self-consciousness. A person whose brain is malfunctioning may be unaware of the form or extent of the damage, to a degree that may be alarming or poignant to the people around them. Our ability not only to perceive pain or the positioning of our body in space but also to be aware of how others perceive us—of the reactions we evoke in other people—is central to what we understand as quintessentially human (Mead 1934, 172, 190). However, a person with a brain disorder may be unable to perceive a distinction between his or her current Self (and how he or she comes across to other people) and the pre-injury or pre-illness Self.

While we regard reason and cognition as essential elements of human consciousness, we also tend to perceive emotion as a "true," unmediated emanation of the Self and the self-regulation or control of emotional states as hallmarks of higher consciousness. Brain disorder can alter mood, cause emotional lability, or flatten the emotional landscape altogether. Alterations in our emotional responses fundamentally alter our connection with the social world. Furthermore, the perception that emotions arising from a disordered brain cannot be trusted may exacerbate the tendency to treat patients as unreliable narrators. Patients' reactions may be dismissed by caregivers as "having no truth-value" and may be seen not as the result of legitimate grievance but as an extension of their illness, a side effect of medication, or the result of noncompliance with medication regimens (Biehl 2005, 202).

Our sense of what constitutes a Self relies, to a great extent, on the appearance of continuity: unbroken self-awareness, stable and consistent self-presentation, and an uninterrupted personal narrative, for which memory is a critical building block. Cohen (1999, 126) points out that

> memory loss, and "cognitive loss" more generally, becomes metonymically identified with the wide range of behavioral and neuropsychological changes consequent with dementia … the cognitive focus of Alzheimer's—as opposed, for example, to a focus on affective or other behavior change or on delusional symptomatology—suggests a broader cultural and historical consensus, that memory is the key to the self.

Gaps in memory are regarded as gaps in the fabric of the Self, an inability to maintain a consistent account of who you are, who you have been, and how you relate to the world and the people around you. Brain disorder can cause painful erosion of social bonds as memory loss erases shared histories and cherished intimate knowledge. Not only are our shared memories central to our understanding of our relationships with others, memory is crucial to our narrative of understanding of ourselves. It is hard to conceptualize who we are if we cannot refer to past actions or to consistent patterns of thought and behavior.

If there is limited hope for a complete “return” or if the changes are regarded as too complete or fundamental, it becomes difficult to treat a brain disorder as equivalent to a disorder of another organ, such as heart disease or diabetes. Personality disorders present another interesting case because, as generally conceived of and popularly understood, personality disorders are intractable and, in some respects, regarded as inextricable from the essence of the person. What can be done if the disorder is not something the person *has* but something the person *is?* (Davis 2012, 91). Personality disorders aside, a brain disorder label tends to become a lens through which all aspects of a person are viewed—behaviors or traits that might otherwise be dismissed as personal quirks or insignificant habits come to be viewed as evidence or extensions of the disorder (e.g., a bipolar person is not perceived as being an animated conversationalist or as excited and enthusiastic about this particular conversation but as displaying signs of mania) (Angell et al. 2008, 83).

This totalizing effect of labeling raises issues of will and agency when a person is perceived as having been overtaken by an illness or when others assume that a particular disorder is “driving” an action or generating a response. Brain disorder also collides with questions of volition when a particular condition or injury saps people of motivation or limits the ability to make decisions or care about outcomes. Anhedonia and/or adynamia can produce the impression of a person who is “like a car in neutral” (Osborn 1998, 140), and conversely, disorders like Tourette’s syndrome that result in seemingly unmotivated or uncontrollable action can create the perception of a person propelled by an outside force and unable to govern himself (Handler 2004, 88). When it appears that the mind has absented itself, leaving a person in a condition of apathy or ineffectuality or when it seems that the body has developed a life of its own and has wrested control from the mind, this loss of control can be experienced as a “loss of self” (Charmaz 1991, 44).

From a practical and logistical perspective, brain disorders can threaten a patient's independence and sense of being a respected, responsible adult (Nochi 1998, 670), and "for [many ill people], dependency remains a greater specter than death" (Charmaz 1991, 80). One of Lock's (2013, 89) informants reflected:

> I'm more worried about getting Alzheimer's than dying. It scares me because, you know that's … you're not a person at that point and you can't do anything for yourself. I'm very independent; I've been working for 35 years and I raised four kids, no housekeepers, no maids. To have to have someone look after me, it's something I wouldn't want to be around for. My mother-in-law had it, my girlfriend's husband had it, and I've seen it and it's worse than being dead. You know if you're dead you're at least gone, and you don't require people to wait on you and feel bad for you.

This loss of self-determination and demotion to what is perceived as a subordinate status is particularly repugnant in the context of the American cultural landscape with its emphasis on self-efficacy, self-reliance, and productivity.

This apparent subordination is compounded when the Self is presumed lost or damaged and the patient's cognition, emotion, personality, memory, will, etc. are believed to be disordered. Caregivers must balance respect for patient autonomy with a desire to prevent harm, and patients' freedoms may be curtailed when a patient is perceived to lack insight or to be incapable of making rational self-care decisions (e.g., when a patient is unaware that he/she has vestibular issues and is restrained in order to prevent a fall or when an anorexic patient is put on a strictly regulated meal plan). Nurses are often charged with mediating this conflict between a paternalistic ethos of care and patients' bids for agency and enforcing edicts handed down by administrators or physicians (Chambliss 1996, 141). This care/protection conflict is thrown into starker relief when patients decide to reject treatment that medical professionals believe is crucial to their wellbeing, as Luhrmann (2001, 125) notes:

> Neither the laws nor the circumstances permitted the staff to take charge of patients who felt they could manage on their own. (I heard one psychiatrist wonder wistfully whether

> the current legal situation didn't infringe the patient's right to treatment.) The problem, then, was that the staff essentially *had* to treat patients as rational adults capable of making reasonable and informed choices about their illnesses, and most of them obviously were not.

Patients and healthcare workers are also often at odds over medication management, with care workers expressing frustration over patient "noncompliance" with psychopharmaceutical regimens (Brodwin 2013).

In the case of patients whose symptoms are particularly disruptive, healthcare workers may have to make a concerted effort to involve the patient in treatment planning and to help the patient gain insight into and understanding of the diagnosis being applied and its implications (Beard 2016, 78). However, brain disorder patients are regularly relegated to secondary status in discussions of their own diagnoses and care, with details directed primarily at family members or other caregivers and the implicit understanding that a patient is not fully capable of understanding or competent to participate in decisions (Beard 2016, 109).

This perception of incapacity carries over to the structural level, with facilities like nursing homes catering, to a lesser or greater extent, to the sensibilities of patients' children or other loved ones, emphasizing features such as safety and security, for instance, that may be less important to the patients themselves, as Gawande (2014, 106) explains:

> Above all, [elder care facilities] sell themselves as safe places. They almost never sell themselves as places that put a person's choices about how he or she wants to live first and foremost…. Many of the things that we want for those we care about are things that we would adamantly oppose for ourselves because they would infringe upon out sense of self.

People with brain disorders are particularly at risk of feeling like (and actively being regarded as) somehow less than human, "devoid of feelings, sensitivities, and basic rights," being talked about rather than to, and being perceived as unreliable narrators of their own experiences (Angell et al. 2008, 76). Although people with brain disorders are often perceived as vulnerable to abuse, and consequently, as potentially ethically fraught subjects for medical and social scientific research, it is important to investigate the experiences and priorities of people whose preferences and agency are chronically overlooked and to find means of communicating and obtaining consent that accommodate, for instance, verbal communication deficits (Hougham 2005; Hougham et al. 2003, S31).

Intersectional[8] Identities and Historical Inequities[9]

The biopsychiatric framework tends to obscure the influence of social and structural features on the construction of diagnostic categories (Metzl 2009, 14–15), so it is essential to examine the various avenues through which human bias impinges on scientific rationality. In the American healthcare system, substantial disparities of access and outcomes across racial and ethnic groups have been well documented. It is difficult to disentangle the effects of race from the effects of other demographic factors, such as age, gender, socioeconomic status, and country of origin. Researchers often advocate for greater awareness of intersectionality in mental health research, but the complexities of mental health epidemiology are such that researchers seldom undertake large-scale studies that take into account multiple intersecting social identities (Brown et al. 2013).

Medical professionals and laypeople alike tend to fall prey to the "fallacy of reification" and consequently treat socially constructed categories, such as race, as though they are inherent facts of the natural world as opposed to mutable creations of the social world (Duster 2005, 1050).

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[8] See Kimberlee Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6 (1991): 1241–1299.

[9] It is overly simplistic to discuss race, gender, and socioeconomic status as individual variables that independently influence the construction of diagnostic schema. What it means to be a black woman, for instance, is a highly situated experience, not reducible to either blackness or femaleness, and a complete understanding of how identity categories shape diagnoses requires careful consideration of the complex intersectionality of social identities. Of necessity then, there will considerable overlap in discussions of the impact of race, gender, and socioeconomic status on the creation of diagnostic categories.

In American medical history, examples abound of scientific or medical "facts" being deployed to naturalize disparities and justify exploitation (Ehrenreich and English 2011, 298). Racist ideologies, for instance, are flagrantly apparent in medical theories that were used to defend slavery, such as assertions that White and Black people exhibited marked differences in body morphology, mental capacity, moral sensibility, personality characteristics, disease susceptibility, and pain tolerance (Washington 2006, 33–43, 156). During the era of American slavery, pre-DSM psychological categories included race-specific disorders, such as drapetomania (a mental disorder characterized by a tendency to run away from one's slave master) and *dysaesthesia aethiopis* ("a form of madness manifest by 'rascality' and 'disrespect for the master's property' that was believed to be 'cured' by extensive whipping" (Metzl 2009, 30; Washington 2006, 36).

Over time, the racial biases embedded in diagnostic categories became less overt, but their influence is observable in the historical evolution of diagnoses that are still in use today. Prior to the Civil Rights Era, schizophrenics were presumed to be "largely white, and generally harmless to society" (Metzl 2009, xii), and the diagnosis was stereotypically associated not with violence or disruptiveness but with sensitive, introverted souls, with a gentle, feminine, even poetic nature. However, as the social context changed and backlash to the Civil Rights Movement stoked fears of societal upheaval, the clinical and social perception of schizophrenia shifted dramatically toward an archetype of menacing Black masculinity, with an emphasis on combativeness, aggression, rage, paranoia (especially anti-White or anti-institutional), opposition to authority, and a threat to society. The population of patients diagnosed with schizophrenia shifted correspondingly (Metzl 2009, 14; 35). If diagnostic categories were purely empirical outgrowths of biological disorders that exist entirely independent of human social forces, we would expect categories to remain fixed over time and across populations, but in fact, diagnostic labels are shaped and reshaped by the institutional and individual biases of humanity (Martin 2007, 211–12).

Alongside racial ideologies, norms of ideal gender presentation and scientific theories interact with and co-produce each other, and disorder is often defined in terms of deviation from "healthy" adherence to gender roles and norms (Wentzell 2011, 225; Washington 2006 33–42, 152; Metzl 2009, 11; Elson 2004, 90). Female reproductive organs were, for long spans of history, believed to render women vulnerable to all manner of neurological and psychological maladies, and every phenomenon from irritability to total mental collapse could be traced back to a corresponding gynecological abnormality. This physically and mentally fragile condition was thought to be unique to middle- and upper-class White women. "Doctors declared the immigrant and black women of the lower classes to be healthy as a (work) horse, naturally fit for superhuman levels of sweat and travail" (Ehrenreich and English 2011, 111; 542–44).

Socioeconomic prejudices that influence the formation of medical knowledge are inherently bound up with race and gender ideologies. In a manner similar to the way resistance to oppressive authority was framed as a sign of mental pathology among enslaved Africans, "the poor as a 'race' [were thought to be] afflicted with pathological rebellious tendencies" (Ehrenreich and English 2011, 790). Diagnostic categories act as a means of social control, particularly when it comes to the public behavior of disempowered populations; the pathological is often closely identified with the morally objectionable and socially dangerous. The poor and visibly physically disabled or mentally disturbed have historically been particularly vulnerable to pathologization as a tool of delegitimizing their use of public space, as epitomized by city ordinances that framed "unsightly beggars" as an affront to social decency, a danger to the general populace, and a public health hazard. Within this "politics of fear and aversion," to be poor and visibly deviant was a double hazard (Schweik 2009, 33). To this day, the mentally ill homeless are at particular risk of stigmatization and victimization (Luhrmann 2008, 15).

Humanity has a long, ignoble history of endeavoring to reify ideas about gender, race, and class by mapping them onto the brain (Rosser 1988), thereby establishing a putative biological basis for existing prejudices and enabling people to dismiss social inequalities as part of the natural order. Fine (2010, 146) identified a mysterious tendency for scientific findings to accord with an era's prevailing beliefs about gender:

> For example, in the nineteenth century, when the seat of the intellect was thought to reside in the frontal lobes, careful observation of male and female brains revealed that this region appeared both larger and more complexly structured in males, while the parietal lobes were better developed in women. Yet when scientific thought came to the opinion that it was instead the parietal lobes that furnished powers of abstract intellectual thought, subsequent observations revealed that the parietal lobes were more developed in the male, after all.

Time and time again, the most respected and supposedly rigorous and objective methods of the day conveniently reinforce hegemonic beliefs about gender, race, and class from early anthropological studies that projected racial, gender, and socioeconomic prejudices onto comparisons of skull morphology, to modern neuroimaging studies on the "gendered brain" that often elide intra-gender differences and "variations that call the two bifurcated [gender] categories into question" (Pitts-Taylor 2016, 119). Relatively novel technology such as fMRI is often heralded as ushering in a new wave of neuropositivism, enabling scientists to lay bare the brain's secrets, once and for all (Racine et al. 2005), but researchers and laypeople alike are too often guilty of projecting preconceptions onto neuroscientific data. Furthermore, our imperfect understanding of the complex operations of the brain often renders results highly interpretable and open to bias, leading to overconfident imputation of meaning to perceived differences in structure or neural activity and generating "just-so stories" (Fine 2000, 145).

Intersectional Identities and Diagnostic Practice

Healthcare workers enter clinical interactions with their own sets of identities (which in turn elicit particular responses from patients), their own life experiences, and their own histories of professional socialization. In their professional training, doctors are taught not only diagnostic categories but also how to apply them in practice, and this process of professional socialization transmits embedded assumptions about social categories, such as race, gender, and socioeconomic status. A psychiatrist in training must learn to map the symptoms listed in the current version of the DSM onto the complex reality he or she encounters in the clinic. The psychiatrist in training learns to recognize what mania looks like, how it "feels" to be in the presence of a depressed person, and how a classic case of anxiety disorder presents (Luhrmann 2001). In combination with a set of socially constructed diagnostic categories, these processes of professional socialization shape what a psychiatrist sees when a particular patient appears in the clinic (Martin 2007, 126). In 1989 and 2003 studies, researchers found that

> psychiatrists tend to give correct diagnoses for a schizophrenic case description or a personality disorder case description when no identifying racial information on the patients is given. When race is specified, however, irrespective of psychiatrists' race, black patients are more likely to be given more severe diagnoses (Brown et al. 2013, 264).

This work presents clear evidence of the effects of race on diagnosis, although it remains impossible to disentangle the effects of individual racial prejudice and implicit biases inculcated by professional socialization from the influence of the racial ideologies encoded in the diagnostic categories themselves.

When a chronic, disabling brain disorder manifests, poverty inarguably puts a person at greater risk, in numerous respects: patients may have inconsistent access to healthcare, may struggle to maintain medication regimens, may be denied more expensive psychiatric services such as inpatient treatment or psychotherapy, and may be at greater risk of downward mobility without the safety net provided by resource-rich social networks (Charmaz 1991, 185). Even when researchers account for socioeconomic discrepancies and differences in health behaviors, however, evidence of racialized physical and mental health disparities persists, suggesting that race and ethnicity play a compounding role in shaping patient outcomes (Monk 2015, 397). Implicit racial attitudes may inflect how patient's behaviors are interpreted. Brain disorders may be characterized by "potentially severe affective instability, aggression, or disinhibition/markedly impaired social judgment, and occasionally by apathy or paranoia" (Max et al. 2001, 169). Unfortunately, these types of symptoms lack an obvious association with brain disorder (in contrast to, for instance, an inability to remember one's loved ones or difficulty maintaining balance while walking), and without the clear explanatory framework of brain disorder, these sorts of symptoms can be interpreted not as medical pathology but as uncooperativeness or an unpleasant personality, particularly when implicit bias comes into play. Racial and ethnic prejudice often intersects with nativist prejudice and can be expressed as a propensity to attribute undesirable characteristics to cultural pathology or racial/ethnic characteristics, as opposed to individual illness (e.g., one patient is thought to behave in a certain way because his ethnic group is notoriously irresponsible or unreliable, but a patient with similar symptoms is presumed to be experiencing difficulty self-motivating due to depression) (Schweik 2009, 180; Davis 2012, 111).

People who visibly differ from the "unmarked categories" of Whiteness, able-bodiedness, etc. may be subject to surveillance in the public sphere and may be targeted by law enforcement or by officious or abusive members of the public who question their right to inhabit the space, their motives for being there, or the propriety of their behavior. At the intersection of Blackness and poverty, people are particularly susceptible to social surveillance and have historically been subject to forms of policing that include medicalization and diagnosis as a form of censure or social control: to be Black, poor, and occupying public space was to be at risk of being labeled a public nuisance or menace, at a time when concepts of morality, individual and public health, and criminality were closely interwoven. At times, these moral-medical ideologies were enshrined into local ordinance, in the form of Wayward Minor Laws, Tenement House Laws, and Unsightly Beggar Laws (Hartman 2019, 221, 241; Schweik 2009) that gave law enforcement officials virtually unlimited latitude to round up and discipline poor people of color who were perceived as not only affronting public decency but also jeopardizing public health by, for instance, "being too loud or loitering in the hallway of your building or on the front stoop" or being a single woman and inviting a man home (Hartman 2019, 241).

Within the criminal justice system, Black defendants are less likely to have their actions framed as resulting from illness as opposed to criminality, and consequently, courts are more likely to hold Black defendants responsible for their actions than White defendants under similar circumstances (Thompson 2010). Within the healthcare system and in society at large, poor people and particularly poor people of color are more likely to be blamed, in some form or another, for a disabling injury, substance abuse disorder, or other mental health condition, even by medical professionals who are themselves people of color (Rich 2009, 17). For instance, Black people are more likely to be held responsible for health problems such as obesity and presumed to be slothful or gluttonous, whereas White people are more likely to be diagnosed with conditions such as "binge eating disorder" (Saguy and Gruys 2010).

Gender ideologies also shape which patients receive a particular diagnosis and which do not, as well as who is regarded as an accurate reporter of his or her experience. The systematic inclination to disregard or minimize women's pain is an illuminating example. "Although women more frequently report pain to a health-care provider, they are more likely to have their pain reports discounted as ‘emotional’ or ‘psychogenic’ and, therefore, ‘not real’” (Hoffman and Tarzian 2001, 21). In treating physical or emotional pain, doctors must rely on patients’ self-reports, and doctors’ medical assessments are systematically biased by stereotypes that women are prone to exaggeration or self-dramatization or are likely to somaticize emotional pain. Women are also disadvantaged by the folk belief that they are somehow built to endure pain or are naturally more capable of withstanding discomfort due to being inherently equipped to suffer in childbirth (Hoffman and Tarzian 2001). This gendered belief about pain tolerance has historically been carried to extremes in medical and political beliefs about poor women (Ehrenreich and English 2011) and women of color—a belief that has been used to justify not only egregious labor exploitation but also torturous medical experimentation (Washington 2006).

Gender stereotypes also undergird perceptions of what is and is not “normal” for a given person. How soon do we recognize increased aggression as a clinical sign of brain trauma in young men, for instance? How likely are we to overlook or delay diagnosis of autism in young women who do not fit the “typical” case (e.g., Begeer et al. 2013)? Do we dismiss emotional lability as a “midlife crisis” or as a shift in hormones, or do we investigate it as a sign of traumatic or degenerative changes to the brain (Nochi 1998, 675)?

Poor people are also more likely to be regarded with suspicion by healthcare workers who may interpret claims of physical or psychic pain as malingering or as attempts to gain access to medications or services (Schweik 2009, 80). Even when the person in question is not housing insecure or long-term unemployed, medical professionals may be suspicious that the patient has ulterior motives and has some form of “secondary gain” in mind, such as qualifying for disability payments or worker’s compensation. Conversely, people who present as highly educated or high status tend to be given the benefit of the doubt, not only because their motives are presumed to be pure but also because physicians may more easily identify with the plight of highly educated, high SES individuals and may be more inclined to lend credence to narratives told by patients who have greater mastery of the biomedical lexicon (Murphy 2001, 90). Patients whose words, behavior, dress, and other sociocultural insignia convey higher SES may in some ways be insulated from the discrediting and stigmatizing effects of exhibiting severe brain disorder.

Variables such as age and nativity may also interact with race, gender, and SES to influence diagnostic interactions. Doctors determine whether an elderly patient's cognitive deficits indicate an underlying pathology or are the result of "normal" aging, and normative beliefs about what old age looks like and how people should reasonably expect to function in old age influence which complaints are taken seriously and whose concerns are minimized or dismissed (Nochi 1998, 675). Healthcare professionals may also adjust their recovery expectations downward for elderly neurotrauma patients due to implicit assumptions that elderly people should already expect to lead more circumscribed, less independent lives. Doctors may also be less sensitive to complaints about mood disorder by elderly patients because they regard their problem as fundamentally physiological or environmental (i.e., brought about by poor physical health or social isolation). Some healthcare workers are inclined to frame certain elderly patients as essentially hypochondriacs who come to the doctor's office because they are bored, lonely, or in need of human contact (Scheper-Hughes 150). Beliefs about what constitutes healthy or unhealthy aging are highly culturally specific (Cohen 199). Stereotypes about national origin may have a considerable impact on how diagnoses are applied, and cultural differences may influence how a medical verdict is received and interpreted by patients and by their loved ones (Scheper-Hughes 2001, 160; Mills 2014, 75).

Among minority racial groups with a long history of abuse and exploitation by the medical establishment, people may be inclined to distrust and avoid medical intervention. The history of people of color in America is one of not only state control but also exploitation by medical and research institutions. Some examples of this include the sadistic and grisly experimental gynecological surgeries performed on unanaesthetized and unconsenting slaves in the 1840s by J. Marion Sims, the "father of modern gynecology;" the notorious and deceptive Tuskegee Syphilis Trials that ran for much of the twentieth century; and the "Mississippi appendectomies," the eugenically-motivated forced sterilizations, often conducted without the knowledge of the patients that took place for decades of the twentieth century (Washington 2006, 63–68, 157, 202). Some members of historically marginalized racial groups may also be acutely aware of the potentially negative implications of taking on a stigmatized identity and may consequently strive to avoid a psychiatric diagnosis and its attendant stigma. However, among people whose symptoms are the most "bizarre, violent or otherwise frightening," this effect lessens, and people of all social backgrounds are likely to seek out psychiatric care (Greenley and Mechanic 1976, 261). When the symptoms are sufficiently acute and alarming, the effects of race and ethnicity on help-seeking seem to be attenuated.

Whether an individual receives treatment and what form that treatment takes are not entirely a function of the treatment options at his or her disposal: social norms about help-seeking weigh into individual decision-making, in conjunction with logistical factors such as the economic and geographical availability of a particular treatment option (Mechanic 1994, 97). Membership in a social group in which mental illness is heavily stigmatized and seeking psychiatric treatment is socially proscribed reduces the probability that an individual will take advantage of available mental healthcare resources. In contrast, an individual will be more likely to seek treatment if he or she is embedded in a community where brain disorders are regarded as biological conditions with biochemical or neurological etiologies, morally and functionally identical to physiological disorders. Gender socialization also seems to have a substantial impact on whether a person identifies his or her symptoms as evidence of brain disorder and reacts by seeking psychiatric treatment. For instance, women may be more likely to seek psychiatric help because women are generally socialized to readily communicate feelings or concerns and are not as heavily stigmatized for demonstrating vulnerability and reaching out for support (Greenley and Mechanic 1976, 261; Philipps 2010).

Diagnosis, Identity Construction, and Role Performance

Disruption of social role performance is one of the most potentially damaging effects of brain disorder and of taking on a stigmatizing diagnosis, particularly if the role or roles in question are central to a person's sense of Self. In the aftermath of stroke or trauma, patients begin to reorganize their identities while being treated on the post-acute ward, within the particular organizational culture of the inpatient rehab and the overarching epistemic cultures of the fields of neurobiology and rehabilitative medicine (Knorr Cetina 1999). This cultural context informs how "recovery" is defined (both in terms of general program goals and for individual patients), how rehabilitation benchmarks are set, how patients' progress is evaluated, and how the efficacy of particular treatments is assessed (Meyers 2013, 20).

Patients and their significant others carry into this context preexisting beliefs about themselves and preexisting beliefs about neurobiology, TBI/stroke, and people in recovery from TBI/stroke (as informed by education, personal experience, media representations, etc.). During their time in the post-acute ward, these preexisting beliefs interact with patients' experiences of their changed brains and with their perceptions of how others now perceive them. Identity formation occurs not just in interactions between individuals but in interactions of individuals with institutional discourses and structures (e.g., if a patient is deemed a fall risk and precautions are put in place to restrain and/or surveil the patient for his or her safety, the patient may begin to identify as less independent, self-assured, or capable of taking initiative) (Glaeser 2000, 91–92).

In a capitalist culture, in which the ideal human being is a fully capable participant in the labor economy, loss of professional identity and attendant status, belonging, and economic power may threaten a patient's sense of Self (Longmore 1997). Murphy (2001) describes his efforts to adapt to paraplegia by emphasizing his retention of cognitive faculties and his continued ability to perform in his capacity as writer, researcher, and lecturer. Through focusing on his role as financial provider, he shored up his masculinity and attempted to stave off the negative identity consequences of his physical disability. He downplayed the importance of the physical body and attempted to protect his identity by demonstrating, in his words, "Hey, it's the same old me inside this body!" In the case of people with cognitive deficits, a great deal of care is often taken to avoid coming across as a degraded version of oneself, as increasingly helpless, childlike, or unable to contribute (Beard 2016, 6). People with brain disorders report feeling devalued in the labor market and relegated to low-skilled, menial work with a great deal of oversight and supervision (Angell et al. 2008, 79). In American culture, disability is often defined with reference to labor market participation, such that one may be able to avoid self-identifying as disabled if it is still possible to fulfill one's professional roles and responsibilities, to some extent (Murphy 2001, 81).

As Mackelprang and Salsgiver (1999) articulated, there is often a presumption of incompetence where disability is concerned, and there is a great deal of precedent for "professionals tak[ing] control of the lives of people with disabilities." Theorists of "social disability" emphasize that "all human competencies (those of people with disabilities and people without disabilities) represent an interaction of the person’s ability to complete a task and the resources of the environment in which this task occurs.” Disability is therefore not an inherent quality of the disabled person but rather a result of limitations imposed by an unaccommodating environment (Corrigan et al. 2004, 485–86). Nochi (1998, 672) describes a scenario in which a woman with a traumatic brain injury was able to preserve her professional role by making the case to her boss that she should be evaluated on the basis of her work product as opposed to her ability to conform to normative work habits (e.g., working 9-to-5 in a hectic and, for her, distracting shared workspace). Success at winning workplace accommodations generally hinges on a re-framing initiative that defines areas of deficit as nonessential to work performance or coming up with compensatory strategies. A teacher explained how she framed her adaptive needs for her class: “I was fortunate enough to be able to tell my class that I had a problem with my short-term memory, dyslexia, and attention deficit…. I explained to them that I had all the answers for them, but I needed their help to get them out” (Nochi 1998, 672). As an instructor, she still “had all the answers,” provided she could rely on the support and collaboration of her students.

Unfortunately, not all workplaces or professions are forthcoming with reasonable accommodations, and in some cases, people have to reconcile themselves to the loss of valued roles and cope with the painful contrast between their current capabilities and the valued characteristics of their “previous” Selves. Awareness of the discrepancy between current and former abilities often engenders embarrassment, frustration, and anguish (Beard 2016, 101). Murphy (2001, 172), for instance, struggled acutely when he could no longer pursue ethnographic fieldwork; he retained his ability to write and teach, but he regarded fieldwork as “the distinctive and defining feature” of his profession.

Charmaz (1991, 58) explains that for people coping with chronic illness, "narrowed worlds resulted when the daily round consisted only of vital activities, work, and self-care. These men and women could not pursue relationships, hobbies, or recreation. They barely maintained themselves, much less their households." If illness curtails one's activities or contracts the scope of one's life, regaining one's professional identity may appear all the more urgent, a route back to a life of meaning and substance, particularly if work has previously been a primary source of pride, stimulation, and independence. Given a residual cultural tendency to identify masculinity with the ability to participate in market labor, support one's family, and contribute financially to one's household, it is possible that this loss of professional identity is all the more threatening to men who are forced out of the workplace, either permanently or temporarily (Murphy 2001, 204). Evidence suggests that when the female partner becomes the sole breadwinner, men may in fact retrench to an attitude of greater gender traditionalism, and women who out-earn their husbands, especially to the point of becoming the sole source of household income, *increase* their relative share of conventionally "feminine" domestic work, perhaps as a means of bolstering their husbands' masculinity or ameliorating their own gender deviance (Bittman et al. 2003; England 2000).

However, gender norms are one of many factors in play, and people of any gender who leave professions in which they have invested considerable time, commitment, and meaning often experience a loss of self-esteem and some degree of identity upheaval (Stone 2007, 147). One of Hochschild's respondents provides an illustrative example of the way the work devotion schema encourages individuals to derive self-respect from professional accomplishments and identity. She muses, "My self-esteem rests on excelling at that one thing—being an ace on the U.S. tax code. I don't value myself for much else. So I worry: what if I'm laid off? Do I know how to value myself for doing the things I've outsourced, let alone remember how to do them?" (Hochschild 2012, 107). Survey data suggest that for 87 percent of working women, the "'sense of accomplishment and personal satisfaction' [is] an 'important' justification for employment, alongside financial motives" (Hochschild 1989b, 159). Many women who leave the labor force experience a sense of isolation and lack of stimulation (Stone 2007, 147). One of Stone's (2007, 145) interviewees described the degrading sense of becoming irrelevant or degraded, within her former social context:

> It was like all of a sudden I didn't exist. If I didn't have an identity in the working world, I didn't exist…. I thought, well, I haven't changed. I'm the same person I was. You know, six months ago I was working in the U.S. Attorney's office doing all this hot stuff. My name was in the *New York Times*, blah, blah, blah, blah, blah. Now I'm nobody. And it was just weird. It was, it was really strange. And people, just, they had nothing to talk to me about. You know, they couldn't relate. (Stone 2007, 145)

People who leave the workforce may experience acute status anxiety, even among strangers, as articulated by a woman interviewed by Hochschild (1989b, 159).: "Being out of work, I felt really *inferior*. When I went out to the supermarket in the morning, I felt fat [she hadn't lost the weight from her pregnancy] and dumb. I wanted to go up to the people in the aisles and say, 'I have an MBA! I have an MBA!' I didn't want to be classified as a dumb housewife." Whether among former colleagues, strangers in a supermarket, or simply in the privacy of their own homes, professionals who leave the workforce may struggle to cope with the perceived loss of identity and social status. Although researchers often discuss the losses experienced by *high* status workers who exit the workforce, one should not underestimate the importance of *any* kind of wage labor in conferring a sense of independence, self-efficacy, and status (Hicks-Bartlett 2000, 38; Zelizer 2005, 170).

It is also important to note, however, that professional identity is not always of central importance to a person's sense of Self, and for "some older workers dissatisfied and weary with their jobs," having a reason to withdraw from the workforce might not be entirely unwelcome (Murphy 2001, 204). Not everyone feels that cognitive prowess, articulateness, etc. are particularly salient factors in shaping their sense of self-worth and social value, and several of Beard's (2016, 100) Alzheimer's patient informants expressed gratitude for their continued physical abilities and downplayed the importance of their mental faculties. (e.g., "Fortunately, everything physically works. It's just my mind. I guess if I was a writer it would be a problem.") Not everyone places equal emphasis on his or her professional role, and many people successfully turn to other sources of identity and meaning, such as personal relationships.

People whose families and social networks rally around them and provide affection and support may be buffered, to some extent, from some of the negative impact of disability and chronic illness. Charmaz (1991, 62) reported that "those who believed that they could rely on family expressed much less anxiety about giving up jobs and other obligations than those without families or who did not wish to rely on them." People who can draw on substantial economic and/or social capital are better situated to weather disabling brain disorder than people who lack the ability to either pay for or voluntarily recruit care and companionship. All forms of chronic illness may cause social circles to contract, to some extent, as people shoulder additional self-care responsibilities or cope with logistical or financial obstacles. This relational "triaging" can be a mixed blessing, permitting chronically ill people to husband their energies and prioritize their most valued relationships but also diminishing their available sources of social support. The chronically ill may also be forced to remain in undesirable or even abusive relationships (romantic or otherwise) because they are reliant on the relationships for care and/or financial support (Charmaz 1991, 81–82).

Even people with robust social lives prior to brain injury or illness onset may find that their social networks diminish, either because they no longer have the energy or appetite for social interaction (particularly when it involves cognitively taxing environments) or because their friends are discomfited by their changed circumstances. When a person is not visibly disabled, it may be difficult or awkward to communicate to old friends and acquaintances that all is not as it was before and that the brain disordered person may face new interactional challenges or require understanding and accommodation (Nochi 1998, 675). People with more immediately obvious impairments may have to negotiate self-consciousness, hyperawareness of how others perceive them, and their own particular sets of interactional dilemmas.

Murphy (2001, 91), for instance, describes how, in addition to the awkwardness inherent in appearing in a wheelchair for the first time and having to deal with people's curiosity and patronizing solicitude, navigating a social situation in a wheelchair involves the physical and social discomfort of craning upwards, finding it difficult to gracefully escape unpleasant social interactions, and feeling ignored or sidelined, all of which can lead to changes in the types of social events one is willing to attend. People whose disorders are heavily stigmatized, poorly understood, and/or not expected to follow a "recovery" trajectory may feel they occupy a liminal social space, both in the sense that they may be ostracized by friends who no longer want to (or know how to) include them and in the sense that they fall outside clearly defined roles, such as the recovery-oriented "sick role" defined by Parsons (1958).

This sense of social failure and rejection can be exceptionally painful, particularly when the person in question cherished his or her identity as a popular, socially adept, or highly community-spirited person. Disillusionment and feelings of abandonment can arise if the desired degree of family or community support fails to materialize or if friends begin to drift away because they are put off or burnt out by the degree of care required or are unsure how to interact with the "new" person the brain disordered individual has become. This effect can be exacerbated if the brain disorder is caused by a particularly stigmatized condition, such as schizophrenia, or by an incident such as a drunk driving accident or an episode of violence, potentially undermining the person's perceived worthiness of social support and sympathy (Devlieger et al. 2007, 1952).

Damage to the relationships in which one is most deeply invested may be most acutely painful. For instance, people with brain disorders can experience emotional dysregulation, resulting in outbursts that may terrify or embarrass their loved ones as well as the anguish of seeing one's child recoil in fear or sensing that one's partner is ashamed of one's public behavior (Osborn 1998, 86; Lock 2013, 90). People with brain disorders may also experience the peculiar torment of watching their loved ones mourn their "loss" or fearing that partners will desert them or come to regret having committed to them because they are no longer who their partners fell in love with, nor are their relationships what their partners originally bargained for (Beard 2016, 126; Charmaz 1991, 63).

Lack of reciprocity in care can also strain even the strongest relationships in the long run (Charmaz 1991, 80). Even if support is abundantly available and graciously and gladly offered, the imbalance in the flows of service and gratitude can be destabilizing, leaving the more reliant partner feeling dependent, useless and devalued, or obliged to be extravagantly appreciative. A brain disorder can "significantly complicat[e] everyday life and often revers[es] social roles such as parent, nurturer, or partner" (Beard 2016, 143). Young children may be called upon to take on household responsibilities that are generally the province of adults, and children of chronically ill parents may face a shift in the normative balance of care, with children learning to assist a parent in navigating obstacles of daily living and keeping a close watch for signs of relapse or escalation of illness (Charmaz 1991, 63). These shifts are often painful and unsettling and may occasion guilt and social and existential discomfort for all parties involved. People often express dread of becoming a burden to their loved ones (Hochschild 2012, 200; Lock 2013, 90), and people may be acutely sensitive to the "debasement of status" associated with "lack of autonomy and unreciprocated dependence on others" in American culture (Murphy 1990, 201). People may find it particularly difficult to adjust to changes in the distribution of gendered forms of labor in the household (Murphy 1990, 205–206.

Social relationships generally maintain a careful equilibrium of reciprocity, with attention paid to matching the type of relationship and the obligations and rights such a relationship generally confers to the proper modes of recompense (Zelizer 1996). In general, relational harmony is maintained in part by careful regulation of the intimate economy: ideally, perceived imbalances in services rendered are redressed and appropriate expressions of gratitude are exchanged (Hochschild 1989a*)*. When one partner becomes the other partner's caregiver, this intimate economy is thrown into chaos. In order to ameliorate this discomfiting situation, people may turn to the market, choosing paid care over care provided by family and friends. By entering into a market relationship, care recipients may establish a relatively straightforward exchange of service for salary and avoid a potentially complex and fraught caregiving relationship with a loved one. The subject of facilitating the sexuality of disabled people has been a matter of considerable debate (Kulick and Rydström 2015), but relying on a paid caregiver to arrange a sex toy, for instance, might be perceived as less transgressive than requesting similar assistance from a non-spouse family member.

Paid caregivers may also shoulder some of the painful emotional labor involved in caring for the elderly and infirm. Market-based care relationships are contractual and circumscribed, while intimate relationships are often embedded in complex relational networks and interpersonal histories. Consequently, market-sourced caregivers may be “less disappointed, less hurt, less agonized” by signs of a patient’s physical or mental decline. A loved one may be hurt and dismayed if a suffering care recipient lashes out; a spouse or child who is mourning a “former” Self may be anguished by signs of physical or mental decline; paid caretakers, on the other hand, are less likely to take slights personally and may be more capable of engaging with a care recipient as he/she is *now* rather than dwelling on or lamenting changes (Hochschild 2012, 176).

Romantic relationships are also crucial components of the process of “doing gender” (West and Zimmerman 1987). The disruption of relationship dynamics and household routines may undermine gender performance, for instance, if a gender traditionalist man is forced to take on feminine-coded caregiving tasks for which his gender ideologies and socialization leave him ill-equipped and to which he is disinclined. Hoffman and Tarzian (2001, 16) noted that gender norms seem to influence how people “attribute meaning to their pain” and under what conditions they seek healthcare, with men more often complaining of “physical symptoms or functional limitations” and women tending to foreground the effects of pain and disability on the people around them and on their personal relationships.

The loss of capabilities that a person deems necessary for successful gender performance (e.g., driving, cooking, remembering personally significant information, doing yardwork, fixing appliances, taking care of children, etc.) may compound frustration and humiliation associated with loss of independence (Beard 2016, 143; Murphy 2001, 206). Women may also be impacted by societal norms linking femininity to motherhood, framing mothering as the “quintessence of womanhood,” and caring for home and family as essential to feminine gender performance (Elson 2004, 90). Elson (2004, 91–92) posits that “[w]hile the ability to give birth is a physical capability for most women, the understanding that *all* women must mother is a cultural expectation," and even women who are not ideological gender traditionalists or who regard motherhood as a social rather than biological imperative may feel that loss of ability to have or care for children undermines feminine gender performance. People with brain disorders may be deemed incapable of caring for their children, may find their relationships with their children altered or strained, or may lose access to their children altogether, and these disruptions and estrangements can be exceptionally painful. Even people without children can suffer a form of loss if they feel they are precluded from having children, either due to social or interpersonal limitations or because they (or others) feel they would be unfit parents.

It almost goes without saying that nonreproductive sexuality is also a highly significant component of "doing gender," and deterioration of sexual and romantic relationships can undermine not only sexual satisfaction and connection but also one's status as a person who is desirable and desired. Murphy (2001, 97) laments that disabled people are often relegated to the status of asexual, infantilized objects of care or are regarded as "malignantly sexual," fundamentally undesirable such that their sexual interest could only be inappropriate or misdirected. The social construction of erotic objects and the socialization of "erotic attention" not only establish who is or is not an appropriate erotic object and who is considered conventionally desirable but also who is erotically *disattended*, ignored not only as a sex object but also as a sexual subject with his or her own erotic urges (Zerubavel 2015, 52). Debates about a right to express one's sexuality and about the logistics and ethics of facilitating access to sexual expression for the mentally and physically disabled are hotly contested and highly complex (Kulick and Rydström 2015), but feeling undesirable (or that one is not even acknowledged as a sexual being) can damage not only a person's gender performance but also his or her sense of Self (Elson 2004, 124–24).

Chronic illness in general and brain disorders in particular can disrupt not only a mutually satisfying sexual relationship but also the sense that one is still a worthy and valued object of affection (Osborn 1998, 184). However, when a person feels loved and supported and able to meaningfully contribute to a happy partnership, the integrity of this relational status can help preserve and sustain a sense of self-worth, such that a person's identity as a spouse or friend or family member may supplant or repair a stigmatized identity (Watson 2002, 516). Handler (2004, 132) writes of his relationship with his partner: "If we went out and I was Touretteing really wildly, Susanna would lean over and kiss me. When people saw someone loved me, they thought of me as more human, rather than some madman." There is considerable social power in being claimed as a loved one, and publicly assuming the status of Someone Who Is Loved, Valued, and Desired can ameliorate stigma.

Conclusion

Disorders of the brain strike at the very core of our definitions of the Self. If cognition, self-awareness, continuity of consciousness, memory of the past, and ability to project oneself into the future are disrupted, how does a person or his or her loved ones and caregivers deal with the resultant ethical, identity construction, stigma management, and interpersonal dilemmas? In discussions of brain disorders, metaphors of the Self-Overtaken-by-Outside-Forces or the Lost Self are frequently invoked, and diagnostic and treatment decisions are complicated by perceptions that the person with a disordered brain may not be an accurate observer, a reliable narrator, or a reasonable decision-maker.

Within the biomedical framework, disorders of the brain are conceived of as genetic, anatomical, and/or biochemical and are consequently framed as morally neutral, no more the "fault" of the patient than diabetes is the fault of the diabetic.[10] However, the implications of being diagnosed with a chronic brain disorder, a neurodegenerative condition for which the prognosis is dismal, or a brain injury that will result in lingering changes, are more complicated. What does it mean when your illness or injury affects the organ that generates consciousness?

When a patient is diagnosed with a brain disorder, he or she takes on a label that has a medical and social history and is likely the product of long-term interactions among numerous stakeholders, including physicians, scientists, patient and caregiver advocacy groups, politicians and policymakers, and medical and pharmaceutical industry lobbies. Despite the imprimatur of scientific objectivity, diagnostic labels are influenced by human ideologies and prejudices, both as they are constructed and as they are applied. Diagnostic categories are not direct emanations of disease entities; the epistemic processes that shape medico-scientific knowledge are constrained by political, medical, and economic institutions and are shaped by local cultures and influenced by prevailing race, class, and gender ideologies, among other sources of bias (e.g., beliefs about age, nativity, etc.). The social identities that healthcare workers and patients carry into the clinic have complex effects on whose testimony is regarded as credible, whose symptoms are treated as cause for concern and whose are dismissed, and whose problems are medicalized and addressed with compassion and who is regarded as evidence of criminality or moral turpitude.

In this work, I intend to build on the literature on identity formation, particularly with respect to disability identity and stigma. First, I draw on the work of symbolic interactionists such as Mead and Goffman; I contribute to the existing body of work by examining how patients, in

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[10] This metaphor is, of course, complicated by that the fact that people may blame and stigmatize Type II diabetics for having "caused" or contributed to their illness through poor diet or weight management. In fact, it's hard to conceive of a condition for which no one could possibly attribute any form of blame to the patient, his or her family members, his or her community, etc.

interaction with individuals, institutions, and discourses, undertake a project of recovery not only of the injured brain but of the injured Self. I look at stroke and TBI as traumatic to both identity and self-narrative, and I examine the ways in which patients, family, and staff enlist culturally available frames to understand what has happened and is happening to the post-stroke or post-TBI patient. Finally, I analyze how patients repurpose biomedical concepts (such as functional localization) to not only avoid identity contamination by disability stigma but also to conceptually distance the mind or the Self from the injured brain and preserve a sense of continuity of Self in the face of experiential, environmental, and interactional flux and uncertainty.

Chapter One: Goals over Time, Goals in Conflict

Inpatient Goals[11]

What objectives are patients focused on during the inpatient rehab stay (in the early stages of recovery)? At the beginning of my research, when I asked patients, staff, and family about goals related to relationships, return to work, or meaningful pastimes, I was almost universally told that inpatients generally aren't thinking about these longer-term goals. Staff reported that while these issues are certainly important to people, inpatients have "bigger fish to fry" (staff, inpatient). Consequently, many of these higher order, longer-term goals tend to come into focus once patients are home and attending outpatient rehab.

Inpatients tended to talk about more concrete goals, like walking. Staff confirmed that walking was a paramount preoccupation, "by far the biggest goal" (staff, inpatient). As one psychologist said:

> Almost always, it's mobility. Mobility is a big one.... So as someone who specializes more in the cognitive and emotional side, those things are much lower in terms of importance to most of the people coming in. Now there are people who are more attuned to their psychiatric or psychological functioning, and sometimes that becomes the most important thing ... but it's very rare that that happens. (staff, inpatient)

Mobility goals went hand in hand with independence goals (and the dignity and privacy associated with them). People wanted to be able to shower, dress, perform personal hygiene routines, and use the toilet, independently. Many patients were uncomfortable with people assisting them in the bathroom and watching them use the toilet. As one patient said,

> To be able to at least stand up on my own. Go to the bathroom on my own.... What is most essential to who I am as a person? To be more independent than I am now. (TBI, White, female, inpatient)

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[11] When talking about goals, I'm referring to two interrelated sets of objectives: the systematically tracked and analyzed therapy goals patients articulated and worked toward in collaboration with therapists and patients' more private and less formalized hopes and expectations.

A corollary to the independence goal was not wanting to "be a burden" to loved ones. As one woman explained:

> I don't want to live with [my son and his wife and daughter] because they're entitled to their privacy...I don't want to be dependent on them. I don't want to be any kind of a burden. They've been very, very kind to me. I hope I'll get better. (TBI, White, female, inpatient)

This patient's concerns were a common refrain among inpatients. No one wanted to impose on family or feel dependent and beholden.

For patients who were unable to communicate verbally, communication was a pressing goal, and of course, being unable to get their thoughts across was a major source of frustration. I couldn't interview inpatients who had severe aphasia or were otherwise unable to communicate, but I was able to speak to staff and loved ones who reported patients' aggravation at communication deficits, and I was able to observe tense interactions myself. I was also subsequently able to speak to several outpatients who had recovered from aphasia and who recalled how agonizing the experience had been, early on.

Inpatients were also focused on goals related to basic comfort, such as managing pain, having tubes (e.g., g-tubes) and trachs removed, and improving their swallowing so they could eat an unaltered diet. Many inpatients prioritized leaving the hospital and returning home. People were tired of hospital living. They also wanted to ensure they'd be discharged home and not to a skilled nursing facility.

Not all patients were eager to leave. Some patients wanted to stay as long as possible, or became anxious as their discharge date approached because they felt safer in the hospital environment and/or feared their recovery would plateau once they left. On the whole, however, leaving the hospital and getting home were primary objectives for inpatients.

At the inpatient stage, patients were often "pretty vague in their goals" (staff, inpatient). Many patients told me they hadn't thought much about the specifics; they just wanted to get back to normal or back to how they were before, as these examples illustrate:

> Interviewer: So what are your goals?
>
> Patient: Just getting back to normal. (TBI, Hispanic, male, inpatient)
>
> Interviewer: What are your goals for rehabilitation?
>
> Patient: Just to be able to do what I did before. Nothing more. (TBI, White, female, inpatient)
>
> Interviewer: What do you think your life will be like a year from now?
>
> Patient: Well, I hope that I will gain my mobility. And will just be as close to my previous one as I could. (TBI, White, female, inpatient)
>
> Interviewer: What do you think you'll be like a year from now?
>
> Patient: Hopefully back to [me]. (Stroke, White, female, inpatient)

Nearly every patient responded to questions about hopes and goals with some version of the above. They hadn't thought through the specifics, but they wanted to get back to the way they were before, to whatever felt "normal" or "Me."

One caveat, however, is that some inpatients were still quite confused and disoriented. They didn't understand and/or consistently recall why they were on the hospital ward, and they lacked insight into their condition. Their neurological disorder prevented them from noticing/acknowledging certain changes. For these patients, there could be a fine line between expressing a goal and perseverating. Many perseverative patients were hyper-focused on one topic—often, getting out of the hospital—as a staff member explained:

> They are mostly really focused on leaving. That's all they talk about is leaving, leaving, leaving. We have to reiterate to them all the time, like you are here because you have a brain injury, and you need the rehab, and you need the therapy, and you need the 24-hour

> care from the nurses and the doctors and the rest of the medical staff. Like, you need to be here ... because a lot of them are confused. (staff, inpatient)

For these patients, leaving was a "goal" in a sense in that they strongly desired to leave and they frequently asked anyone and everyone to get them “out of here.” But they didn't fully comprehend their present circumstances or understand and acknowledge the steps that stood between them and what they wanted. For more lucid patients, getting home was also at the forefront of their minds, but they understood that they weren't captive on the inpatient ward, that they needed to be there, and that if they worked toward recovery, they would not only be able to leave the hospital but might also be able to return home.

Why Are Inpatients Focused on These Goals?

Inpatient goals tended to be either very tangible (e.g., toileting independently; managing pain; eating solid foods) or fairly vague (e.g., getting back to my life). Inpatients were largely focused on goals oriented toward regaining independence, increasing comfort and minimizing discomfort, and returning to normalcy.

Mobility, Independence, and Avoiding Dependence

Many patients focused on walking for a variety of reasons. To begin with, physical changes (such as difficulty walking) were more readily apparent than cognitive deficits, especially when patients lacked insight. Certain types of neurological damage caused patients to become, as a physician described it,

> very concrete thinkers.... So something that is, for them, easily demonstrable, where they can see that, "Okay, yesterday, I was able to walk 50 feet; today I'm walking 200 feet." That's what they want to do.... You know, it's very concrete task. I want to walk. (staff, inpatient)

Conversely, patients often had a harder time recognizing cognitive or behavioral changes, so some patients were focused on mobility because they had yet to recognize that anything else was wrong. Often, families were far more aware of cognitive and behavioral changes than patients were, so family tended to more strongly prioritize cognitive goals, which could be a source of conflict between patients and families.

Some patients were, quite frankly, delusional about their own capabilities. They believed that if staff permitted, they could leave anytime they wanted and return to their usual routine, as this exchange illustrates:

> J, a stroke patient, asks again why he can’t go home. The doctor explains that they need to make sure J's wife will be able to take care of him at home. He needs to recover enough that she'll be able to handle his care needs.
>
> Patient: [She] ain’t got to take care of me! She’s not going to have to. I can do stuff!
> Doctor: Then show us that, and we can send you home. That’s how it works.

This patient, a stroke patient with hemiparesis, wanted to improve his walking and get movement back in his arm, but he was only sporadically and imperfectly aware of the extent of the changes that had occurred in his body and mind. He had hemi-neglect, so he often failed to notice any action occurring on his left side or forgot about his left arm and leg altogether. He was lethargic, confused, and disoriented, on and off. Sometimes when I visited, he kindly offered to go out and get me food. He wanted to offer hospitality, and he insisted he was able to leave the locked ward at any time. J and similar patients weren't particularly invested in the goals set for them in rehab because the only problem they consistently acknowledged was that they were in this uncomfortable hospital, being hassled by all these therapists and nurses, and they weren't allowed to get up and move around.

Even for patients with relatively good insight, mobility was a major priority, not because they weren't aware of other problems but because mobility was closely linked with independence.[12] As a staff member explained, "Whatever seems to be the most limiting for that person in their view is going to be the thing that they focus on most," and for many patients, that was mobility. In many cases, patients had been entirely mobile and independent until very recently, so they emphasized that they weren't used to having physical constraints.

Patients with limited mobility felt restless and restricted. As one patient said:

> I'm able to walk with a therapist in the lab now, but I'm not allowed to get off of my chair or my bed at all on my own. So I'm confined. I feel like an animal in a cage a little bit. (stroke, White, female, inpatient)

They also felt helpless and dependent. Many patients hated having to call for help every time they wanted to perform a basic task. They wanted to get up and proceed about their day, at their own pace and according to their own desires. Patients also found it infantilizing to have to constantly ask for and accept help; as one patient recalled, "[when I was cleared to walk on my own again], that's when I really felt like you know, like a person, an adult again" (TBI, Black, male, outpatient).

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[12] Although independence was the overriding theme, I also encountered a few wild cards; some people prioritized mobility for reasons that would never have occurred to me. For instance, a retired priest spoke at length about wanting to be able to stand to say Mass. I asked why it was important not to say Mass sitting down, and he said:

> Because it's a sign of hope to my people.... In many ways, my being there, you know, walking around, they see me upright, it's a sign of hope. So that's important to me in terms of a goal, I could probably say Mass sitting down. I just don't want to do it. You know, part of saying Mass is giving out Holy Communion. So you walk down to the people, and, you know, put it on the tongue or the hand. So that's—you know, it's a personal preference. But I think I can get there. (stroke, White, male, inpatient)

To this man, saying Mass from a standing position was spiritually significant, but it also had to do with how he preferred to present himself to the world. Although he was retired, he chose to remain in his parish, and he was still involved in his church community. He updated his parishioners regularly on Facebook, and he cared deeply about how they perceived him and about appearing as a symbol of strength and hope.

Patients emphasized the humiliation and indignity they felt at having to rely on others for help with intimate tasks, as this patient described:

> At first they wanted me on the bedpan. And this morning, I used the female urinal. Because I only had to pee. And the reason why is because, um, my nurse, she couldn't find no one to help her. And she said she couldn't [help me to the bathroom] by herself. And so I—like, we couldn't find nobody else to help us. So I told them, "Well, look, I don't have a problem using a female urinal. But I'm not using that bedpan to take a dump." That's just like humiliating. I would just rather squat on the floor like a dog. (stroke, Black, female, inpatient)

Patients were understandably eager to avoid what they experienced as degrading. Many patients also drew a clear line from mobility to independence to maintaining and preserving their most important relational ties. In part, it was a matter of pride and dignity; many people didn't want their spouse or children having to help them in the bathroom.

Patients also mentioned that active hobbies or physicality were significant aspects of particular relationships (e.g., patients might mention wanting to be able to play with and carry their kids or how fishing or hunting were important social outlets and bonding rituals). In many cases, however, the principal concern was that dependency would strain relational bonds. Some felt their relationships might not survive the pressures of caregiving, as this patient explained:

> Get as healthy and back to normal as I can, to be less burden on my wife when I get home. That's my goal. [Don't want to make] her leave me, you know? We always said, We up together, we down together. But you never know, when a thing like this happens. She's still with me so far. I want to keep it like that. But the better I get for myself, the better my chances of us staying together.... So I don't have to call for her to do everything for me. Because that'd end up breaking us up maybe, you know? How much can she handle? How much can she take? So I worry about that. The better I can do here, the less I'm gonna need her when I get home. (stroke, Black, male, inpatient)

For many patients, maximizing mobility meant minimizing their demands on those around them. As I'll discuss at greater length in Chapter 4 (Shifting Relationships), patients and their loved ones also feared altering the balance of power and reciprocity in their relationships. Many patients hated feeling like an imposition, as this patient expressed:

> Interviewer: So what are your goals for rehabilitation?
>
> Patient: Really getting this leg to work again, walking on this leg. That's the biggest thing right now.... With other people, it just seems like it's kind of wasting their time and whatnot. So if I can get this thing to work again, it takes a lot of my time, instead of theirs ... I don't want them to be involved if they don't have to. (TBI, White, male, inpatient)

Adjusting to disability often meant adjusting to a slower pace of life: certain routines and activities were logistically more difficult and required more time. Patients were often leery of "wasting" other people's time by asking them to assist or accommodate their needs. They didn't want to depend on or inconvenience anyone else.

Comfort Goals

In many ways, it seems obvious why patients were focused on goals that involved maximizing comfort and minimizing discomfort. When people were in pain or acutely uncomfortable or deprived of pleasure, they developed tunnel vision. Pain, in particular, tended to supersede other concerns; it became difficult to focus on anything else. As a patient explained:

> Interviewer: So what do you think you'll be like a year from now?
>
> Patient: I hope in less physical pain. I really do. Because this has exacerbated the chronic pain that I'm in. In every moment—a minute hasn't passed, between us, where I haven't been cognizant of my pain. (TBI, White, male, inpatient)

Chronic pain could also be a barrier to a desired lifestyle. Several patients expressed concern that lingering pain could prevent them from pursuing active hobbies, traveling, or otherwise engaging in valued pursuits. If their current level of pain lingered, they couldn't imagine getting back to elements of life they cared about.

Similarly, patients who were on restricted diets were eager to get back to eating and drinking, as they liked. People who were on tube feeds missed the taste and experience of eating, and people who were on altered diets (like pureed foods and thickened liquids) not only missed eating favorite foods but also hated the foods they were currently able to eat. "Nasty" was a frequently applied descriptor, for the pureed meals.

Many patients had difficulty communicating, for a variety of reasons, both mechanical (e.g., tracheostomy or vocal cord paralysis) or neurological (e.g., dysarthria, dysphasia, or aphasia). Communication goals also centered comfort/discomfort. While chapters 4 and 5 (Shifting Relationships and Re-Constructing Identity) go into greater detail about the importance of communication, at a very basic level, inability to communicate made it difficult to get your needs met. As a PCT explained, regarding a patient who couldn't speak or use a communication board or eye gaze device:

> A lot of times, she's—she's wet. And she—nobody can understand that she's wet. So she's frustrated ... like, we're asking, "Do you want this? Do you want that?" When she's really just wet. But sometimes she can't get those words out. (staff, inpatient)

A patient might have soiled themselves or might desperately need to use the toilet, or a patient might be in pain or stuck in an excruciatingly uncomfortable position. But without a reliable means of communication, they couldn't make their complaints or desires known. Additionally, patients were often acutely frustrated by failures of understanding, as staff, family, and patients further along in their recovery all reported.

Communication was also associated with independence. Often, family members who spent a great deal of time with a patient became relatively adept at anticipating their needs and understanding their communication, so family members often became *de facto* interpreters. While patients appreciated their assistance, they often didn't want to rely on their family member (out of concerns around imposition and dependency), and they wanted to be able to make simple statements and requests on their own without having to wait for an intermediary.

Many of the reasons patients wanted to leave the hospital and return home also revolved around seeking comfort and avoiding discomfort. People missed their familiar environment. A Russian patient was reminded of a saying she translated roughly as, "at home, even the walls help." Many patients had a variety of complaints about the hospital setting—the food, the bed (too small; uncomfortable), the shower (too cold; not like their shower at home), and the constant ambient noise. And no one enjoyed being awakened throughout the night, as one patient said:

> And it's like, I don't understand why you got to wake me up 3:30 in the morning to take my blood? It's all going to be here in the morning. It's not like Dracula's coming in and going to take it all away. And they did it again last night to me. At 3:30 they woke me up to take my blood. Then I had the nurse come in. And she was—you know, she took my sugar. And she gave me an insulin shot. She gave me a heparin shot which hurts. And did all that. And to me, can't we have a better schedule than what we're having? You know, especially you see, I was in a deep sleep. And I was sleeping fairly—for once—fairly well. (stroke, White, female, inpatient)

Many patients were confused about and annoyed by the routines of the hospital. They didn't understand or appreciate the nightly intrusions or the invasion of privacy. Patients missed having a door they could lock, and many were less than thrilled at the frequency of the interruptions, as one spouse explained:

> Like there was one time where it was a twenty-minute time frame and we had four interruptions. And I understand that's necessary because of the environment. We have nurses, we have doctors, we have therapists, we have housekeeping. We have dieticians. we have XYZ, A, B, and C. And it's—the more we do it, the more difficult it is to be patient with it. (wife of stroke patient)

Patients and families overall tried to be understanding that staff had a job to do and were trying to help. But they often didn't understand the rationales behind certain elements of the hospital routine. For instance, many patients noted that staff came in through the night to empty the trash. It woke people up; why couldn't it wait until morning? As I learned, it was protocol for PCTs to empty the trash in each of their assigned rooms at the end of their shifts. It wasn't considered courteous and professional to leave it for the next PCT, and especially if they had changed diapers or disposed of other odorous items, they didn't want stench to build up in the unventilated rooms. But patients weren't privy to these rationales. They just knew someone was coming in and rustling around with the trash in the middle of the night.

Patients were also frustrated by their lack of control over their own routines. They wanted to do things their own way and in their own time. People disliked having no authority over their schedule. They couldn't shower when they wanted to; if someone offered them a shower at an inconvenient time, they often had to accept it or miss out entirely. People especially rankled at having to wait for help to use the bathroom. As a patient described:

> I had to go to the bathroom. And then I had to go again a couple hours later. And I had the patient care tech, "You need to learn how to hold it."... And the nurse agreed. I'm sorry. That isn't—Yeah, I really—that upset me. I drink a lot because I'm diabetic. And so I have to go to the bathroom. Better I call you than wet the bed. But they don't look at it that way. (stroke, White, female, inpatient)

Many felt embarrassed or like an inconvenience, and it could be nerve-wracking and uncomfortable to wait for help knowing you might not be able to hold it.

Some patients were more set in their ways or attached to their routines than others. As one patient's son described, his mother had lived a long life and was used to having things a certain way, moving through her day according to her own desires. At home, she would get her coffee, make some calls, read, watch TV, figure out dinner. She was unaccustomed to having the minutiae of her day dictated by others.

Like many patients, she missed the dignity of choice and, as another patient put it, wanted to "be able to just generally have a command of my surroundings" (TBI, white, male, outpatient).

Patients often felt constrained and even infantilized by the degree of oversight. A therapist cited a recent example:

> He was like obsessed with coffee. He was drinking way too much of it. If his mom said, "I can't get you one right now, the doctor said, you have to wait till after lunch." That would set him off. Like, "I'm an adult man. I can drink coffee when I want to!" (staff, inpatient)

As adults, patients were used to being able to make their own decisions about what they ate and when they showered. They chafed at the constant surveillance and lack of autonomy.

Restraints were a particular focus of patients' ire; they were perhaps the most visible and tangible symbol of control. Restraints were used not only to control agitation but also to protect patients who might try to stand or walk, despite being unable to do so safely. However, if patients weren't aware of their own limitations, they were generally also unable to understand the need for restraints. As one patient recalled:

> At first they had like the netting up around the bed. And you know, where they zip it. And late at night when everyone would be gone or my visitors would all be gone. I'd wake up in the middle of the night and have to go to the bathroom.... I'd hit the call light. Nobody would come for like a really long time. And it would get to the point where I'm hurting so bad because I had to go the bathroom. I would try to unzip the thing myself, but I couldn't. You know, I wasn't there yet, cognitively, to figure that out. So I'm just like trying to rip this thing open with whatever I can because I can't hold it any longer and nobody's coming. So that part was pretty miserable. (stroke, White, male, inpatient)

Beyond simply not understanding why they were being restrained and feeling caged or claustrophobic, patients were frustrated by the restriction to their free movement, especially when they desperately wanted to get up. They weren't able to take into account the risk of falling.

Image 1: A bed enclosure intended to minimize fall risk
Source: Photo by Author

Aside from comfort, dignity, and independence, there were many reasons people wanted to get home as soon as possible, both complex and simple. Some patients disliked medical settings and distrusted medical personnel and institutions. As one patient said:

> The dependence on other people is the worst thing for me. They help me to do stuff, but they only doing it because they're getting paid ... I don't try to push [the call button] if I don't need to. But ain't that what you here for? I don't say that because they'd put something in my food or something, you know? Or my medicine. They got control of my IV. So no telling what they'd do. You know what I mean? It's like, you piss the cook off and go cuss them out before your food ready, there's no telling what's gonna be in your food. That kind of thing, you know? (stroke, Black, male, inpatient)

Given the storied history of racialized medical disparity and exploitation (Washington 2006), it was to be expected that some patients, particularly Black patients (Boulware et al. 2003; Newman 2021), might not feel entirely at ease in the hospital.

On the simpler end of the spectrum, many patients wanted to leave because they missed children, grandchildren, and pets. Under COVID restrictions, children under twelve weren't allowed in the hospital, so in many cases, people were unable to see their children and grandchildren for weeks or months. Many people found this separation acutely painful. Patients also talked about feeling isolated and lonely in the hospital, and in some cases, patients felt the time alone caused them to ruminate and become anxious or depressed.

Although many people were intent on leaving the hospital, it's important to note that other patients wanted to stay as long as possible or were reluctant to leave. A doctor explained before rounds one day that she recently had a patient who believed he would remain at inpatient until he was completely independent; when his team broached the subject of discharge, he threatened to slit his wrists. He was sent out to an acute hospital for psychiatric care. This patient's reaction was unusually extreme, but the misconception at its root was fairly common. Many patients initially assumed that they would remain in the hospital until they were more or less recovered (as I'll discuss more in Chapter 2 on Managing Expectations), and they were disheartened to learn they would be going home with a long road left to recovery.

Other patients expressed trepidation at leaving the hospital environment because they felt safe there; they were hesitant to exchange a safe, supportive, disability-accessible environment for the uncertainties and hazards of the outside world. Many patients also feared their recovery would plateau if they left the hospital. They appreciated the progress they were making and the quality of the therapy they were receiving, and they weren't certain it would be the same in outpatient rehab. For instance, when I visited one patient, Naomi, to congratulate her on her impending discharge, she told me she was anxious about leaving because she wasn't yet “at 100 percent.” She preferred to stay inpatient, but barring that, she wanted to go to day rehab at the downtown site near the inpatient facility. She was told she would be assigned a day rehab location based on her home address, but she lived on the South Side. Naomi felt the downtown day rehab would be better quality than the South day rehab, and she said she felt motivated and energized being downtown, around the skyline and the lake, and the flow of commerce.

Return to "Normal" and Vague Goals

Beyond specific goals like walking, toileting independently, returning to a solid diet, or getting out of the hospital, inpatients often had a single, somewhat broad goal: they wanted to get back to normal, to their lives and their Selves before this happened. As a therapist explained:

> Our patients are pretty vague in their goals. Because I always start by asking them their goals and all they'll say, "I just want to get back to normal." So then we have to kind of break it down and say, what's normal? What do you usually do during the day? You've got to go and make specific goals. (staff, inpatient)

Many patients adopted a first-things-first mentality. If they couldn't yet dress themselves or feed themselves, anything more complicated seemed entirely out of reach. As one woman explained:

> Someone talked to me about driving and I was just like, uh uh, like, let's just not even go there. Like I can't—I need to make sure that like I'm safe walking and like doing all these things first before I even think about like getting In a car. It just sounded like the most crazy conversation. Like, not there at all yet. But I do have to get there. And hopefully sooner than later. But I just want to make sure that I can fully control my muscle movements and stuff before I like have to control a 2,000-pound vehicle, and my kids seatbelted in it ... I want to make sure that I can take their car seat in and out and like, you know, maneuver as well. Because it's not like they'd sit quietly in the backseat ... they're gonna be like mommy, mommy and this, that. (stroke, White, female, inpatient)

For Naomi, it felt ludicrous to imagine performing a complex, potentially dangerous task like driving (let alone with two distracting children in the backseat). Regaining basic motor function and control was a more immediate concern and seemed like a necessary precondition for targeting more complex goals.

Another major reason goals tended to be vague at this stage was that the inpatient setting was a relatively controlled, structured environment; hospital staff set the schedule, brought the meals, took patients to therapies. It was hard to anticipate issues that would become challenging down the road (like difficulty setting, organizing, and keeping appointments). People hadn't yet returned to their daily routines. Patients and families acknowledged that once they were out of the hospital "bubble," as a patient's wife described it, additional goals would likely occur to them. At the inpatient stage, patients were making new discoveries all the time. One patient reported that he hadn't realized he couldn't write legibly until a couple of weeks into his stay; he hadn't tried to write before that.

Patients varied in how insulated they were from outside stressors. Cleè, a stroke patient, was already on the phone paying her bills, and she gave me a detailed rundown of how she planned to get her house back in order when she came home. She was concerned that her husband had let things slide in her absence. For patients in more gender traditionalist relationships, especially older patients, gender was certainly a factor. For instance, male patients whose wives kept track of the finances and maintained the household weren't worried about getting back to doing these sorts of tasks because they weren't on their plate to begin with.

Many patients and families were satisfied to let family members handle all outside concerns while patients focused on recovery. In some cases, however, family worried about what they saw as myopia or avoidance. As a patient's wife reported:

> Everything with him, when I've tried to ask him about it, is very short term. It's—a lot of it is, "I can only focus on one thing at a time." Which is great. But life doesn't work that way. You have to do multiple things at the same time.... You know, we've talked about when you come home, you should have some goals, what are some things you want to do when you come home? And he's like, "well, I don't know even what I'm going to be capable of. And I don't know when I'm going to be capable of certain things. So I don't want to tell you because I don't know. I don't want to come home and tell you I'm going to get a job because I might not be able to get a job when I come home"... So he keeps telling me, right now his focus is just trying to get back to 100 percent. And that's it. But it's gonna have to expand when he comes home. Because here, that's all it is. It's just him. And getting better. But when you come home, it's not just you and getting better. It's you and getting better and me and the kids and the school and the house and everything else. (wife of TBI patient)

Understandably, it could be worrisome if your partner and co-parent seemed unwilling to consider the long-term logistics of your shared life. As much as family wanted to shield patients from stress and help them maintain positivity, they also wanted to be able to plan for the future.

In many cases, patients' lives had been abruptly disrupted. They weren't prepared to spend weeks to months in the hospital, so there were a lot of loose ends at home. Patients' lives didn't stop because they were hospitalized. Some patients had a robust support network dedicated to keeping outside stressors at bay during their recovery. But in a few cases, patients' outside responsibilities made it harder for them to focus on recovery and also gave them a sharper than average sense of what their challenges would be at home.

Staff highly encouraged patients to focus on the present, which meant both tuning out distractions and targeting goals that were considered "appropriate for this level of care." Staff felt that if patients were too preoccupied with long-term goals or anxious about future problems, they would be distracted and unfocused in therapy, so staff encouraged them to "take it a day at a time" (staff, inpatient). Several inpatient staff members mentioned that, in a way, they felt lucky to work at the post-acute level, as a therapist said:

> Our job is to keep patients in the here and now. Focus on what are the things that you need to do to discharge safely, by the date that we have set for you. Within, you know, a week or two. We can always move things around if we need to. We can talk about what it's going to look like in three months, six months, but really, we have to focus on getting you ready to leave by this day. (staff, inpatient)

They could encourage patients to focus on small, manageable goals and set aside, at least temporarily, weighty questions about the future. And as other staff pointed out, the inpatient stage was characterized by hope for recovery; in general, patients and staff weren't yet at the point of thinking about permanent adaptation to disability.

Many inpatients deliberately avoided introspection or thinking too much about the future. They focused on working as hard as possible, day to day, to maximize recovery. As a patient explained:

> I focus on working hard. I try to only think about the present. I try not to think about the future. I want to focus on getting better. And if I do that, I will have a better opportunity in the future. Because if I focus on getting better, I will make the best progress I can. (stroke, White, male, inpatient)

Patients were sometimes quite open about putting on blinders, as this patient said:

> To be honest, in here, nothing else out there exists. So it's like I even blocked my mind out to not even think about [my husband]. And some of my family members.... You know, I never really thought about what the biggest challenge is or anything like that. I never really thought about it. You know, I just blocked everything about home out and tried to focus on getting myself back to myself, as much as possible ... because it's like, I'm still like, in a state—I'm not gonna say denial...I have to live—I'm living with it right now. (stroke, Black, female, inpatient)

Patients wanted to avoid anxiety and maintain positivity so they could be motivated and focused in therapy. They talked about avoiding any thoughts that might have a negative effect on their mental health. One patient's coworker had been killed in the incident that caused his TBI. She had a beloved dog, and if he let himself think about his coworker and the dog she left behind, his mood spiraled. He tried to avoid dwelling on survivor's guilt, or how he had to miss her funeral, or what would happen to the dog. He couldn't afford to succumb to despair.

Similarly, patients tried to avoid thinking about the future and any negative outcomes it might hold. As one patient said, "I'm gonna tell you the truth. I can't look that far" (stroke, Black, male, inpatient). Patients didn't want to imagine any worst-case scenarios or think about possibilities that frightened them, like not being able to return to work or live independently. Patients who had unresolved medical issues (e.g., an arteriovenous malformation that had bled and caused a stroke and would require future surgery) did their best to compartmentalize thoughts about future medical risk.

Often, family tried their best to encourage positivity; as a stroke patient's wife described it, "So I'm very consciously not downing [him] out about anything, you know, and I'm just encouraging him and doing the best I can." They might avoid troubling topics that (they hoped) hadn't yet occurred to the patient, such as whether the patient might be permanently unable to drive.

Insofar as patients and families were aware of negative possible outcomes, they often didn't feel ready to contemplate them. As a patient's wife told me, early in his recovery, she considered the possibilities that he could die or end up severely, permanently changed, and for her "neither one was acceptable." Another patient's wife explained their attitude:

> We aren't—we stopped looking at the future, because with the locked-in [syndrome] portion it is so incredibly unknown. [tearful] We went from a 1 percent of survival to, your husband's gonna blink for the rest of his life, to where he's at now. I think we're starting to drive each other crazy thinking of all the what ifs. And since we've made that promise to each other [not to think about the future]. I think things have become a little bit easier to navigate. And you wake up every single day with the expectation that something could change today, or something could be the same.... So I think just the biggest fear is that he won't, at some point in life, whether it be five or ten years down the road, won't be able to fully care for himself. (wife of stroke patient)

There was a significant chance—a likelihood even—that this patient would not be able to "fully care for himself" five or ten years down the road. I interviewed the patient too, and he echoed this perspective: for now, they were avoiding thinking about the future, in too much detail, because they hoped they would never have to confront unpleasant outcomes. For this reason, many inpatients deflected questions about the future. Their attitude was that a lot would depend on who the patient would be and what they would be capable of, when they reached that point. As many patients saw it, these were questions for a future Self:

> It depends on how well I get. Really. You know, you can't say what you're going to do, because you don't know how well you're going to be. Are you ever going to move your leg on your left? Or not. So you can't say what you're going to do. (TBI, White, female, inpatient)

As a patient's wife explained, they had decided any "big decisions" should wait until the end of the year because by then "we should have a better idea of what the future is going to look like" (wife of TBI patient). On the one hand, patients and families wanted to avoid thinking about outcomes they feared, but on the other hand, some patients and families were wary of getting their hopes up and being disappointed. As another patient's wife said:

> Well, expectations are something that I don't really play around with anymore. Because I had a lot of them, before all this ... I have a really hard time visualizing what he will look like or what he will be able to do. And that's because I don't want to cling to some idea. And then it never comes true. I think if you were to ask his dad, his dad would say he'll be walking in a year. But I can't jump to that because my heart is pretty broken as it is. [tearful] And I would rather see what comes than try to have a vision and rest all my hopes on that. Hope is a very delicate thing for me. (wife of stroke patient)

When I spoke to her husband, he emphasized potential and determination, but both were very aware that their lives had changed suddenly and drastically, and there were a lot of unknowns ahead of them.

Due to the structured and protective inpatient environment and, in some cases, lingering lack of insight, inpatients often focused on very concrete and short-term goals, such as improving mobility and mitigating issues that were currently causing them discomfort. At the same time, patients often cited a single, vague goal: getting back to normal. Staff encouraged patients to focus on the task at hand and channel all their energy into recovery, and patients and family were often reluctant to think too far ahead and consider outcomes that were, as yet, unthinkable or "unacceptable." As patients transitioned to outpatient, however, they were forced to confront problems and possibilities they had been consciously or unconsciously putting off.

How Do Inpatients Talk about Return to Work?

Some patients during their inpatient stay were focused on getting back to work, but in many cases, these were the patients who lacked insight and didn't grasp that they couldn't (yet) perform their professional responsibilities. For the most part, patients and staff regarded return to work or school as a down-the-road goal, a challenge to be addressed at the outpatient level. Inpatients who were aware and oriented often acknowledged a desire to go back to work eventually, but they generally explained that it wasn't an immediate priority, as this patient expressed:

> I don't know [when I'll return to work]. Whenever my leg starts working. A month, two months, whatever it takes.... They were asking me to come back to work. And I was like, I can't right now. You know, I'd love to, but I can't. (TBI, White, male, inpatient)

Staff emphasized that for the moment, recovery should be the patient's full-time job. They made it clear that patients should concentrate on making the best possible gains while they were still in the optimal window for neurological recovery (a concept that will be covered at greater length in Chapter 5 on Re-Constructing Identity). Patients were instructed to husband their energies and focus on the immediate task at hand. Staff also pointed out that therapy was time-intensive and exhausting; patients could be in therapy for three to six hours per day, leaving little time for outside work.

Patients and family members were told to shut out distractions, as this spouse explained:

> She wants to come back to work. She tried several times. "Oh, let's go through emails." But we specifically—I asked the doctors, hey, what do you think? What does she need to do? And they all said, "well, before you come home, [recovery is] your work. There is nothing else in the world you need to worry about." And that's what we follow, and that helps her. (husband of TBI patient)

"You're working on yourself" (staff, inpatient) was a common refrain. Repairing the body, mind, and Self were supposed to be the overriding concerns. Patients absorbed the message that rushing back to work could jeopardize their recovery; they didn't want to undermine their health and safety by jumping the gun.

Staff were also upfront about the professional risks of premature return. For patients who were disoriented and lacked insight, the risks were fairly obvious. Family generally recognized that confused and obviously impaired patients shouldn't be joining remote meetings or trying to make calls and answer emails. In these cases, staff and family tried to safeguard patients' professional reputations by redirecting them and limiting their access to laptops and cell phones.

For patients further along in recovery and patients with insight, staff directly explained that they wanted to "set [patients] up for success, not for failure" (staff, inpatient). They warned that patients' jobs might not be protected if they were medically cleared to return to work and then failed to perform as expected. As a physician explained:

> Their supervisor may not be understanding, may not be giving them extra time to complete a task, will want them to maintain the same volumes as before. And it's just not possible after brain injury, especially moderate or severe. And it they're here, you know, there's—presumably they have moderate or severe injury. They don't have a concussion. So these guys, if they go prematurely to work, they get overwhelmed, they get depressed, they start drinking, they lose their job.... There may be [disability] benefits available to them, but then once they go back to work, if they lose a job because of misunderstanding with coworkers [they can lose access to those benefits]. (staff, inpatient)

Staff were often blunt about the risks, when talking to patients. During rounds, a physician told a TBI patient: “Way too often, [return to work] fails miserably." He explained that patients shouldn't be in a hurry to return; they should focus on recovering as fully as possible, first. Therapists talked through the details of patients' professional roles and responsibilities and helped them understand exactly what interim goals they had to work on (e.g., improving attention to detail; multi-tasking), to consider returning to the same job, but in most cases, return to work was an outpatient consideration.

Outpatient Goals

Depending on their progress in recovery and the time elapsed from injury, outpatients often had many of the same goals as inpatients (getting back to “normal” and increasing independence and comfort). However, several additional objectives came to the fore in outpatient rehab. Patients often developed more specific goals and began to focus on higher order goals, like driving and returning to work, that seemed out of focus or out of reach, at the inpatient stage.

Outpatients had a more fine-grained sense of what they needed to work on and what the path ahead would look like. Patients at this stage brought up cognitive goals more, and they often cited specific skills they wanted to rebuild, as this patient did:

> Speech [therapy], I feel like I get more out of because it's more of the cognitive stuff, like planning.... But I have stated that I'm wanting to be better with note-taking, for instance.… So, my work is mostly I guess with organizations, writing, and thinking. (TBI, Black, female, outpatient)

Patients still wanted to "return to normal," but they were more specific about what that return would entail. People talked about wanting to get off their medications, for instance, or getting rid of assistive devices like a cane or brace.

Now that they were back home, patients talked more about rebuilding intimate relationships, improving their ability to care for or play with children and grandchildren, and getting back to their social lives. At this stage of recovery, staff really emphasized "community reintegration," and patients were beginning to think about getting back to specific hobbies, social outlets, and routines. Patients were more aware of the impact the stroke or TBI had on their most important relationships. In many cases, addressing this change was a top priority, as this patient reported:

> The most difficult part of my recovery or my life—you already know the answer to this. You learned it in the [speech therapy session]. The most difficult part of my life now is my relationship with [my wife]. (TBI, White, male, outpatient)

Outpatients were particularly focused on higher order goals like driving, returning to work or school, and getting back to retirement plans. As a staff member reported, driving was of paramount importance:

> Number one, drive. I'm not even kidding you. Ninety percent of my patients want to get back to driving. That is the first goal. (staff, outpatient)

Many patients were also invested in getting back to work and/or school, as soon as possible, as this patient indicated:

> Interviewer: What are you looking forward to most to get back to?
>
> Patient: Work and school. Working and going to school. Two things I really enjoy. I always had good jobs. I was on my way to finishing school. That's it. (TBI, Black, female, outpatient)

Patients in or close to retirement often talked about travel and other active hobbies and interests. As a patient described:

> I used to love to go to—we have a cottage. I used to love to, lik,e float in that lake for hours. I would just lay on a raft and float. I can't even do that because of my nerves. The damage. It's too sensitive to cold now. So I'd like to just get back to normal, where I just don't have all this pain, and I can walk. And the nerves don't hurt. And I could think straight. (stroke, White, female, outpatient)

This patient talked about their vacation property and their boat at length. She showed me photos of fish and talked about ordering an adaptive fishing rod. Many patients, at this stage, were preoccupied with getting back to their passions and regaining the parts of themselves and their lives they most valued.

In some cases, patients were hoping not just to return to how they were before but to improve upon their pre-stroke or TBI lives. Many patients talked about working on their health or diet, but patients also talked about shifting their priorities, as will be discussed in Chapter 7

(Understanding and Finding Meaning). One patient said the following, when asked about her goals:

> To get back to my life. To get back walking. On a full diet. No tubes. To get my voice back, if it comes back. Just—get to a space where I'm genuinely happy with myself and my life. I want to work again. I want to go back to school ... Aad I just want to be with my brother and his wife and their family. I want to continue making a better relationship with God. I want to build my self-esteem up. I want to accept myself and my life. I just—I really want to find who I am and what I'm worth. So that other people can see who I am and what I'm worth. (TBI, Black, female, outpatient)

This patient's response encapsulates the perspective of many outpatients. She still wanted all the things inpatients were focused on (gaining mobility and independence, losing the discomfort of tubes and limited diet, and getting "back to my life"), but she had also begun to prioritize getting back to work and school. And beyond that, she was thinking in detail about who she had been before the TBI, who she wanted to be in the future, and how she would go about effecting that change.

Why Are Outpatients Focused on These Goals?

Return of Insight

To begin with, outpatients were farther out from injury, so many patients who once struggled with insight had regained self-awareness, at least to some degree. Outpatients were more likely to recognize what exactly had changed and the complications arising from these differences. As a patient's wife reported, as an inpatient, her husband wasn't particularly concerned about issues like whether he would return to driving because he didn't, at that point, understand that driving would be a problem:

> I think the only ones I see are the ones that, from what I can tell, are the frontal lobe [problems] that they've kind of really stressed upon ... and I think his reasoning is the biggest one. You know, where he– there's things he thinks that he's going to be able to do when he gets home, where he's not grasping that they're unsafe for him. The driving part,

> he's having a hard one, you know. "I don't have to wait that long before I drive." Hence why we took his truck to [another state]. It's not even there. So he can't even see it to try to think about driving it. (wife of TBI patient)

Outpatients were not only more likely to recognize changes in themselves but they also had more opportunity to observe the material effect of these changes on their lives.

More Specific Goals and The Transition Home

The transition home played a significant role in opening patients' eyes to what, specifically, had changed. As a day rehab staff member explained, patients hardly had time to get oriented at inpatient rehab before beginning the often stressful discharge process and transition home:

> But when someone suffers a stroke, or heart attack, or is in a car accident, gunshot wound, there's no warming up. They've been thrust into it, bam! Show up at the hospital, and everything's moving so fast. By the time we get to rehab, they're really just starting to breathe. Right? Like they're alive. And they've seen all these gains from maybe comatose, to they're alert, and maybe they're talking, maybe they're moving things that they weren't. And so as soon as they kind of catch their breath, "Go home!" (staff, outpatient)

I'll describe the discharge process at greater length in Chapter 3 (The Transition Home), but in effect, patients left a structured environment built around accommodating disability and returned to all the complexity of their previous lives. In some cases, patients went back to less than ideal circumstances—they didn't have a bathroom that could accommodate a wheelchair or they were homebound because they couldn't leave the house without assistance. The transition home highlighted a lot of problems that might not have occurred to patients before. Day rehab patients reported unexpected complications ranging from missing appointments due to trouble with memory, organization, and executive function to repeatedly adding salt to his coffee instead of sugar (in the case of one man).

As patients tried to ease back into old routines, they encountered stressors that had been buffered by the controlled inpatient environment. For instance, outpatients had to manage their own medication, cope with side effects, and confront the financial cost of being on numerous new drugs. Day rehab staff helped patients troubleshoot these problems, as this nurse explained:

> You know, sometimes it'll be like "[that medication] really makes me sleepy" or "that diuretic makes me go to the bathroom a lot." Okay, well what time are you taking the diuretic? Let's look at, you know, timing a medication too. So you know, sometimes some of the meds might make them a little tired, you know, might cause them to have a little bit of nausea. Well, are you taking it with food? You know, how are you taking your meds? (staff, outpatient)

Despite this support, for many patients, getting off all these medications became a major outpatient goal. In many ways, outpatient life was complicated to manage, even for patients without cognitive changes.

Patients also reported changes in mood as they became more aware of the discrepancies between their lives pre- and post-injury. One young TBI patient went from living independently with his partner to moving back in with his mother. Prior to his TBI, he described himself as active and spontaneous:

> Like, previously I, you know, I'd get up and as soon as [my girlfriend] woke up, be like, "oh, you know, I rode my bike—I rode the Divvy bike around at 4 am and it was so pleasant. We should do that. Let's schedule a time. Or let's go like jet-skiing or—" you know, I'd have like five or six things that I wanted to do. (TBI, Black, male, outpatient)

Since his TBI, he felt his daily objectives were smaller (e.g., use the bathroom independently or improve his gait), everything was more laborious and required more planning, and he had lost some of his joy in life. As he put it:

> Like before, I might feel like, joy and fulfillment by, like, from like watching my favorite TV show, or I might look forward to something. But now, being at home, it's like I don't know, why I even watch TV. Just because it's there and I need to pass the time. (TBI, Black, male, outpatient)

Patients also found that their social relationships had changed. I'll discuss Shifting Relationships at greater length in Chapter 4, and I'll discuss Re-Constructing Identity (e.g., around role performance) in Chapter 5. In some cases, patients were more irritable or quicker to anger, which could strain relationships. Neurological damage could cause personality change, in some patients. Fatigue was an even more common symptom, which itself could make patients short-tempered. As patients reintegrated into life outside the hospital, they often found they had less mental and physical stamina than they had before.

In leaving the hospital, patients also left a social environment where most people were comfortable with and trained in accommodating disability. As they once again began interacting with the public and their extended social circle, many patients began to feel isolated due to perceived stigma, communication problems, or self-consciousness over changes in social presentation. And in many cases, family members and friends who rallied around the patient in crisis redirected focus to other responsibilities and couldn't offer the same level of support, in the long term.

At the same time, the reality of caregiving and patient-caregiver dynamics began to set in. Staff explained that even caregivers who were fairly confident at time of discharge often reported that the adjustment was harder than they bargained for. Patients and caregivers struggled with the stress of this transition, and patients became increasingly aware of the changes in their relationships. As a physician reported:

> I think probably in the outpatient setting is where we see more of your day to day, you know, family dynamics start—maybe take a change. You know, I had a patient who is a male who, you know, suffers from depression because they feel they can't provide for their family anymore and feels—you know, in their terms, useless. And so the dynamics between them have changed compared to before. (staff, inpatient/outpatient)

Outpatients' goals became more specific and began to include areas that inpatients often didn't foreground. When patients left the hospital and returned to "real life," what exactly had changed became more apparent. Many outpatients noted shifts in relationship dynamics or changes in their mood or quality of life, and often people encountered problems that hadn't occurred to them when they were removed from their daily routines (e.g., how to keep a calendar and remind themselves of appointments; how to keep their temper when exposed to chaotic environments).

Longer Term Goals

Outpatients were also starting to focus on goals that for many inpatients, seemed far out of reach, such as driving and returning to work. Both issues took center stage because of their logistical importance and because of their salience to patients' sense of Self. Of course, many patients were anxious to return to work for financial reasons, but often people's occupations were also central to their identities (see Chapter 5 on Re-Constructing Identity). Patients experienced the inability to earn an income and resume a valued profession role as profound losses.

Driving was also economically important because many people had to drive to work or drive for work. But for many patients (especially in rural and suburban areas) driving was also crucial to independence. If they couldn't drive, they were reliant on paid transport or the support of friends or family to go anywhere or do anything. Driving and working were also closely tied to patients' sense of normalcy and ability to get back to what they valued in life. As a patient's wife explained:

> That will be the hardest loss of all of this, if he can't drive. Because he loved to *go*, you know? He would be off three, four days, and he'd go see our daughter in [another state] ... He'd just shoot down there. And he, you know, he loves to travel, he loves to drive. (wife of TBI patient)

Driving meant not only independence and mobility and the ability to be spontaneous, but also the capacity to maintain significant social relationships and pursue hobbies and interests. As another patient explained, driving could also be central to patients' sense of themselves as capable adults:

> I'm actually going for my driving test. And for—to get certified, that I could drive again. And as I've said to my wife, so many times, because she's so nervous about everything, I said, "Honey, I'm not thinking about being an Uber driver. Don't worry about that. I just want to, at some occasion when you're somewhere and it's raining out, and I have the chance to come pick you up, to be able to do that." (TBI, White, male, outpatient)

His wife questioned why he needed to rush back to driving. They lived in the city; they could easily afford to take Ubers, if needed, and she could drive them both. But for the patient, driving meant being an equal partner and being able to take care of his wife, if needed. He was a very independent, traditionally masculine man, prior to the TBI. He didn't like the idea of being reliant on his wife or being unable to chivalrously pick her up if she got caught in the rain.

At the outpatient stage, driving and return to work took center stage, in part because of the passage of time. Patients had been out of work for months. They were suffering financial stress, or getting restless, or receiving pressure from their employers. Outpatients were also further along in recovery, further out from the overwhelming shock of the injury, so it no longer felt as unthinkable that they might be able to take these major steps. In many cases, being out of the hospital and back to their lives also made it clear to patients just how different and restricted their lives could be if they were unable to drive or work.

A New Normal?

Some outpatients were beginning to confront the fact that they hadn't recovered to the extent that they hoped, that they might never return to exactly how they were before, and that they might have to make long-term adaptations. Outpatient staff tried to prepare patients for a "new normal." As a staff member explained:

> But certainly in the day rehab and outpatient setting, it's a conversation of, "I know mom used to be X. Now mom isn't."... because there's not room for improvement anymore. (staff, inpatient)

I'll discuss how patients cope with the dawning realization that they might not get entirely "back to normal" at greater length in Chapter 5 (Re-Constructing Identity). At the outpatient level, patients' goals began to reflect this shift. They started to think more specifically and strategically about how to adapt to permanent change. For instance, a classroom language teacher with enduring aphasia talked about confronting the possibility that she would have to find other meaningful work, like tutoring or working on education policy, if she couldn't return to teaching.

In general, inpatients were more focused on what they could see and feel, on changes that were easily demonstrable and experientially intrusive, like mobility difficulties and nerve pain. They were often vague in their goals, insisting that they just wanted to get back to "normal." Staff had to question them carefully to get them to think about what exactly normal consisted of for them, and how their bodily and cognitive changes might affect their specific routines and valued pursuits. Outpatients, however, had been dropped back into daily life and were more acutely aware of the many ways, from logistical to interpersonal, their lives had changed. They also began to focus on higher order goals that seemed too far down the road for inpatients to contemplate, and in many cases, outpatients began to think about what it would mean to adapt to a "new normal.”

Conflicting Goals: Patients, Family, and Staff

Patients' goals for themselves often came into conflict with what staff thought was realistic or what family members preferred or prioritized. Family could be either more or less realistic than patients. In some cases, of course, patients lacked insight and weren't aware of problems that were readily apparent to family, but in other cases, patients had a keen sense of their own mental and physical limitations, while family members were adamant that patients should aim for goals neither staff nor patients believed were achievable

In the next chapter (Chapter 2 on Managing Expectations), I'll go into greater detail about how unrealistic goals arise and how staff manage expectations, but at the most basic level, as a therapist explained, "I think it's first and foremost, like, making sure patient and I are on the same page and then kind of involving and educating family as much as possible." In some cases, of course, patients were highly disoriented or confused and were unable to participate significantly in setting goals, but on the whole, staff made an effort to ensure that patients' needs and values were prioritized.

Of course, families weren't monolithic in their opinions; stakeholders could differ considerably in their judgments and aims. A therapist reported a case that fit a common pattern:

> The patient, unfortunately, is too impaired to verbalize those goals or anything like that. And I think, even like, the wife of the patient is understanding it a little bit more. It's more the children that are not. So it's kind of a multi-layer thing where I feel like wife and I are starting to get on the same page. But then children keep coming in, and I have to keep reiterating that it's not safe. And it's not, he's not going to be—like the G-tube is the main source of nutrition. Like that's not a realistic goal. (staff, inpatient)

The children wanted their dad's goal to be eating a solid diet, but he was still being tube fed, and the therapist didn't think the children had a reasonable grasp of what was possible. In some cases, this sort of dissension simply created tension among patients, family, and staff, but if the patient wasn't capable of making decisions and there was no designated power of attorney, the issue might involve more than interpersonal management. In those cases, staff needed to forge consensus among the stakeholders to get permission to proceed with care.

What Contributes to Differing Perspectives?

In cases where a patient was disoriented and/or lacked insight, staff often tried to gather contextual information from family to get a sense of what the patient had been like pre-injury. However, depending on how close the family relationship had been and how much time family had spent with the patient recently, their perception of the patient's baseline might not be entirely accurate. As a staff member pointed out:

> Sometimes family doesn't know the patient real well. So yes, it's mom, but they haven't talked to mom in quite a few years. Or maybe they live across the country, and they talk to mom, you know, once every few weeks. So they don't know where things are at. (staff, inpatient)

Especially with elderly patients, family might not have a true, current sense of what the patient was like before, and this distortion could color their sense of what was achievable in recovery. If a patient was already struggling to manage household tasks before, for instance, it might not be realistic to set a goal that they would go home and live independently.

Family members, like patients, might also be in shock in the aftermath of sudden, unexpected change, and they might not yet be ready to contemplate the possibility that some of these changes would be, to some extent at least, permanent. In many cases, families were concerned about their ability to arrange care, so they rejected the possibility of any scenario where the patient is discharged from the hospital with major care requirements. As a therapist explained:

> There are lots of cases where, you know, we're like, someone is going to need constant supervision, at time of discharge, and family member's like, "Well, he needs to be independent because I'm still working, or I'm caring for the grandkids, or, you know, I have my own life. And I just can't commit to being at home with this person for twenty-four hours a day," kind of thing. That happens pretty frequently. Or, you know, we could have a patient where we have goals set for caregiver abilities. And the caregiver's like, "Well, I want him to be exactly like how he was before he was injured. So I'm not going to accept that." (staff, inpatient)

When staff was fairly certain a patient would leave needing a certain degree of care and assistance at home, they made caregiver training a central goal. They continued to work toward recovery with the patient, but they also prioritized getting the family and patient comfortable with the likely post-discharge care routine. In some cases, families pushed back against these caregiver training goals. Many family members hoped the patient would remain at inpatient rehab until they were past the point of needing family care. In general, however, discharging inpatients were unable to live independently.

Some families came to terms with that reality. In many cases, family goals shifted over the course of the stay as they gained a more concrete sense of where the patient truly was in their recovery and what providing for the patient's needs would entail. Families that had planned to take a patient home might, for instance, decide to opt for skilled nursing after observing the patient's progress or participating in family training and getting a hands-on sense of what caregiving would mean. As family observed the patient over the course of the inpatient stay, they might also notice changes they initially missed and prioritize goals they hadn't before. For instance, early on, many families focused on physical goals (e.g., the patient needs to be able to transfer with minimal assistance because the primary caregiver has a bad back), but as time passed and they saw how the patient performed in therapies, they often noticed issues like concentration or word-finding.

In some cases, everyone was fully informed and on the same page about a patient's medical status and care needs, but different parties had competing priorities. For instance, a patient might be very focused on independence goals because they hated the idea of letting their children assist with personal care, whereas the children might be perfectly willing to help with personal care and were more concerned with cognitive change. In some cases, of course, patients and families disagreed about end-of-life planning and what constituted a tolerable quality of life. A patient might insist on a Do Not Resuscitate order, while family begged them to reconsider and agree to full measures.

Of course, pre-existing family dynamics came into play. Disharmony often translated to conflict in the hospital. For instance, adult children might have a tense relationship with a stepparent, and when their parent was hospitalized, children and spouse disagreed over everything from their assessment of the patient's condition to goals for therapy to planning for post-discharge care. As a staff member explained:

> Some families are very much in sync, some families not. And it's not even just patients and families, it could be—we have a number of families on my floor now, where the spouse wants one thing, but the children want another thing, or the grandchildren want something. And they've never gotten along, or maybe they've never talked to each other, but now they're forced to. Or they've been estranged for other reasons, and now they're thrown together, but there's a lot of animosity. It certainly introduces a challenge.... But again, whatever the family dynamics were before, the crisis is going to exacerbate that because of the underlying stress related to it. (staff, inpatient)

Staff could only do so much to head off, mitigate, or manage these sorts of conflicts. Family counseling resources were available, but a couple of sessions generally wouldn't get to the root of deep-seated and long-standing animosities. Patients could be caught in the middle of family squabbles and/or there could be conflict between patients and family over what goals were important and achievable.

Discharge Planning: A Common Area of Contention

Especially in cases where the patient was oriented and capable of self-assessing and identifying goals, family was primarily involved in discussions about discharge. In many cases, the family played a decisive role in determining where a patient would go next and what their post-discharge life would look like. If family was involved, what support they were willing and able to offer was a key factor in setting goals and making discharge plans.

As previously discussed, patients were often eager to leave the hospital as soon as possible, while families generally wanted the patient to stay as long as the hospital would allow. As a patient's wife explained:

> But you know, [my husband] don't really want to rehab, you know. He wants to come home. It's like, "I don't know how much longer I can stay here." I say, damn it, you're gonna stay here until you do better. Okay? You got to do better. You know, you have to help—you have to help me be able to help you. And so you can't just do nothing and think that you can come home. (wife of stroke patient)

Family was, generally, sympathetic to patients' complaints about hospital living, but as this example demonstrates, family members also got frustrated if they felt a patient was prioritizing immediate comfort over working to make the greatest possible gains before discharge. The less the patient recovered, the more onerous the caregiving requirements would be, as families were well aware.

Staff reported that family often came into the process with a critical misconception: they believed the patient would stay in the hospital long-term until they were ready to live mostly independently. Some families understood and accepted that their family member would likely be discharged with care needs, but they wanted more time to get care organized and make alterations to living arrangements. Families who came in expecting a longer inpatient stay often felt panicked when they realized they had to start preparing for a discharge date in a few weeks.

Many family members felt overwhelmed as they approached the discharge date and realized the patient would return home significantly changed from their pre-injury norm. One patient's daughter explained:

> I thought she would at least be able to walk, like maybe with a walker? I thought that, you know, she'd be able to just be a little bit more mobile than she is at the moment.... It just doesn't feel like we had—we're leaving therapy with any big wins. It's like, yeah, she can speak a little better. She can—she's a little stronger. But it just feels like—that's why I guess part of me was like, oh, maybe if she can stay a little longer, she could—then again, I don't know that that's necessarily true. (daughter of stroke patient)

Her mother had severe aphasia and hemiparesis. The daughter wasn't sure whether her mother would ever recover much beyond where she was now, but as discharge approached, the daughter reflected that she had initially counted on greater inpatient progress. The idea of moving in with her mother and caring for her while working remotely, hadn't seemed as daunting when she expected more significant recovery:

> And I think at the time, I wasn't as worried. Maybe because I thought she'd be further along.... But I think now that I'm kind of coming up on it, and realizing how much more help she needs ... and I don't know, just last night, it kind of got me like, oh, like we're just gonna go home and like, be alone. And like, at least now, like, if I'm having trouble, there's someone. Like I can call a PCT. There's someone who can eventually come and help. Where like, once we're home, it's just like, okay, it's just the two of us.... The stakes feel really high. (daughter of stroke patient)

Like this daughter, many family members felt anxious at the idea of going home and having to perform all the complex care currently being handled by professionals on their own. In some cases, family caregivers were spooked by the family training sessions. Family training was intended to prepare people for discharge, but in doing so, it highlighted the extent of care the patient would require and the range of tasks family would have to master.

In other cases, families hoped they wouldn't have to prepare at all because were banking on a quick and complete recovery. Some families declined to come in for family training because they wanted the patient to spend all available time working on recovery. They didn't accept that no matter how hard the patient worked at inpatient rehab, they would be going home with certain care requirements. As a social worker explained:

> You know, I think some families are so overwhelmed, and they're just kind of avoiding and ignoring. "Well, let's just wait and see. I think he'll get better!"... well, you know, we hope he gets better and makes improvements too, but we kind of have to plan for what we're seeing now. We'd really like for you to come in and start engaging with our team, engaging with the therapists, just so that we can try to make the transition home as smooth as possible. And we certainly, certainly have families who do everything they can to avoid and ignore being hands-on, engaging with the team. There's just like a lot of magical

> thinking. Well, no, he'll get better; you'll make him better; you'll make her better. (staff, inpatient)

Staff had to negotiate conflict between what they felt were realistic goals for therapy and what the family insisted staff must achieve.

In some cases, conflict centered around whether the aim should be to prepare the patient to return home or to transition to a skilled nursing facility (see Chapter 3, The Transition Home, on the factors taken into consideration in this decision). Sometimes the disagreement was between the family and the patient (e.g., the family wanted the patient to agree to a skilled nursing placement, and the patient wanted to return home), but often both family and patient were reluctant to consider skilled nursing, and staff were trying to prepare them for the likelihood that the patient wouldn't improve as much as they hoped in the time available. This excerpt from a case conference illustrates the complexity involved:

> The entire care team (physicians, therapists, social worker, and representatives from nursing and psychology) are discussing a TBI patient named "Damien" at his weekly care conference. Damien's family are pushing the team to set goals staff don't believe he can meet, during his inpatient stay.
>
> Doctor: I want to hear from all of you, so we don’t do endless emails. His sodium is up, despite the tube flushes. We did a CT. He had terrible hypoxia. His CT shows pretty significant atrophy. He’s showing some signs of hydrocephalus. His family has unrealistic expectations.
>
> SLP: His wife may be overwhelmed when she starts assisting, and the discharge plan may change to skilled nursing.
>
> Doctor: We have to get her in for training. I think it’s a little bit of avoidance, on her part. I’ll have to be bad cop at the family conference. He had his injury [months ago]. He’s not going to get better. We all know that. I haven’t been able to talk to the wife, at all. I’ve been able to talk to his daughter, but not his wife.
>
> OT: She’s nice. She’s just a lot.
>
> Doctor: Should we extend Damien another week? You guys tell me.

> They all agree that they should plan to extend his stay, but they shouldn't tell the wife they're thinking of extending.
>
> OT: If we extend, she'll put off training again. So in our minds, we'll think about extending, but we won't tell her.
>
> They all agree the rest of his stay should focus on family training.

As in Damien's case, staff often arrived at a point where they were reasonably certain where a patient would be in recovery by the discharge date. Family might still hope the patient would improve by leaps and bounds, but staff felt they'd be better off pivoting to training family to manage the patient's current care needs.

Ultimately, whether or not patients and family members were in agreement about extending the inpatient stay or discharging as soon as possible, staff had the final say.[13] Insurance providers always pushed for discharge, so staff had to choose to fight for continued insurance authorization. As the case conference example illustrates, staff might push to keep a patient longer if they believed the patient could benefit from additional inpatient rehab, or if family members hadn't yet been adequately trained and were unprepared to bring the patient home. Within reason, staff would buy time with the insurance provider to make sure the family got trained and/or had a chance to work out a skilled nursing placement or a home care arrangement.

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[13] Doctors, nurses, social workers, and therapists also faced institutional pressures to empty beds. Doctors especially could push back, but administrators could override their opinions. One doctor told a story about an incident early in his career. The patient was a college athlete who had been in a terrible motorcycle accident. His sodium was swinging massively in the course of a day; they had him on twice daily labs with an endocrine doctor on call. It was a complex case. The medical director handed the patient to the doctor like "here! be baptized by fire." He treated the patient for seven months. The man went home, and he died two months later. His family had wanted him to stay longer, but the medical director really pushed staff to discharge. The social worker assigned to the case quit over it. I asked whether the medical director still worked at the facility, and the doctor said, "she was booted—appropriately so."

In some cases, staff wanted to move forward with discharge, and the patient and family were dragging their feet. Staff wanted to discharge if they felt a patient was medically stable enough to go home and continue therapy as an outpatient or if they felt a patient was unable to benefit from inpatient rehab because their recovery had plateaued or they couldn't or wouldn't participate in therapy. In cases of intractable disagreement, staff went through a process of evaluation, negotiation, and damage mitigation.

Irreconcilable Differences

A nurse practitioner gave me an example of a case in which staff and family couldn't reconcile their differing viewpoints. The patient was a physician; she had a brain injury and was "completely disoriented," so she was effectively unable to participate in planning. She was admitted to inpatient rehab from a long-term acute facility. Her family had been bouncing her around to different rehabs. At each one, the staff would get to the point of discharging her because she wasn't progressing, and the family would move her on to the next one. I asked how they were able to get insurance to cover this facility-hopping, and the NP said she wasn't sure how they were able to get so many Medicare days, but she thinks they were also willing to pay out of pocket. *Insurance is baffling to me*, she said. *Even people who work with insurance plans all the time have to look up regulations.*

The patient's family wanted her to go home with her sister. To do that, she had to be able to walk up twenty stairs, but she couldn’t even walk up one stair when she arrived at inpatient rehab. And unfortunately, she would be leaving in the same condition. She just wasn't making progress. The family really fought to keep her at inpatient rehab, but staff had no grounds to extend her stay. Medicare denied the appeal. As soon as a denial comes back, staff is under pressure to discharge that day or the next. Families often wanted to fight the discharge, but NP explained that as soon as you tell them “you’re going to get a bill now,” they’re like “okay, we’re going to make it happen.” Inpatient rehab cost about $3,500 a day, depending on whether the patient was getting additional services like casting (to prevent contracture due to spasticity), neuro-ophthalmology, etc.

In this case, the conflict was resolved by the financial reality that the family couldn't pay for continued treatment without insurance coverage, but if the opposite scenario arose (i.e., the patient and family wanted to discharge at a time or to a location staff disagreed with), the negotiation could be a lot more complicated. What if, for instance, a patient's goal was to return home instead of transitioning to skilled nursing, but the family couldn’t provide for the patient's care and supervision needs, and staff thought the home environment wouldn't be safe? A staff member outlined an example:

> So they've done an assessment and PT says, you know, [the patient] really needs supervision when they do transfers. But they've only got somebody there during the day. They're going to be alone at night. We know they're going to need toileting at night; we know they're going to transfer at night; they're going to be unsafe at night ... And the patient said, "Yeah, well, I'm willing to take that risk. I'd rather do that than go to a nursing home" ... And people have said to us, in a very rational way, sometimes, "I'd rather—say I fall and fall down the stairs and, you know, break my neck in my own home, I would rather do that than go into a nursing home ... I understand the risk. I'm willing to accept that risk"... that's one of the scenarios we hear a lot, in terms of refusal. (staff, inpatient)

In that case, staff first had to assess whether the patient had the capacity to make that decision. If staff felt the patient might not be cognitively capable of deciding and might need a surrogate decision-maker, a team that included ethicists and psychologists would be called to assess the patient's decisional capacity. Unfortunately, decisional capacity could be a moving target, particularly for this patient population. Some patients fluctuated in their alertness, depending on factors such as sleep, time of day, or whether they had recently taken certain medications. Patients also improved over the course of the stay and could become "competent" later on. As staff bioethicists explained, assessing decisional capacity was not a one-time, global determination: the question was whether a patient was capable of making a specific choice, at a particular time.

If the patient was declared competent, then staff was faced with an "informed refusal" scenario. The situation was similar if a patient was not decisionally capable, but their surrogate decision-makers (often family) insisted on a discharge plan staff felt didn't best serve the patient. Staff would do what they could to make sure it was truly an informed choice. As a physician explained, they could be quite frank in their recommendations:

> [I tell them], "I say and the whole team here says it's a bad decision. You're making a huge—" I say, "You're making a huge mistake." I will just tell them that. And I don't—I'm usually not that direct with people. In this case, if I'm concerned about their safety, "You're making a huge mistake." And you know, again, I've had people, you know, tell me off or swear at me or whatever ... I say, you're gonna fall, you're gonna hurt yourself. You're gonna break your neck, you're gonna hit your head, you're gonna land in the hospital. And make it sound terrible. And you know, a lot of times they'll understand it and agree. Sometimes they won't. I've had many who said, "Forget it." And I have to say, a couple of them have landed back in the hospital with injuries and falls. One in particular, I remember, fell out of bed and got lodged between the bed and the nightstand and was there for like, thirty-six hours till somebody found them. (staff, inpatient)

They also tried to get to the root of *why* a patient was making this choice so they could attempt to negotiate and arrive at a compromise. For instance, if a patient insisted on eating and drinking whatever they wanted, even though staff strongly recommended a modified diet, staff might agree to trial certain foods for a week while the patient was still in the hospital and could be monitored for aspiration and signs of pneumonia. But in many cases, staff had to accept that there was no perfect answer.

If the concern was that family hadn't done enough training to safely care for the patient at home, staff would do what they could to make more training available. But they might suspect a patient and family would go home and do whatever they preferred, regardless of staff recommendations. As a social worker explained:

> And I think it gets hard to know when we have to intervene, or when it really is like, the family is allowed to make their own choices, even if it's not what we think is the safest plan. You know, we'll have patients that we know are being left alone, and that's not our recommendation. And then the challenge is, you know, is this neglect? Or is, you know, this is the family figuring it out? (staff, inpatient)

In most cases, if everyone seemed to have the patient's best interests at heart, staff preferred an imperfect solution over getting authorities involved and landing the patient "in the system." Staff and patients also pointed out that, in many cases, patients had no desirable alternatives. The level of care and assistance or home modification staff recommended just wasn't available, so adjustments had to be made. As a patient said:

> I asked to be trained multiple times with a cane, knowing that I was gonna have to take care of myself. I was told that that wasn't a good idea, but I don't know how I was supposed to be getting up the steps with a walker because they never trained me on how to walk up fifteen steps with a walker. So I don't—I don't know. So I modified. I need to modify throughout my life. (TBI, Black, female, outpatient)

In many cases, patients, families, and staff all understood that the setup at home or the plan being made involved a degree of risk, but if the patient was decisionally capable (or the surrogate decision-makers disagreed with staff and staff didn't feel the situation constituted neglect and warranted reporting to government entities), there wasn't much staff could do beyond warn, document the warnings, designate the discharge "high risk," and task a social worker with checking in more frequently than usual post-discharge. In part for liability reasons, staff put a major emphasis on "educating and documenting," as a doctor explained:

> If we deem or if a professional deems the person has decision-making capacity, then we have to, we're obligated to do what the patient wants. But I go out of my way to document all of my conversations. I'm big on sort of documenting and explaining to the individual, explaining what the risks are. (staff, inpatient)

If family and patient were unwilling or unable to accommodate the staff perspective, staff pivoted to mitigating damage and leaving a paper trail to prove they had issued appropriate warnings.

Staff, patients, and families might fundamentally disagree on therapy and discharge goals. All three groups had power to shape the outcome. At the end of the day, staff exercised control over how long a patient remained in the rehab facility (although staff also had to haggle with insurance providers). Staff collaborated with patients in setting therapy goals, and they also did their best to steer patients and family toward goals they deemed appropriate for the inpatient setting, as I'll discuss at greater length in the next chapter. In some cases, staff were unable to win patients and family over to their perspective. If staff felt a patient and family were unrealistic in their goals, they would try to appease them and take their preferences into account, but staff ultimately set the therapy agenda.

Family had significant agenda-setting power too, insofar as they could stipulate what support they were and were not willing to provide at home. If, for instance, family were able to contribute to creating a supportive, disability accessible home environment, staff and patient could focus on pushing toward longer term goals, rather than training functional strategies. On the other hand, if for instance, a patient represented a high fall risk and wouldn't have a lot of support at home, they might have to alter therapy goals to focus on teaching wheelchair competency instead of working on walking because family wouldn't be around to supervise. Degree of family support was also a significant factor in whether staff and patient worked toward preparing for a return home or for a transition to skilled nursing.

Patients, of course, had the ability to state their preferences and articulate to staff what mattered most to them. Staff tried to center the patient and their preferences in goal discussions, and staff tried to tease out specifics from patients who were vague about their goals (as was often the case with inpatients). If, for instance, a patient was a chef or a gourmand, staff might understand that the ability to eat an unaltered diet was central to the patient's quality of life and a top recovery priority. Staff might even accept that such a patient was willing to assume a higher level of risk to regain the ability to taste food. Patients were also in control of how hard they worked, in and out of therapy. Although the extent of their recovery wasn't entirely within their control, patients could tip the scales one way or another through diligence and motivation. And at the end of the day, patients (and families, if patients were not judged decisionally capable) had the final say in whether they chose to accept medical advice or assume a degree of risk staff deemed unwise.

Does Hassan Have Hemineglect?

I had seen Hassan around the halls. He always recognized me and greeted me. But I was officially introduced when I was shadowing his PCT, Irma. Irma said there was a mystery surrounding Hassan: she heard the therapy team let him use the swimming pool downstairs for aquatic therapy, but as far as Irma was aware, there had been a firm rule since the pandemic started that no one could use the pool. Why did they make an exception?

When we came in to check on Hassan, he was watching a documentary about a rediscovered shipwreck. *That's my friend!* he said, pointing to one of the divers. Hassan explained that he worked as a commercial diver—not just treasure hunting, of course, but also pipelines, underwater welding, bridge building, bridge inspections, etc.

Hassan had been missing the water so much that he begged to use the pool, until they bent the rule for him. *I just want to be in the water*, he said. *I love every moment of it. I don't want to do nothing else. That's why I want to walk. So I can dive again!*

Irma told him not to push himself. He needed to let himself recover.

But I do *push it!* Hassan said. He told us he'd been "up and down, psychologically" lately, distraught at being sidelined from diving.

When we left the room, Irma told me Hassan and his wife had a reputation for having a bad attitude, almost to the point of being combative. It was hard to imagine. He seemed like such a sweet, earnest man. It wasn't until later that I understood the context.

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When I met Hassan as an inpatient, it was the night before his discharge, so I didn't have a chance to ask for an interview. Fortunately, I ran into him again, at day rehab. I quickly learned that Hassan and the staff had divergent perspectives on his inpatient and outpatient experiences.

Everyone agreed on a few points.

First, Hassan was highly motivated to get back to his job. Diving was his great passion in life. When I interviewed him, I eventually asked if there was anything *other* than diving he wanted to get back to, and he said, "Diving. Just Diving.… It's the best thing that's ever happened to any human being." As he explained to the vocational therapist, he hadn't even told anyone associated with his job about his stroke. He made up a story about a family emergency that required him to be away for an extended period. If they found out about his stroke, he feared they wouldn't allow him to return.

Second, Hassan discharged from inpatient rehab earlier than staff recommended.

Third, Hassan disliked speech therapy. As an inpatient, he was adamant he didn't need it, and when he got to day rehab, he refused even an initial speech therapy evaluation. He continued with OT and PT, but he wanted nothing more to do with speech.

Beyond that, accounts differed. After talking to Hassan at day rehab, I went back and spoke to several of the inpatient therapists who treated him, and they all told the same story: Hassan had hemineglect (a neurological condition that caused him to "forget" about or fail to notice objects on his left side, including his own left arm), but he refused to recognize his hemineglect and other cognitive changes because of another neurological symptom, anosognosia. Hassan had a right-brain stroke, and as one of his inpatient therapists put it, self-awareness comes from the right side of the brain. Inability to acknowledge one's limitations was a common effect of a stroke like Hassan's. One therapist gave an example of a recent patient who told her the reason he couldn't move his foot was because it was glued to his wheelchair's footrest. His stroke caused paralysis in that foot, and the stroke also prevented him from drawing a logical connection between the stroke and the paralysis. The only explanation that made sense to him was that someone glued his foot down.

Helping a patient regain insight could be a long process. First, you might put the patient in a situation where you knew they would fail and then try to gently call attention to the failure and the reason behind it. You might ask them to raise both arms and then say, *so I'm noticing, when I asked you to lift your arms over your head, you seemed to have trouble with the left—why is that*? If you could get them to agree that the left arm wasn't moving the way the right was, you could then say, *well, remember you had a stroke that affected the left side of your body and caused weakness in your left side*. But even if a patient had an insight breakthrough, it wouldn't necessarily stick. Staff often had to repeat this process again and again. And in some cases, calling attention to a problem could lead not to insight but to a meltdown.

As the therapists told it, that's what repeatedly happened with Hassan. He refused to accept that he had any problem with hemineglect, or with cognition in general, and he saw speech therapy as a waste of time. The therapists thought they had a few breakthroughs with Hassan, but he always returned to insisting his problems were purely physical. His speech therapists tried to appeal to him by highlighting the ways cognitive symptoms could prevent him from returning to his beloved job, but he brushed them off. He said someone else could set up and check his equipment for him, so it didn't matter if he couldn't do it. To the therapists, it seemed obvious his job would be dangerous for someone with cognitive symptoms. He told stories about tasks like underwater welding that required many precautions to keep from electrocuting yourself. But Hassan insisted the only hurdles preventing him from returning to work were his hemiparetic arm and leg.

Eventually, he insisted on leaving the hospital even though therapists told him he'd get more intensive therapy six days per week as an inpatient, than he'd receive two to three days a week as an outpatient. But Hassan insisted he would work hard at home, on his own, and Hassan's wife backed him up.

In anosognosia cases, family member "buy in" was particularly important. A patient who didn't realize he wasn't noticing objects on his left could easily trip or run into obstacles, so it helped if a family member acknowledged the patient's blind spot and could watch out for trouble. Family members could also encourage patients to cooperate with therapy. Even if the patient didn't think anything was wrong in the first place, they might go along with therapy if a trusted family member said, *I've seen your progress, and I know this therapy is helping you.* As a therapist explained, if the patient is having problems with reasoning, they need family to "be their reasoning."

The therapists tried to get Hassan's wife on board, and at times, it seemed like she accepted the reality of his problems. Therapists pointed out his performance at certain tasks and asked her, *was he like this before*? She seemed to acknowledge the issues, but the next session, she'd agree with Hassan again. Hassan and his wife were united in their insistence that he didn't need speech therapy because he had no cognitive problems.

As Hassan told it:

> I felt for a minute that [my speech therapist] is trying to block me mentally. So she can keep doing her job, regarding my speech therapy. And I tell her so many times that I am not—my brain is not dysfunction. I can think, and I can read, and I can have a conversation with people, and I know what I'm talking about. But she always was bringing the point, your brain is not functioning correctly. And you cannot say that about yourself because we know better than you what's happening to you. So I try to tell her, my brain was not the problem, my body is the problem.

He felt the therapists refused to listen to him. As he saw it, he tried to tell them what he needed: he wanted to push as hard as possible in OT and PT to regain strength and mobility in his arm and leg, as fully and quickly as possible. Hassan felt they were telling him they knew his body and mind better than he did. To him, they were wasting his time with hours of speech therapy, forcing him to sacrifice valuable OT and PT. So he left inpatient rehab earlier than staff recommended because he didn't see the point in staying. They weren't giving him what he felt he needed.

Speech therapy, to Hassan, meant "[sitting] down with a pen and paper." He didn't want to do logic puzzles or tally up a bill. As far as he was concerned, his mind was fine, and to add insult to injury, this sort of "paperwork" was just the sort of boring, indoor task he'd chosen his diving career to escape. Even when the speech therapists tried to set practical tasks that mimicked the skills required by his job (like using a map to navigate around the hospital), he couldn't see the connection, and it felt liked wasted time. The situation came to a head in a speech group. As the therapist recalled it, Hassan started bawling, telling her she was standing between him and the water. In Hassan's version, he was sitting in speech therapy working on a logic puzzle, a pointless "riddle." The room had a window looking out onto the lake. As Hassan described it:

> And I thought to myself for a minute, "What I'm doing here? I need to stand up on my feet and try to walk. I need to use my hand. I need to get out there into the water, to do the best thing that I ever done in my life, which is diving." And [the speech therapist] was sitting down right by the window. For a minute, I felt like, she is the obstacle standing between me and myself, to jump in the water. And I broke down in this time. I just started to cry. I started to feel that I don't want to be here, I really don't want to be here. So that being said, I completely broke down, and I yelled and screamed, "I want to get out of here as soon as possible."

When he arrived at day rehab, he refused speech therapy because he couldn't take it anymore. His experiences in inpatient rehab were "a huge black mark in my head and my brain, regarding speech therapy." But the alleged hemineglect followed him. One day in OT, during a test, he was instructed to roll to his right. He rolled right, but his left arm stayed behind. Hassan claimed it was because as someone accustomed to working as fast as he could, at depth with a limited air supply, he follows instructions as quickly as possible. He "forgot" to move his left arm because of this default to efficiency. But the OT pointed to the abandoned arm as evidence of hemineglect.

Hassan felt, "Because I did one thing, for example, that you are not happy with, that means that whatever that's in the report, whatever they saying about me, it's the truth." Once again, Hassan melted down. Every time a therapist pointed out evidence of hemineglect, Hassan said, "I felt like nobody cared about me. It's just whatever that they have on the report that they read."

To further complicate matters, Hassan claimed his neurologist agreed with him entirely. He reported that at his last neurology appointment, his doctor was "extremely happy" with his progress and said, "I don't think that you have a left side neglect whatsoever." She even approved him to drive.

When I asked the therapists, they had two theories to explain the neurologist's contradictory diagnosis. They said most neurologists give credence to therapists' evaluations since therapists are the ones doing extensive, ongoing testing, but some neurologists are "old school" and disregard therapists' reports. It's possible Hassan's neurologist believed he didn't have hemineglect and thought he would be safe behind the wheel of a car. But it was also possible Hassan either misinterpreted or misreported what his neurologist said.

Ultimately, of course, I'm in no position to judge whether Hassan had hemineglect. It came down to an intractable difference of opinion. On one side, therapists stacked up their professional training and experience and their knowledge of Hassan's stroke and its potential to cause both hemi-neglect and anosognosia. On the other side, Hassan insisted on his superior knowledge of his own mind and body. He felt the therapists disregarded his priorities and opinions. In his mind, the problem wasn't hemineglect but the hemineglect *label*. Once "hemineglect" was in his chart, he believed, subsequent therapists saw what they expected to see.

Henry and Grace and the Wheelchair Dispute

Image 2: Mobility equipment
Source: Photo by Author

Henry was scheduled to discharge the following day. The wheelchair he would take home was set to be delivered sometime during his PT session.

I don't need the wheelchair so much anymore. I'm doing the walker now, but the wheelchair will be helpful when we have to speed somewhere, Henry explained.

Henry and his wife, Bella, were an older, Black couple. Henry, a tall, slender man, had been inpatient for about a month, post-stroke. Bella was finishing up a video call for work. A few minutes later, she received a call about Henry's healthcare, so she had to juggle, answering questions about urine output while muted on her work call.

While they waited for the wheelchair to arrive, Grace, the PT, started Henry's pre-discharge assessment. She asked him to show her a transfer from bed to wheelchair.

Shouldn't the chair be over where I can reach it? Henry asked, nervously.

What do you mean? You're going to stand and pivot into it, like we've been doing. It has to be this distance away, to give you room to stand.

Sorry, he said.

That's okay! Good job.

They headed to the gym, to continue the assessment, Bella still on the phone.

We're going to assess how you walk over uneven surfaces with the walker. So, you're going to start back over here, walk up to here, walk over this mat, pick up this box on the ground, and then keep going, Grace explained. *These will all be discharge assessments, just to track your progress. Day one, we did these, and you probably couldn't do most of these things.*

I'm going to pick the box up? Henry sounded apprehensive. *My legs are already tired from what we just did. I never do that.*

From propelling yourself to the gym? I think we did that recently. I'll give you a ride down to the start point though. Grace pushed his wheelchair to the starting line.

Because I want to be good for these tests!

I think you will be, Grace assured him.

Thanks, dear, Henry said.

Grace set him a six-minute walk text. He was supposed to get as far as he could, within six minutes, with Grace holding his gait belt for safety. Bella and Grace walked along with him, offering encouragement.

Nice maneuvering!

*Good, job, hon*ey, Bella said. She kept up a gentle marching cadence. *Bring it up, right, left. And UP!*

Just as they finished, the wheelchair arrived, accompanied by Jaxon, a tall, athletic, tattooed White man. Grace introduced Jaxon to Henry and Bella, got Henry re-situated in his current wheelchair, and then went to look up Henry's previous six-minute walk scores.

Jaxon began to introduce Henry to his new chair.

Looks a bit narrow, Henry said, dubiously.

They would have measured you, Jaxon said. *The new chair should fit you better. It looks like you have a lot of room on the sides in your current one. The new one will be easier to get through doorways when you get home.*

Do we have an option to make the new chair wider? Henry asked.

I'm pretty sure they took measurements, Jaxon said.

We have accommodations at our home now! I had a narrower chair before my current one, and that was a horrible two weeks. I got sores on my arms.

You might be able to swap it out, at a later date, but I definitely don't have an 18 inch with these specs on my truck now, Jaxon told him.

This is tight, man, Henry said.

Grace returned and tried to intervene. *That's the right measurement, Henry. And it's just for transporting you to and from doctor's appointments. You won't be in it much.*

With the one before, I had sores.

That was before your left arm was moving as much. Now your left arm is mobile. It's not just in one place against the armrest. So sores shouldn't happen, Grace explained.

Okay. Let's wait for my heartrate to go down. Sorry.

They waited a few moments for Henry to feel calmer.

I agree with Jaxon that narrower will be better. It will be easier to get around, Grace said.

But—sorry. Just—wait till my—Give me a minute. Henry tapped his chest and held up a finger to indicate they should wait until his heartrate steadied.

When Henry felt better, Grace reported the walk test stats. *You walked 69 feet your first time, 156 feet last week, and 262 feet this time. So you can see how much progress you've made, from day one to now, which is another example of how it's hard to compare now to before. Because you're totally different now. You're past a lot of the obstacles that were a problem when you first got here.*

What was the first distance? And we're at 262 now? Wow! Bella said.

Good for you! Jaxon agreed.

Grace tried to make a pitch for the new chair. *The new chair is a rental. I don't anticipate you needing it more than a year. It's probably just a great tool for going out in the community.*

We'll pay for a different chair! Henry said, plaintively.

It's not a matter of cost. You'll be walking into the bathroom at home, anyway. Not using a chair. Let's just try the new chair, Grace suggested.

Shall I just talk about it? Jaxon said. He demonstrated the features of the new chair: how to take off the seat cover to wash it, how to put on and remove the footrests, how to move the armrests, how to set the brakes, how to take out the rigid backrest and fold up the chair. Bella moved in closer to observe. Henry watched, apprehensively.

Let me go ahead and lengthen up those pins. Jaxon started making adjustments.

Let's just try, Grace cajoled. *Jaxon, is this true—that if he ends up not liking it, he can order a different size in the future?*

But what is "the future," may I ask? Henry asked.

If you go home, and you already hate it on day one, you have service as part of the rental contract. You can call the number on the chair and order a different one, if you really wanted to switch it out, Grace explained.

I do. I do! Henry said. *Because it took us almost three weeks to get my current chair. And I'm paying, at home, to make things wider to accommodate. I already know I want the wider chair.*

Remember how we talked about how your circumstances have changed from when you were in the first chair? I want you to try to keep an open mind. You've made a lot of progress, Grace said.

Henry remained unconvinced.

How long would it take for you to give him a wider chair? Grace asked Jaxon.

Not sure. But I wouldn't have it before his discharge tomorrow, Jaxon said.

But you need to have a chair when you discharge, Grace told Henry.

Maybe I could just go home with the walker?

Grace explained that he needed to discharge with a wheelchair, but if he decided he didn't like the new chair, she could call and get it replaced. Henry was concerned about how long it would take for the replacement to arrive.

I don't have an exact date. It could be as soon as a week, Jaxon said.

A week would be the soonest though? Could I just request it right now? Henry asked.

You haven't even gotten in the new chair yet. Just try it, Grace suggested.

Henry conceded, and they got him seated in the new chair. Henry was apologetic about holding Jaxon up.

I appreciate your time, Henry said.

No problem, Jaxon assured him

How do you feel? Grace asked. *I feel like you still have room in the new chair. Kind of like in your current chair. Truthfully, I wouldn't have ordered your current chair for you. It's not the right measurements.*

Bella, finished with her phone call, returned to the group.

If he feels uncomfortable, can we order a different size? Bella asked.

I'm trying to order it now! It's too tight, Henry told Bella.

And you'll have a winter coat on. Your down coat wouldn't fit, Bella agreed.

I suffered this for three weeks already, with the first chair I had here! Henry said.

Just know, this is the right size for you. But we'll switch because of your preference. You shouldn't have this much room. It promotes bad posture, Grace explained.

So I'll have this new one for a week? Henry asked.

I'm not sure, Jaxon said.

It's not your fault. You only brought it out. It's just that I dealt with the first chair for three weeks, and then I finally got my current one and was happy. I've got a carpenter coming to the house to accommodate that size. I'll pay whatever! Henry said, despondently.

You don't need to pay, Grace said. *I'll follow up with the company. But by the time a new one arrives, I don't think you'll be using it much. In the home, anyway.*

It's not even for the home. When Bella takes me different places, I just want the space, Henry said.

Bella stepped away to take another call, and Grace started transferring the bags hanging on the back of Henry's current wheelchair over to the new one.

Oh! You're taking the current chair now? I won't be using that chair until I leave? Henry asked, alarmed.

I'm just transferring your stuff over. You can keep that chair in your room, but I want to see if you get used to this one, Grace said.

Grace and Jaxon began to adjust the footrests. Henry looked distraught.

How does the backrest feel? Grace asked.

Tight, Henry said.

After some wrangling it turned out the backrest couldn't be adjusted in the direction Henry wanted. Grace explained they wouldn't want the backs of his knees up against the seat anyway. His knees would rub, and besides, that position wouldn't be correct for transfers.

I think it's fine! There's a little bit of flex here, Grace said.

Henry's eyes filled with tears.

And we'll get you the new chair, Grace assured him.

I would have paid whatever!

It's not about—it's not about cost, Grace said.

Hold on, Bella said to her caller. She was on the phone, dealing with a day rehab scheduling adjustment, but she came over to observe Jaxon, as he adjusted the footrests.

On the paperwork, I'll put in the request to swap, Jaxon said.

I'm just letting you know. This is how it's supposed to fit, Grace told Henry.

If I'm going to have it for years—I mean, if I have to have it in my house another six to eight months, can't I just have the size I want? Henry asked.

We'll order that. But let's focus on this for now. Is the backrest okay? Grace asked.

No. It's too tight, too short, and my behind is….

The only thing we can do is change the angle, Grace explained.

I waited a long time for my current chair. My arm was bleeding. I said I would buy a chair, if I needed to! Henry said.

We're coming up with a solution. What's the solution? Grace prompted.

Order it. But I just don't know how soon it will get here, Henry said, dejectedly. *It's no reflection on you.*

You'll mostly use it to get to doctor's appointments. This chair will be safe and will function just fine, for the week or so you'll be using it before the new one comes, Grace assured him.

Can you guarantee me it's going to be a week? Henry asked.

I cannot, Grace said.

Would it be possible to send him home with his current chair, as a loaner? Jaxon asked.

No. It's a hospital chair. It has to stay here. The new one will work. It's functional. It fits nicely. Give it a chance! Just sit in it today, Grace pleaded.

I am in it! Henry said.

Are you in pain? Where?

Henry indicated his back. He started to cry, and Bella came over to comfort him. “What’s the matter? This one’s too small and you don’t like it? You only have to be in it for doctor’s appointments.” Bella returned to her call, and Grace brought over some tissues.

I appreciate that I have to have a wheelchair, for my life. But at least I want a wheelchair that fits, Henry said.

We have a solution. It’s already in motion, Grace reminded him.

I apologize, Henry said. *How much does a wheelchair cost?*

You don’t need to purchase it.

Bella returned, finished with her calls. *Do you need us to walk you through using the chair?* Grace asked her.

I was paying attention, but it would be good to go over it again, Bella said.

Jaxon started to pack up. *Are you going?* Bella asked. *I wanted to practice while he was here.*

I know how to use it. I can make time to go over everything with you, Grace said.

Grace has got it. And I have more stops. I’ve been here 45 minutes already, Jaxon explained.

I want to get back in the other chair, Henry said.

You can keep it in your room if you want, but I want you to give the new one a chance. Sit in it a little bit. Let’s get back to your room, okay? Grace said.

Bella pushed Henry’s chair, while Grace wheeled the old chair, behind them.

I’m sorry about the mix-up, guys. I’ll follow up with the company. It’s already in process because Jaxon submitted the follow up request, Grace said.

This is a really cheap chair, compared to the other one, Henry said.

It's a rental, Grace pointed out.

There's no place we can buy a chair? Henry asked.

There are places. Just not here. If you want to buy a chair, we can buy a chair, Bella said.

I'll come back later to go over the chair with you again, Bella. Maybe during my lunch, Grace promised.

Yeah. And then Bella will learn how to put it in the car. Is it heavy? Is it too heavy for Bella? Henry worried.

Grace assured them she would follow up later. She was already five minutes late for her next session, and they hadn't even managed to finish the pre-discharge testing.

Good job today! Don't lose sight of the progress we made, Grace said.

Did you write it down? The progress? Henry asked.

Depression or Despondency?

I met Mr. Dawson for the first time, on rounds with his medical team. He was a Black man in his sixties at inpatient rehab following his second stroke. His nurse told me he made a lot of gains after his first stroke, but following the second one, he hadn't rebounded as well. He seemed lethargic, somewhat slow to respond to questions. His doctor told me Mr. Dawson didn't have "a lot of deep insight" into his condition.

Outside Mr. Dawson's room the resident reported Mr. Dawson was "a little teary" yesterday because he was given a new brace. Mr. Dawson was concerned the brace would be permanent and the staff were "giving up on him" and assuming he'd make no further recovery. The team assured him the brace was just to support and augment his therapy.

Given the tearfulness, the resident suggested they prescribe an antidepressant for Mr. Dawson.

"In all honesty, what do *you* think is going on here?" the doctor asked the resident.

The resident said it seemed like Mr. Dawson was just starting to realize how his life would change; the reality of his condition was beginning to sink in. The doctor suggested maybe the resident should talk to Mr. Dawson about what was going on and not just medicate. He should be sure the change in mood wasn't just a situational response.

"Do we know where he's going?" the doctor asked.

The resident reported that they weren't yet sure whether Mr. Dawson was headed home or to a SNF. They hadn't broached it with him, yet.

"The [brace] is just a big symbol for him of his impairment. We tend to take your disability and throw it in your face here," the doctor said. The challenges of therapy threw patients' new limitations into relief.

If the resident wanted to prescribe an SSRI, he should tell Mr. Dawson "exactly what you're using [the SSRI] for." The resident couldn't just order it. Mr. Dawson had every right to consent or refuse because, in the doctor's opinion, Mr. Dawson was "not truly depressed," and evidence that Prozac helps with motor function wasn't strong enough to justify it as "standard of care" for motor recovery. He also explained there was "a long history of these drugs in the African American community" leading to ongoing concern about these drugs as a means of medical control.

"So now, if you want to start an SSRI, feel free. But I just want your reasoning to be good," the doctor cautioned.

When we were in the room, Mr. Dawson brought up the leg brace. *It's groovy looking*, the doctor said, pointing out its swirly blue color scheme. Mr. Dawson said he had a problem with the brace.

"They said it's to help me—that's the only reason." He said, "It was not a question of whether I wanted it or not. They said I have to use it."

The doctor explained that the brace was just "a tool we use." *The use of the knee and hip come back before the ankle, so to start making rehab progress with the knee and hip, you have to support the ankle, until the ankle is ready.*

"I felt like you were putting a leg brace on me and then you would just forget about me," Mr. Dawson said.

"Nah. I'm the king of getting rid of braces," the doctor assured him. *I don't like them, and I try to get my patients out of them as much as possible.*

"Well, if you say I need it, I do," said Mr. Dawson.

"Do you ever drive a car?" the doctor said. *The brace, like a car, is "a tool to get stuff done." It helps you get where you need to go. But*, the doctor conceded, *some people end up needing the brace all their lives.*

Mr. Dawson wasn't happy with the idea of a permanent brace.

"Well, if the goal is to use [the brace] now and get rid of it later, that's a good goal," the doctor said.

The resident didn't bring up the antidepressant.

When we left the room, the doctor asked the resident, "So you're going to defer the SSRI conversation?"

PT: Sneakily Coggy

Image 3: Fall risk tracking poster
Source: Photo by Author

On the way to Nate's room, physical therapist Bree told me he had "not great insight," which was "part of his stroke." Nate thought he could do more than he really could. The other day, he fell trying to get to the bathroom on his own. Recently he asked her if he would be able to run around with his kids when he returned home, and Bree said, "what do you think?" trying to get him to reason it through on his own.

Bree said Nate was a "good patient." His stroke was caused by an arteriovenous malformation, so he didn't have any of the usual stroke risk factors, and he was young and would hopefully recover well.

When we met Nate, Bree asked him to propel his wheelchair out of his room, on his own. "How's your maneuverability?" Bree asked. "Sub-par," he said.

"Well, you're not going home with the chair anymore, so that's okay!" Bree said.

In the therapy gym, Bree suggested they start on some stairs. Nate asked if she meant the small practice sets of steps or the "real stairs" between floors. "What do you think?" She gave him a look. Bree said she "had a giggle" the other day when she saw him over on the little stairs with another PT, "taking it easy."

Bree asked, "Do you know what it means that they switched your belt and that you have a talking belt?" Nate had one of the wheelchair seatbelts that sound an alarm if the patient removes it. He thought about her question for a second and suggested, "to find me at night?" She said, *You may not remember, but you tried to walk to the bathroom and fell, so that's why you're wearing the alert belt*. "I just don't want you to think it's a punishment or that I don't trust you," Bree said.

At the top of the steps, Bree asked Nate which foot he should start down the stairs on. "The bad foot?" he said, uncertainly. Bree asked how confident he was in that guess. He wasn't confident, but he was right. She just wanted to make sure he knew the rationale for starting on the "bad foot." As he moved down the stairs, she held the "gait belt" around his waist, in case he became unsteady.

Nate was about to start down on the incorrect foot, but he hesitated. "Just remember—why can't you do that?" Bree asked. Bree reminded him: because the brace he's wearing on his "bad foot" doesn't allow his ankle to bend.

For the next exercise, she instructed him to step up sideways, holding onto the railing. "Why might we be going up sideways?" Bree asked. Nate guessed, "uh, to change it up?" *Yes*, Bree said. She wanted him to use different muscle groups. *Think of how many directions the body* *walks in a day*, she said. *And we move at different speeds,* and *we have to dodge around other people in a crowd*.

Bree directed him to start down the other side of the stairs. This time, she warned, he wouldn't be able to feel his arm on the railing as well because his hemiparetic arm will be on the rail.

Nate attempted to start facing the wrong way, away from the railing. Bree prompted, "so does this seem like a good, safe manner to go up sideways?"

"One more time up and down—double, okay?" She checked his heart rate. This would be the last time up the stairs, and she wanted him "obviously" to be safe, so she said to go a little faster, but under control. "Why is it harder on this side?" Bree asked. "Because of the distance?" Nate suggested. She explained that, no, it was the same distance on both sides. The increased difficulty was because his hemiparetic side couldn't support him as much.

"Do you need to take a break, Nate? Let's take a break." Bree said. "I tell him, if he's not sweating, I'm not doing my job."

For the next exercise, Bree had an assistant sit on a rolling stool and put a therapy band around Nate's leg with the brace on it. As he walked around the gym, he had to pull the assistant behind him, on the rolling stool. "Come on, let's go, let's go!" Bree encouraged him. "I changed my mind—we're doing a whole lap like this," Bree said. "Get it up! Get your heel down!"

Next, Nate walked backward, dragging the assistant on the chair. Bree told him to "really throw your leg back" and explained he should be getting his hamstring working. "There you go, Nate. Make sure your hips are a little more straight though. Turn your foot a little better." She said they would go to Navy Pier tomorrow, for some extended walking. At this stage of COVID, patients were allowed outside for “ambulation work,” but they weren’t allowed to go into buildings.

“You got another lap in you?” Bree asked.

“I’ll try!”

“Do you need a standing rest break?” They were nearly at the end of the circuit. “There you go! Whatever you just changed, keep doing that—home stretch!”

“Maybe we’ll pop you on the treadmill for the rest [of the session].” She directed him back to his wheelchair for a rest and a water break. “You remember where I said we were going?”

“Uh, my chair?”

Bree asked if he knew where it was and if they had already passed it. Nate wasn’t sure. He said the chairs all look the same. Bree prompted him, and he realized it was back by the stairs.

After the break, Nate got on the treadmill, but facing the wrong direction. “Which way are we going to be walking on the treadmill?” Bree prompted.

As he walked, Bree and Nate chatted casually about a client she had who was a ghosthunter. Then she brought the conversation around to his upcoming discharge. *I want to be very clear. You probably won’t need the cane forever, not even around the house*, Bree said. *You may just need the cane for going out, especially if it’s going to be a long walk.*

“Seems like a more viable solution than the wheelchair” Nate said.

“We always say, plan for the worst, hope for the best,” Bree said, but “I love it when I can ditch a chair.”

There was a clattering sound. *Sorry—that was me*, Bree said. Nate said, “I can’t always feel my legs,” *so I can’t necessarily tell if I’ve bumped into something or not.*

I'm going to speed up for a minute and then let you recover for a minute, Bree said. She explained he would be going faster, but she didn't want him "out of control fast."

"I think I'm going too slow—I'm being too nice," Bree joked. "Not that this is easy!"

"Whatever gets me there," Nate said.

Bree said they might do another strength assessment. *You probably don't remember your earlier one—do you remember day one or is that foggy?* Bree asked. Nate didn't remember. "And I kind of expect that—it's common," Bree said. *That was the big assessment to see what needed to be done* "to get you home," Bree explained.

Bree asked how he was feeling. "Like I could catch one of my kids, maybe!" Nate said.

Bree said she would increase the incline for the last five minutes. "Don't try to jog! I know your body wants to," Bree said. But he couldn't jog because it would be "for lack of a better word, sloppy." He needed to build good form first. Bree said he would work on that a lot, in day rehab.

"Last two minutes! How. High. Can. We. Go?!" Bree encouraged.

"Nate, great session!" Bree said. "Do you remember where your chair is?"

"Do I remember where my chair is? I'm guessing it's still by the stairs?"

Once he was sitting in his wheelchair, Bree inspected the brace, to make sure the fit was correct, and it hadn't left any marks on his skin. "I know you really can't feel that leg, but any pain in that brace that you're noticing?" She sat on the ground and showed him how, if the brace was too loose, it could cause shin pain. Bree offered to leave the brace off because he was scheduled for speech next and wouldn't need it.

It's always fun to work with you. You're a really hard worker and you push yourself, she said.

When Nate had gone to his next session, I mentioned to Bree that I was surprised to see the extent of Nate's cognitive changes. I didn't notice any cognitive symptoms during our interview, and Nate talked mostly about physical problems, like his concerns about using a keyboard for work and keeping up with his children.

"He's sneakily coggy," Bree said. "He fools a lot of people." *But when you go out with him, for instance, he doesn't look before crossing the street. He has executive function and memory problems. He doesn't remember conversations we have, and you have to go over something repeatedly*, Bree said. Nate was recovering very well, especially in comparison to most stroke patients, but she worried he would get in trouble when he went home. He might try to do something he didn't realize he couldn't do, like lift one of his kids, while walking.

Chapter Two: Managing Expectations

Origins of Unrealistic Expectations

As discussed in Chapter One (Goals Over Time, Goals in Conflict), staff believed many patients (and their family members) had unrealistic goals or expectations for recovery. For some patients, their neurological conditions inhibited accurate self-assessment and prevented them from recognizing changes or realistically gauging their potential for recovery. In many cases, however, patients who had no neurological problem with insight also harbored hopes and expectations staff felt were unrealistic. Family members, of course, also had no neurological excuse, but as staff saw it, they were often in denial, as a therapist described:

> [A patient] had a brain injury. Let's say they're very impulsive. They, you know, they will try and do something that they're not safe to do. And the family's like, "Oh, no, they were always like that. That's not new." And you're trying to explain an impairment that is very directly related to their brain injury or their stroke, and the family's like, "No, no, no, they were like this before, this is always like this, this is not new." And you're like, maybe that's true, to some extent. But it's worse now. (staff, inpatient)

For staff, the challenge was to re-frame the situation and convince family to share the staff's neurological interpretation of the patient's behavior. It could be difficult for patients and family to figure out whether behaviors were neurological symptoms or "normal" behavior, perhaps exacerbated by the hospital environment or medication side effects. I'll discuss this process of interpretation at greater length in Chapter Six (Brain, Body, and Mind). Staff acknowledged the complicated, multifactorial origins of patients' behaviors, but they also felt patients and family were often willfully ignorant. As described in Chapter One, many inpatients deliberately avoided thinking too far ahead or focusing on what their lives might look like down the road; coupled with this "focus on now, focus on recovery" attitude was what staff often characterized as denial. Some patients, looking back from the vantage point of day rehab, agreed with this perspective, as this patient described:

> Even though they explained it to me, I still didn't—and maybe I was still going through denial that I have a stroke. Because I was thinking that I was going to go back to work in like, six to eight weeks. I honestly—even though they were telling me that this will be a process.... But in my mind, I was just like, “Oh.” Because if I set my mind to do something, it's done. And so I'm like, “Okay, yeah, I'll go through this therapy. And, you know, come here.” But I was thinking that I would be able to come here and still go to work. Don't ask me how I thought that, but that was just my thought process. (stroke, Black, female, outpatient)

Many patients and family members underestimated how long recovery would take. Often, they assumed the patient would get back to "normal" quickly, even when staff felt the better question was not *when* a patient would get back to certain activities but *if* the patient ever would. As described in the last chapter, there was an element of shock involved. As a stroke patient said:

> I can't even believe I had a stroke. It was just too far-fetched. I never—I never would even think of that. (stroke, White, female, inpatient)

They were still absorbing the fact that the stroke or TBI happened. They hadn't even begun to imagine the full extent to which their lives might change. As another patient explained:

> It happened so fast. I thought it would go away so fast. Like when you are sick. You get sick, and then you get better. So I thought, I got sick, I will get better. And it's true that I have. But I have a long way to go. So my recovery, it is not as instant as my illness. (stroke, White, male, inpatient)

Most patients had no prior experience with disability. To them, illness had always given way to recovery, within a reasonably short timeframe. They weren't prepared for the possibility that the recovery process could drag on for months, and even then, might not end in a complete return to pre-injury health. Patients and family also engaged in forms of magical thinking. As a patient's husband said, "miracles happen;" his wife and he weren't yet willing to accept the staff’s prognosis. A common variant on the “miracles happen” framing was the exceptionalism argument. Staff might explain that a desired outcome was highly statistically unlikely, and the patient and/or family would acknowledge the statistical reality but insist the patient would be among the tiny percentage of people who got lucky.

In many cases, the exceptionalism argument relied less on luck and more on belief in a patient's uncommon grit and fortitude. As this patient explained:

> I understood it, you know. I didn't want to accept it. But I guess all stroke patients are like that. I didn't want to accept that. I was like, “Give me two or three months. I'll have this thing beat.” But now I know that's not true. At first, I told them, the doctors, y'all don't know me. Imma show y'all. But that was just me talking. I know now that it's gonna take a while. So. I've faced that fact. (stroke, Black, male, inpatient)

He talked about moving from insistence that he would beat the odds to acceptance that he too would need more than a couple of months to recover from stroke. But later in the same interview, he circled back to a similar framing:

> Come to find out, my sisters have made arrangements for me to go to another place. But not my home. Man. That kind of bugged me for a while ... and the other place I'm going to, I don't want to be there long. My brother's talking about six months. Half of that, the way I see it.... Everybody say, “Well, that's a good thing to work for, six months. But it could be more.” I don't want to hear them people. Six months. That's how long I plan on being away ... that's all it's gonna take. People in here, they don't know me. Six months, all it gonna take. (stroke, Black, male, inpatient)

Maybe he accepted he wouldn't recover in two to three months, but when his family and the staff broke it to him that he wouldn't be able to return to his apartment and would have to transition to a skilled nursing facility, he once again took the stance that he would recover sooner than anyone expected. He "didn't want to hear" the naysayers. Many patients had faith that miracles happen or that they would be the exception, regardless of what staff told them about the likely outcome.

Misleading Outside Sources of Information

While some patients disregarded staff assessments on the basis of faith, many other patients were misled by inaccurate sources of information. Staff told many stories about misunderstandings rooted in conversations patients had with other healthcare providers, often at the acute hospital. In many cases, it seemed likely the acute staffers had no idea how they were being interpreted. For instance, one physician talked about having traced misinformation back to its source, at an earlier stage in his career when he was treating spinal cord patients. As it turned out, after these patients had surgery to stabilize their spine, the surgeon was telling them there had been a good outcome. To the surgeon, a good outcome meant the spine had been stabilized, straightening the spine and hopefully alleviating pain, but not that the spinal cord had somehow been reconnected. To the patients and their families, a good outcome was that the patient would walk again. So when the inpatient rehab doctor told these patients it was unlikely they would walk again, they pushed back, insisting the surgeon had told them otherwise.

Beyond this type of misinterpretation, many rehab staff members felt acute staff gave patients the wrong idea, either because they weren't experts in rehabilitative medicine and gave unintentionally inaccurate information or because they shirked the responsibility to have a difficult conversation and tell the patient what they didn't want to hear. Some patients reported having been misinformed at the acute stage, as this patient described:

> There was probably some mixed messages. So like, I feel like one doctor, he was like—because I asked about return to work.... But he's like, "Oh, you should probably go back to work in two weeks. Because you don't want to lose like, the cognitive edge or whatever."... And so it wasn't until I got to [inpatient rehab] that I kind of got a better understanding comprehensively. (stroke, White, male, outpatient)

This patient ultimately did return to work, but it was nearly six months later. In many cases, acute hospital personnel may not have had the expertise to assess to what extent and in what ways a patient would be affected in the long-term.

Predictably, rehab staff also felt a lot of misinformation came from patients doing their own research. In many cases, they felt patients stumbled on information that didn't pertain to them. As a TBI physician explained, at the most basic level, TBIs could be focal, diffuse, or a combination of both:

> The presentations are a little bit different. The prognosis is different. I'd say the focal brain injuries almost look similar to stroke patients. Where they have a focal impairment, you see recovery kind of over the first year or so. Whereas some of these patients who have diffuse axonal injury, sometimes their deficits are a little bit more—I'd say less focal. I mean, things like cognitive processing speed and fatigue and other issues seem to be more of an issue for those types of patients. And we do actually see that they often take two to three years. (staff, inpatient/outpatient)

Patients or family could easily develop unrealistic expectations for recovery if they Googled without knowing the particulars of their case. In some cases, patients and family encountered contradictory and confusing information.

One of the first things people came across on Google was the concept of the neurological recovery window. If they happened upon this information online and didn’t follow up with the staff for guidance, they often thought about the "window" in overly concrete terms. As a physician explained: "Obviously, it's not a single day cut off, right? ... So just because you hit that two year mark doesn't mean that you can't still progress" (staff, inpatient/outpatient). Many patients fell into the trap of regarding the window as a hard and fast deadline instead of a guideline. For some patients, this perception might quash their optimism, leading them to assume working toward recovery was futile if they were approaching a landmark date. Other patients might insist on continuing therapy after their recovery had plateaued and staff wanted to discontinue therapy because at some point they had read or been told that they needed to continue pushing as hard as possible for the entire duration of the window.

Along with data they didn't have the context to properly interpret, patients also read powerful personal anecdotes. Many patients encountered stories about patients who were once in the same position they were currently in and were now running marathons or climbing mountains. These triumphant narratives often fed the hope for a miracle and undermined staff's careful, probabilistic explanations.

On the other end of the spectrum, unguided Googling could also trigger unfounded anxiety. Staff members often discouraged patients from doing their own research because they might stumble on out-of-context or irrelevant information that caused undue stress. I witnessed this process play out for Scott, a stroke patient. As Scott later reflected, "I made the mistake of doing my own personal research one morning and just went into a panic attack" (stroke, White, male, inpatient/outpatient). His stroke was caused by an arteriovenous malformation; during his inpatient rehab stay, he was aware the AVM could begin to bleed again, and he knew he would need to have surgery to fix it after discharge.

One morning on rounds, he told the medical team he had been Googling his surgical options, and he was, in his words, "spooked." As discussed in Chapter One (Goals Over Time, Goals in Conflict), staff and families often pushed patients to focus solely on recovery and set aside any stressors that could distract them. The doctor discouraged him from worrying about the surgery and pointed out that the option that particularly frightened Scott—open brain surgery—was an unlikely outcome, which Scott would have been told upfront if he sought information from his medical team rather than Google.

Staff and patients also frequently mentioned that the inpatient rehab's reputation and marketing materials contributed to the belief that staff were miracle workers and led patients to expect extraordinary recovery. Patients mentioned having read glowing reviews or having heard through word of mouth (even from acute care staff) that this facility was "the best place to go" (stroke, White, female, inpatient).

With a high ranking and a sterling reputation came an expectation that they could "fix" anything. As a therapist explained:

> So inpatient rehab, in particular, is like [a highly ranked] hospital, and families know that. And this is the research hospital. And this is the place where miracles happen ... And—this

> is how any hospital is—when you're advertising your hospital, you advertise the success stories. The patient who couldn't even move his head that now leaves, you know, two years out and is back to work and has a family and this and that. And so, when people learn about the different rehab hospitals, and they look up [our hospital], that's what they see.... And so I think that's the biggest misconception is, you know, you're gonna use all your technology, your robotics, your research to heal them and cure them, and they're going to get back to normal, you know?" … My 50-year-old husband is going to get back to his job and kind of back to normal life, even though he can only move three fingers when he comes in, or even though he can't tell you his name." (staff, inpatient)

The word-of-mouth success stories and the tremendous recoveries highlighted on the hospital website contributed to the belief that this hospital could accomplish anything. I repeatedly heard stories framed along similar lines: *I heard/read about this person who was in my position and who walked out of here.*

Lack of Prior Knowledge

Most patients and families came in with limited experience with the neurorehabilitation process. Many patients had no personal experience with severe injury and extended recovery, so they had no basis for estimating how long rehabilitation might take, as Hayden, a locked-in syndrome (LIS) patient, explained:

> Interviewer: What were your goals in rehab, the first time you were in here?
>
> Patient: They were completely unrealistic. Because I guess I didn't know what really happened. All I knew was that I was locked-in, and I was in the best place I could be. So I figured that four, five months I'd be walking, running, getting back to normal life. It really didn't hit me until month three [of my inpatient rehab stay] what a full process this was gonna be....
>
> Interviewer: How did you feel when you came to that realization?
>
> Patient: Defeated. (stroke, White, male, inpatient)

Hayden was in the hospital significantly longer than average, but many patients took a similar trajectory, from assuming they'd be entirely recovered within a short span of time, to realizing recovery would be a long haul. As previously discussed, people commonly assumed the patient would stay in the hospital until fully recovered or largely independent. Even if a patient and family understood that outpatient rehab would follow inpatient, they weren't always clear on the purpose of inpatient vs. outpatient, as a patient's wife explained:

> And I knew we were going to have months of outpatient afterwards. But I really thought that was going to be rebuilding stamina and rebuilding muscles, and it feels like we still have a ways to go before we even get to that point.... We kind of thought he'd be able to come home and, you know, if I had to go into the office to work for a day, he would be fine for eight hours by himself. He's not. That's not the case. So it's different, trying to just align what I've got in my head versus where we are. (wife of TBI patient)

People who assumed inpatient rehab got you most of the way and outpatient helped you fine-tune or regain your strength and get "back to 100 percent" misunderstood the purposes of the different stages. Patients were only meant to remain inpatient until they were medically stable enough to continue therapies outside a hospital setting. But patients and families commonly arrived at inpatient rehab with a limited understanding of the different levels of care. If they didn't know the patient would continue intensive therapy at day rehab, some patients and families panicked, as inpatient discharge approached. They didn't understand that inpatient wasn't the end of the therapy road, so they felt they were being abandoned, that staff was giving up on them.

Similarly, when people approached day rehab discharge, they weren't always sure what to expect, as a patient's sister reported:

> And then he was here for a couple of weeks, and then they said they think he'll be done in December. Now, I'm not sure what that means exactly. I don't know if that means he can drive. I don't know if that means he can work. I'm unclear. So I'm gonna look for some clarification on that. But I was surprised. (sister of TBI patient)

As this woman explained, staff gave them an estimated day rehab discharge date early on, but the patient and family weren't always sure what to make of that date. Did they expect him to be back to work and driving that soon or were they planning to discharge him before his recovery was complete? Of course, staff pointed out that not all patients would ever recover to the point many hoped they would, and besides, outpatient wasn't intended to take them through their entire recovery. As a therapist explained:

> I think a lot of people think that if you have deficits at all, that you will always be in therapy, which is not the case. So there's a lot of frustration with those types of patients. Because therapy isn't meant as, "Oh okay, well if you don't want to do your home exercise program, we'll do therapy with you." That's not what therapy is for. Therapy is skilled, it's intensive, especially day rehab. A lot of our patients just want to come because they don't want to do anything at home, or family say, "Well, they won't do anything for me, but they'll do it for you." And while I understand that, that's not really a reason to be getting day rehab therapy. (staff, outpatient)

At the core of this misunderstanding was not only lack of background knowledge about rehab as a process but also two competing definitions of "need." Therapists saw intensive rehab as a scarce resource meant to set people up so they could continue working on their own at home. But many patients and families felt they still needed day rehab because they didn't yet feel like the rehabilitation process was complete—they weren't where they hoped to be, and they didn't feel comfortable out on their own without the routine guidance and support day rehab provided.

Miscommunication Between Patients, Family, and Staff

In some cases, a patient or family made an assumption or failed to ask for clarification around an area of confusion. In other cases, staff failed to convey information, sometimes because it seemed self-evident to them. Staff cited instances where patients and family misinterpreted therapeutic actions, and staff only later realized they had the wrong idea, as this therapist explained:

> I was with this patient where the son was questioning me. They keep being like, "Well, when is he going to eat? When is he going to eat?" And I've had to keep saying, "He is not going to be a func—like, he's going home with a feeding tube." Like having to be very direct about that. Because they're kind of misinterpreting something I'm doing therapeutically as meaning that he's going to eat again, and this—he is only awake for like five minutes of the day or something like that. (staff, inpatient)

A speech therapist might work on swallowing exercises for a variety of reasons, but in this case, the family observed these exercises and assumed the goal was to get the patient back on an oral diet. A similar misunderstanding could arise when, for instance, a PT had a patient up on a treadmill in a harness. The PT didn't necessarily think the patient would walk again. The exercise might just be intended to build core strength and/or help regain more limited leg mobility. But an untrained onlooker could easily assume the objective was to build toward walking.

For a variety of reasons that I'll cover in greater depth in future work, communication among patient, family, and staff could be complicated and fraught with pitfalls. Many patients had issues with communication, memory, or cognition, so they were prone to misunderstand, forget having been told, or mis-relay information between staff and family. Several patients and family members were frustrated by what they saw as a lack of cohesion in staff communication. Patients often interacted with numerous medical specialists (neurologists, cardiologists, pulmonologists, neuro-ophthalmologists, rehab physicians, etc.), not to mention various therapists in multiple rehab disciplines. And no single staff member was responsible for collating, streamlining, and translating all these disparate aspects of a patient's case. To some patients and family, it seemed like no one was responsible for the entire patient—each staff member discussed only their part of the medical care or therapy. It was unclear to patients and family how much staff were coordinating behind the scenes, and it often felt like no one was tasked with presenting the overall picture and ensuring it was clear to patients and family. Rehab staff communicated among each other behind the scenes, but even so, there was occasional confusion about whether a patient had been told a certain piece of information yet, and if so, how and by whom.

In some cases, information was intentionally withheld. As discussed in Chapter One (Goals over Time, Goals in Conflict), staff and family might deliberately avoid bringing up information they thought might make a patient anxious or depressed. As one patient's niece explained:

> We haven't discussed that she probably isn't going to drive anymore. I don't want to burst her bubble, and I don't want to break her spirit. So I'm not lying to her. None of us are lying to her. But there's certain—you know, we're just trying to be supportive, and assist in keeping her motivated to continue. (niece of TBI patient)

Family members were sometimes grateful the patient didn't seem to be cognizant of the more negative potential outcomes, as a patient's father described:

> And then last Thursday, them saying, you know, "We're very, very confident your son's gonna walk"…[My son] was just like sitting there [seemingly unmoved by the news]. I don't think, in his mind, even for a millisecond he ever thought he was not gonna walk. I don't think it ever entered his mind. Maybe it did and he just went, "Oh, I'm gonna walk." We didn't—I didn't think there was any helpfulness to say, you know, "It's possible, you might not walk"… I mean, realism is important. But I also don't want to scare the shit out of a [young] kid. And so I mean, to me, I left the room, and I went and I cried out in the hall. And he's like, he's just kind of shrugging his shoulders, like, "I was always gonna walk" … I'm like, if he's working hard and being all positive, I'll clear the decks and he can run with that as long as he wants to … because he deserves it, he needs it. (father of stroke patient)

It's absolutely understandable that a father would prefer not to share the weight of his fears with his son. And in their case, the outcome was ideal: the son didn't worry about the negative outcome, and it never came to pass anyway. But in other circumstances, the deliberate positivity could leave patients feeling blindsided down the road. As Hayden, a locked-in syndrome patient explained, in the beginning, no one seemed to be giving him much information, and his wife was very supportive and positive. "So I never thought I was hurt really badly. I thought everything was fixable," he said. He didn't realize until later how serious his condition was.

Making Predictions

How Much Do Staff Know

In discussing how staff share and frame information about prognosis, it's important to first discuss how much staff actually believe they can predict about patient prognosis. Many doctors and some therapists—particularly those who had been practicing a long time—believed they could very accurately predict how a patient's recovery would progress, or at least had "an idea generally of what that patient is going to look like when they leave" (staff, inpatient). As one therapist explained:

> I would say, I can pretty much guess around what I think they're going to be functioning at. I mean, we set long-term goals for their discharge on their very first day. But it's flexible. We change it every week, if needed. But I would say, most of the time, on the first day I can get pretty close to what they're going to be or what I'm going to hope for. Things that might get in the way of them meeting that is if they have a medical turn of events that results in, you know, a different level of functioning. (staff, inpatient)

Staff acknowledged that goals might need to be adjusted down the line, but barring unforeseen medical events (e.g., another stroke, an embolism, an infection, etc.), many doctors and therapists felt they had a good sense of what to expect, at least through the end of the inpatient stay.

The rehab facilities had what staff called a "data-driven" ethos. Based on data collected from previous patients and taking diagnosis and demographic factors into account, staff could predict a given patient's recovery trajectory. At each care team meeting, they compared the projected curve to how the patient had been performing so far. This empirical approach gave staff a reasonable degree of confidence in their expectations.

However, staff also acknowledged that cases could be complex and involve numerous variables, as this therapist explained:

> When I see, you know, this is where you came in at, this is what I was seeing, this is the strength I see that you have in your weaker side, this is the sensation, this is—you know, all these things that I assessed, all the impairments. This is how much function you have,

> how much I have to help you with transfers, with walking, with stairs. And based on my experience, when patients come in at this level, they often leave at this level. And then I will, you know, include prognostic factors that we know. With, for example, stroke recovery: younger age versus, you know—younger tends to have better prognosis than older; having some movement on your side that was affected by your stroke is better than having no movement. Did they get certain medical interventions when they went to the hospital? That matters too. There are certain medicines that doctors can or can't give that may impact recovery. Do you have sensation on that side of your body? Or not? Do you have inattention or neglect? Do you even realize what that side of the body is doing? What's on that side of the room? (staff, inpatient)

In some ways, staff framed patient motivation as the most significant wild card. They often stated that patients who worked hard could exceed expectations, and patients who were lackadaisical in therapies might underperform staff's initial forecasting.

Staff recognized that given the myriad factors considered, there was room for error in predictions. They also allowed for unexpected outcomes. Physicians talked about having seen "miraculous recoveries" (staff, inpatient), but also patients who didn't progress as well as anticipated. "Every patient is unique" was a common refrain among staff. They believed—and tried to convey to patients and family—that while they had "a roadmap" (staff, inpatient/outpatient), a set of expectations based on data and past experience, they "don't have a crystal ball" (staff, inpatient).

Although staff didn't always believe they could predict outcomes exactly, they were often fairly certain patients wouldn't achieve the complete recovery many of them hoped they would. This exchange is representative of their general outlook:

> I ask if [the patient] can expect a full recovery. Dr. Z is pretty unequivocal that he won't.
>
> Dr. Z: *He can expect to walk. And without a device like a cane or walker. I don't know about that arm function though. It's going to be up to him.*

On the whole, staff had a set of expectations, but they left room for deviation from their projections.

How Much Do Staff Share?

Even staff members who believed they could accurately predict prognosis were often unwilling to share these predictions with patients for a variety of reasons discussed later in the chapter. Nurses and therapists often said it wasn't appropriate for them to share predictions, and, when asked, they encouraged patients to speak to their doctors, even if they felt they had a strong idea of what to expect. As a nurse pointed out, if family wasn't present during rounds, some family members rarely (or never) got to see the doctors, so they asked whatever staff member was available. Nurses often had to dodge and defer questions they felt were outside their purview.

Even physicians generally didn't get too specific and definite about predictions. They tended to speak in probabilistic terms, talking about what was "most likely" or "what often happens or what typically happens" (staff, inpatient). On the whole, staff tried to convey the message that as a therapist described, "I'm not perfect…. In my experience and in my schooling, this is what I've generally seen. There are patients who may exceed my expectations, and there's some that may come a little bit short" (staff, inpatient).

How Much Do Patients and Family Want to Know?

Some patients and family were reluctant to hear predictions. As discussed in Chapter One (Goals Over Time, Goals in Conflict), inpatients in particular often preferred to focus on working as hard as possible toward recovery and avoid the question of long-term outcome. Other patients recognized that staff didn't have all the answers, and they appreciated that staff didn't offer exaggerated certainty or false hope. As one patient explained:

> I think when a new patient comes in, I would assume that the first question is, "How long am I going to be here?" I would hope that all they answer is, "We don't know." It's a terrible answer. But that's the truth. We don't know. You could be here a month; you could be here two months. You could be here a couple of days. Everyone's recovery is different. It sucks

> when you're a patient. You hate that answer. But it's the truth. Will I get 100 percent of my speech back? “You're presenting with symptoms that I would think, yes. However, we don't know.” Terrible answer, but it's the truth. (stroke, White, male, inpatient)

However, many patients wanted concrete predictions and expressed a great deal of frustration at what they perceived as a lack of knowledge or lack of transparency on the part of the staff. Over and over, patients and family told me they were tired of hearing, “We don’t have a crystal ball.” They wanted prognostications, especially when the stakes were heartbreakingly high. Many family members, for instance, talked about the pain and anxiety they felt when no one could tell them whether their loved one would ever wake up or “come back” and be themselves again.

Sometimes, family had to make difficult decisions in medical crises, while patients themselves were unconscious or not decisionally capable. In some cases, they bristled at how little staff were willing to weigh in and advise them on the best course of action. As a patient’s wife described, “And everything that I tried, all the decisions that I made for [George], I had to make on my own. And you know, they're the experts; they should be helping you. And yet, they don't” (wife of TBI patient).

Patients and family often used the phrases “nobody will tell you” or “nobody can tell you.” When they said “nobody *will* tell” it wasn’t always clear they were implying that staff were deliberately withholding information. Some people seemed to use “nobody will” and “nobody can” in roughly the same context. But in other cases, patients and family thought staff knew more than they were saying. Some patients thought members of staff were delivering information to their family and keeping it from them. Some patients and family thought staff were obfuscating to protect their own interests. Sometimes they felt staff were not delivering detailed predictions because they underestimated what the patient or family would understand. As a patient’s wife put it:

> Maybe they're used to not being technical with people. I'm a very detailed person. So I want to know everything that's going on. “Educate me!” kind of thing. And there was a lot of—I felt like they weren't telling us things. I also feel like—because of liability—they can't tell you certain things without knowing for certain if it's gonna be. Because they can say something, and then if that doesn't happen—I think there's a lot of that that goes on too. (wife of TBI patient)

Some patients and family thought staff might be avoiding giving predictions because they didn’t want to be held accountable if they were wrong.

In many cases, however, patients and family understood that staff weren’t certain themselves. They were no less frustrated, but they didn’t necessarily believe staff had information they weren’t sharing. Patients and families, understandably, found it difficult to sit comfortably with all the unknowns. They were often annoyed by what they recognized as stock phrases:

> What's going on here? What am I supposed to expect? What is happening? Is he going to get better? “Well, people mostly get better.” That's what they would tell me. “People mostly get better.” Or, like when I got here, you know, he was in post-traumatic amnesia. And I'd say, “How long does this last?” “It varies with—every patient is different. It varies. You know, depends on how hard they hit their head, but some people get through it in a few days, a few weeks. Some people never, never get better. It lasts forever.” Okay, well, in your vast experience of people like [George], what would you say? “Well, every patient is different. And we—you know, we just don't know. We just don't know.” (wife of TBI patient)

Even if staff were being entirely truthful in claiming they couldn’t be sure, many patients and family wanted them to go out on limb and give them an estimate or even a guess.

Given the amount of hedging that went on in discussions of prognosis, concrete predictions were rare. As a patient’s wife explained, that made them all the more valuable:

> [The doctor] has held it pretty close to the chest, I would say. The nurses or the PCTs are like, “You'll be walking out of here” or “Just give it time, honey! You'll be walking in no time.” Or whatever. And I'm like, “Yeah, okay, but you're not a doctor. So you don't really know.” But so when [the doctor] said that he thinks [my husband] could be walking around the house, it was like, a pretty intentional statement. I didn't think it was flippant or exaggerated or like—I think it was very grounded in research and his own experience. (wife of stroke patient)

Not only was the doctor considered a superior authority, but the wife and patient also noted that he didn’t offer empty optimism and encouragement. So when he gave a prediction, it held weight because they not only trusted his expertise but also recognized that he took care not to make casual pronouncements.

Ultimately, patients and families craved information and certainty. Even though I made it clear I was in no way medically trained, many patients asked me if I thought they would get better. Often people just wanted someone to give them hope. But many others recognized that not all predictions were equally valuable.

What Do Staff Consider When Confronting Unrealistic Expectations?

Preserving Rapport

Staff are human and generally wanted to be liked and preferred to avoid uncomfortable interactions. No one wanted to be the bearer of bad news. As a therapist explained, sometimes she deferred a prognosis question to the doctor, in part because “I never want to be the one to tell someone that their family member will never be the same. I just don't want that to be on me. And I don't want to believe that myself either” (staff, inpatient). In some cases, physicians had a similar impulse, as one outpatient physician explained; “But I just—I think that they've probably had [negativity] a lot from other doctors, and I want to be a source of like, encouragement and hope for them. So I try not to put things in [negative] terms” (staff, outpatient).

To an extent, this understandable reluctance could lead to a scenario in which everyone assumed someone had told the patient and family, but in reality, no one had delivered the bad news, at least not in bald terms. Ultimately, however, some kind of confrontation between reality and expectations was inevitable, as this therapist described:

> I just recently had a family meeting where we talked about how the patient unfortunately has not been making as quick of progress as they were [in] inpatient [rehab] … And just letting them know like, "things are slowing down" and being honest with them—it's really hard. But you just have to be honest with them because if you aren't or you kind of beat around the bush, it's not helpful. And then their expectations aren't super realistic. (staff, outpatient)

In some cases, family wanted staff to be the "bad guy" and deliver a message the patient needed to hear but no one wanted to convey. Sometimes family just wanted staff to back them up (e.g., reinforce that a patient wasn't safe to drive so the patient might be more cooperative when family tried to impose restrictions at home). But sometimes, family wanted to avoid relational conflict by outsourcing a difficult discussion.

Unfortunately, staff also had reason to carefully manage their relationships with patients. A doctor described a situation in which rapport broke down:

> Dr. Z says once, in a family meeting, a patient's father asked him what the patient would look like in a year. Dr. Z "hedged," but the father was really insistent. He said he wanted to know what to be prepared for, and he said, "If you know, you have to tell me." So Dr. Z told him honestly that the patient would still need assistance to walk in one year. And then on the post-discharge evaluation, there was a comment calling Dr. Z "the most negative doctor we ever met." If asked a similar question now, he would say "You know what, that's something [the patient is] going to have to discover [for himself]." He would say people put "different levels of effort in, get different outcomes out," and we just have to see how it goes.

Staff were not just concerned a patient or family might get angry with them (and possibly complain or leave unfavorable reviews); they were also aware that if patients and family dismissed them as "negative" they might disregard their therapeutic and medical advice. They wanted patients and families to feel they were all on the same "recovery team."

Staff also knew that how patients and family received information depended, in part, on how and when it was delivered. Patients and family might be "so overwhelmed" they're "just not hearing" what staff are trying to convey (staff, inpatient). A patient educator explained that patients and family might "shut down" if given information that "really wasn't what they wanted to hear," if the tone and messaging weren't carefully calibrated (staff, inpatient). One doctor recalled an incident early in his career:

> I had a patient who was completely quadriplegic, and I spent a lot of time with the family. I explained, "This person has quadriplegia, unlikely to improve." And we met several times to talk about this. And I get the patient satisfaction survey. And it says, "Doctor never met with us to tell us what to expect. Never!" And of course, at that time in my career, I was totally outraged and defensive and everything. But that's just—people are not processing it all the time. (staff, inpatient)

Staff tried to assess what patients and family were "ready" to hear, and how much they seemed to have recovered from the initial post-injury shock.

Balancing Realism and Hope

When considering how to confront unrealistic expectations, preserving the patient's motivation was of paramount importance to staff. Staff worried that giving patients bad news would lead to hopelessness and diminished participation in therapy. Conversely, they didn't want patients who received a favorable prediction to assume the outcome was assured and become complacent.

Even if the patient's desired outcome was unlikely, staff didn't want to "put a ceiling on recovery" (staff, inpatient). Pushing to achieve a longshot goal might motivate a patient to work as hard as possible; even if they didn't meet their goal, they would at least have maximized their gains. As staff pointed out, many patients didn't yet realize how much of a difference smaller improvements could make in their quality of life. Patients might focus on walking instead of more achievable goals like standing independently (which would make transferring from bed to wheelchair to toilet or shower chair easer). But in working toward the pie-in-the-sky goal, they might achieve the less high-profile goals therapists knew would be crucial in determining whether they could, for instance, return home.

At the same time, staff knew that unrealistic expectations would set patients up for disappointment in the future. Not only did staff want to avoid devastation down the road, but they also wanted to make sure patients and family didn’t leave rehab unprepared for the realities they would face. If it was unlikely a patient would be walking by the time they were discharged, for instance, staff had to ensure the patient was equipped to function in their post-discharge environment and wasn’t just banking on “getting back to normal” before going home. Especially when patients and their families were faced with discharge planning decisions, staff wanted to make sure they had the information they needed to make an informed choice, as this therapist explained:

> And those [conversations] can be sometimes really brutal because you have to be very upfront with them about, you know, what it's going to look like at home. I think that's a huge disservice we can do to families, if we don't prepare them for the realistic expectation of what home is going to look like. Like, [the patient has] to be toileted every three hours, they need to be changed, if they're incontinent. You know, some of our brain injury patients who are very confused and agitated—someone needs to be with them potentially 24/7. So making sure like, you know, there's restraints or some kind of plan in place that the patient won't be getting up, once they leave here, in the middle of the night and trying to roam around the house or get themselves into trouble that might harm the family member or the patient. (staff, inpatient)

Ideally, staff wanted to be equally transparent with patients and family, recognizing that “even if the patient has cognitive impairments, you know, it's their care and their life that we're talking about and their future” (staff, inpatient). They also wanted to make sure staff, patient, and family were all on the same page so as to avoid confusion and miscommunication. Making sure patient and family received the same information, at the same time, from the same source, also meant that family and patient could help each other process the news.

In some cases, however, staff were more forthcoming with family because they were less concerned about preserving family members’ motivation, and they wanted family to be able to make adequate and realistic plans for post-discharge care. Patients might also have a harder time understanding and assimilating information due to cognitive changes, and patients might also be in a more fragile emotional state, as a physician described:

> So in general, I want to be as upfront as possible with both [family and patient] ... I had patients recently who were very, very depressed when they came in. Suffered from premorbid depression, tearful every single day, when I saw them. We worked with psychiatry, got them back on medications…. But the way I talked to him, the patient, and the way I talked to their spouse was different. Because with the patient, I needed to be very motivational. With the spouse, the spouse had asked me, "Well, will he walk? Will he do this?" So she needed more upfront information so that she could plan for how to help him at home. (staff, inpatient)

Overall, however, with both patients and family, staff wanted to achieve informed hope. As a doctor explained:

> It's very difficult, you know, because we're obviously seeing patients who can be severely injured, who may have what we think is very poor prognosis ... I want to be realistic, but hopeful at the same time.... But, you know, I don't promise things that we can't deliver. And at the same time, I don't take a negative approach where I don't feel it's my role to damper somebody's hope, if you will. (staff, inpatient)

As another doctor described, they might tell a patient something like the following:

> Well, you know, we're all with you…. We share your optimism. We hope it happens. We're not so sure. And in the meantime, it's really important that you do this for practical reasons. That you go to therapy, learn how to take care of yourself, learn how to take care of your skin and bladder and bowel, those things, to prevent problems. (staff, inpatient)

Staff wanted patients and family to feel they were rooting for them, on the same team and not adversarial. But they also wanted to make sure patients weren't set up for a fall, either in the sense that their unrealistic optimism left them unprepared for the road ahead or in the sense that they were in for a brutal disappointment in the future. But at the same time, they wanted to preserve hope (and motivation) by leaving room for the possibility of extraordinary recovery

Strategies for Managing Expectations

In striving to preserve hope while managing expectations, staff had a variety of strategies at their disposal. First, they endeavored to gain the trust of patients and family as the foundation for a therapeutic relationship. If patients and family trusted staff, it would be easier to get “buy in” and ensure patients complied with treatment recommendations and therapy regimens. A relationship of trust also inclined patients to believe staff had their best interests at heart and were rooting for them to succeed.

In some cases, staff had an uphill battle in building this trust because patients were wary of medical institutions and practitioners. Patients might have had recent negative experiences at the acute hospital that primed them to be mistrustful, but in other cases, trust was even harder to repair, as a bioethicist explained:

> We've had some informed refusals that I felt were mitigated by distrust that were really painful for me to watch. You know, individuals from ethnic minorities who have experienced poor treatment in the medical system, who then came here after their experiences and declined elements of care that would have greatly benefited them. And rebuilding that trust sometimes requires a longer timeframe than we might be able to offer and resources that, you know, we might not have because it's sometimes deeper than the relationships that are formed here can mend. (staff, inpatient)

Staff tried to build (or re-build) trust by setting expectations and discussing plans as early as possible. Ideally, they didn’t want patients and family to feel blindsided (e.g., by learning the week before discharge that their plans were incompatible with the medical reality). They also stressed consistency and repetition; they wanted to make sure all staff members were delivering the same message. Staff tried to keep all team members apprised of concerns patients and family raised. Sometimes they asked each other to reinforce a message they were trying to get across that the patient and/or family were resisting or failing to absorb or retain.

At family meetings, staff aimed to present a united front to patients and family. As a physician explained: “We show the pictures, we present the objective assessment, and everyone's assessment. And it's just a whole theme” (staff, inpatient). If the care team presented a unified front, patients and family were more likely to accept what they were trying to convey, even if the information was unpalatable (e.g., that the patient shouldn’t expect to walk by the end of inpatient rehab). The team effort also allowed staff to diffuse responsibility, as this exchange on rounds suggests:

> The doctor is telling a patient she will require a high level of care, so she will either need a caregiver at home or she will have to discharge to a skilled nursing home. She is very dissatisfied with this pronouncement.
>
> “It’s not my decision—it’s the decision of the team!” the doctor said.

In this way, staff could discourage answer shopping and distribute blame. If they were all collectively “the bad guy,” hopefully no single staff member would be the focus of the patient’s displeasure.

Staff also continued to check in with patients and family at regular intervals to maintain an open channel of communication and make sure expectations were in line with current events. As a therapist explained:

> And I usually tell families we'll check in halfway through and see how we're recovering. And we'll see, you know, where are we at? Are you progressing like I expected? Is it going better? Is it going worse? You know, do I have to upgrade goals because you're doing better than I expected? Or am I a little nervous that we might not meet the goals I promised? And how is that going to change discharge? (staff, inpatient)

By checking in, staff tried to ensure that a patient and family weren’t counting on an outcome that no longer seemed likely. Insurance required staff to demonstrate a patient was making significant progress within a reasonable amount of time, so staff also wanted to keep patients and family apprised of whether the original estimated discharge date might change. If a patient wasn’t progressing as expected, staff would try to prepare the patient and family for the possibility of an earlier discharge. On the whole, staff tried to be open, communicative, and consistent to preserve trust and rapport.

Presenting Data

Therapists especially collected a great deal of data. This data-driven approach could be helpful in achieving patient buy-in because therapists were able to point to standardized assessments that could seem more objective and authoritative than a therapist’s professional opinion. A therapist described how they might use data reporting to frame their expectations for a patient’s recovery:

> How much assist do they need to roll over? How much assist do they need just to sit up in bed? How much assist to get into the chair? I talk about that, but then I also use those outcome measures. You know, this sitting balance test is out of 56 points. Fifty-six is the best score you can get; your family member's scoring three points right now. They can't even sit unassisted. Because of that, you know, we're really going to be hoping that by the end of their stay they're able to sit a little bit more unsupported, so that they can sit up and eat a meal, so that they can sit up and help get dressed for the day. But if they're really struggling with these easier skills, it's going to be very hard to imagine them being able to walk independently. (staff, inpatient)

A score of 3 out of 56 could be more persuasive than a therapist’s recommendation on its own. Without the numbers, it was easier to dismiss a therapist’s assessment as opinion rather than fact.

Data reporting was also used to help patients track their own progress and make sure they were aware of where they stood in relation to the goals they set. This interaction between a patient and SLP demonstrates how therapists routinely incorporate updates, explanation, and data into their sessions:

> SLP: *So you just finished your sets. You got 19 out of 25. Much better than yesterday. Yesterday you got 17 out of 25. So I heard some more puff. Any questions about why you’re using this device?*

> Patient: *To help my voice.*
>
> SLP: *Exactly. And respiratory endurance. We're strengthening the muscles around here. Remember when I asked you to say ahhhhh for as long as you could, yesterday? You could only do it for 3 seconds. So when we speak, we're sustaining sounds. This is to build up your strength so you can shout across the hall. How do you think your vocal quality is today?*
>
> Patient: *Better. In the back, much better.*

In one short dialogue, the therapist shared progress data, made sure the patient knew how the exercise they worked on related to the patient's speech goals, and gauged the patient's perception of her own progress.

Some patients were particularly responsive to numerical data. A patient might be a self-described "numbers person" who preferred quantitative benchmarks to qualitative feedback, or they might enjoy the ability to track and tabulate gains. Most of all, however, data could be helpful in making it clear to patients that staff were not being arbitrary and capricious. As a therapist explained:

> I mean, some patients respond really well to data. And those patients, I'll be like, "You got this score on like the Berg [Balance Test]. This shows like, you're at a pretty high fall risk. And right now, you need this walker. If it gets here—which, you've already improved by this much—if it gets up to here, we can work without it and see how it goes. (staff, inpatient)

In this way, the therapist could set up an external arbiter. It wasn't the therapist who determined whether a patient was able to use the walker; the Berg Balance Test demonstrated it was unsafe. At the same time, the patient had clear targets to hit if they wanted to reach their goal, and they could see empirically how close or far they were from reaching it.

Resetting the Timeline

"Rehab is a marathon, not a sprint" was among the most common sayings used by staff. First, staff tried to convey to patients that neuro-recovery was a long-term project; and second, they tried to reframe this lengthy recovery as a positive. As a nurse phrased it:

> Some people, I'm like, "Don't find [the timeline] depressing. Find that encouraging." Like, how long does it take to recover? Probably like a year, which means you have up to a year that things can keep getting better.…You have a long time to keep working hard. (staff, inpatient)

Staff tried to frame the "marathon" of neurorehabilitation as a generous window of opportunity, as opposed to a tiresome slog. In some cases, patients were demoralized when they found out recovery would take longer than expected, but in other cases, patients were pleased to hear their recovery was only beginning, as a patient's wife described:

> But [my husband] was relieved to hear that stroke recovery can take anywhere between one and two years. Because he had in his mind so far that it was a matter of months. And he was starting to worry that he was like, running out of time.... [Hearing it would take longer] brought him immense relief because he realized that he's not running out of time. And that given one to two years and where he is today, he's actually doing really well. He's actually doing remarkably well. Like, nobody thought that he would be talking today. (wife of stroke patient)

On a broader timescale, the patient was able to think of himself as ahead of the curve, with a lot of time left on the clock.

Staff also tried to prepare patients and family for changes in the rate of recovery over time. If patients expected to continue making gains as they had in the early weeks and months, they could become disheartened and demotivated when recovery speed began to taper off. They emphasized that in day rehab and beyond, patients should be prepared for a plateau, but they should still continue pushing for gains. As recovery progressed, staff also introduced the concept of good days and bad days. Especially at the later stages, patients needed to be prepared for the fact that recovery wasn't always linear. As a day rehab patient explained:

> The more I do something, the better I'll get at it. But it's more to it than just that statement. Like, you know, my arm … [Today] I can do it just a little bit. But then tomorrow, my arm may say, "Not today!" But I can still do it. (stroke, Black, female, outpatient)

Under the good days and bad days framing, patients were prepared to accept that progress would slow, but recovery would still continue. Similarly, an arm might be uncooperative today, but that didn't mean yesterday's gains were lost. Today was just a bad day, and there would be good days ahead.

Shifting Focus to Short-term Goals

When setting goals with patients, therapists emphasized the difference between short-term and long-term goals; it was all right to have an ambitious long-term goal, but they encouraged patients to set interim goals (e.g., if a patient says he wants to regain use of his left arm, an occupational therapist might outline intermediate steps like working on holding the arm up, working on wrist and finger extension, etc.). For instance, when a patient with severe mobility issues said she wanted to work on her basketball jump shot in PT, the doctor told her, "Not quite yet, but that's a goal—that's a really good goal, actually." The "good goal, but" framing was a commonly used strategy that allowed staff to encourage more realistic short-term expectations, without invalidating a patient's hopes. As a therapist explained:

> Sometimes when people set inappropriate goals, I'll say, "You know, that's a great goal. However, I think we need to start smaller and work our way up to that." Just so, again, I'm not completely taking away all their confidence and motivation, right? (staff, inpatient)

Staff used a similar frame to bolster patients who were despondent about (or resistant to) their current restrictions or adaptive needs. They framed restrictions and adaptations as a short-term inconvenience or a temporary expediency. If a patient complained that they weren't allowed to drive, staff might tell them they couldn't drive "yet." Conversely, if a patient balked at having to use a walker for mobility, staff might say they had to use the walker “for now.” As a psychologist described:

> They'll say, “I can't drive,” and I say, “Yet.” “I can't speak.” Yet. “I can't go back to work.” Yet. It changes everything. It completely shifts the focus and makes the situation temporary. I err on the side of encouragement. (staff, outpatient)

“Yet” and “for now” struck a balance between managing expectations and preserving hope by framing obstacles as potentially surmountable and hopefully temporary, as this interaction on rounds illustrates:

> Cleè wants to know what she’ll be able to do. For instance, if a girlfriend calls and asks if she wants to go out, “will I be able to get in the car and meet her? ... Am I ever going to drive again?”
>
> Doctor: “At this point, I would say no, not yet.”
>
> Cleè: *But that’s not “not ever” so I could drive again, in the future?*
>
> Doctor: “That’s a reasonable goal.”

“Yet” made it clear that driving was off the table at the moment, while preserving hope for the future. “For now” acknowledged patients’ lofty long-term goals but encouraged them to focus on learning strategies to improve their quality of life, in the meantime. For instance, a patient might hope to regain full use of their arm, but occupational therapy might focus on teaching the patient techniques they could use “for now,” like using the hemiplegic arm as a stabilizer to assist in lifting an object. Staff might encourage patients to apply for short-term or long-term disability to meet their financial needs “for now,” even as they worked toward returning to work. Some patients thought of their lives as being on hold until they recovered. With the “for now” framing, staff urged them to continue engaging with activities that brought them joy, even if they couldn’t (currently) do them the way they used to.

"For now" also applied to the goals themselves. Staff stressed that goals were meant to be continually assessed and adjusted. As a therapist described:

> So, I always kind of phrase it like, "These are my goals I have set for you now. That's not to say, in the future, we're not going to get past this. But it's only for the anticipated three to six weeks that you're normally in inpatient rehab for … And I always kind of phrase it to like, you know, goals can be adjusted and changed every day. (staff, inpatient)

They made it clear what their current outlook was, but they also left room for hope by emphasizing that they could adjust those expectations upward, if the patient excelled. Staff also repeatedly emphasized that patients should "plan for the worst, hope for the best." As a therapist explained:

> A lot of times, when I'm telling families, "Oh, you're going to go home and you're going to need a wheelchair, you're going to need a lift." And it's still like three weeks out, and they're like, "Well, I still got three weeks left." But, you know, in the back of my mind, I'm like, "Yes, but I know prognostically we're not going to achieve that." Sometimes just having that conversation like, "Well, we have to plan for this now, you know, and then we'll always adjust things from there." (staff, inpatient)

Staff might not think a patient was ready to accept their "new normal," or they might be trying to preserve morale and motivation by avoiding giving the patient a brutally honest prognosis. By using "plan for the worst, hope for the best," they allowed patients to hang onto their (potentially unrealistic) hope while still ensuring patients and family were equipped for the most likely outcome.

At the same time, staff tried to help patients understand exactly what would be required to meet their long-term goals by helping them come up with concrete interim goals. As a therapist explained, she might say:

> Okay, you want to return to driving and return to work. But that's a big, big plan. Let's first focus on, can you remember my assignment I gave you? Or can you complete this executive functioning task or whatever that may be without needing X number of help? (staff, inpatient)

In many cases, patients simply didn't comprehend what a particular task demanded. As discussed in Chapter Six (Brain, Body, and Mind), patients weren't used to mentally breaking down actions like walking and driving into steps and stages; they were used to performing these actions automatically and without a great deal of self-reflection. As a patient explained, “My biggest concern, of course, is driving. I thought once my foot came back and everything that it [would be] just get in a car and go, but apparently I was wrong” (stroke, White, female, inpatient). Part of managing expectations was explaining to patients that tasks like driving are more physically and cognitively complex than they seem, as a physician explained:

> But driving, for example, you know, a lot of people don't understand all the components that are key to being a safe driver. And so I have to explain to them, it's not just about being able to hold the steering wheel or push the gas pedal. It's about reaction time, it's about visual capabilities and scanning your environment. It's about not only hand-eye coordination, but strength. Not being dizzy, for example, when you turn your head right to left. And not having vestibular—there's a lot of things that go into safe driving. (staff, inpatient/outpatient)

Staff also explained how the tasks they worked on in therapy were in service to meeting the cherished long-term goals. For instance, by making it clear how a visual field scanning task could help the patient return to driving, a therapist might increase the likelihood a patient would cooperate enthusiastically. Pointing out how something that seemed insignificant to the patient was an important step toward a larger goal or a promising prognostic indicator encouraged patients to celebrate small gains.

Shifting the Benchmark for Recovery

Staff also worked to shift patients’ reference points for what recovery would mean. One of the more prominent strategies was encouraging patients to compare themselves not to who they were prior to injury but to who they were on the first day of rehab. If patients expressed dejection about their present circumstances, staff often enjoined them to remember how far they had come from when they first arrived. They constantly pointed out these gains in casual interactions, such as:

> Doctor: *Hey, you did great. Congratulations! You're graduating [from inpatient rehab].* The doctor and patient shake hands.
>
> Doctor: *Wow! Look how strong your grip is. You couldn't do that when you started.*

Ultimately, staff also sought to redefine recovery to allow patients to accept the possibility that they might have to adapt to a new normal. As staff explained, even if a patient didn't meet the goals they initially hoped for (e.g., regaining verbal speech), patients could still improve their quality of life (e.g., by mastering alternative tools for communication). In this framing, staff tried to establish that recovery was a spectrum, not one pole of a binary.

Staff also tried to emphasize the importance of "functional" progress. Patients might not end up exactly as they were before, but they could perhaps do the same things through the use of adaptive strategies and devices. Staff pointed out that although neurological recovery could not continue indefinitely—especially when patients were outside the optimal window—functional recovery was always an option. And working toward functional recovery didn't preclude pushing for neurological recovery. As a therapist explained, "You remediate, but you also need to compensate at the same time" (staff, inpatient).

In some cases, however, patients and family tried to reject adaptive strategies. A physician told a story about a recent disagreement between an SLP and a patient's daughter:

> [The patient] has aphasia, [and the daughter said], "You know, I don't want her using that iPad to communicate. I want her to talk." And the speech therapist said, "Well, the reason we started using the iPad is that she wasn't making any progress in speech therapy, and I wanted to give her a way to communicate"… And then also the speech therapist said, "You know, there have been studies that have shown that actually using the iPad can help with communication with regular speech." (staff, outpatient)

In this case, the SLP tried to convey that the iPad could be useful "for now," while also potentially aiding in neurological recovery. Using the iPad didn't mean giving up on pursuing the type of recovery the daughter hoped for. Ideally, the daughter would accept that using an iPad was a recovery in itself—a functional recovery, restoring her mother's ability to communicate. But the SLP recognized that, in some cases, people weren't willing (or ready) to accept the possibility that recovery might not mean "getting back to normal."

Leaving Room for Hope

Even if staff felt a patient was highly unlikely to achieve their desired outcome, they avoided foreclosing the possibility entirely. In general, they tried to "never say never." As a physician explained:

> I really avoid ever saying that anything is permanent…. I think if someone were to be sitting in front of me two or three years out of their stroke, and they hadn't made any change in the last one to two years or something, I guess, then I might kind of gently talk about, you know, having to work with these symptoms for the long term. I don't say anything, like "the rest of your life" or whatever. (staff, outpatient)

Staff shied away from definitively negative language like "you will not." They wanted patients and family to prepare for what they believed would be the most likely scenario, but they carefully preserved a sliver of hope. In some cases, they used the construction "this is what I expect … but I hope I'm wrong" (staff, inpatient), and they also emphasized that they would work as hard as possible to help the patient exceed their expectations.

For some patients, spirituality could be a source of comfort and a reason to hope for divine intervention. Patients also found solace in hearing about research. The option to enroll in a registry for future research participation could help them believe that while their problems couldn't be entirely "fixed" right now, in the future, scientists might find a solution.

Shifting Responsibility to the Patient

Another common refrain among staff was “you get out of rehab what you put into it.” Staff explained that patients themselves were a crucial variable. As one physician put it, “I basically say, ‘We don't know. We're gonna work with you. The harder you work, the better things might get’” (staff, inpatient). Staff frequently talked about patients having to take responsibility for their own recovery, especially at the day rehab stage when they weren’t in daily therapy and were supposed to be practicing on their own at home. As a therapist put it:

> The patients that work really hard are some of the best patients to work with. It's really tough whenever your patients don't want to work because, I mean, it makes your job like-it kind of stinks, right? ... But in the end, it's not on you. It's their—they have to decide to do it ... I mean, those are also the patients that you see the most improvements with and the most success with just because, I mean, it says a lot, like, whenever they do it outside of therapy and whenever they try hard in therapy. (staff, outpatient)

This framing strategy was also a useful rebuttal to patients’ complaints that therapies were too arduous. The general theme was, as a staff member said, “If you're not feeling uncomfortable, then that's probably not helpful” (staff, outpatient). I noticed one PT wearing a shirt that exemplified this tough love ethos:

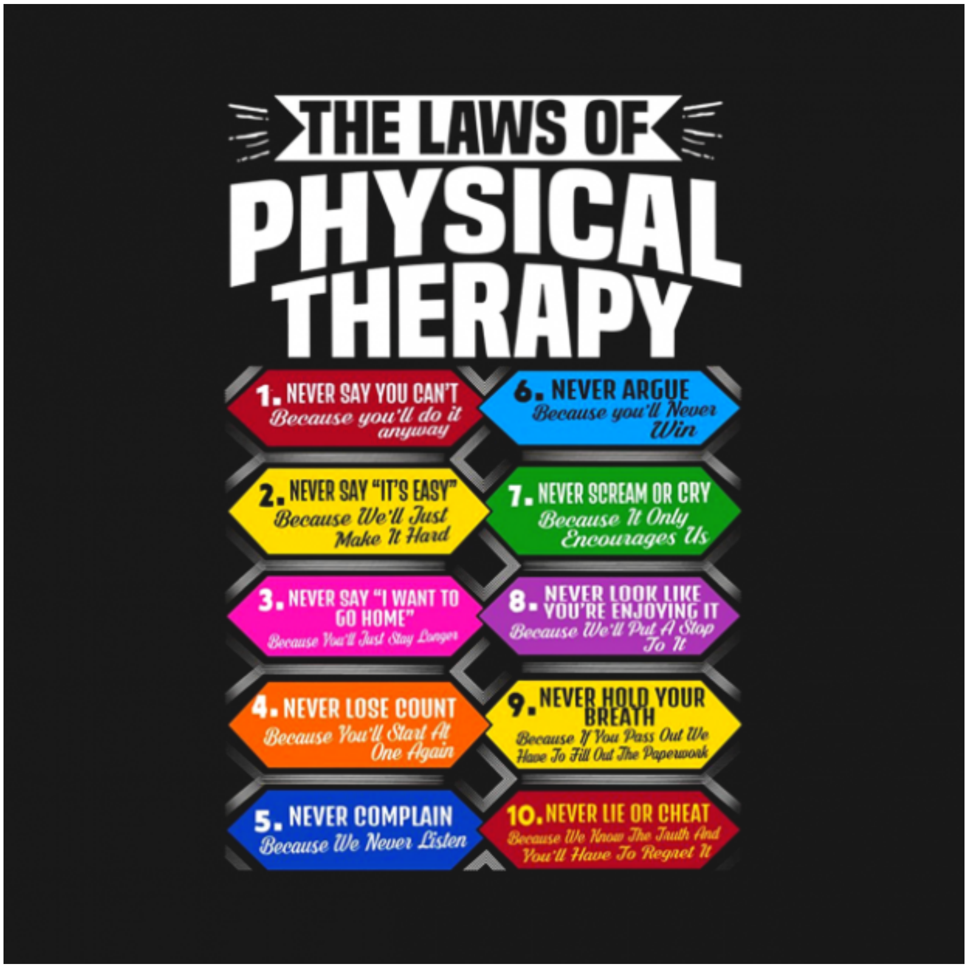

Image 4: "Laws of Physical Therapy" text
Source: Taken from the website Teepublic
https://www.teepublic.com/t-shirt/9798802-the-laws-of-physical-therapy-awesome-therapist-gif

Perhaps the PTs most vocally reveled in setting challenges, but all staff members reinforced the idea that therapy was supposed to "kick your butt," as an inpatient nurse put it.

Recognizing the Limits of Ability to Convince

In some cases, despite the staff's best efforts, a patient remained unwilling to revise their hopes or expectations. If the problem was lack of insight, staff might "let the patient fail" by deliberately setting tasks they knew the patient would struggle to accomplish. For instance, if a patient erroneously thought they were ready to return to work, staff might agree to schedule the neuropsych testing required to approve the patient for work. Staff didn't believe the patient would clear this hurdle, but they hoped the experience of sitting through hours of testing, struggling to perform, and being shown objective measures of cognitive change would help the patient come around to staff's perspective.

In other cases, staff simply decided to entertain what they saw as harmless delusion—for instance agreeing to write a referral for vocational rehab even though they believed the patient was not yet ready and might never be. Staff also talked about the necessity (and even virtue) of allowing patients to arrive at a realization in their own time. I saw this rationale used in dealing with Hayden, a locked-in patient. Hayden was over a year out from stroke, so the staff opinion was that Hayden would never regain much more than he already had. When I asked Hayden's physician how much more recovery Hayden could expect, he said, "For him? Not a lot…. It's more figuring out how to use his body, at this point." He explained that Hayden could continue to make functional gains, but he had limited potential for further neurological recovery.

At that point, Hayden had returned to inpatient rehab for a "functional upgrade." He'd been at inpatient rehab the year prior, but he continued to recover after discharge, and his physician was able to arrange a second inpatient stay so that Hayden and his wife could learn and practice techniques he hadn't been advanced enough to work on last time. One of his therapists described his previous inpatient stay:

> So when he first got here, despite him not being able to move any limb or feel the entire right side of his body, his goal is still to walk out of here. And so even despite what we worked on, me continuing to say, "You know, we're still at a standstill. Like prognostically, the fact that you can't feel that side does not set you up for ambulation in the future right now. But we're still going to work on secondary benefits of gait training through, you know, cardiovascular benefits, getting up and moving, working on head control, just working on core movement." You know, when he left here twelve weeks later, his goal was still to walk. So a year later, he actually just got readmitted a few days ago, for a functional upgrade … And it's been almost thirteen months since his injury. His perspective and goals and attitude have completely changed. I mean, physically and functionally, he's at the same

> level as when he left, which we all knew. But he's been able to come to terms with it. So you know, it's always better for patients like him who have cognitive awareness of what's going on to come to that realization on their own—which doesn't always happen, but it's great when it does. (staff, inpatient)

Last time, she essentially tried to tell him they could work on walking, not because she expected he could actually achieve the goal of walking, but because working on walking could help build other skills like, for instance, core strength, which would help him hold himself upright in his wheelchair. In her opinion, Hayden rejected her assessment at the time, but was now more realistic about his prognosis.

When I interviewed Hayden, however, that didn’t seem to be the case. Hayden also believed his attitude had improved this time around. He was further from the initial shock of the accident and the abrupt and total life change. He was on more stable emotional footing and in a better position to focus on rehab, so he was more cooperative with staff. However, he hadn’t necessarily accepted their assessment of his chances for further recovery. When I asked Hayden to talk about his future plans, he said:

> I don't know what the future looks like in a wheelchair. I'm still trying everything to get back out. So I haven't lost that focus yet … [I hope] to be back to work. Because if that happens, that means I was able to get better, and from there it's just the snowball effect. There's really no limit. (stroke, White, male, inpatient)

When I asked where he saw himself a year from now, he said:

> Well, hopefully out of the chair … But if I'm still in this condition, I see us figuring out how to basically survive this, and dealing with that, working with that. I mean now, I feel like I'm fighting it. Because I don't want that. (stroke, White, male, inpatient)

Because Hayden seemed more upbeat and agreeable, his therapists thought he had reconciled himself to continued disability, but as Hayden saw it, he was “still fighting it.” I asked Hayden’s doctor if he was concerned about Hayden holding onto hopes staff believed were highly unlikely. The doctor felt that Hayden had to come to terms with his new Self in his own time. “It’s a process of self-discovery," he said. The doctor would never want to "take away his hope." If Hayden thought he might walk again, the doctor felt he should, "hang on to that, you know?"

"They eventually come to a place of acceptance," he said, "but they have to do it at their own pace." Hayden was stubborn in his hope, and in many ways, staff saw this persistent belief as a virtue, at least insofar as it motivated him to work as hard as possible. As long as his hope for recovery didn't get in the way of his cooperation with therapy or cause him to eschew adaptive strategies, they saw no need to crush his dreams.

The challenge of managing expectations was, in many respects, an interactional problem. Staff had to be honest while still coming across as compassionate. They had to sympathize with where patients found themselves, in the moment, while remaining cognizant of the patient's future needs. As a staff member explained, they had to provide a "gentle education," telling patients what to expect but "allowing for the fact that sometimes there are unexpected things or miracles or whatever term you want to use" (staff, inpatient).

T-R-A-N-Q-U-I-L-I-Z-E-D

Hayden was in a terrible accident. It caused a series of brain stem strokes that, in turn, caused locked-in syndrome. Hayden and his wife Katie lived in a different state, so the inpatient rehab wasn't their initial choice for post-acute care. There were only two long-term acute care (LTAC) facilities in their state, and after reading all the reviews, Katie picked the one that specialized in vent weaning because Hayden was still on a ventilator.

Due to COVID, Katie couldn't tour the facility prior to Hayden's admission, which worried her. The LTAC also wasn't allowing any visitors. Katie insisted that if she wasn't allowed to visit, they had to place a camera in Hayden's room so she could check on him at any time. They weren't on board with that plan, so they finally granted her a single two-hour visit, per week. They also promised they could set up a video chat anytime Hayden or Katie asked, but later, when she requested video chats, none of the staff knew how their tablets worked.

Katie recalled:

> One day a week for two hours. [tearful] So I'd go up there every Monday for two hours, and I very quickly caught on that—I mean, I walked through the doors of that place, and [tearful] it looked like a jail or a mental facility. It was dingy and dirty and smelled. And I just felt it in my gut that something just wasn't right.

After two weeks, Hayden began to regain the ability to communicate, using eye blinks and a letter board. One day, Hayden's nurse called Katie to say he was "demanding" a video call. As Hayden later described it, he could tell "something was not right" with his medication. He was still struggling to convey his thoughts via video chat, eye blink, and letter board, so he knew he had to use his facial expressions to drive his message home. He described it as having to "over-enunciate" his face to telegraph his distress.

Letter by letter, he spelled out the word TRANQUILIZED. Katie happened to have a nurse practitioner friend with her, and the friend asked Hayden questions. "Do you feel like you're tranquilized, or do you feel like you're being given something that is tranquilizing you?" As they eventually found out, Hayden was being dosed with the opioid Tramadol. It had been prescribed "as needed," but Katie knew Hayden hadn't been requesting it. She called every day and asked the staff whether he was reporting any pain. But the nurses had been giving him the drug every four to six hours, regardless.

As Katie reported:

> On the phone [the nurse] said, "while we understand it's not ideal, we give it to patients as a form of management." Because Hayden was a high maintenance patient. They would medicate him so he would sleep because he was—he was needy. [tearful] And they were understaffed.

Tramadol also slows respiratory rate, so it was having a negative effect on Hayden's recovery. Two days before he left the ICU, he was on pressure support on the ventilator. He was breathing on his own, with the machine as a backup, kicking in if he didn't take enough breaths. But after a couple of weeks at the LTAC, he was back on full ventilator support.

Katie, as Hayden's guardian, asked that he be taken off the Tramadol, but when she checked the next day, she found they had continued to give it to him. She threatened legal action and got the Tramadol discontinued, but she knew she couldn't leave him at the LTAC, so she started looking for other facilities immediately. Hayden was telling her they weren't feeding him or giving him water. Katie said, "He arrived at [inpatient rehab] severely dehydrated and extremely underweight."

Due to the overmedication, Hayden's memories of this time were hazy. He said, "I remember dreams of things. Associated with what was happening." As he put it, he knew "something was not right about the last place…. So I reached out for help, the best I could."

Mr. Andrews and Dr. W Deal with Insurance

What's happening with Mr. Andrews? the attending, Dr. W, asked. Mr. Andrews was an elderly black man. He was kind, but he didn't suffer fools. When I approached him to ask consent to interview him, he was willing to sign the observation consent, but he wasn't up for an interview. As he put it, he wanted to help me "get my degree," but he was wary of researchers. Someone always made money off research, and he knew it wouldn't be him.

The resident reported that Mr. Andrews would receive his COVID vaccine that day and would be discharged to skilled nursing tomorrow.

Where's he going? Dr. W asked.

The last the resident heard, the family hadn't decided on a facility yet.

Dr. W was surprised Mr. Andrews wasn't going home. Mr. Andrews seemed so physically well! But Dr. W said a lot of home vs. SNF decisions are based on behavioral and social issues.

Maybe the family just isn't prepared or available to provide care at home, the resident suggested. *Maybe Mr. Andrews will eventually go home after a stay in skilled nursing. It might give the family a chance to get care in place.*

"Tomorrow's your big day!" Dr. W said, when we entered Mr. Andrews' room.

"If you want to call it that," Mr. Andrews said.

Don't you consider it that? Dr. W asked.

"Well, it's not a day of certainty," Mr. Andrews said. They asked where Mr. Andrews was going after discharge. *I think I'm going home,* "unless you know something I don't," he said.

They went back and forth about whether Mr. Andrews should have his COVID shot that day. It wasn't on his official schedule, but Dr. W was confident they would get him vaccinated today. Mr. Andrews was skeptical that it would happen. "I don't have complete confidence in this staff," Mr. Andrews said. *Because if they say they're going to check on something, chances are that means you won't get it*, he explained.

Y*ou can doubt if you want, but I think you're pretty certain to get the shot today*, Dr. W said.

Mr. Andrews said he had "reason to believe" they won't get it done. He said they don't answer buzzers around here, but he made a point of saying that, on the whole, he was more grateful to the staff than not.

The team asked about his regularity. The medical fellow asked if Mr. Andrews would be interested in a probiotic. Mr. Andrews didn't recognize the term, so she talked about gut flora and said a probiotic was like the bacteria in yogurt. *I don't eat yogurt*, he said. She explained that this would be a pill, like a "less medicine-y medicine." *I might try it, once I get home*, he said. They offered him a variety of options to improve regularity, but he was adamant he "won't take anything that has to do with that." "I'm not trying to be difficult," he said, *but a 70+ year old man doesn't want to be having accidents like a 3-month-old*.

Mr. Andrews worried he was going to go home and die. "I don't want to make anyone feel bad," he says, but "I was close to death." He had to stay alive for his adult children.

He seemed entirely aware of the possibility of being regarded as a difficult patient. And he wasn't wrong. Once we left the room, Dr. W said, "he sure gets fixated on things," which is about as close as medical staff came to saying a patient asked too many questions or pushed back too much.

The resident said he thought Mr. Andrews' family *had* talked to him about discharging to skilled nursing. *Well,* Dr. W said, *either they didn't, or Mr. Andrews doesn't remember it, or he doesn't accept it.*

***

Two days later, Mr. Andrews was still there.

"What happened yesterday?" Dr. W asked. The resident explained that Mr. Andrews' planned discharge fell through. They called and called and called, but they couldn't get someone on the phone to get insurance approval for his discharge.

"Did the authorization come late?" Dr. W asked. The resident said it just didn't come at all.

In Mr. Andrews' room, Dr. W once again raised the issue of post-discharge plans. *Do you know where you're going?* Dr. W asked. Mr. Andrews knew he was going to a SNF. He said his daughters "tricked him," but he agreed with them, now that they'd explained it. He was hoping it would be a short-term stay.

The doctors talked to him about the delay, due to lack of insurance approval. *Most likely, I'll be out of here today*, Mr. Andrews said. *Whatever happens*, he said, "I'll be somewhere—either at my home or with another company." Dr. W assured him it will get sorted out today, and he would definitely be discharged to the chosen skilled nursing facility. Mr. Andrews said he had "a cynical view" of the insurance company, but "I thank them for letting me come here."

Dr. W once again assured him he'd be discharged to skilled nursing care. He wasn't going to end up being discharged home. Mr. Andrews maintained, *You never know. Because of the insurance.*

Once they were out in the hall, Dr. W opined about the complexities and annoyances of dealing with insurance providers.

"There was a time, believe it or not, that the doctor and the patient made a decision to discharge, and the patient was discharged," Dr. W said.

The resident observed that they certainly seemed to spend a lot of time talking to insurers. He asked if Dr. W talked to the same insurance representatives regularly. *Yes, sometimes*, Dr. W said.

But worse than the discharge confusion, he said, is that "we have to beg and plead and offer to sleep with the insurance people, give up our children" to convince them to extend a patient's stay. Dr. W said the insurance representatives are "often very unsophisticated" in their knowledge of rehabilitative medicine. Once, when he was appealing to them on behalf of a quadriplegic patient, they told him “he’s quad—what could he possibly do in rehab?” Another time, a case manager told him, “I didn’t even know that could happen to someone!” When he talked to insurance people, he tried to educate them on rehab needs, and he advocated for his patients. But, he said, *doctors shouldn’t have to do this*.

They had a few bureaucratically challenging discharges on their caseload, at the moment. “If you’re successful in both of these discharges, you’ll get a social work degree,” Dr. W joked. The resident had been spending a lot of his time each day on the phone, contending with insurance representatives and getting discharge options lined up. “That’s what we do!” Dr. W said, wryly.

Cleè’s Discharge Conflict

My “honey” is next, Dr. P said. Yesterday, when I stopped by Cleè’s room so she could fill out a consent form, she told me she called Dr. P “baby,” and he called her “honey.” Cleè, a white woman in her early 60s, had a stroke caused by an aneurysm.

Dr. P reported that the peer-to-peer meeting was pushed to Friday. He was attempting to get coverage reinstated after Cleè’s insurance provider announced on Monday that they were denying coverage, as of last Friday. *So we’re going to have to keep her until Saturday*, he said. *What can we do? We’re not going to kick her out on the street.*

Good morning, honey! Dr. P said, as he entered Cleè’s room.

Hey, baby, she replied.

How are you?

Hanging in there.

You’re not just hanging—you’re doing good!

Cleè seemed unconvinced by his optimism. *It’s just this pain*, she said. *I’m dealing with it.*

Where?

Arms.

Did you take anything for it?

No.

I've been hurting too—this heat, and the humidity. It's going to be a heat index of 105 today. Anyone with any issues with joints—it's terrible. It's an insane summer. I've never seen one like this in Chicago. I have a friend who's a rheumatologist, and he says everybody is coming in. It's the humidity—it's like a swamp.

Dr. P later explained to me his strategy with Cleè. As he put it, *She brings up pain, you talk for a bit, and she brings up another issue instead. It isn't pain.*

Are you talking to insurance today? Cleè asked.

Dr. P explained they wouldn't be able to meet until Friday, but she should be all set for discharge Saturday. Cleè was highly motivated to get out of the hospital. As she later told me, *the rehab here is really great, but being here sucks*. She wasn't sleeping well; there were two "screamers" on her floor. The staff put a seatbelt on her wheelchair that set off an alarm if she tried to stand. The meal portions were too small, and with all the exercise in therapy, she got hungry between meals. Overall, she was not loving the hospital experience, and she wanted to get back home to her husband, Robert.

Cleè told Dr. P she wanted to go to day rehab after leaving inpatient. She didn't want home health therapies. Dr. P said, *We have had both those orders done. But they want to get the ball rolling with home health first and then switch to day rehab. It can be switched in a snap.* Cleè reiterated that she didn't want home health. Dr. P said, *In the past, there were difficulties with Robert and transportation.*

I've talked to Robert about it, and he's on board with driving me, she said. *It won't be a problem, this time.*

They chatted about her progress. Dr. P assured her there was a "day and night" difference from when she first arrived to her current state. Eventually, Dr. P brought the conversation back around to home health vs. day rehab. He said, *But I'm going to have to argue—once you left last time, I was uneasy. I wasn't very confident in Robert's ability to take care of you. And I saw your chart when you came back in. You weren't able to get to follow-up appointments. I want to make sure we close this chapter safely. And I want to make sure you're set up at home.*

After rounds, I asked Jess, the nurse practitioner rounding with Dr. P, what happened last time. Apparently, Cleè was initially admitted about six months prior following a bleed caused by an aneurysm. After she was discharged, she didn't show up to day rehab or to neurosurgical follow-up appointments. When she finally came back in, she had been having balance issues, and the doctor found she'd developed hydrocephalus and needed a shunt to drain it. When she returned to inpatient rehab, Dr. P and Jess were determined not to permit a repeat of last time. They scheduled her neurosurgery follow-up at the nearby hospital immediately following her discharge, so she could go directly there. Jess said, *You do everything you can to set them up for success. But sometimes you see them end up back in the ER. Sometimes you can see it coming a mile away*.

When I stopped back to see Cleè, it sounded like she may have misconstrued the medical team's concerns. She said Dr. P and her husband had some kind of conflict last time. *I want to tell Dr. P "no need to take it out on me!"* she said.

She was also unhappy he told her she wouldn't be able to drive right away. *It's not like I'm getting on a racetrack*, she said. *From our house, it's just a straight shot on Lakeshore Drive, to day rehab*.

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Before rounds the next day, I mentioned that Cleè still seemed displeased with her discharge plan.

“Yeah. Don’t worry about it. We’ll enforce, and then she’ll do whatever she’s going to do,” Dr. P said, in a resigned tone. He explained that Cleè had a therapist send a detailed email to him, immediately after rounds yesterday, asking all the same questions they covered in the room. *We had ethics involved last time she discharged because we had no confidence in Robert*, Dr. P said. *He seemed unreliable. So it’s not that I don’t care. It’s just that I’m very aware it’s a problem. I don’t want to fight with Cleè over it. There’s no point in discussing it. We know from previous experience that she likely won’t follow up with care. It’s not her—it’s Robert. I’ve seen him only once, and it was very pleasant. There was no confrontation. But last time she was here, no one was feeling confident about her going home. And it turns out, that was a good gut feeling because she didn’t get the care.*

Dr. P updated Jess about the insurance situation. He said, *Insurance can’t get it together to do a peer-to-peer. We probably won’t get paid for those five days. I have my ammunition for why we needed to keep her. So we’ll see how it goes. You can’t win. And patients think I don’t advocate for them.*

In the room, Cleè asked Dr. P how he was doing. *Better now, after I see you*! he said. Dr. P walked her through the logistics of her discharge, which was now set for Monday. He told her they scheduled her neurology follow-up, directly after. *We’re trying to simplify things—make it easier*, he said.

You are. Thank you, baby, she said.

But then they were back to the home health vs. day rehab debate. Cleè began, *Now what's this shit I hear about you putting me in home health?*

We've written orders for both. If you don't show up at day rehab, you'll have to deal with your primary care doctor to get into home health. If you don't come to your appointments, the guys at day rehab won't hold that spot for you. They'll give it to someone else who needs it.

It's all changed from last time! she insisted.

We just need to make sure you have some continuum of care.

Cleè said she discussed it all with Robert and he agreed—she'll go to day rehab three times a week and "just get it all done at once." That would be better than having people coming to the house every day.

Okay. We'll get day rehabs orders, he said. He instructed Jess to cancel home health.

I heard home health is shitty, Cleè said.

It is, Dr. P agreed. *But you have to understand I'm putting my butt on the line. You have to go to day rehab regularly.*

Cleè asked, *I want to sit for half an hour later and discuss a few things. Did you get that email?*

I'm very busy today and tomorrow, but I will try. There's one thing I can tell you now though – 100 percent no driving, as of now.

But is that never?

Not never. It's about the speed of your responses. At day rehab, tell them your goal is to return to driving. Just like you told me. And they'll work with you.

Outside in the hall, Dr. P said to Jess, *Let's put in the order for day rehab.* I've got to trust her. *The care manager said oh no! But overruling Cleè's wishes is* "contrary to my belief." *And I* *really think home health isn't as good as day rehab. Day rehab is more structured*. "We have to give her the benefit of the doubt," Dr. P concluded.

When Cleè talked to the therapist and got her to email Dr. P yesterday, she was "looking for another answer," Jess explained. She wanted someone to tell her she was safe to drive, go to day rehab, etc.

We just have to document as such—that we educated her about driving. I'm just crazy busy today, but I will make time to talk to her, Dr. P said.

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When I visit Cleè that night, hoping to schedule an interview, I met her husband Robert, an older Black man from the South Side, more than ten years Cleè's senior. As they both told me, given the age difference, they were entirely unprepared for Cleè to be the one to get sick.

I sat and chatted with them for a while. Cleè mentioned Dr. P, and Robert said, "The one who thinks I threatened him?" What filtered from Cleè through to Robert was that Dr. P felt Robert and he had a dispute.

Robert had a good manner with Cleè. Sometimes he teased her, and she flipped him off or gave him a playfully annoyed glare. He brought her some smoked salmon. When they finished it, she asked if he got her chocolate cake. He told her, gently, that she shouldn't have chocolate cake—it wasn't good for her diabetes.

A bit later, she again asked if he brought chocolate cake, seemingly not remembering the previous chocolate cake conversation. Although Jess thought Cleè was answer-shopping when she asked the therapist to email Dr. P, it seemed entirely possible Cleè truly forgot they covered those topics.

Cleè said she was frustrated because she wanted to talk to Dr. P one on one. She wanted to ask him why this stroke happened and what she could do to prevent another one. She had written a list of questions. Most of all, Cleè wanted to know when she would be "normal," when she would get "back to Cleè again."

While Cleè was being helped to the bathroom, Robert talked to me about how hard the past several months had been. Being older than Cleè, it never seemed possible she'd be the one to fall ill and require care. And now, it was like his wife was a different person.

A while ago, she had a hallucination that her dead father was in the house. She asked Robert about his son, but they only had a daughter. It was sad and unnerving to hear her talk like that, he said. What do you say to her when she asked where her deceased parents were?

The nursing staff member helping Cleè told her they were short-staffed, so they might not be able to give her a shower tonight after all. Robert said she should ask to see a supervisor. How could they make her go without a shower for three nights? Cleè said it wasn't a supervisor; it was a charge nurse. And she knew that because she *had* tried to push back in the past.

Robert said they even misspelled Cleè's name on the whiteboard in her room. They wrote her name down as Clea, instead of Cleè. At some point, they had a printed sign on her door that also had her named misspelled "Clea." To him, it felt sloppy and disrespectful.

Sometimes, staff posted signs to inform each other of a nickname or clarify the pronunciation of a patient's name; e.g., "Bill" written over William or "Clea" written over Cleè. So it may have been sloppiness, but it might also have been well-intentioned. But in the broader context of their experience, the incorrect name compounded Robert and Cleè's negative impression

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The next day, I interviewed Cleè, and I finally heard her version of why she never made it to day rehab:

> I talked to Dr. P about that today. Him and Robert having a conflict. I said, "you know I'm really sorry, and *ba ba ba*," and he said, "No, Cleè, you don't understand. Let me explain it to you." And what had happened is, his coordinator was scheduling—trying to schedule with Robert, for me to go to outpatient. And Robert had a reason not to take me or not to drive me or, you know, and there was always—Dr. P said, "You came twice." And I guess, [the coordinator’s] version versus, well, Robert not saying *anything*, made things worse. So Dr. P understood today. I go, "No, that was not what happened here." I said what actually was the problem is, I had the problem going on with the aneurysms inside, that every time I would get up from bed, I'd want to throw up. Every time I lay down, I'd want to throw up. This was going on a lot. And so I didn't want to go anywhere. And I didn't. And when [the coordinator] would call Robert, I would tell him, “Tell her no, I'm not coming." So they were blaming him for something, instead of him explaining why I wasn't doing it.

Dr. P and Jess were still uneasy about the discharge plan, but Cleè was confident this time would be different.

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I stopped in to say goodbye to Cleè and Robert the morning of her discharge. She told me again about her conversation with Dr. P, not seeming to remember she already filled me in. She said Dr. P talked with her for about forty-five minutes. He emphasized how important it was that she not fall again; she might not recover as well next time, and she could end up in a wheelchair, permanently. Dr. P made some safety suggestions for the home, such as placing chairs at intervals along her hallway, so she could sit and rest, if necessary.

He explained the process of getting back to driving, how they would work with her and evaluate her in day rehab. She said Dr. P told her she could be back on the road in four to six months.

You should make sure to get off the road, when that day comes, Robert jokingly told me.

Luke and Sarah and the SNF

When I first met Luke and Sarah, an older, Black couple, they both seemed set on bringing Luke home. They wouldn't even have an estimated discharge date until after his first care conference, but Luke was already fed up with hospital living. Sarah had been working remotely through the pandemic, so she would be home with him. At the start, bringing Luke home seemed doable.

But when I talked to Sarah, the complications became apparent. She was nervous about taking care of Luke at home. They had no idea how much he would recover from the stroke, and right now, he required a lot of care. So far, he'd been in the hospital, looked after by professionals, but Sarah was already concerned about whether she'd be able to do everything by herself. The other day when she came in, he had a diaper on. She hadn't bargained for diapers.

Sarah was still working, with a while to go yet before she could retire, especially now that Luke was going to have to retire early. She was also older than Luke (not to mention smaller than him), so she worried about her physical ability to help him move around. "I never planned on this," she said. Last time she went to a doctor, they told her she was borderline diabetic; now, she was scared to go in for a checkup and potentially hear bad news. She couldn't afford to have them both sick.

She was banking on Luke recovering well, at inpatient rehab. As she explained:

> And hopefully, he'll get stronger and better. And we can just take him home, and he'll just take his medicines at home and just walk from the front of the house to the back of the house for his exercise. And then we'll have somebody come in for therapy, maybe three days a week.

As of now, she said, "the picture is really just kind of grayed in," and "until the colors come in," it would be difficult to make concrete plans.

Frankly, Sarah was also frustrated. Luke had been to the emergency room several times over the past year, and Sarah talked to him repeatedly about his drinking and drug use. She warned him there could be serious implications for his health and she felt, “he did [this] to himself.” Sarah told me she loved him, that much was undeniable, but she was also worried about the future and exasperated at Luke. Part of the reason they never got married was because she didn’t want to be responsible for his choices, but she said, “now I have to be responsible for him anyway.” He called her from the hospital, complaining about the care and about being cooped up, but as much as she sympathized, she also felt like saying, “I tried to warn you about this. I tried to talk to you about this. Now you have to suck it up and be a big boy and take your treatments. So you can come home.”

Sarah was also managing her own emotions, from the traumatic period in which she didn’t know if he would live or die to the overwhelming present. It was frightening and sad when he called her multiple times, not seeming to remember that they recently talked. She felt like she was on her own. Luke’s friends and family were looking to her to take care of him, but it seemed like no one was willing to step in and help. Luke had a daughter, but she lived out of state. She was telling Sarah, “I don’t want my dad in a nursing home,” but she wouldn’t be around to help.

Luke and Sarah had “made a pact,” at some point in their lives together that, if one of them got sick, the other would find a way to care for them at home. But now, that hypothetical scenario was a reality, and Sarah was worried Luke would be a challenging patient. If he came home, would he listen to her if she tried to enforce medical recommendations? As she explained:

> They said you need to give yourself at least a year of recovery to try and just get back, to see how far you can come back. But I can't think that all out for him. I can't—you know, he has to either be willing to be my child, which he's not gonna be, or he's gonna have to come to the conclusion that if he wants to live, he is gonna have to do this. And I just don't know. I don't know how serious he is about that…. If he goes home and he acts a damn fool, I'm gonna put him out. I'm gonna put him in a nursing home.

On the one hand, Sarah loved Luke, and she felt a strong sense of obligation to respect his wish to come home, but on the other hand, she didn't want to drag someone through recovery if he wasn't willing to put in the work to help himself.

And Sarah had her own problems to deal with. She was struggling not to be weighed down by depression over the whole situation. Sarah tried to tell herself that "crying doesn't solve anything." She said, "If the Lord should allow him to live, then I'm not gonna abandon him. And some days, if I don't feel good about it, I'm just gonna have to go outside and scream or go curse him out, and then just readjust." Sarah felt she couldn't afford to break down.

Despite it all, Sarah was trying to come up with practical plans. In her extended family network, she knew someone who wasn't working at the moment, but who had done nursing care work before, so Sarah could possibly hire her. But at the end of the day, Sarah said:

> There's the doctor and the professional opinion, and then there's real-life reality. And the real-life reality is, I'm gonna take him home. And if he can't go anyplace but back and forth in the house, he'll be back and forth in the house for as long as he lives.

Without additional support, there was no way Sarah could provide the ideal home environment the rehab staff recommended.

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A few weeks later, I heard from the medical team that they had been talking about a skilled nursing facility (SNF) placement for Luke. They were concerned about his fluctuating mental status. Even I had noticed that sometimes when I visited, he was alert and talkative, and other times he seemed confused and disoriented. The medical team reported that his markers of kidney function were trending in a positive direction. If there were a metabolic cause of his cognitive fogginess, you would expect to see the symptoms dissipate as his kidneys improved, but they hadn’t seen improvement. Medical, nursing, and therapy staff all reported he was uncooperative, difficult to redirect, and unwilling to participate in therapy.

At the team conference, his therapists reported he had plateaued on all measures. He no longer seemed to be benefitting from inpatient rehab. But at the same time, they were worried his care and supervision requirements would be too much for Sarah to manage at home. Sarah was due to come in for family training that day—about four hours with OT, PT, speech, and nursing. How her training went would be a deciding factor in the home vs. SNF discussion.

When Sarah arrived later, she said, *He wants to go home, so what else can I do*? She took some comfort in the fact that his daughter would visit for a week to help with the transition, and hospital transportation would bring him home and help get him inside. Sarah was also exploring the options available through the VA. She hoped Luke’s veteran status might qualify him for some nursing care.

Luke and Sarah made it through the OT training session, but as they waited for the second session to begin, the strain was already beginning to show. Luke complained of exhaustion. He said he didn’t want to practice any more, today.

You don’t get to not want to practice. You have to practice, Sarah said.

Luke was also more optimistic about their ability to manage at home. Sarah worried about her physical strength. She didn’t know how she would lift Luke, without hurting her back.

You’re strong for a woman, Luke told her.

I’m not. You just want to get home. And kill me, Sarah said.

Luke said his daughter being there would really help.

She’ll only be there for a week, Luke. And then we’re on our own.

I’ll be getting better and better. Day by day, I pray, he said.

It won't be good for either of us if you hurt my back.

I'm not trying to do that.

I know you're not TRYING *to do that.*

I'm not GOING to do that.

You don't know what you're going to do.

Worryingly, Luke didn't seem to realize the extent of his injuries. He offered to go out and bring us food, and when Sarah pointed out he couldn't go anywhere, he seemed confused. Every few minutes, he asked her again if she could bring him home today.

I can't do that, she said.

They ain't gotta know!

Sarah was very nervous, unsure if she could cope. The doctor had given her a list of SNF options, but Luke didn't want to go to a SNF.

Luke's confusion made matters worse. He didn't always remember he couldn't walk on his own, so he was a fall risk. At inpatient rehab, they had a mesh enclosure around his bed, but short of tying him down with a sheet, Sarah wasn't sure what she would do with him at home.

The first week is going to be rough, she said.

Luke laughed.

You think it's funny—but it's true! Sarah said.

You're going to be mama now, he joked.

I'm going to be whatever I need to be, now. It's not funny. You think it's funny.

We sat and waited for the nursing training session to begin.

Thanks, Sarah. For putting up with everything, Luke said. *I'm lucky she doesn't leave me. A lot of women would say, "not what I signed up for." You stuck around.*

I'm stuck. I don't have a choice, she said.

After the nursing session, Luke was flagging. He was in pain from sitting up in his chair for the hour, but he couldn't go back to bed yet. His left arm slipped off the rest. He often forgot about the arm, due to hemi-neglect. Sarah went over and picked it up for him. He asked for some of the fruit she brought him, and she fed him.

Sarah had a mixed reaction to the training session. She took detailed notes throughout, and she said the information wasn't unfamiliar. She had taken care of her mom and dad, when they were elderly. But she told me she had "a little panic attack" at the start of the session and had to get it under control and act like nothing was wrong.

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A few days later, Sarah made the decision: she couldn't take Luke home yet. He would go to a SNF and, hopefully, continue to recover and be ready to come home in the future. The social worker assigned to Luke gave her a list of about forty facilities, and she was anxious to make the best possible choice. "I don't want to put him somewhere he will become a vegetable," she said.

Luke seemed to take the news well, all things considered. As he told me, *My head's all screwed up. That's why I'm not going home yet. I'm going to another facility to get ready to go home.*

He said Sarah "had one of those attacks" because she was worried about the logistics of taking him home. Luke was in a pensive state of mind.

I actually want to live, he said. *For a while, when this happened, I wasn't sure I wanted to live. But I'm going to struggle on. There's always someone worse off than you. And if they can do it, you can.*

Luke was struggling to find meaning in what happened to him.

I tried to do well in this life, he said. *I've done all I could do. I tried. And it's not over until Jesus say it's over. I tried to be a good man.*

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A short time later, they received the bad news: Luke's insurance plan didn't cover skilled nursing. It might not even cover additional time at inpatient rehab. They had to scramble to work out a home care plan, as soon as possible. And in the meantime, Luke wasn't doing well at the inpatient facility.

Next time I saw him on rounds, the medical team seemed disheartened. "Poor Luke," his doctor said. The resident tried to inject some optimism into the discussion:

We finally have his renal function stabilized! He slept through the night, so he may be more lucid this morning. He may be doing a bit better. But he needs someone with him all the time. He's constant, direct supervision. We went up on trazodone. They were working on weaning him off the restraints for the SNF. It didn't go well the night before last, but maybe it was better last night.

They'll have to do that, even though he's not going to a SNF. They won't have a bed enclosure at home, the doctor pointed out.

When we arrived at Luke's room, he was sleeping. They tried to gently rouse him, but he was barely responsive.

It's about 7:30 Wednesday morning. Did you sleep okay? Pain or anything bothering you? the doctor asked.

I just want to go home, Luke said.

You're pretty close! But the best thing you can do is to do your best with therapy, the doctor told him.

Unfortunately, he wasn’t managing much better in therapy. He was more alert, later in the day, but he was at the limits of his tolerance. At one point, I was visiting him when a PT arrived for therapy. She updated him on the equipment she was ordering. His wheelchair would arrive soon, and his shower chair would be sent to his home. He would discharge that weekend.

She tried to get him to do some therapy.

“My mind’s not into y’all therapy no more,” he said. “I don’t like how y’all treat me … I get negative vibes period.”

What can we do to improve? she asked.

I don’t know what to say. I’m no psychologist, he said.

She tried a few more tactics to encourage or cajole him, but he wasn’t having it.

Last thing I’m going to say—it’s important to get you as strong as possible before you leave here, she said.

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At the next team conference, the staff seemed to feel they were out of options.

Luke was refusing therapy, and it no longer seemed productive to push him. *We’re not under a minutes crunch with him because he’s not a Medicare patient. And no offence, but there are other patients who could want the time*, a therapist said.

The social worker explained how his insurance denied SNF benefits. They could extend his time at inpatient and try to appeal the decision.

Until his stroke, Luke was a federal employee. *You’d think government employees would have better insurance*, a therapist mused.

You would? the doctor said, dryly.

He’s a veteran too, another therapist pointed out.

True! The VA has skilled nursing, the doctor said.

The resident reported that Sarah hurt her back during the family training. It was supposed to be a trial to see if she could handle Luke at home, but it didn't go well.

Nursing reported, *Sarah didn't attend training yesterday. After Friday, when we agreed he was going to a SNF, she said she probably wouldn't come today.*

It's not safe to train her. She hurt herself once. We're going to be liable, if she gets hurt training. We can do training from a distance, if she wants to come in Thursday or Friday, but we can't do hands on training, a therapist said.

He was restless through the night. Probably his mood is bad today because of bad sleep, the resident suggested.

Today is not a one-off. He has been regularly refusing PT, a therapist countered.

He can't be left alone, even for a short time. He will fall. He has hemi-inattention, cognitive impairment, impulsivity.

They all agree he needed "constant, direct supervision." How would Sarah provide that at home?

The doctor summed up the situation: *So, he's not making improvements here. He's not participating. He has no insurance for SNF.*

In my experience, with this type of federal insurance, you just have to open up a case to get benefits. But his SNF allowance is probably pretty limited, if he does have it, the social worker said.

So what are the next steps? the doctor asked.

No one voiced any suggestions.

What does it take to open a case? the doctor asks the social worker.

The social worker said she would see if Sarah found out anything. *This isn't my case. I'm just filling in*, she explained.

When he does participate, his movement is improving. His metrics are improving, the PT said.

After the meeting, I asked the resident what would happen. *This discharge is a hot mess express*, she said.

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Meanwhile, Sarah was figuring out how to make do. They were longtime partners, but they weren't married. She wasn't eligible for family medical leave, so it was hard for her to take time off work to come in for trainings. But she was starting to feel more confident. The OT showed her techniques to support Luke that didn't rely on brute physical strength, and the PT showed her how to help Luke up and down stairs, sideways.

Sarah had been talking to a friend whose husband had a stroke and went to a SNF. He developed a horrible pressure sore, due to lack of care. Even if Luke had gone to a SNF, Sarah would have had to be there as much as possible, building relationships with the staff, making sure they knew Luke had family keeping an eye on them, maybe even slipping them some money under the table. Otherwise, she would have worried he was being mistreated.

She was making the most of their extended social network. She could pay their young downstairs neighbor to help get Luke in and out of their building, and she also had a connection to someone at the VA who was advising her on benefits. She was trying to figure out whether Luke would be eligible for social security. He wasn't yet old enough for Medicare, but maybe he'd qualify for SNAP. Frustratingly, it felt like no one was responsible for working through all this with her. The social worker at rehab helped somewhat, but it was scant support. She said you needed to be a warrior to cope with all this bureaucracy.

I expressed amazement that she hadn't crumbled, under all the stress.

I did *crumble*, she said. *I would be lying in bed at night thinking "god, help me get up tomorrow."*

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When I came to say goodbye to Luke, a PT was coaxing him through the end of a session. He was lying in bed, doing leg lifts. I told him I was impressed at how well he was doing.

I wish you could have seen him walking, but he wouldn't do it this session, the PT said.

Why you gotta tell everybody my business? Luke muttered.

What's that? she asked.

Nothing.

Before she left, she tried to get him to slide up a bit more in bed, but he insisted he was fine.

I know what's comfortable for me, he told her.

She went into an end of session summary, but he was through.

Stop talking. Break time, he said.

Before I said goodbye, I told him I was sorry he went through all this.

Nobody planned for this. It just happened, he said.

I told him to take care of himself. I didn't want to see him back in the hospital.

I would shoot myself, he told me.

Chapter Three: The Transition Home

Home vs. Skilled Nursing Facility (SNF)

Inpatient rehab only lasted three weeks, on average, and at the end of that time, some patients were medically stable enough to discharge but not yet able to return to a home environment. A SNF might allow them to further recover before transitioning home, as this patient's niece hoped would be the case:

> She cannot go home right now because she can't walk. She lives in an apartment. She doesn't own it. It's an older apartment. The doors aren't wide enough for a wheelchair. And what I tried to explain to her, as did the doctors and nurses, if she can transport herself from like the wheelchair to the toilet or the wheelchair to the bed, it would help. But the wheelchair won't fit. So she's got to get to a point where she can either walk with a walker or be semi-mobile somehow like that.... So we've talked about the skilled facilities, see what happens. A nursing home might be down the road. You know, I—we're hoping not. We're hoping. You know, she's working really hard.... It's kind of funny, because she said, "Do I have to bring my own bed?" And I said, No, when you go to a nursing home, you bring your own bed, because now you're living there ... I said, no, this is strictly therapy at this point. Our goal is to get you home. (niece of TBI patient)

In many cases, insurance would pay for a SNF. If, ultimately, a patient needed permanent residential care, it would likely not be covered by insurance; residents would essentially pay "rent," using their own funds and/or other forms of financial assistance. So while patients talked about being "sent to a nursing home," SNF placement wasn't precisely that. In many cases, a SNF was intended as a bridge, although some patients would end up transitioning to a permanent residential facility.

Staff and patients alike were very invested in whether patients would be discharged home or would be (temporarily or for the long term) sent to a nursing facility. Several factors influenced this decision.

What do the patient and family prefer?

Patients varied in their ability to participate in the decision. The vast majority of patients who were able to express a preference were hesitant to even consider skilled nursing as an option. For disorders of consciousness patients or patients who were severely cognitively affected, the decision might have to be made by surrogate decision makers. Even when patients could participate in the discussion and decision, they often weren't in a position to handle the logistics on their own. As one patient's wife said:

> I think he kind of goes back and forth with [how he feels about going to a SNF]. Because his—because of his memory. And so at times, he'll tell me, “You never told me.” And I have, but he doesn't remember. And I haven't showed him the list of the facilities. Just because of the brain injury, it's overwhelming for him to look at all that information. (wife of TBI patient)

Family members often expressed guilt at even contemplating sending a patient to a SNF because their loved one hated the idea and/or they had always promised their loved one they would never "put them in a home.” Many patients and families had heard (or witnessed) nursing home horror stories: patients left unattended, slumped in wheelchairs lined up in the hallway. COVID-19 compounded patients' and families' fears, both because they were concerned that nursing facilities were a COVID hotbed and because, at the height of the pandemic, many facilities were closed to tours. Patients and families were hesitant to choose a place sight unseen, especially knowing how variable these facilities could be in quality.

Staff tended to agree that SNF placement was undesirable. Nursing staff and therapists who formerly worked in SNFs were particularly negative. Some staff felt patients sent to SNFs were more likely to decline and wouldn't receive the same level of care. Staffing ratios weren't as favorable in SNFs, and rehab nursing staff felt that SNF patients often weren't given adequate care. Pressure sores could develop, and other needs might be neglected, leading to a downward spiral.

Therapists had a lot to say about the quality of rehab available at SNFs, as this therapist stated:

> [When I worked at a SNF], I was like the only physical therapist, and with being a new grad it just—the priorities of being in that type of setting versus here are very different. Like, they're less worried about patient outcomes and less worried about quality of care and evidence-based practice and all that and more concerned about how many patients that we're going to be able to see and get evaluated. And there's a lot less accountability, and like, the ethical line is a lot more gray. Whereas here, it's like, that's all very important. (staff, inpatient)

If the goal was for the patient to continue rehab and ultimately transition home, staff worried that they wouldn't be getting adequate quality therapy in a SNF. For brain injury patients especially, options were limited. As another therapist said:

> We don't have enough good brain injury facilities out there for people to go to after inpatient rehab. So like, if someone doesn't make progress, to be sent to a nursing home is horrific. I worked in a nursing home, a lot of them aren't great. Especially for behavioral management. They just drug them. (staff, inpatient)

The attending physicians at inpatient rehab took pains to make sure patients weren't on any medications that might limit their ability to participate in therapies or get in the way of neurological recovery. Many drugs commonly used to manage behavior in nursing facilities (particularly in settings with poor staffing ratios) were anathema to rehab doctors. On the whole, staff, patients, and family all hoped to avoid SNF placement, if at all possible, but many other factors came into play.

What are the patient's needs?

How much "supervision" does the patient require? Does someone need to be with the patient constantly, or would some routine help with cleaning and meal prep suffice? How much assistance does the patient require with activities of daily living (ADLs)? What are the patient's medical needs—does the patient simply need someone to help keep track of their medications or does the patient require trach suctioning, tube feeding, incontinence care, etc.?

Staff generally didn't make explicit recommendations whether a patient would require skilled nursing care. They tended to lay out information about the level of assistance and supervision a patient would require and let family and patients determine whether they could make that level of care available at home. Even in a controlled hospital environment with staff trained to work with neurorehab patients, some patients could be challenging. Often, family balked at taking home a patient who was particularly "behavioral" and/or would need constant supervision.

Safety also weighed into the decision. As one minimally conscious patient's partner described, the initial plan had been to bring him home, but then he started vomiting frequently, and given his aspiration risk, his partner didn't feel comfortable having him out of a medical setting. In other cases, family and patients downplayed the safety hazards and insisted they wanted to bring a patient home, against staff advice. Staff might not feel that family was adequately trained or could provide a safe environment. In some cases, families weren't compliant with staff instructions (e.g., a family member might refuse to keep an agitated patient's protective mitts on, and the patient might start pulling out tubes). In these cases, staff might get the ethics team involved. Ultimately, however, staff only had so much control; they could advise and document that the advice was given, but they couldn't always ensure that patients ended up in optimal environments.

Where was the Patient Living Before and Can Modifications be Made?

Does the patient require any accessibility modifications to their living space, and if so, is it possible to make them? Does the patient live in an apartment or own a home? Can the patient move in with a family member or friend, either permanently or temporarily, if their own home is unsuitable? Worker's compensation policies may pay for home modifications such as building a ramp or remodeling a bathroom, but basic medical insurance generally won't cover accessibility alterations. Even smaller scale modifications may not be affordable for many families to pay out of pocket. Families may or may not be able to make even simple, reversible changes like adding grab bars or a shower bench, and certainly larger scale changes, like widening doorframes or swapping a tub for a walk-in shower, can be cost prohibitive.

What Degree of Assistance can Family and Friends Provide?

Does the patient have adult children? Are those adult children primary caregivers for their own young children? Does the patient have a spouse? Is the spouse elderly and/or disabled too? Was the patient a primary caregiver for young children or an elderly or disabled family member prior to their own hospitalization? One patient I met had been the primary caregiver for his wife with advanced MS before being admitted to the hospital himself. One patient had been the primary caregiver for her adult son with Down's Syndrome. Often, families were already struggling with caregiving responsibilities. In other cases, potential family caregivers were also concerned about managing their own health, as this patient's wife explained:

> I'm a chronic pain patient, too. So. So it's kind of like, now the onus is really falling on me. I've learned over time how to balance, in many ways. I know when I can push through things. And I know when I have to stop. So I've kind of learned that, over time. And I've learned to kind of function within my capabilities, because if I don't, I'm going to be in excruciating pain ... I've had to learn to balance physical activity. And sometimes things don't get done that really need to get done. And so right now, I'm trying to take advantage of the time while he's here, to do the things that I just haven't been able to. (wife of TBI patient)

For some family members, it was hard to imagine absorbing these often physically demanding, caregiving responsibilities, along with taking over much of the patient's share of household labor. Many family members weren't confident in their physical abilities (e.g., would they be able to support the patient's weight to assist with transfers?) and/or in their capacity to learn all the new skills required. Often, they were hoping a patient would become a little more independent before returning home, but patients didn't always progress as far as family hoped.

Especially for patients who were predicted to go home with high-level care needs, staff tried to initiate family training as early as possible. In some cases, when families realized exactly what home care would entail, they started to doubt their ability to provide it. Of course, family dynamics also complicated the situation. If a patient cannot be discharged home to live independently, are there family members involved who are willing to work with the patient and with the hospital social worker to come up with a plan? The entire range of complicated human relationships could come into play. Some patients were divorced or separated at the time of injury. Some patients were out of contact with their adult children. Not everyone had a deep bench of people able (or willing) to rearrange their lives to help make a return home feasible.

What Can the Patient and Family Afford?

Many patients initially assumed that their insurance would cover care in the home. The social workers often had the unfortunate task of informing them that most insurance will not. Insurance plans generally offered either ongoing day rehab or home health. Even if a patient opted to forego day rehab and receive home health, that generally just meant in-home therapies and sometimes one or two nursing visits a week if the patient required ongoing wound care, blood draws, etc. Insurance wouldn't pay for round the clock care or even for limited help with mobility, personal care, and housekeeping for a couple of hours a day. Can the patient and family pay out of pocket for in-home care? Can a family member afford to forego wage labor to provide care? If the plan is to discharge the patient to a SNF, which facilities will the insurance pay for? Which covered facilities currently have open beds? Are the patient and family willing to accept any of those options?

Money could solve a lot of problems. As a therapist put it:

> Interviewer: So what are some of the logistical obstacles to getting patients home?
>
> Therapist: Definitely, money. It's all about, if someone has more money, then anything's possible. But if someone doesn't have any money, it makes their lives a million times harder—which correlates to their like insurance benefits and their follow up care and their ability to purchase certain things out-of-pocket that would maximize their success at home versus not. Or their accessibility to their home. Like if they live in a four-story walk-up versus an elevator building, that's going to dictate whether or not someone can go to outpatient or they're gonna be homebound. Or is it even a good idea to bring this person home if they're gonna be homebound? You know? So, at the end, it all comes down to like, money, and how much of it you have. Because that will fix a lot of things, essentially. (staff, inpatient)

Even for a patient who could afford to hire in-home care, however, it could be difficult to staff round the clock shifts, especially if the patient had a lot of preferences (e.g., they wanted someone who can drive, someone who speaks English, someone they're confident can lift them, etc.). Some patients were also a bit cantankerous and might not get along with everyone. As one patient's granddaughter put it, the issue was, "also just with her personality and finding someone that she accepts, and doesn't yell out all day, like truthfully, right?" Dealing with staffing in-home care could be a time-intensive operation, and not every patient was able to take on this role themselves or had family willing and able to devote the necessary time.

How Long do the Patient and Family Have to Figure out a Plan?

Staff often did whatever they could to extend a patient's inpatient stay if it would make the difference between sending the patient home instead of to a SNF. If a family said they would be able to take the patient home if the patient recovered a bit more and gained greater independence, or if a family just needed a little more time to make arrangements, staff would hold off the insurance provider for as long as possible. In some cases, staff also had to extend a patient's stay until the right SNF placement could be arranged. As one patient's family member explained:

> Our priority is a clean, safe place that will give her the therapy she needs. We live in the inner city. The places that are in the on-deck circle right now that they're trying to get her into are, you know, these outside suburbs. Because the beds in the Chicago area are filled, other places that we've selected. So we've given the social worker like twelve different places. Five are automatic declines because they don't have bed space available. The other seven are under review right now.... She was supposed to be discharged today and had nowhere to go. And I was like, "What? Do I put her in a car and ride around for two weeks till something comes?" So they're kind enough to keep her here and give her the therapy until something becomes available. (family of TBI patient)

In some cases, however, SNF placement just wasn't possible. Oftentimes insurance didn't cover skilled nursing. Some patients were limited because they had a history of incarceration or a mental health history, and many facilities wouldn't accept them. Other patients were rejected for behavioral reasons. A therapist gave an example of one patient who was in this sort of bind:

> This is one that was yelling at me in the hallway the other day. The patient is too agitated to go home because I don't think family could handle his behaviors. We can. I mean, we're handling them. But it's, it's tough for the staff, every day. So he can't go home. His Medicare, I believe, won't—he can't go to a brain injury facility, which would be the ideal thing for him, but I guess their plans don't—they don't have contracts with them ... Unless the family can privately fund the brain injury facility, they couldn't go there. And that's really expensive. Family can't do that. So can't go with family, can't go to a brain injury facility, may have to go to a SNF, but family doesn't want him to go to a SNF. Also, I don't know how well a SNF would accept him. Oftentimes, when you go to a SNF, you have to be restraint free for—I think it depends on the SNF, but two to three days ... and so thinking about, he's been here for three weeks, his discharge is coming up in two weeks, we need a plan. (staff, inpatient)

In some cases, the inpatient rehab realistically couldn't keep a patient long enough to get them to a point where they could go home with the level of care family was capable of providing, so it came down to a difficult decision to opt for a SNF. If SNF placement wasn't an option, however, staff, patient, and family had to adapt. Family might cobble together a support plan by sharing the schedule among numerous family members and friends. Therapists might alter their treatment plan to focus more on functional goals than longer term recovery goals. For instance, if a PT had been working on walking, they might have to pivot to training wheelchair skills and making sure the patient agreed to remain in the wheelchair when no one was available to supervise walking. Staff, patients, and families had to work with the best available option, even if it was far from ideal.

Day Rehab vs. Home Health?

When transitioning home from inpatient rehab (rather than to a skilled nursing facility), patients generally continued with rehab, either at an outpatient "day rehab" facility or through home health. Day rehab was a more intensive program that required a patient to travel to a facility several days a week for OT, PT, and speech. Home health sent therapists to the patient's home. In some cases, patients were discharged with an initial referral for home health but could transition to day rehab, if appropriate.

Staff explained that day rehab was the more intensive option. You received more hours of therapy per week, and you had access to all the therapy equipment available at the day rehab facility rather than having to work with what you had at home. Home health wasn't staffed by the rehab facility, and staff and patients reported that home health therapies were more variable in quality.

Day rehab also had the virtue of getting patients out of the house and "back into the community," and staff also talked about the benefit to patients of a somewhat structured schedule. Day rehab patients had to reliably be there, two to three days per week, for half or full days. As one patient who had received home health therapies while she was waiting to get into day rehab put it:

> [Home health] wasn't intense though. Like [day rehab]. You know what I mean? Yeah, I got away with a lot. If I told them I was tired, they'd let me go back to bed. You know, especially speech would let me do it in bed. But I'm glad I have to get up and out. It wasn't intense like this at all. (stroke, White, female, outpatient)

Access to reliable transportation was a significant barrier to some patients. Most patients weren't able to drive themselves. If you couldn't afford to pay for transportation, and you didn't have family or an extended network of friends willing to drive you and pick you up regularly, getting to day rehab could be challenging. Patients who missed therapy too many times due to last minute transportation issues, would be discharged from the program.

Insurance was another factor, of course. Plans wouldn't pay for both home nursing/therapy and day rehab, so if patients needed continued in-home nursing care, they might have to opt for home health and forego day rehab, at least initially. Staff also judged whether patients were able to "benefit from" the more intensive day rehab program. This example illustrates some of these considerations:

> We had a patient come in. I'm reading his notes, and he was barely participating [at inpatient rehab], had no functional gains, hadn't met any goals. And then they recommended him for day rehab, which was actually, probably not a good recommendation. He should have gone to home health. But we were very upfront. All three of the therapists had read his chart, and it was consistent across the board: OT, PT, and speech, he wasn't like participating, he wasn't making any progress. And so, we inform the family right away that we want to make sure that we're serving him and his needs and meeting him where he's at, and doing what's best for him. And this program might not be it. We're going to do a two-week trial and see how it goes. If we're not seeing any change from inpatient, then we're going to refer to home health ... [this patient] actually died two days after we discharged him. So, you know, I mean, an intensive program like day rehab

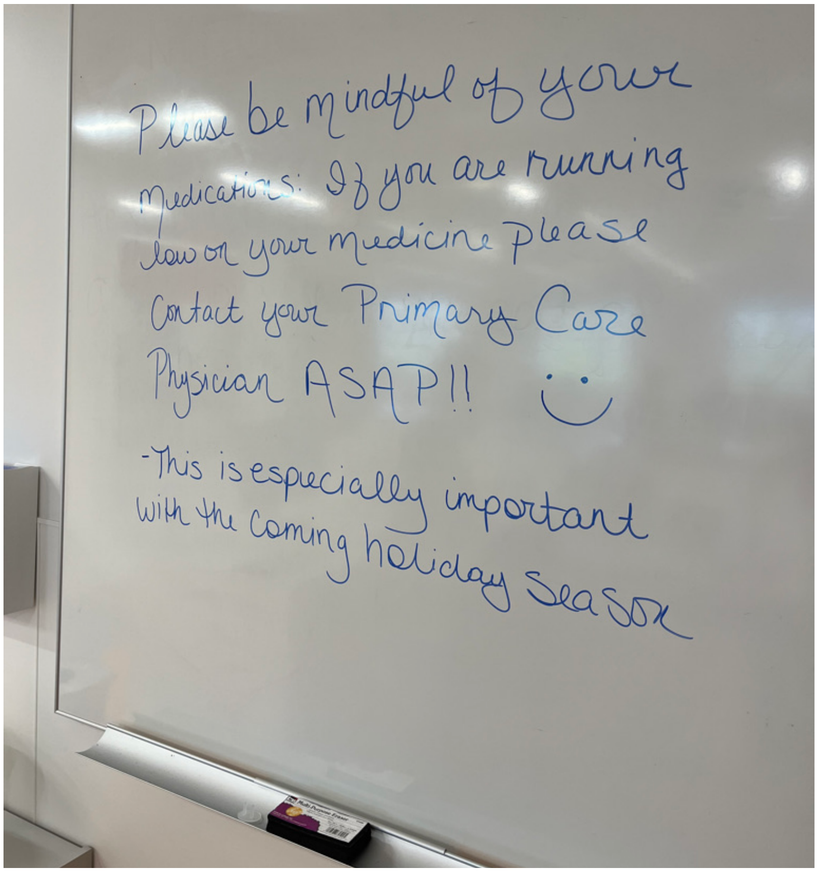
> wasn't serving him. And we actually had those family members come in and sit in on those sessions with him, and they saw that all he was doing during the sessions was sleeping. And the daughter was like, “Oh my god, I didn't realize it was this bad. Like, he's not at all participating.” The home health is kind of a mixed bag. Sometimes patients get really good home health care, and then sometimes they don't. But ultimately, we have to look at, are we helping this patient? And then in this poor man's case, we were like, torturing him by bringing him to therapy, you know? He was just—he was so tired, he could barely stay awake. It was rough, you know? And then that kind of goes into our practice—is it ethical what we're doing, can we bill for skilled therapy if the patient is sleeping for half of the time? (staff, outpatient)

Patients were supposed to be physically robust enough to participate in intensive therapy, and they were also supposed to be in a position to make meaningful gains. For instance, sometimes patients wanted to return to day rehab once their insurance caps reset for a year. But day rehab was a scarce resource with a long waiting list. If a patient's recovery had plateaued, they were unlikely to be considered appropriate for day rehab unless they could benefit from learning functional strategies they hadn't had a chance to work on before. Staff also felt that some patients saw day rehab as a substitute for continuing to work on their own at home. Day rehab was supposed to provide an initial intensive burst of therapy and then leave patients with the skills and knowledge to continue following an at-home exercise plan. It wasn’t meant to be a service like personal training that would continue indefinitely.

Discharge Planning and What Falls through the Cracks

Discharge planning is a complex process. Preparing for discharge often involved making modifications to the home; ordering medical supplies and adaptive devices (e.g., a shower chair); making follow-up appointments with the primary care physician and other specialists; scheduling ongoing outpatient therapy and arranging transportation several days a week; making arrangements for caregiving and housekeeping needs; getting family members trained for whatever support they would be relied upon to provide; and picking up and dispensing medications. I heard examples of each one of these elements going wrong, sometimes catastrophically.

When patients left the hospital, their primary care physician (PCP) was supposed to take over routine care and prescribing from the attending physician at the inpatient hospital. Many patients didn't have a primary care physician at the time of their stroke or TBI, so inpatient and day rehab staff emphasized the importance of establishing a new PCP relationship as soon as possible. For patients continuing to day rehab, the day rehab physician could take over prescribing for a month or so, but only for as long as the patient remained in day rehab. So the goal was to get patients set up with a prescribing PCP as soon as possible. The PCP would also, ideally, continue to monitor the patient’s health in the long run since many patients, particularly stroke patients, had multiple comorbidities.



Please be mindful of your
medications: If you are running
low on your medicine please
Contact your Primary Care
Physician ASAP!! ☺
-This is especially important
with the coming holiday season

Image 5: Note written by the nurses on the nursing station whiteboard
Source: Photo by Author

Often, patients and family also had to arrange numerous follow-ups with specialists—pulmonologists, cardiologists, ENTs, neurologists, neuro-ophthalmologists, orthopedic surgeons, and so on. In many cases, specialist follow-ups were deliberately delayed until after inpatient rehab discharge in large part because of a quirk in billing practices. If a patient went to an acute hospital for a medical procedure without first being discharged from inpatient rehab, the money for the procedure would come out of the pot of money the rehab hospital received for the patient's stay. For financial reasons, it made sense for the hospital to have patients schedule follow-up appointments and procedures for after inpatient rehab discharge. Consequently, patients and families often had a laundry list of follow-up appointments to make, post-discharge. It wasn't always clear to them whether they were responsible for following up on referrals or whether someone would take care of it for them. As a patient explained:

> Well, I will get referrals to the doctors, one for leg, one for arm, eye doctor. And we will make appointments. I don't know who's going to make appointments. That is kind of blurry. We need a caseworker for that to talk to us. Because one person told me we make an appointment, and another said the caseworker or somebody will make an appointment. (TBI, White, female, inpatient)

The confusion was, in part, due to an acute shortage of inpatient social workers. Until recently, social workers had often made follow-up appointments for patients, but at the time of my research, the remaining social workers were so overburdened that they were asking staff to direct patients and families to make these appointments on their own, except in cases where a language barrier or other circumstance made social worker assistance necessary.

Patients and family also had to make sure all equipment the patient might need would be ready and waiting for them at home. Inpatient therapists were responsible for ordering equipment like wheelchairs, braces, and other assistive devices, but family members had to coordinate delivery and make sure everything was set up at home. Often, other types of equipment like shower chairs and other bathing devices and medical supplies wouldn't be covered by insurance, so therapists would make recommendations, and patients and families would be responsible for ordering the appropriate supplies. I observed more than one panicked conversation with family members who felt that, due to lack of time or information, they hadn't been able to adequately stock up on products like incontinence and wound care supplies before discharge.

As patients progressed in day rehab, their assistive device needs would change. Inpatients were often given devices like dressing hooks for free to take home, but day rehab therapists didn't have the same ability to supply these items. Outpatient therapists, especially OTs, often found a device that worked well for a patient when they tried it in clinic, but the patient couldn't afford to source the item for home use. Costs added up, even for smaller items like free weights or long handled sponges.

Family also had to rearrange the home environment in preparation for inpatient discharge. This preparation could involve simpler tasks like rolling up rugs that might trip the patient or adding visual supports like colored tape around the house for visually impaired patients, but it could also involve more major renovations like organizing bathroom remodeling or ramp installation or setting up a downstairs sleeping area. Patients and families also had to arrange for any care needs and work out transportation (to and from day rehab and medical appointments, at the very least). Many people also had to negotiate financial and professional bureaucracies, dealing with medical leave and/or filing short-term or long-term disability paperwork. From the reports I heard, disability processing backlog had only gotten worse at the time of my fieldwork, and people were being told to expect to wait six months or more.

Patients often came home with a substantial list of new medications, and procuring and managing these prescriptions could be a major task. One inpatient staff member explained how confusion could arise on the hospital's end:

> But a lot of times, like, if it's not communicated properly—especially the meds getting to the pharmacy is one big area, I would say. Also, just the way you reconcile the medications. For example, if you go to a SNF on discharge, you don't need to send prescriptions usually. However, if you don't actually reconcile the medications, it shows everything from the previous hospitalization. [It] shouldn't be what the patient continues on. So I've had that a lot, where that's not been completed. And it's usually like the day of [discharge] and they're going out the door. And I'm like, wait, please! Like, let me—give me a minute and then reprint the discharge. (staff, inpatient)

Ideally, nursing staff went over the list of medications with patients and families before discharge to ensure they had some familiarity with what they were taking. And in theory, patients were supposed to be sent home with an updated and comprehensive medications list in their discharge paperwork. There was also a program that encouraged patients who were cognitively capable of doing so to take charge of their own medications during their inpatient stay. These patients were provided with a medication list, broken down by time of day, and they were instructed to call their nurse for the appropriate medication within the proper window of time. Therapists and nurses worked together on this program to help patients learn what their medications were for and when they were supposed to take them. Of course, if they forgot, the nurse would still come administer the medications, but the idea was to give them a chance to ask for it themselves.

Of course, many patients weren't capable of fully taking charge of their own medications, but inpatient and day rehab staff worked hard to make sure patients and families were as familiar as possible with what patients were taking and how and why. Even so, mix-ups could occur (see Finn's story), and for a variety of reasons, patients could be "non-compliant" with their medication regimens. Patients ran out of a medication and, for whatever reason, didn't or couldn't get it refilled; patients stopped taking drugs with unpleasant side effects, without informing their physicians; and many patients didn't understand the purpose and importance of certain drugs. As an inpatient nurse explained:

> So I try, when I go through meds, I try to be like, if you take nothing else, these are the really important ones. And like this other stuff, you know, this is a vitamin, this is a stool softener. But this is your blood pressure medicine. This is really important. And like, it's not expensive, it's generic. Take it, please. And even—you're not gonna feel any different if you take it or don't take it. Take it anyway. Or this is your anticoagulant. This is gonna keep you from throwing a blood clot and having another stroke. Please, please, please take this one. And I'm like, if you decide to go off this and this and this in the future, that's fine. But do it with your doctor. Don't do it on your own. Like, do it gradually. (staff, inpatient)

Staff were largely aware of all the potential reasons behind patient noncompliance, so they tried to prepare patients for discharge as best they could. Given all this preparation, why did problems still arise? As described above, there were so many moving parts that some amount of confusion seemed inevitable, but there were several other contributing factors.

Inpatient staff tried to give patients and families an estimated discharge date as soon as possible, but this timeline was subject to change, and unexpected change could lead to pre-discharge scrambling. Several family members talked about how they had planned on a certain number of days inpatient, only to find that number abruptly cut down. One spouse explained her frustration:

> Well, so about a week after he was here, they said, 9/11, our plan is [to discharge him on] 9/11. And I talked to her and I said, “Is that *your* plan? Or is that insurance approved?” Because I've been through this once before ... So she said, “No, that's our date. But very rarely do people leave sooner than their date. And if they do, the doctor calls, and we explain to insurance why they need to stay”... So we had this 9/11, 9/11, 9/11, 9/11. And then we come Thursday to find out insurance had actually denied the entire [past] week he was [inpatient]. And they weren't gonna let him stay till 9/11. So the doctor called and got insurance to approve the week he was already here. And then insurance said he had to be out this weekend. So I literally had three days. Like, I don't even have all the stuff for home. Because we were planning on a 9/11. (wife of TBI patient)

Staff engaged in a lot of wrangling over insurance approval. I encountered many cases where a discharge date was up in the air because the medical team had to schedule a "peer to peer" call with an insurance company physician to appeal an insurance decision and try to extend a patient's stay (or even secure payment for part of the time a patient had already been there). As one medical staff member explained, "sometimes they tell you on Monday that they stopped paying as of Friday." As the following exchange illustrates, this uncertainty could make it hard for staff to give patients and families a definitive discharge date:

> The nurse practitioner reports that she talked to P’s mom yesterday. The mom wanted to know how long P would stay at inpatient rehab. The nurse practitioner said she would have to see what insurance says.
>
> NP: I asked “what did [the doctor] say?” and they said three to four weeks. And I know that wasn’t you.
>
> Doctor: Two to three weeks is what I said. And I also corrected insurance because ten days is low.
>
> NP: They only guaranteed seven days.

Doctor [tone of resignation]: That’s what they do.

"P" was a TBI patient with multiple other injuries, so ten days would indeed have been a stingy inpatient rehab stay. Needless to say, staff spent a lot of time on these insurance battles. In other cases, however, patients had to truncate their inpatient stays for reasons of their own. One woman I interviewed at day rehab went straight home from the acute hospital despite her medical team's recommendation that she continue to inpatient rehab for her TBI. Unfortunately, the woman's partner had recently died, and they had young children. She opted to forego additional inpatient treatment because she couldn't leave her children under their grandmother's care longer than she already had.

Patients and families were navigating a complicated system, often with limited resources. When planning for discharge, family and patients had the support of an assigned social worker. During my study, there had been a huge amount of turnover among the social workers, and the ones who remained were even more overburdened than they generally were. Patients and families didn’t get much hand-holding.

Negotiating the various bureaucracies involved often required a lot of specialized knowledge, and it wasn't always clear where to turn for advice. A staff member gave me an example of a recent case in which a patient asked whether ADA required their landlord to add a ramp to their residence, but the staff members on hand weren't familiar with the relevant regulations, so they had to refer the question to the social worker. The social workers were, at their best, an excellent resource and repository of knowledge, but they were pulled in a lot of different directions, and patients and families commonly felt unsupported. One patient's wife described how she felt utterly on her own:

> But all during that time there was no one to help me. The social worker here, I think, was young. And just was worthless. I mean, she was not—not in a negative way. And the idea that she would give you like a list of fifty, these are the fifty places that take, you know, nursing long term care facilities in Chicago. And I'd say, "Well, what do you recommend?" "Oh, well, we can't recommend." And so you're looking at this list of fifty. (wife of TBI patient)

This woman was highly educated, affluent, and had personal and professional connections to draw on. Ultimately, she was able to seek recommendations and support from highly placed medical administrators and other helpful authorities. She was put in touch with a caseworker from another facility, who walked her through the Rancho scale and provided information about how her husband's recovery would likely progress.[14] The caseworker also explained that her facility wouldn't be an option for him: Medicare wouldn't pay to admit a patient who was already inpatient at another rehab facility. Another option on the table didn't have a Medicare contract at all and would have cost $1,700 a day. Finally, with this advice and other connections (as well as the fact that her husband had to be discharged to the acute hospital to treat an infection, which meant he wouldn't be coming direct from inpatient rehab), they found a place for him at a third facility. This woman was capable, tenacious, and had a social-capital-rich network, but she still found the discharge planning process supremely trying.

Many patients faced the additional impediment of limited health literacy. Nurses at day rehab reported significant (and sometimes dangerous) gaps in patient and family member knowledge. Many of the day rehab nurses had themselves worked at the inpatient facility and knew firsthand how much effort went into preparing and educating patients and families for discharge. The day rehab nurses had some suggestions for patching holes, but from what they reported and

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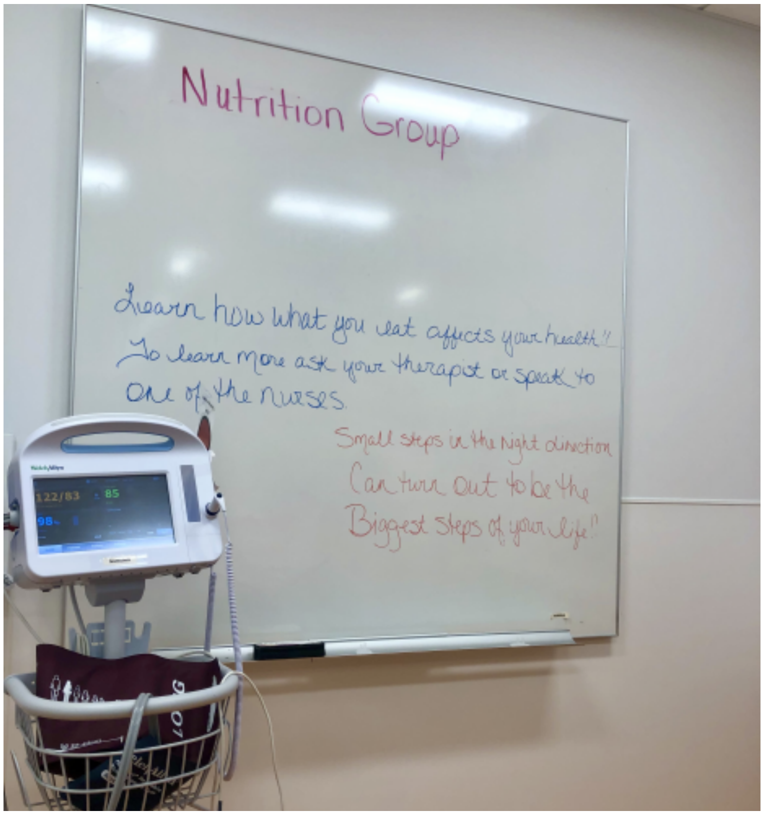
[14] The Rancho Los Amigos Scale or the "Rancho scale," as it's commonly referred to by staff, is a clinical tool used to assess and track recovery following TBI. As patients' cognitive-behavioral measures improve, they progress up the numerical scale.

from what I observed, the problem mainly came down to the sheer volume of information being conveyed to patients and families who are generally not medically trained, who may have poor health literacy, and who are trying to juggle the demands of their daily lives while managing a medical crisis and coping with the anxiety of dealing with disability in a country with a limited social safety net.

Staff emphasized that a lot of patients and families lacked even basic health literacy, such as an understanding that—especially post-stroke—they needed to monitor blood pressure and, for diabetic patients, manage blood sugar. Patients and families lacked not only the understanding that this kind of routine monitoring was important, but also practical knowledge, like how to procure the necessary equipment. Staff pointed out that many patients had been instructed to modify their diets, post-stroke, but they often had huge gaps in their nutrition knowledge. For instance, many patients had been told to reduce sodium, but they didn't know how to read a nutrition label or that a can labeled "low sodium" might not be low sodium but just lower than the very high sodium alternative. As one nurse explained:

> [Patients] say, “Oh, yeah, no, no, I don't put any salt on my food.” So I found this amazing handout that says 70 percent of the sodium in our food comes from restaurants, pre-packaged, or processed foods. Only 5 percent comes from the table. So it's really good that you're not salting it at the table. But you don't need to, because there's so much already in it. I've had three patients ask me in the last week, I'm not kidding you—"But I just have ham. But I just had a ham sandwich! That doesn't have sodium in it." It's kind of the name of the game with ham. (staff, outpatient)

Even if patients absorbed their physician's recommendations and fully intended to follow them, they weren't always equipped to do so.



Nutrition Group

Learn how what you eat affects your health!!
To learn more ask your therapist or speak to one of the nurses.

Small steps in the right direction
Can turn out to be the
Biggest steps of your life!

Image 6: Note written by the nurses on the nursing station whiteboard
Source: Photo by Author

Medications were another liability. Patients and families might not know that certain drugs, like Coumadin and Warfarin, require ongoing monitoring via blood tests. They might not know that it's important to follow instructions on when and how to administer drugs. Nurses had horror stories about patients who were taking neurostimulants like Ritalin before bed and sleep aids (or drugs with major drowsiness side effects) in the morning, before therapies. Patients might think they were doing everything right by taking all the prescribed medication, but if they didn't know how and when to take them (and, in some cases, when *not* to take a medication), they put themselves at great risk. A nurse gave the following example:

> And, you know, we had we had a patient come with a horrible discharge from inpatient. When she discharged, this woman was on every blood pressure med that she had ever been prescribed. Somehow, the discharge paperwork had every blood pressure med that she had been prescribed. When she came to our clinic, I mean, *maybe* [her blood pressure] was 60 over 40. Oh, my god. Oh, my god. I'm putting an abdominal binder on her. I'm trying to

> get ted hose on her. We're doing every—I'm like, essentially, like, opening her mouth, shoving water down. I'm like, Oh my god, oh my god, what are we gonna do with you? And the family came in. And they're like, "but they told us these are the meds and this is when she's supposed to take!" I'm like, she's on too many meds.... The problem is that I'm not a doctor ... what I can say is, typically doctors will put parameters on hydralazine. So if blood pressure is less than [a certain number], you would hold hydralazine. So you might want to reach out to your doctor and see if her systolic, the top number, is lower than 170—I wrote it all out. She comes back in [to day rehab], she's 80 over 60. I'm like, ahhh, you guys are killing me. She was 80 over 60. And right before we walked in, he had just given her blood pressure meds. (staff, outpatient)

It wasn't uncommon for patients and families to believe they were fully compliant with instructions when in fact they were doing more harm than good due to lack of medical knowledge. While many people were lacking in basic health literacy, it was also true that navigating the Byzantine complexities of the healthcare system could be a problem for even highly educated people. I recorded the following exchange on rounds:

> As we walk away, the doctor says to the resident: I feel like I have to have a medical degree to know how to manage my own healthcare. I just feel bad for people. [Our patient portal] is nice, but it isn't that simple for everyone to figure out.
>
> Resident: Especially older people.
>
> Doctor: For people with money, concierge services are a good option

But, of course, very few patients could afford concierge medical care. Some patients had family members or friends who were medical professionals of one kind or another who could advise them or direct them to support resources, but many people were just at sea, especially when it came to navigating insurance plans. As a social worker explained to me, these plans were not only complex but also variable. A lot of her job involved counseling patients and families on what their specific plan did and did not provide, and how to access those resources, and then trying to connect patients with community resources to fill in the gaps. As she explained:

> Medicaid is state run and most folks get put into a Medicaid managed care plan. So, for example, like Aetna has a Medicaid plan, but so does County Care. And so does Meridian. Like there are all these different ones. And each has their own, a little bit different, things

> to navigate in them. So, like, I work a lot with transportation, for example. Getting patients to and from appointments. Well, each of those Medicaid plans has a different company they do transportation with. Different phone numbers to call, different forms potentially to fill out. So it's just, you know, people get put into these care plans, these Medicaid plans, and then don't really know where to go from there. And so I feel like they are the trickiest to work with just because there's a little bit of difference in each one. So it takes me a decent amount of time just to look at that person's plan, review what's accessible to them in that plan, and then provide that education. (staff, outpatient)

Not only was navigating this bureaucratic labyrinth eating up the time of already swamped staff members, but the degree of complexity meant that it was challenging, if not impossible, to go through this process without professional support.

There were also major disparities in family and community resources across the two day-rehab sites. The north site was located in a predominantly White, relatively wealthy suburb, and another was to the south of the city, drawing from a population of majority Black and Hispanic, lower income patients as well as some lower income rural patients from Indiana. To begin with, patients at the south facility were often in a less financially secure position prior to their stroke or TBI. A nurse gave an example of the pressures some of her patients faced:

> We discharged him, and he went back to work for the postal service. And he called me and he's like, "Can I work overtime?" And I pull up the return-to-work order. And I'm like, yeah, doesn't look like you can't. We didn't say that you couldn't. He's like, "Okay!" He's like, "Yeah, yeah, I just, you know, I just need to just get that extra eight hours of overtime. I got a lot of bills. I got a lot of bills from everything that's happened to me." I'm just like, I understand. So I said, Yeah, there's no work restrictions. He calls me back, three days later. "Can [the doctor] write a letter saying that there's no work restrictions because they're trying to tell me there's work restrictions?" Sure. He's like, "it's just I—you know, I just have so much medical bills." And I'm like, I understand. We'll do what we can. He would take the bus to come to therapy. His clothes would be holes, tattered and torn. He'd carry his medications in a [grocery] bag. (staff, outpatient)

These patients also tended to have less social and economic capital flowing through their networks. It was often harder to cobble together support (financial contributions, transportation, caregiving, etc.) from friends and family who were themselves stretched to the limit. The ability to find someone to drive you to therapy or help you at home depended on whether you knew people with cars and flexible work schedules. If most of the people in your network were hourly workers, could they afford to lose hours to help with care or transport? Often, staff were aware that patients lived in far less than ideal circumstances, but they couldn't do much about it. As a therapist reported:

> A lot of times too, family struggles to provide the necessary amount of supervision that we're recommending at home. I have a guy right now with dementia, and he also had a stroke recently, and he is basically sitting in his room by himself twelve hours a day while family work. And obviously you would never want to leave a patient with dementia home alone for that much time. Or for any period of time. But that's kind of, unfortunately, the rock and the hard place where a lot of our patients are stuck. (staff, outpatient)

Practicing therapy exercises at home was a crucial part of day rehab. Therapists emphasized that patients wouldn't make progress if they only worked during the two to three hours of therapy they had each week, per discipline. But to work on assigned exercises at home, patients needed space, equipment, and often support from family. Not all patients had family at home who could regularly take the time to assist with exercises.

Many patients, particularly at the south site, struggled to afford essential recommended equipment, let alone more expensive items (like an electrical stimulation bike) that generally weren't covered by insurance but that therapists might recommend to patients who could afford to pay out-of-pocket to give them the best possible shot at recovery. Some patients lacked stable housing or lived in environments that were not only unsuitable but were also detrimental to their recovery. A therapist provided examples of how housing could affect patients' access to treatment:

> And then I got another patient who had bedbugs too. He was terribly impaired, had a really significant dysphagia. Was not eating orally, of course. Was barely intelligible because of the stroke, desperately needed therapy. But the family had bedbugs at home. And we really worked with social work to try and rectify that situation to get their house fumigated. And ultimately, they just could not afford anything. And because we are a program where you're working with other patients, we can't have somebody bringing those to our clinic. That's an obvious infection control issue. He ultimately had to be discharged, and I'm not sure what ended up happening with him. We've had patients who were homeless before. That's really hard right? How do you ensure carryover at home? How do you ensure if somebody has supervision? How do you ensure somebody can get any sort of equipment that they need, when they don't even have an address to ship it to, right? (staff, outpatient)

Given these fundamental disparities, not all patients had equal access to treatment or an equal shot at recovery.

Of all the barriers I heard about, transportation was perhaps the most troublesome. Transportation access was a major issue across sites, but it disproportionately affected patients at the south day rehab. Before COVID, the day rehabs provided a subsidized transportation service, but when group transportation became unsafe, it was discontinued, with no plans to bring it back. At the north site, many patients were able to find someone to drive them, but at the south site, most patients struggled to find reliable, disability accessible transportation. As one social worker explained, a roundtrip might cost more than $200, depending on where a patient lived and their accessibility needs, if they had to hire private. Public disability-accessible options were complicated and often unreliable. They had to be booked well in advance, and they often wouldn't cross county or township lines. Staff noted that patients would often wait hours, on either end, as this staff member described:

> I just reached out to the senator to find out what could be done because we have patients that are waiting, sometimes three hours at the end of their therapy. Three hours. Yep, that wasn't a glitch. Three hours to be picked up ... We'll have patients waiting for their ride from Pace, and Pace just never shows up. So, like, to get a patient who has a stroke or spinal cord or traumatic brain injury ready for the day, sitting in a chair and outside waiting, sometimes two hours before the ride gets there, to find out that they're not coming? That's not right. It's not right. (staff, outpatient)

To complicate matters, the day rehabs could only afford to be so flexible about lateness and no-shows caused by transportation issues. They tried to extend patients as much grace as possible, but eventually they had to discharge patients who couldn't show up consistently or cancel ahead of time. Lateness also meant wasted therapy time. As previously discussed, patients' insurance only afforded them a certain number of visits, so day rehab therapy time was precious. When transportation came late or failed to arrive, it could cut into that crucial and ever-diminishing allocation of time.

Day rehab was an important antidote to the various problems that complicated patients' discharge and transition home. As long as they were in day rehab, patients still had regular access to medical staff and therapists, and (theoretically) a social worker who could help direct them to resources. At the time of my study, neither day rehab site had a social worker on staff. They used to share a social worker, but that person had recently quit and hadn't yet been replaced. In the interim, a social worker covering other day rehab sites was allocating one day a week to helping out at both locations. Obviously, demand for her services massively outstripped her ability to assist.

Patients often arrived with many, often dangerous, gaps in their medical knowledge and their understanding of the instructions they had been sent home with. Day rehab provided a troubleshooting window in which medical and therapy staff did their utmost to do as much training and education as they could before patients and families were on their own. Day rehab nurses did their best to identify and remediate knowledge and resource gaps, but they weren't afforded much time to do so. They performed a quick intake evaluation on every patient who came to the facility, but their time with the patients wasn't billable, so they had to snatch time where they could.

Generally, they asked to pull a patient from therapy for ten minutes, and they tried to pack in as much as they could. They ran through a brief litany of questions meant to assess the patient's overall health status and identify any glaring issues or areas of confusion. They tried to determine any concerns the patient might have and leave them armed with a list of questions to bring to their next doctor's appointment. With the rapid-fire questioning, it could be difficult to build rapport, so they had to be strategic. They wanted to ensure that patients would tell them crucial put perhaps sensitive information (e.g., that they were having trouble with their bowel program or they had stopped taking their blood pressure medication because it was causing erectile dysfunction).

And that was all the time they got. Nurses tried to check back in with patients at opportune moments, like when patients were sitting in the hall waiting between therapy appointments, and nurses encouraged patients to come to their desk with questions, at any time. But since their time wasn't billable, nurses had no dedicated time to spend with patients. They tried to set up education sessions, like a nutrition group, but these sessions had to be organized as "co-treats" with one of the therapy disciplines or they wouldn't be billable.

Family training sessions were another major resource intended to clear up misconceptions and ensure a smooth transition home. Toward the end of the inpatient rehab stay, the assigned social worker scheduled a number of family training sessions. The amount of training depended on the patient's care needs, whether they were going home or to a SNF, who would be involved in their care at home, and family availability. As many therapists pointed out, family training was important, in part, because many neurorehab patients couldn’t take in much of the information themselves. Even for patients who were cognitively unaffected and capable of absorbing and remembering training on topics like stroke recovery and diabetes management, it helped to have family present as a backup, taking notes and helping reinforce the education.

A lot of information (much of it new) was thrown at patients and families at once. To prevent families having to take too much time off work, education sessions were generally grouped. Families would often come in and receive an hour of OT, an hour of PT, and an hour of speech training, and potentially an additional hour of nursing education in the course of a tightly packed day. If the patient's care needs were complicated, family might be asked to come back for additional training, but even so, staff found that most people struggled to absorb all the new information.

A small group of therapists were working on producing a series of videos to help patients prep for training and to give them material to refer back to. For nursing education, they put together packets of relevant material for patients and families to take home. As a nurse explained:

> They'll say, oh, this person has x condition and y condition and this. And so let's do something on blood pressure monitoring. And let's do blood sugar monitoring. And let's have them talk about this. And the easiest thing is their list of medications. So if you only have a little bit of time, you could just go over meds ... But it's also—it could be tube feedings, it can be incontinence care. It can be dressing changes, ostomy care, trach care. If they're going home with a trach. Doesn't happen very often. But once in a while. Skincare, like pressure wound prevention, pressure wound recognition, what you do if you have one, like pressure release. Like all the things like that. (staff, inpatient)

Although the packets were a helpful pre-session prep, nurses didn't always feel they had sufficient time to prepare for these sessions themselves. They weren't always familiar with the particulars of a patient's case, which made it hard to answer questions, as this excerpt suggests:

> Luke and Sarah are having their scheduled nursing education session with a nurse and a nurse trainee. They've been over the medications list. Sarah is taking extensive notes. The nurses are now walking them through a series of handouts relevant to Luke's medical history.
>
> Sarah: They said he basically had two kinds of stroke. Is the endocarditis what caused the clot?
>
> Nurse: I don’t know. I would have to look at his notes. But it could have played a role.
>
> ***
>
> Luke: Would you say I had a massive stroke? Is that the term or is that just a term used socially?
>
> Nurse: I couldn’t tell you, Luke.
>
> ***
>
> The trainee shows them a diagram of the brain (one hemisphere on each side of the paper), with areas of the brain labeled with the functions associated with them.

Luke: What part did mine affect?

Sarah: Can you talk about the areas that affected him?

Nurse: Let me look further into the notes.

The nurse goes outside for several minutes to review his charts on her computer. Fortunately, the nurse trainee can continue on, in the meantime. Eventually, the nurse comes back with information about what happened to Luke. He had a PCA—a posterior cerebral artery stroke. The artery was blocked, which decreased the flow of oxygen to his brain. They believe it was due to the endocarditis. Endocarditis can create "vegetations" that can break off and cause blocks.

The nurse says this type of stroke causes "memory issues, a little bit of cognitive deficit, balance issues, things like that."

Luke: Short-term or long-term memory issues?

Nurse: Not sure about that one. That would be more of a doctor question.

As this exchange illustrates, patients and family members can have a lot of lingering questions as they approached discharge. They were anxious and unsure about discharge logistics, concerned about mastering the skills they would need at home, and often still unclear about the specifics of what had happened. In some cases, staff had only limited time to cover quite a lot of ground.

As the nurses pointed out, it took longer than the allotted time to, for instance, teach someone to manage diabetes. And at home, the equipment they would use wouldn't be the same as the glucometers they used in the hospital. They encouraged families to buy the recommended equipment and bring it in for training, but it often didn't happen. On top of this logistical education, nurses also had to spend these sessions persuading patients and families of the value of what they were teaching. Some patients were set in their ways; they had never done X, Y, or Z before, so why should they do it now? Nurses had to tactfully explain how these previous health behaviors might have contributed to the patient's stroke and/or might be detrimental to stroke or TBI recovery going forward.

Nursing education often seemed like an under-appreciated afterthought. Interpreters weren't scheduled for nursing education, although they were for other disciplines. So if there was a language barrier, nurses tried to use the translation carts or they tried to pop into sessions where an interpreter was available so they could accurately deliver the absolutely essential information. Of course, some hospitals don’t have in-person interpreters on staff, to begin with.

Many nurses felt they weren't given enough time. As one nurse put it, "we get all the leftover time." Nursing education was sometimes assigned just half an hour, often at the end of the day when patients and families were already burnt out from a full day of education. Nurses had to try to give patients the bottom-line summary, as this nurse explained:

> So if nothing else, I try to tell them about the medications. I tell them how it's going to work at discharge. Like, you're going to take these. They're going to be at your pharmacy. We only give you thirty days' worth. After you leave here, you're going to go see your regular doctor, and whatever they prescribe will supersede this. So if you see your doctor the day after you leave here, you're gonna start taking what they give you. If you don't, if you see them twenty-eight days after you leave here, take what we give you until then, and then you take what they give you. It may be the same, it may be a little different. I try to encourage them. I'm glad that they get set up with their follow-up appointments. (staff, inpatient)

Staff have to bear in mind that not all patients and families are familiar with the basics of the discharge process, let alone what comes after.

Nurses and therapists alike also stressed the importance of longitudinal, hands-on education. Ideally, families would have many opportunities to practice skills and become comfortable with caregiving tasks, during the inpatient stay. If family members visited frequently, nursing staff often tried to engage them outside of scheduled education sessions by demonstrating as they worked and encouraging family to get involved in care. The hope was that by the time they left, they would have had a chance to make mistakes while under supervision and would feel confident and capable doing it on their own. As a nurse described:

> And we can be like, Hey, would you help me turn your family member? When we change them, would you do this? Like, do you want to try crushing up the meds? You can see how it feels in the crusher and see when they're small enough for them to take. Do you want to like—here, we're doing the flush. Why don't you do it? (staff, inpatient)

Family members were often intimidated by these tasks, and it helped if they were able to slowly build their skills over time as opposed to having everything thrown at them in one or two short sessions. Often, questions didn't occur to people until they were in the trenches, doing it themselves. Inpatient and day rehab nurses were an important source of caregiving tips and workarounds that could make patients and families lives significantly easier.

Unfortunately, COVID had a negative effect on this training infrastructure. I plan to touch upon this subject in greater detail in future work. Of course, having to conduct training remotely complicated matters considerably. But at the time of my research, family was allowed to come in, two at a time, for in-person training, and COVID was still having a significant impact. For one thing, some patients had multiple family members who would be participating in their care, and training them two at a time was inefficient and could introduce inconsistencies. And family members still weren’t allowed in common areas. Before COVID, visiting family could regularly accompany patients to therapy, observe what they were learning, ask questions throughout the session, and even practice assisting. COVID limited these opportunities for more casual, consistent, immersive training. Of course, even prior to COVID, not all patients had family around. Some people were on their own, for one reason or another, or had involved family members who couldn't get time off work to spend days in the hospital.

Overall, inpatient discharge and the transition home was an incredibly complicated, often stressful process for patients, families, and staff alike. People did their best with the options open to them, but staff were frequently frustrated, and often patients and families were left feeling anxious, confused, and alone. The inpatient facility and day rehabs had a lot of mechanisms in place to ease the transition and prepare patients and families as much as possible, but staff were very cognizant that they were frantically trying to plug holes in a troubled system. Issues like insurance complexity, an inadequate social safety net, and inequities across communities were impossible for patients, families, and staff to fix on their own.

Luke and Sarah's Family Education

Image 7: An OT practice area
Source: Photo by Author

Sarah was scheduled to come in for family education in preparation for Luke's discharge, but she was running a bit late. The occupational therapist (OT) said they'd go ahead and start without her. He asked the nurse to call him if Sarah arrived.

The nurse and the OT got Luke ready, putting on his brace and shoes. Luke had hemineglect, so he occasionally forgot about his left arm. *Watch your arm*, the nurse reminded him. It happened a couple more times in the next few minutes. When Luke's arm dropped off the armrest and dangled, the nurse and the OT prompted him. "Where's that arm?"

The OT told Luke to remember to look for his arm. He instructed Luke to scan back and forth, like a lighthouse.

I'm cooperating, right? Luke asked, in a tone that suggested he wasn't sure.

Yes. Now let's stay like that, the OT said.

The OT wheeled Luke to a therapy room off the main gym and then dashed off to get his laptop so he could record Luke's performance on the assessments. While he was gone, I asked Luke what he'd been up to in therapy, but he didn't have an answer.

The OT returned and explained the plan. *We're going to do two exercises. One we just did recently, and one we haven't done for a bit. Remember this one?*

Luke was having trouble concentrating. He worried Sarah wouldn't make it. He worried she would arrive, but we wouldn't know because we weren't in Luke's room. The OT repeatedly reassured him the nurse will call.

Luke asked if the assessment would determine whether Luke was doing well or not. The OT said, *It's not good or bad. It's just where you're at. And you already know how your arm has been—you see your arm in action all the time. This is just to put a number to how you're doing. It's just a way to name function and dysfunction.*

Luke was supposed to pick up a block using his affected hand and put it on top of a tool kit. Luke forgot and started reaching with his right hand. *This hand just rests*, the OT reminded him.

Again, Luke's right hand started drifting toward the block. *I'm going to hold this hand to make sure you're only using that one*, the OT said. Luke couldn't accurately place his left hand on the block and grip it. The block slid and flipped over, but he couldn't lift it. *Aaaand let's take a break on that one*, the OT said.

The OT introduced another exercise, and Luke made his attempt. *Is this more mental or physical?* Luke asked.

It's both. The more you think about doing it, that's how your brain heals, the OT said. *There's some brain damage. You had a stroke. It's like the signals to your left arm are like a route in your brain, and there's a roadblock up. Some information is still getting through—you're moving it. But the way you find a new way around the roadblock is practice. So you think about it, and you practice doing it.*

For the next task, Luke was supposed to pour water from one glass to another. The OT started to say he would stand nearby to make sure it didn't spill, just as Luke knocked the glass over. *Okay, we'll come back to that one*, the OT said.

I was right on it! Luke said.

Well, you were definitely right on it. That was for sure, the OT agreed, wryly.

For the next task, Luke was supposed to pick up a metal tube from a vertical dowl rod and place the tube on another dowl rod. *I'll hold this steady. Keep trying. Left hand only*, the OT instructed. Luke knocked the dowl over. The OT picked it back up. *Twenty more seconds. I'll just put this back in the starting position*, the OT said. Luke tipped it into his lap.

Aaand relax. Good attempt though. This stuff is hard. If it was easy, you wouldn't be here, the OT said.

Luke was anxious about Sarah. *She's not coming*, he fretted.

I do wish she would be here right now. But it's okay. We can always make up the time. Schedule more trainings. She's a wonderful woman, the OT said.

Almost immediately, the nurse let us know Sarah had arrived. *We'll go snatch up Sarah. But first let's finish in here*, the OT said. *There won't be much time left to work with Sarah. That could be the motto for neurorehab—not enough time*, he said.

Luke was instructed to pick up a small object from a shallow, round tray, using only his left ring finger and thumb. *Nope! Just your left hand*, the OT reminded him, when he reached with his right.

The OT reported how many seconds remained to complete the task. *I'm trying, man*, Luke said.

I know you are. I'm just trying to keep you updated on time, the OT reassured him.

We headed back to the room to pick up Sarah. Luke asked the OT to push his wheelchair back to the room rather than making Luke propel himself with his feet. *I'll give you a free push because when we're working with Sarah, you'll be doing a lot of walking*, the OT agreed.

The best thing for you and Sarah to try together, if you're going home, is walking together. It's the most dangerous thing for you, as a couple. We have concerns about you falling, the OT said. Luke didn't respond. He seemed listless. *Was the session tiring*, the OT asked?

Sarah was back at Luke's room. *I told you Sarah was coming!* the nurse said.

I figured you'd be here, Luke said, his nonchalance belying his previous concern.

The OT took us to a room with a bed, dresser, and a full practice bathroom with a tub/shower, sink, and toilet.

Luke was distracted. *Let's concentrate on what we have to do here today. Let's just focus. This is complex. We're going to practice getting you into the shower. It just takes time to get good at it. You'll do okay*, the OT said.

The first challenge was to get Luke up from his chair, walk to the bathroom, and then transfer onto the bench in the tub. "Ambulate right on in," the OT instructed. The OT remembered Sarah told him their bathroom at home couldn't accommodate a wheelchair, so they had to practice standing Luke up outside the bathroom and walking in together.

Is he not a candidate for a walker? Sarah asked.

Not currently. With that arm, it's a grip issue. And his awareness would be a problem. Canes can be useful, the OT said. *And you're not bad with a cane, if someone is watching*, he told Luke.

I'm here for support, but you do it on your own, the OT said. Sarah moved to start getting Luke up. *Be careful, Sarah!* Luke said, sounding very concerned.

You'll need a tub transfer bench. You should order that ASAP, if you haven't already. You can get it on Amazon, the OT said.

And shower shoes, Luke interjected.

There you go! You're remembering too.

The OT walked them through the procedure they were about to attempt. *Before you stand, check the lock, armrests, leg rests, and make sure the seatbelt is off and the gait belt is on. And before he stands up and walks, make sure what he's going to walk with is there. You need to be in charge of all those steps, Sarah. But that's why we're practicing*, the OT explained.

Luke was distracted again. *I want you to just listen more*, Sarah told him. *I have to learn this from him*.

The OT was instructing Sarah, and Luke chimed in, confused. *You lost me on this one*, he said.

Babe. Give me a minute, Sarah said.

The OT prompted Luke to remember his arm. *I'm trying to feel it*, *Sarah*, Luke said. *I'm trying to tell my brain "hold that arm."*

The OT stopped Sarah. *Before we do that, one last thing*, he reminded her.

The belt? she asked. Luke was distracting her again. *You have to be quiet*, she told him.

Sarah tried to get the gait belt on Luke. *Don't crush me with the belt, okay?* he said.

The stress was building. *Take a deep breath,* the OT said. *I feel like we're rushing.*

As Sarah helped Luke out of the chair, the OT coached them. *You can also tug on the shirt, the pants, to get him up. See how loose that belt is? Put it a little lower. Feel how tight it is. Nice and snug. You want that underhand grip, and then he leans forward.*

They're on the move to the bathroom. *Go slowly*, the OT instructed. *If he makes a big move though, you can't reverse time. You just have to get him down safely.*

Sarah and Luke made it over to the tub, positioned to make the transfer to the shower bench. *Ten seconds to rest. And then do it*, the OT said.

He talked them through sitting Luke down and swinging his legs over the edge of the tub.

This shit hurts, Luke said.

Listen to Sarah. She's in charge, the OT told him.

Slide over a little bit, Sarah said.

This shit ain't no fun, Luke said.

Now stand up! the OT instructed.

Do I have to? Luke asked.

The OT explained the order of operations: leave his clothes, shoes, brace (the AFO or ankle foot orthosis), and gait belt on, until Luke was safely seated on the bench.

The OT quizzed Sarah: *What does he have to have on to enter/exit the shower?*

AFU?

AFO. The name doesn't matter, as long as you know what it is.

They successfully got Luke onto the shower chair and then back out of the shower, so all that remained was to get him safely back in his wheelchair. Sarah coached Luke and the OT coached Sarah.

Slow, direct cues. You want him turning which *way? You should be specific*, the OT told Sarah.

That was a thousand times better! That turn was great. Always turn toward the left. So the left doesn't have to move as much, the OT instructed.

Where's your arm? the OT prompted Luke again.

You think about that arm more than me! Luke replied.

I do. And that's why we're trying to work on it. What do you do?

You probably told me, but I forget.

Luke asked when he would be allowed to drive again. The OT said, *Driving isn't on the table, for the moment. Now we're talking about walking.*

The OT told Sarah, *Loss of balance is consistently an issue. You'll need to be there all the time. If he stands, at any point, you need to be there*.

Finn's Rocky Day Rehab Transition

Dr. Rose wasn't sure what Finn would be like today. Last time he came to day rehab, he had a panic attack at the door. He also refused to put on the mask required under the day rehab's COVID policy. He said the staff members who tried to intervene were trying to suffocate him. After that day, he nearly refused to come back and continue with rehab. Dr. Rose, the psychologist, was called to intercede.

As Finn later explained, he started having a panic attack in the car on the way to the facility. Being enclosed in the car, surrounded by traffic triggered unbearable claustrophobia. His sister told me it was fortunate their other sister was in the car with them too. She was afraid Finn would jump out onto the road. When they pulled up outside the day rehab, Finn recalled, he "literally tumbled out of the car and crawled on the pavement." He huddled there, unable to move, unsure what was happening. The mask exacerbated his sense that he was smothering, and he couldn't bear to keep one on.

Staff got him a wheelchair, and Dr. Rose intervened. Finn and his sister were effusively grateful to her, crediting her for calming Finn, advocating on his behalf, and later, convincing him to give day rehab a second try. As they later found out, the whole episode was due to a pharmaceutical error. For whatever reason, when Finn's prescriptions were refilled post-discharge, the pharmacy didn't refill the risperidone. Risperidone is an antipsychotic medication prescribed in this case to alleviate post-traumatic agitation following Finn's TBI. Patients are supposed to carefully taper off the drug, under medical supervision, but Finn accidentally went cold turkey, causing the symptoms that turned Finn's introduction to day rehab into a nightmare.

By the time a doctor figured out what had happened, Finn was already off the medication, so when given the option to begin taking it again, Finn opted against it. He hardly remembered the period of time during which it had been prescribed, and he had an uneasy relationship with that version of himself. As Finn described:

> When I was at [inpatient rehab] and I was disavowing that I was really in an accident, they were like, “This guy's dangerous.” That's what they had to be thinking. So they put me on a drug for their own sake, and for probably sound therapeutic reasons. I'm not quibbling with that at all. (TBI, White, male, outpatient)

Finn had hazy memories of his agitated phase. He had an image of being pushed backward into bed, as staff closed the bed enclosure around him. Finn understood now that he had been “unreasonable,” as he put it, during that time, yelling that he was being unlawfully detained and refusing to believe the accident occurred. As he saw it, he was put on the risperidone because staff were scared of him and found his behavior threatening.

When given the opportunity to re-start the risperidone prescription, he asked the doctor and his sister if they felt there was anything wrong with his behavior that warranted medicating him, and when they assured him that his behavior was fine, he declined the drug. But he subsequently checked in with the sister he was living with, asking “Is my behavior okay for you?” Finn was aware he had, for a time, been an unreliable judge of his own behavior, so he made sure to seek external verification.

When he arrived in Dr. Rose’s office his first day back, she told him he was like a “new man.” Finn, a gregarious, middle-aged white man, looked healthy and clean-cut, but the day of the panic attack, he hadn’t been sleeping or eating well, and he hadn’t had a haircut since his accident, so he cut a far different figure.

He was also adjusting to wearing a mask. Finn explained, *It doesn’t matter whether I judge it to be valid or invalid, scientific or unscientific. This is a blue state. They’re always going to maintain this.* Finn might have been a mask skeptic in the best of times, but he was willing now to tolerate the mask, for the sake of expediency. Having talked to Dr. Rose and attended the pain management group, he had begun to understand his mask aversion as related to his panic response. In a session with Dr. Rose, Finn said, *Cognitive distortions can be a product of the brain or an input that the brain distorts. I wish I could flip a switch and have this go away.* But on Dr. Rose's advice, he was both recognizing the panic-induced mask aversion as a cognitive distortion, and through exposure and cognitive re-framing strategies, working to reduce the feeling of claustrophobia.

It's important that you're able to recognize now, in retrospect, that while your feelings were understandable, they weren't reasonable, Dr. Rose told him. *You're like Jekyll and Hyde! It's completely opposite from your first day here. You know, in my first interaction with you, you said, "this isn't me—I'm a nice guy."*

Well, that's the irritability and agitation from the brain being messed up! Finn said.

I'm glad this is the real Finn, Dr. Rose replied.

As they both framed it, agitated Finn in the hospital and panicking Finn at day rehab were not the "real Finn" but were the result of trouble with his brain, caused by the TBI or by unintentional medication detox. But as Finn explained, he still wasn't quite the person he had been before the accident, in more ways than one.

Well, this is a seismic shift in my life, you need to understand, Finn told Dr. Rose. *Being bombarded with feelings that were never on the table before. Like low-level claustrophobia. And I'm sensing that stuff's different. How I'm processing information, how I'm able to retain it, feelings of uneasiness. I'm not going to call it panic, but—things I'm not comfortable with.*

In many ways, Finn's cognitive and emotional landscape felt unfamiliar. He was also aware that his brain could play tricks on him, and he concentrated on weeding out true and false thoughts and perceptions. In another sense, Finn felt "reborn" or "rebooted" since the accident. He spoke at length about how the accident altered his priorities and made him want to live a life that centered family, charity, and fulfillment. He not only felt unlike his old Self, he wanted to actively become a new man.

The Importance of the Correct Diaper Cream

Image 8: Diaper cream alternatives
Source: Photo by Author

When I arrived at the nursing desk at South day rehab, the nurse was already on the phone. Willa, a White woman in her forties, was making another attempt at fixing the intractable patient transportation issue:

I'm calling because our patient spent two hours on a Pace bus this morning and was late for therapy. It's not so much that he was late for therapy. It's that he was picked up at 7:45, and he's just arriving now. And this is not the first time this has happened to him. Can you give me that number? Okay. That's the toll free? So is there any end in sight to these delays? Because I just *pulled it up, and it's a twelve-minute ride that took two hours. And I get it. I get that you guys are understaffed. But it's not even a fifteen-minute ride, and he was on the bus for two hours. Perfect! Thanks for all the info.*

Willa explained what she learned from the call. Pace used several subcontractors, but the complaint number went directly to Pace. If a patient called to report that a ride was late or never arrived, the feedback never got back to the contractor responsible.

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Willa needed to find an opportune time to pull a new patient for an intake evaluation. Mitchell was a middle-aged Black man. She had reviewed his chart, and it raised some questions. A physician started him on Plavix and aspirin to reduce risk of clotting, post-stroke, but he stopped taking it. Why?

Mitchell had been put on a medication to increase his blood pressure. According to the chart, he reported that he didn't take it. Then he was put on a different medication to *decrease* blood pressure. He said he was taking that medication, but he was still reporting blood pressure readings with systolic in the 170s.

In the hospital, he was on a medication to decrease his overall blood pressure, but then he was on meds to raise his blood pressure because of hypotension with position changes. His chart said they ran tests but didn't find an explanation. Willa planned to ask him what was going on, but she said he probably wouldn't know.

I want him to tell me his story. Like WHAT is going on? she said.

Willa found Mitchell while he was waiting for his OT session to start.

How are you? she asked.

She inquired about the seemingly contradictory blood pressure medications. *They had you up, then down, then up, then down*, she said.

I wasn't taking my blood pressure meds, he said.

How can I put this? There's a reason you weren't taking them. So why? Were they making you feel sick or were you not able to get them?

They did something to my manhood, he said.

Did you follow up with your doctor about that? No judgment. That's an important concern. If you told a male doctor about that, he'd say, "Man, we have to get that changed!"

A doctor said there are these meds for blood pressure that don't cause that problem, he said.

There are! Do you have a primary care doctor? she asked.

Fortunately, he did. And he had an appointment scheduled, the next day.

The thing is, you're not going to keep taking your blood pressure meds if they cause this problem. That's very important, and we don't always consider that enough, Willa said.

Mitchell promised to talk to his doctor at his appointment tomorrow.

Okay! We're on the same page. Will you let me know what he says? Because that helps me be a better nurse.

Mitchell assured her he would.

So this is a new primary care doctor? Were you going to a walk-in clinic before?

He was.

So that's important, having a primary care doctor. I'm glad you have someone you can consistently raise concerns with, Willa said.

Willa ran through her battery of questions, starting with height and weight.

And how much do you want *to weigh?*

Mitchell said he wants to lose about thirty pounds.

Great. We can make that a goal and make a plan for that, Willa said. *Are you taking your Plavix and aspirin?*

I think they took me off the Plavix. But I still take the aspirin.

Stay on the aspirin. That's not going to cause any problems with function. And you're on Keppra? But you haven't had a seizure? Talk to your primary care doctor. I want you to advocate so you're not on this for six months when you don't have to be. This is one they slowly taper you off, so you can ask, "Do I still have to be on this or can you start weaning me off?"

What one is that? he asked.

That's the seizure med.

What's it called again?

Willa gave him both the trade name and the generic and offered to leave him with her printed copy of his medication list with her notes.

Willa progressed through her questions. Pain? Sleep? When you wake up, do you feel rested? Appetite? Any numbness and tingling? Who's helping you at home now? Do you have someone to help you, if you needed it? How's your bowels? Are you able to get to the bathroom? No accidents

Mitchell said he'd had a few incidents, since the stroke.

Because of the stroke, instead of your bladder sending your brain the signal, your brain is going to have to send your bladder the signal. So you have to plan to go to the bathroom regularly. Not just when you feel like you need to go, Willa explained.

Did they run your bloodwork? she asked. *Did they check to see if you're pre-diabetic?*

I just found out, Mitchell says. *I'm diabetic.*

But they don't have you on metformin or insulin. Willa suggested he follow up with his doctor. She wrote out notes for him, so he would remember exactly what to ask.

So, you want to ask them to test your A1C—5.7 is the best. That's where I want all my patients to be. But it's okay if that's not where you are. I just want you to know the range. Even if you are pre-diabetic, you can reverse it at this stage. There's honestly stuff you can do to turn it around at this point, she said.

She reeled off a list of diabetes complications he could, hopefully, avoid.

Any vision changes? And you didn't leave the hospital with any fractures or sores?

Willa reviewed the notes she was leaving him.

So this is going to be yours. These are the questions I want you to ask. I also want you to ask for parameters for your hydralazine. When you ask, they'll say "I want you to take it if your BP is above this number, but not if it gets below this number."

She gave him a brief systolic/diastolic tutorial and apologized for having to throw out so much information so quickly.

I don't want to be that low again, Mitchell said.

I know! Having your blood pressure that low will make you feel awful, she commiserated.

As the OT arrived to collect Mitchell for his session, Willa encouraged Mitchell to come find her or one of the other nurses if he ever needed anything. He assured her he'd check back in with updates, after his appointment tomorrow.

On our way back to the nursing desk, I said it seemed like a successful intake. Willa managed to gather a lot of information, in the fragment of time between therapies. *But how much of that did he retain? I got a lot of information, but it's not about me*, she said.

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A PT came to find Willa. It wasn't an emergency, but a patient with chronic blood pressure issues wanted to check in about his blood pressure management plan. Willa promised to come find him, momentarily. She had just returned from speaking to the mother of one of the pediatric patients, a ten-year-old who was in a motor vehicle accident, and she was compiling some resources the mother asked for. The child had day/night confusion and wasn't sleeping at night, so the mother talked to her pediatrician. The pediatrician prescribed amitriptyline and mirtazapine without even discussing sleep hygiene or non-pharmaceutical options.

When she checked, Willa found amitriptyline was not approved for patients under twelve, and mirtazapine wasn't approved for patients under eighteen. Willa explained that the physician should have told the mother, "This isn't approved but what I've seen in my patient population is…." The drugs shouldn't have been prescribed without discussion.

Willa presented the mother with a Mayo Clinic report on sleep. She suggested the mother ask the pediatrician about over-the-counter options, like valerian and melatonin, and she provided recommendations on meditation apps and an app to limit screentime, citing research on the effects of screentime on post-concussion patients.

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A PT called Willa into a session to help a patient and her mother troubleshoot some care issues. The patient, a White woman in her forties, had a stroke that severely affected her mobility and communication. She was nearly nonverbal, and her mother was her primary caregiver.

So we're worried about this foot? Willa asked.

The mother was concerned about skin irritation under her daughter's brace. She explained when she first noticed it, and what it looked like before.

I tested her extension today, the PT said. *She's having a hard time getting to ninety degrees, and this brace is fixed at ninety, so that might be pushing her foot up against the brace.*

So I think getting a bigger shoe is a good idea, Willa said. *Go to Goodwill so you don't have to spend a lot of money buying just one shoe.*

And if you can bring in the name of the person who made this brace, I can get it adjusted for her, the PT explained.

When it was all red, was there pain? Willa asked the patient.

The patient looked at her mother and nodded. The mother elaborated that the daughter woke up from her nap and indicated she was in pain by saying "hurt" and gesturing toward her feet. They usually took her brace off when she wouldn't be walking, but they had just flushed her g-tube, so it seemed likely she would need to get up and use the toilet soon.

As a rule of judgment, in nursing, we typically advise to leave the brace off when you're not moving around. You could maybe leave it on if you're just sitting and resting for a short time but then getting right up. But typically, you want to take it off if you're resting to decrease risk of pressure sores, Willa explained.

We don't usually keep the brace on when she's resting, but she wanted to sleep for about fifteen minutes, and then we were planning to get up and walk. It was a mistake. I should have just taken it off!

A really good mistake to make! Because now you know, Willa said.

Willa asked if they had any other concerns, and the mother explained she was having difficulty with her daughter's incontinence care. She seemed very scrupulous, concerned about getting everything right. Another family member bought CVS brand pads and diapers instead of

Poise pads and Depends, as the hospital recommended. "I'm not sure if they're okay, if they're as good," she said.

More troubling, her daughter's skin was irritated. When the daughter had bowel movements, the diaper-lining pads pushed the feces back into her vagina. The mother bought baby wipes with aloe and applied Aquaphor, but the cleaning made the area raw. *She's been so sore and uncomfortable*, the mother said.

Willa clarified with the patient did it itch or burn? The patient described her sensations by pointing to choices Willa wrote out.

Baby wipes with aloe are not horrible, but the pad might be causing problems, Willa said. *The skin can't breathe. It locks in moisture.*

The mother pulled up a photo on her phone of an "extra protective cream" someone at work recommended. As Willa later showed me; there were two products that came in similar packaging—a "protective ointment" and an "extra protective cream." To a novice caregiver, the "extra protective" might seem the obvious choice, but in fact, it was thick and difficult to rub off. Without access to expert tips, a caregiver could easily choose a remedy that actually exacerbated the problem by forcing the caregiver to scrub harder at the affected area.

No. Don't use that. You can use Aquaphor or Vaseline, but most of all you want to leave it open to air as much as you can. When she's in bed at night, for instance, Willa explained. *I put blankets on her last night because she was cold, but otherwise I leave it open to the air. I just put pads on the bed*, the mother said.

Is it getting any better? Or worse? Willa asked the patient. The patient nodded at "better," but Willa took care to confirm the response because the patient was prone to yes/no confusion. The mother helped ensure the choices were clearly laid out.

Make sure you try to leave it open to air after your shower. That's most important, to keep from getting sore, Willa said.

She's not getting a shower. She's been getting a sponge bath. The only shower is upstairs. I'm not sure where to take her. I was hoping they'd have one here. We don't have any family nearby with a downstairs shower. I'd hate to take her to a truck stop, the mother explained.
With sponge baths, you can line the bed really well and make sure you get a good wash and rinse. Desperate times call for desperate measures. Even if you have to put a blow dryer down there. It's not going to be forever. It's just for this small slice of time, Willa said.

Do you know when you have to pee? Willa asked the patient.

The patient and mother confirmed that she generally didn't.

Are you able to stop your stream? Able to start it or it just leaks out?

The patient had no control of either.

That's why we left the brace on. I had just flushed her g-tube, and we knew she would need to pee in a while, so I didn't want to take off the brace in case we had to take her right to the bathroom. I knew she would have to go. I should have just taken her right then, the mother said.

This is a dance! You're all learning, Willa encouraged.

Willa explained to the patient that she should try to work on her mind-body connection:
One thing I would like you to try is to work on opening that sphincter when you want to. I want you to concentrate on opening up that sphincter. It has to happen up in your head. You have to trick the system. And when you're already going, try to grab ahold and stop the flow. That will help wake it up, get it activated again. You need to make the decision. It used to be that your

bladder would send the message to your brain, but because of the stoke, now your brain will have to send the message to your bladder. You have to think about peeing.

Since the mother recognized that her daughter generally had to pee a certain amount of time after a g-tube flush, Willa suggested they could plan ahead. *Because you seem like you're way in tune with her*, she told the mother.

You can work on that too, the PT told the patient. *If you find there's a certain time you've been needing to go, like at 9 am, we can put you on the toilet here.*

You've already made so much progress! Willa said.

Yeah! Look how far you've come, the mother agreed.

Willa told them to stay in touch and that she (or any of the other nurses) would be thrilled to help.

OMG, I'm so excited to see you progress through here! Willa said.

Three Day Rehab Discharges

Esther

Esther was almost finished with her final day at day rehab. All that remained was a discharge evaluation with her "primary," an SLP named Molly. For each patient, one therapist (an OT, PT, or SLP) was the assigned point person on the case, the liaison between the staff and the patient and family. Esther's discharge was straightforward, even a best-case scenario. Esther, a Black woman in her forties, dressed in coordinated athleisure, took a seat in front of Molly's desk.

Bittersweet! Molly said.

I know, Esther agreed.

Any question for speech? Any thoughts?

No questions. Just—I don't know. Nervous.

About what?

This new life. Nothing more, nothing less. I don't really know what to expect.

It is new from a few months ago, but you're still Esther. You can accomplish anything! As you've already shown. But it is *scary. I know this feels like a safe place, so it's hard to leave.*

Exactly, Esther agreed.

Well, I want you to remember: A) we're always here; And B) I wouldn't discharge you if I didn't think you were ready; and C) you're ready to conquer without us! But it's important you keep up this routine. Have you thought any further about volunteering? How to stay active, stimulated?

Esther was planning to return to work, but not for a few more months. In speech therapy, they had been working on skills relevant to Esther's job. I observed a session in which Esther performed complicated data entry while Molly interrupted her at random intervals with other tasks, to work on attention to detail, concentration, and divided attention. For now, though, Molly wanted to make sure Esther stayed active and engaged after leaving the structure and consistency of day rehab.

My husband is going to get me a membership to the gym near us. And my PT gave me exercises to do at home. I thought about volunteering at the library, Esther said.

That sounds good! Or maybe an animal shelter? There are things around. But it will give you confidence, which is important. And when you're thinking about return to work, I think it could be helpful to initiate more outpatient speech therapy. Just to reinforce some of these higher-level cognitive skills and maybe get really specific on tasks related to your job. Any questions with that?

Esther didn't have any questions, so Molly pivoted to summing up their work in speech. *In terms of speech, how do you think you're doing?*

I think my attention skill has gotten a lot better. Still, I think other things could improve, Esther said.

Like what?

Like detail, paying attention to detail. What we did yesterday.

You know exactly what you're doing. But there are these little things where it takes your brain longer to do what you need to do, Molly agreed.

Molly reviewed all the skills they worked on and the progress Esther made.

At first, we were working on getting used to the day rehab schedule. But as you progressed, your overall demeanor was more confident. It was nice to see you able to teach other people and generalize what you learned. Like you said, alternating attention, divided attention, and memory have progressed nicely as well. When you started, I was asking you to recall a piece of information after ten or fifteen minutes. Now, you're able to remember after a two- to four-hour delay on something like a to-do list. And you get those little details, like six vs. seven pounds of chicken. After four hours, you may need cues, but again, it's just those details. And that working memory has progressed! When you're home, as tasks get more complex, you may need a little cueing. When you go back to work or if you're working on your finances—for some of these high-risk tasks—I would just recommend supervision, for now. Questions? Thoughts?

Therapists in each discipline had prepared a short summary of their recommendations, and Molly read them off. *Follow up with your physician in four to six weeks. Continue your home exercise program. Utilize your strategies. Continue orthotics. Avoid heights, ladders. No driving* *until you have the driving eval. Follow up with vocational rehab to touch base when you're thinking about returning to work.*

Esther asked for some speech worksheets to take home, and Molly gives her a packet of logic puzzles and "perplexors." Molly said, *The best thing you can do is just stay active, continue to exercise your mind. You could do crossword puzzles, sudoku.*

She presented Esther with a day rehab graduation certificate and a handout about the facility's brain health support group. Esther filled out a survey and gave Molly glowing feedback. *You should feel proud*, Molly said. *Accomplished! You've done it all. This is not the end. And you have our contact information!*

Pete

Pete, a White man in his fifties, came to rehab following a workplace accident that caused a TBI and a limb amputation. Molly had attempted to discharge Pete from speech therapy five times already. Each time, he told her he wanted to continue. Molly didn't think Pete needed further speech therapy. Being discharged from speech didn't mean being discharged from day rehab. As long as a patient still needed the two other therapy disciplines, they could continue the program, so it wasn't as though discharging from speech meant Pete would be done with rehab.

But Molly didn't need to discharge Pete. He was very "groupable," so she could schedule him in groups and not take time away from other patients. And he was still making progress, so she could meet the insurance justification requirements. As far as Molly was concerned, however, he seemed very "functional," able to perform any cognition-related tasks he needed to, in his daily routine. He didn't excel at tasks like logic puzzles, but Molly thought he might have had a premorbid learning disability. Were these cognition exercises the sort of thing he would have been good at before? He hadn't even been in speech therapy as an inpatient. He only started speech at day rehab after the OTs and PTs suggested he could benefit from speech based on what they were seeing in their sessions.

Pete told one of the other SLPs he didn't like speech, so Molly wasn't sure why he was reluctant to discontinue speech. In her conversations about the issue, she tried to make it clear she wouldn't be personally hurt or offended if he chose to terminate. Today, Molly attempted to broach the subject once again.

Again, just your two-week follow-up, she said. *Just checking in, to see whether you want to keep going with speech.*

Yeah. We can do another couple weeks, Pete said.

Do you think you need it? Do you feel like you still have more you want to work on?

"I just think my comprehension's not there," Pete said.

What specific tasks in your life do you notice comprehension problems with?

Well, sometimes I understand, sometimes I don't. Not sure if that's from my brain injury or not.

Do you still feel like you're getting benefit from speech? Molly asked.

"Well, it makes you think," he said.

I'm happy to keep working with you, if you feel you're still making progress. As long as you still think there's improvement to make.

I want to go a few more weeks before they send me over to long-term outpatient. I think I'm making progress. But I'm not sure I'm ready to go up and down the stairs like they want me to do in outpatient.

Well, that's more of a PT goal. You could keep going in OT and PT, even if you stopped speech. We could reduce speech, or continue the same schedule, or we could discharge you from speech and you could have the extra hour for OT and PT.

Let's do it for another two weeks, Pete said.

As long as you still think you're getting something out of it.

And if I'm not, I'll let you know, he suggested.

You'll let me know, she echoed.

It's all about money anyway. I'm not sure how it works with workman's comp. But we'll see how much longer they let me keep coming.

Well, it's not about money for me, Molly clarified. *I'm looking at it clinically, from a clinical perspective. It's not an insurance coverage issue.*

I'm not saying for speech it's about money. Just on the whole. How long they'll let me stay here, he clarified.

I look at progress. How much you've made and whether you're still progressing. If you think, "I'm at where I was before," then I've done my job, and we can stop working together. I think you're doing great! And I think you've carried over a lot of your strategies to your life. And if you feel like you can keep going on your own, working with those strategies you've learned, you don't need me anymore.

Pete didn't take the bait. He expressed no desire to end speech therapy.

So. A couple more weeks? We'll reassess then, Molly said.

Yeah. Couple more weeks, Pete agreed.

Valerie

An OT, a PT, and Dr. Rose held a family meeting with Valerie, a White woman in her fifties who was discharging soon. The OT and PT were concerned about how Valerie would manage after leaving day rehab.

Are you eating your lunch, dear? I'm sorry I'm taking your lunch hour over, Valerie apologized to the therapists.

Did you talk to your church? Valerie asked Dr. Rose.

Remind me what about?

About assistance, Valerie said.

Valerie and her husband, Kevin, had been struggling financially, since her stroke.

Kevin arrived, and the therapists outlined the purpose of the meeting. Valerie had been at day rehab for about six months, so they wanted to check in and give Valerie and Kevin a chance to ask questions before discharge. They summarized Valerie's gains.

You're walking relatively independently now, in a controlled environment, the PT reported. *But the risk for fall at home is still not zero. We've also worked on practicing without the cane for short distances, for efficiency purposes. But you should use the cane when you're out.*

When you first got here, we used to work on basics, like toilet transfers, the OT said. *But now you've improved by leaps and bounds. You have your own strategies, and that's exactly what we're looking for. You're consistent about carrying those strategies over from therapy. Your arm recovery was slow to start, but it's getting there. Even if your arm is not the way we want it, you still have to find ways to use that arm and participate in life. If you stop those things, you won't feel good. You won't be doing things you enjoy. You won't be motivated. You should pretend like the stroke almost didn't happen. As if it didn't change things.*

Valerie said she would have help with exercises. She arranged for a friend to work as her caregiver.

The therapists transitioned to a more delicate topic: what Valerie could expect for further recovery.

It's tricky because the further you get away from the date the stroke happened, the harder it is to make a change, the OT said.

They explained that as the window of optimal neurological recovery closed, the likelihood of complete recovery declined. As the therapists framed it, however, even as recovery plateaued, Valerie could still make functional improvements by adapting and applying new strategies.

Sometimes it's how we feel about the arm that stops us, Dr. Rose said.

Valerie looked downcast, so Kevin injected a note of optimism.

But there's still opportunities for improvement, right? he said.

There is. But it's going to be harder. But that's why we're referring you to outpatient OT, the OT explained.

I just don't want to believe that progress can't still be made, Keven said.

It definitely can, the OT agreed.

Just more effort and more time, Kevin said.

Valerie was in tears.

This is the typical recovery trajectory, the PT said.

It probably didn't help that she was in the state she was in for four months, Kevin suggested.

As Valerie later explained in an interview, she'd had the stroke about a year before, but she spent several months in the ICU and a skilled nursing facility before she finally made it to inpatient rehab and then day rehab:

> So all this time, I was like out of it. I couldn't really communicate very well. My family would call me on, like, the video chat, and I would keep hanging up on them. And I don't remember this. This is everything people told me. So then, when I was in the nursing facility, my surgeon put a shunt in because I had all this fluid on my brain. So I went back to [the acute hospital], had the surgery, came back to the facility. And I, like, immediately woke up. I was myself … I had my brain back, and the next day I started wiggling my toes.… So [for over four months] I have no memory of anything, and I was just out of it.

While the underlying medical issue went uncorrected and Valerie was "out of it," she lost a crucial chunk of her optimal recovery window.

Valerie was tearful, on and off, throughout the family meeting.

And you mentioned your doctor recommended a psychiatrist? That's a really good thing, to make sure you can focus in therapy and make progress, the OT suggested. *And having backup plans is important. If you don't get to 100 percent, does that mean we don't enjoy life?*

At this point, the therapists raised the delicate what-is-rehab-for question. They explained that day rehab was intended to be short-term.

Therapy will always be there, but it won't be something you'll always be doing. More like a tune-up, the OT said.

And that's what I told her. I'm not recommending outpatient PT right now, but if you see gains in three months and want to come back in and do some more work, you could. But we don't see anyone lifelong. And neither does outpatient, the PT explained.

I'm going to put in here: I think life will be therapy, Dr. Rose said. *Going up to your lake house. And, as you're leaving the structure of day rehab, our goal is to launch you with support.*

We're not going anywhere. We're here. You do still get emotional, but I have to point out, not as much as before. And unless you're crying 24/7 and can't function, it's good to get the tears out. I think it's going to be all about willpower, Valerie. And I'll be here for you, Kevin said.

Kevin seemed to be hanging onto the idea that Valerie could still reap benefits from hard work, while the therapists were trying to prepare Valerie and Kevin for the prospect of limited additional recovery. They were trying to shift Valerie and Kevin's perspective, from hoping for complete return to her previous Self to adapting to a "new normal."

You tried to set up me up with the social worker, Valerie said. *If she could reach out again, that would be great. She called when I was at the doctor.*

What are your thoughts, Valerie? If you feel like sharing, the OT asked.

Just tired, Valerie said.

Physically, mentally, emotionally? the OT asked.

All of the above, Valerie replied.

Remember the balanced thinking we practiced, Dr. Rose said.

Don't think of this as the end. You know this is far from the end, Kevin said.

I know. I won't. I won't give up, Valerie said.

You're going to be okay, the PT reassured her.

In the last few days, tell us what you feel would be most beneficial to you, the OT asked.

Valerie was too dejected to express a preference for her final day rehab sessions.

The therapists encouraged her to focus on how much she'd improved, since she first arrived.

I know. I came here in a wheelchair. You really did a lot for me, Valerie said.

YOU *were the reason you got better*, the OT said.

Like they say, it's not goodbye, Kevin assured her.

After Valerie and Kevin left, the therapists continued to discuss their grave concerns about Valerie's discharge. They worried about her emotional state, and they hoped she would follow up with a psychiatrist. And they knew she was in a precarious financial position, still waiting for disability to be processed.

She was donating plasma, the PT said.

I feel like she's super high risk for bad coping strategies, the OT reported. The therapists were concerned that Valerie's dejection over her incomplete recovery, coupled with her numerous stressors, would lead to depression and possibly substance abuse.

Dr. Rose tried to quell their anxieties. *They already asked her parents for money. The parents gave them $20,000. And she was abusing alcohol and cocaine and smoking before this. There's only so much we can do,* she said.

She still smokes, the OT said.

She's obviously—whether you want to call her an addict, she has addictive behavior, the PT insisted.

That needs to be addressed, but not here. If I focused on that in therapy, her guilt would prevent her from focusing on rehab, Dr. Rose said.

Her drinking buddy is her caregiver. That friend who's going to help take care of her—she met her at a bar she used to go to. I don't know how or if she's getting paid. I'm not sure she'll be the best person to have around Valerie, the PT said.

Valerie is more of a dual diagnosis person—addiction as well as mental health. I have people I can refer her to, but my guess is she'd rather keep seeing me in my private practice. Because a lot of times people don't want to start over. But I could be wrong, Dr. Rose said.

The therapists were distressed at the thought of Valerie leaving the support and resources of day rehab behind.

She's doing these things I don't feel are in her best interests, the PT worried.

They have financial options, Dr. Rose said. *I'm not trying to make light. But you can't feel responsible for their financial situation. They have that lake house they could sell. But I see you're emotionally invested.*

She's regressed over the last months! It's hard not to get emotionally invested. What if they were my parents? Or me in the future? Like you said, I know I can't control their financial position, but it's pretty clear she's not going to be okay, the PT said.

And her husband has health problems too, the OT pointed out.

Yeah. He's got some things, Dr. Rose agreed.

Definitely life things are why she's regressing. The stress of everything. But they're banking on her arm improving, and it probably won't, the OT said.

They were at a stalemate. The therapists agonized over the likelihood that Valerie would decline after leaving day rehab. They wanted to do something, anything, to help. Dr. Rose, as the psychologist, argued that they had to establish boundaries. They couldn't feel personally responsible for solving every patient's problems. They shouldn't start thinking "what if these patients were my parents?" They simply didn't have the resources to help Valerie further.

I'm just scared that we're not going to be there, the OT said.

We're launching her. That's always scary. It's hard not to become too invested, and I include myself in that, Dr. Rose said. Dr. Rose's primary duty was to support the patients, but she also felt a responsibility to protect staff from burnout. It was an emotionally taxing job, and it was hard not to get deeply invested in solving patients' problems. But at the end of the day, there were too many patients, too many problems, and too few resources.

Chapter Four: Shifting Relationships

Relationships in the aftermath of brain injury could be the focus of a separate thesis. I will by no means do the topic justice, in all its complexity, but it is important to touch on some key areas, given the centrality of patients' relationships and social roles to their identities. I will begin by focusing on the concerns relevant to specific relationships (e.g., parental roles), before moving to a broader discussion of patients' experiences surrounding caregiving and in/dependence.

Patients as Parents of Young Children

Due to COVID-19 precautions, at the time of my research children under twelve were not allowed in the inpatient facility. Universally, parents of young children talked about the pain of separation. Darcy (stroke, White, female, inpatient), for instance, described herself as "fiending" for her children, and unsuccessfully tried to plead with her doctor to bend the rules for her. Naomi was a particularly tragic example, having spent only a week with her newborn before being separated from him by a postpartum stroke. Video calls only made her more painfully aware of what she was missing, as she described:

> And I won't answer the phone. Especially when my husband wants to FaceTime me. Because I know he'll want to put the baby on FaceTime and that's gut-wrenching sometimes, to not be able to see my son. Then it's like, when I cry, [my husband] gets upset because he wants me to stay strong. (stroke, Black, female, inpatient)

Changes in Co-parenting and Caregiving Dynamics

Naomi and others were also acutely aware that their partners were holding the fort at home, managing the pressures of their household on their own. And when patients came home, they often worried their partner would continue to be burdened by a disproportionate share of household labor and childcare, as well as potentially having to tend to the patient's own care needs. In the long-term, some patients struggled to balance their desire to be a supportive partner and coparent with the demands of ongoing recovery. Staff emphasized the importance of compliance with home exercise programs, and they also encouraged stroke patients in particular to maintain their cardiovascular fitness. Some patients found themselves wondering whether it was fair to carve out time to work on their home exercises and/or visit the gym when it meant leaving their spouse to take care of the children, possibly denying their spouse time to look after their own health.

In some cases, grandparents, other relatives, and friends might have to step in to assist with childcare. In these situations, patients might feel obliged to defer to someone else's decisions about how to parent their children. A grandparent, for instance, might be stricter or more indulgent or decline to enforce the parents' household policies, but the patient might feel beholden to the grandparent for their help and unable to assert their own parenting preferences.

Parents also worried about their children's roles in the household changing. It could be difficult for children to adjust when one of their parents now required the care and attention of their other parent. As Hayden's wife Katie described:

> The other thing is [Hayden] being gone through [his inpatient stay], [our son] had my sole attention. It was me and [our son] for five months straight. So, when daddy came home, I think it was hard for him to accept that—you see an adult who was supposed to be taking care of a child. And I think in [our son's] eyes it's- it's the other way around. So to process that, I think, was a little hard for him. Obviously, with the trach and the suctioning, [Hayden's care] was extremely demanding, extremely demanding throughout the day and the night. So even when we tried to have [son] time, it was always interrupted by a suction or showering or, you know, something along those lines. (wife of stroke patient)

In some cases, children had to come to terms with a changed relationship with a disabled parent who might no longer be able to provide care and attention in the same way or to the same degree they had before; simultaneously, children might have to learn to "share" the non-disabled patient's care and attention.

Parents also worried about children having to take on new responsibilities or mature more quickly than they might have otherwise. As Hayden explained:

> [Our son has] been really amazing. And then he is very understanding. And he really helps out. But at the same time, I want him to be doing [young child] stuff. You know? I think that's the hardest part. [tearful] (stroke, White, male, inpatient)

The pressure could be even greater for single parents. Jada's partner had recently died. She came home from the hospital suffering serious aftereffects of her TBI, and she reported:

> And my daughter wants to help me, but she's just a child. I don't like to put [my children] in that spot for them to do adult things. I want them to live their childhood life. So they kind of try to be quiet, and not make too much noise, and do what they're supposed to do. And mostly help clean up the house and stuff that I—things I couldn't do. (TBI, Black, female, outpatient)

Patients in Jada's position felt guilty about needing their children to take on more adult roles and responsibilities and sacrifice some of the frivolities of youth (e.g., not having to worry the noise they made while playing might be agonizing for a parent with sensory sensitivities).

To the extent that they could, patients and their partners tried to minimize the disruption to their children's lives, in some cases going to extraordinary lengths to do so. As a TBI patient's wife explained, they were planning to move into temporary accessible housing (arranged by the inpatient rehab) while her husband continued day rehab. They were told they might end up staying there for six months to a year. But her son was developmentally delayed and had an individualized education plan, so she didn't want to force him to change schools. It took her about an hour each way to commute to her job from where they would be living. Even so, she planned to keep driving her son to his current school to ensure he didn't feel uprooted.

Changes in the Parental Role and Image

Patients frequently worried that changes in physical mobility would prevent them from being the active parents they had once been. Naomi was afraid she might be unable to hold her newborn, and many other parents talked about wanting to be able to run around after their children or get down on the floor to play. As one father explained, “horseplay” and “roughhousing” (TBI, Hispanic, male, inpatient) were central to his relationship with his children. Parents agonized about losing physical forms of bonding and showing affection, and they also mourned the potential loss of their idealized vision of parenthood. As Hayden said, “And when [my son] was a baby, you'd think, ‘Oh, I'm gonna teach him this, this.’ And now, I feel like I have to teach him different things. Some of the stuff that was important, that I wanted to be a part of [I can’t do anymore]” (stroke, White, male, inpatient). Patients considered what it would mean if they couldn’t teach their children to play soccer or swim or even (eventually) drive.

Some patients also feared losing parental authority or their children’s respect. Fathers particularly feared they might not be perceived as the father figure they hoped to be, both in the sense that they no longer embodied idealized masculinity and in the sense that their role in parental discipline had to change. In a few cases, parents could no longer speak or struggled to project their voice, so they felt they had to take a backseat in discipline. One father described how he felt his children no longer listened to him the way they once had:

> I used to tell my sons anything. And [now] it's like, instead of just listening to what I say they will ask for a second opinion…. Normally, they don't play with me. Dada whup ass. I will whup they little ass. But I can't—I just—I ain't whuppin’, I'm not whuppin’ them. And I don't—I'm not the disciplinarian—“Hey, if you don't do that, I'm gonna tell your daddy on you.” They like, “Eh, tell my daddy”… They mama, she—she's more the authority figure because she whupping ‘em now. (TBI, Black, male outpatient)

In this context, I didn’t take “whuppin’” to mean physical discipline exclusively (or even primarily); it seemed more a matter of who was respected as the parent who laid down the law.

In some cases, patients were concerned about whether their children would be afraid of or afraid for them. Some patients talked about changes in physical appearance. As Scott reported, following brain surgery, “I was pretty worried after that. That like, I'd have these scars that would be scary to my kids” (stroke, White, male, inpatient/outpatient). In other cases, young children were adjusting to seeing parents with new styles of movement or unfamiliar assistive devices. A TBI patient and his wife talked about how painful it was to see their son hesitate to approach his father in his new electric wheelchair.

Children might also be aware of and alarmed by changes in affect or behavior. Caroline (TBI, Black, female, outpatient), for instance, had become emotionally volatile post-TBI. In our interview, she rapidly cycled from crying to yelling and swearing, as she described her frustrations with her new life. Her children were older and did not live with her, but she was deeply wounded that their behavior toward her had changed: “When they come, they act funny like—like I'm not their mother … I'm like, ‘I'm your mama!’”

Scott also worried about the impact of his altered emotional state on his children. After coming home, Scott fell into a deep depression.[15] He reported “crying a lot in front of my kids,” and he was concerned that his evident distress would frighten them and/or would change their view of him. As he said:

> Oh, yeah, both of them noticed. Both of my kids did. The smaller one would constantly be coming over and be like, “Are you okay, daddy?” ... I definitely don't want my kids in their early stage to think that, like their daddy is just a broken mess. (stroke, White, male, inpatient/outpatient)

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[15] See *Scott’s Disappointing Near-Complete Recovery.*

One of Scott's children actually witnessed his stroke. Scott had been alone with him, and the child had to phone for help when his father fell down and was unable to move. Another patient, Isobel, recounted a similar event:

> I don't think [my daughter] understood anything. She's [young]. But she did, you know, see the EMTs come and put me on a chair and trying to figure out what was going on…. And then they strapped me and then they took me off. But she was crying, and I would say the residual effect for her is, when she does imaginary play with her dolls or whoever, everyone goes to therapy or the hospital. (stroke, Hispanic, female, outpatient)

Isobel and Scott wanted to ensure that the potentially traumatic experience would have no long-term effects on their children or on their relationship with their children. They didn't want their children to fear for their parents or begin to fixate on illness and death.

As much as patients missed their children in the hospital, returning home could raise complicated emotions. They wanted to get back to playing and spending time with their children as they had before, but in some cases, their neurological changes made it difficult for them to cope with the noise and chaos of young children. Despite having wanted nothing more than to see their children again, some patients returned home to find they couldn't handle being around their children. A staff member cited an example of a day rehab patient:

> I've got a patient right now who—he has a nine-month-old daughter, and he had a brain injury. I think it was before she was born. But just like, a few months before she was born. And he's had clear personality changes from the brain injury. And he's made comments about throwing the daughter out the window. Like, he can't stand her crying. He's never tried to hurt her. But he also has a lot of suicidal ideation. (staff, outpatient)

This patient's discomfort was likely greater than average, but it was often difficult for both parent and child when a parent returned home with sensory sensitivities and personality changes.

Parents (and in some cases, grandparents) also worried that exuberant children might accidentally reinjure them. Many patients were understandably anxious to protect what they now perceived to be their vulnerable brains. One TBI patient reported having had a talk with his son about prepping his grandchildren to see him; they weren't used to having to be careful around their grandfather, and the grandfather worried they would be too rambunctious. Scott described a similar predicament:

> The kids didn't really understand that I was in recovery. So they were like running around me, jumping around me. Like, throwing things. And I was very, like, protective of my head at the time. Because I wasn't sure what it would take to like, cause another rupture or something. So the first day I actually had a panic attack, with them screaming and making noises. I had to go in the other room. It actually made me really sad thinking like, I can't be around my kids. (stroke, White, male, inpatient/outpatient)

Patients worried about changes in their coparenting dynamics and their relationships with their children, and they were anxious to preserve their ability to experience joy in parent-child interactions. They were also concerned about alterations in the way their children perceived them and in their ability to live up to their own parenting ideals.

Patients Being Cared for By Adult Children

There were certainly cases in which parents were estranged from their adult children or, for any number of reasons, had adult children who could not be (or preferred not to be) involved in their care. But in many cases, patients with adult children had to navigate changes in parent-child relationships, particularly surrounding the dynamics of care. Some patients had adult children who still relied on them for support, whether as a confidante and voice of comforting authority or as a source of material and caregiving resources. For instance, Shane and Serena were both hospitalized with COVID-19, and Serena had a COVID-induced stroke. Their adult daughter and her two children lived with them at the time. With Serena retiring early and Shane only just returning to his job after an extended medical leave, they had to broach the possibility of starting to charge the daughter rent to help make ends meet.

Becca, another post-COVID stroke patient, had an adult son with Downs Syndrome, and her husband had recently passed away from COVID. She was still struggling to recover from her stroke and manage the care needs of her son, and her daughter was in the midst of a cancer scare. Her daughter's husband had passed away a year prior, and Becca was contemplating what she would do if her grandchildren became orphans. Could Becca handle taking them in? Could she bear not to?

Change in the Direction of Care

In other cases, patients' adult children were now caring for them. Often, this arrangement involved one party moving into the other's space (i.e., the child moving home or the parent moving in with their child), so cohabiting tensions could often interact with stress arising from changes in the parent-child relationship. Adult children were often coming to terms with a newfound sense of their parent's vulnerability. A stroke patient's daughter explained that, although her mom had health problems in the past (including cancer), she had always recovered. The daughter and her sisters joked that their mom was going to live forever, since the cancer and other problems hadn't taken her. *She's the strongest woman in the world*, the daughter said. It was strange for her to see her strong and active mother lying in a hospital bed, looking so small.

Parents and adult children mutually struggled to adapt to a sudden reversal in the direction of care. On the whole, parents were particularly concerned about becoming a "burden" to their kids. Far from being prepared to receive help from their children, many parents still wanted to be the ones doing the caregiving. As one patient explained, she had always planned to move to her daughter's city to help take care of her grandchildren, after she retired:

> Because [my daughter’s] too busy. She always expected us to help, and I always promised her to help. And I want to keep my promise. So being—relying on her is not in my plan. (TBI, White, female, inpatient)

Many parents were all too aware of the pressures their adult children faced (e.g., demanding jobs; disabled spouses, and children) and they were determined not to add to their stressors.

They were also reluctant to give up their own independent lives. Rose, for instance, had been invited to move in with one or another of her daughters, but she was happy living in a housing complex for people over sixty years of age and engaging with her community of friends. She didn’t want to move away from her network, and she especially didn’t want to move to a small town or suburb where she would struggle to make connections, especially if her mobility and ability to drive were curtailed. “I have to have socialization … because even though [my daughters] want me to live with them, I said, ‘I can't. I need people,’” Rose explained.

Patients also struggled to relinquish control of their lives. In some cases, although patients didn’t want to be fussed over, they accepted a higher degree of support or oversight than they thought they needed to preserve household harmony and their children’s peace of mind. As one patient described:

> For me, I didn't think I really needed anything significantly, in terms of support. But for—to alleviate—to give my daughters comfort, I kind of let them lead, and they kind of took over with my care. My daughter stepped up and was like, “Okay, this is your new regimen for your pill taking, taking your medications. You know, you can get a warning alarm, and—but then this is the actual time at which you take it.” So I've come to, like, okay, if she feels good about it, I feel great. (stroke, Black, female, outpatient)

This patient was aware her daughters were anxious about her health, and she felt there wasn’t any harm in indulging them and letting them set up systems she didn’t feel she needed.

In other cases, parents bristled at what they saw as intrusiveness or overbearing control. As Becca reported:

> But then they were trying to help me balance my checkbook and stuff. And I don't need them balancing my checkbook. You know, they don't need to know what I have, what kind of money I have, or whatever. That's—so I don't want them to do that. And that's what I told them. I said, "No, you don't have to help me with this" (stroke, White, female, outpatient)

Patients might feel they needed to assert boundaries or push back at attempts to help them in ways they didn't want to be helped. To complicate matters, parents weren't generally accustomed to deferring to their children or following their lead. In many ways, learning to care for one's parent or be cared for by one's child represented an uncomfortable role reversal.

Intimate Partners

Brought Together and Driven Apart

Some patients and their partners reported feeling closer than ever because the injury or the brush with death had caused them to reevaluate their priorities or highlighted the partner's devotion. Caregiving could bring patients and their partners to a new level of intimacy, as a stroke patient described: "Well, we've kind of got really close actually. Because he had to do things for me I never thought he would have to do. So that vow, sickness and in health, that's no joke" (stroke, White, female, outpatient).

Male patients, in particular talked about feeling more in touch with their emotions and being prompted, by the traumatic event, to be more emotionally open with loved ones. As a patient and his partner explained:

> You know, our relationship has grown drastically. I used to be somebody who internalized my emotions. I've let her know how I'm feeling. I've also made her very aware that, you know, look, I—thank you, again, I'm so appreciative of everything she's done for me. So I would say we together are stronger than we've ever been. (TBI, White, male, inpatient)
>
> He's much more vulnerable. That was something that I've always struggled with him is he's very—he always was very calculated and, with his emotions, very controlled, internalized a lot. He's not very outwardly with a lot of feelings and things. Since the crash, I mean, I

> know part of it is the brain stuff, where he is more emotional when he talks about things, but it's refreshing to see…. He's very outwardly affectionate with—and praise. (wife of TBI patient)

As the wife alluded, patients and family weren't always sure how much of the change was a neurological symptom (e.g., emotional lability) and how much was a deliberate response to extraordinary circumstances (e.g., being moved to express appreciation for care and dedication), but partners still appreciated the effects.

In some cases, couples had been estranged before the injury. The sudden illness of an estranged partner could put both parties in a difficult position. The uninjured partner's role might be unclear. As an inpatient staff member explained, they "don't want to abandon their loved one at such a critical time," but at the same time, they might question how much care they were obligated to perform and whether it was appropriate for them to act as a surrogate decision-maker, if necessary. The injured partner could be left with limited options if the uninjured partner was unwilling to participate in discharge planning or post-discharge care.

In a few instances I observed, injury brought a couple back together. In one instance, it altered the circumstances that drove the couple apart to begin with, as the patient described:

> But she was at the point where she ended up planning divorce and stuff like that. But then my accident happened. And she had to be there for me … I'm not drinking anymore. So that's not an issue. We can take that off. You know, that's a big one. (TBI, Hispanic, male, inpatient)

Prior to his accident, his wife had moved out with their children. As they were preparing for his inpatient discharge, she moved herself and the kids back in. "And so we're all gonna kind of—we're gonna try being one happy family," she said.

Life-threatening events also tended to reorder people's priorities and provide opportunities to demonstrate loyalty. I unwittingly played a minor role in one couple's reunion. When I met Bennett, a stroke patient, I told him I was also interviewing significant others—partners and family—and I asked what relationship he had to the woman currently visiting in his room. *That's my girlfriend*, he said. *If you want to interview a significant other, you should speak to her*. When I later interviewed her, she told me this was news to her. As they both explained, they were broken up at the time of the stroke, but when she heard about Bennet's stroke, she reached out to offer help with no expectation of a romantic reunion. When I asked who she was and he called her his girlfriend, she thought, "Okay. There will have to be a second conversation about this," once they had some privacy.

Prior to his stroke, Bennett said, he hadn't appreciated her qualities: her loyalty, her practicality, her down-to-earth lack of materialism. She was independent and the sort of person who would rather cook than go out to eat. He was touched and grateful she had shown up in his hour of need. And conveniently enough, she was a professional home care nurse. "Maybe I'll get married and settle down," Bennett mused.

Managing Changed Roles and Dynamics

Even in loving and stable relationships, injury and disability caused a shift in dynamics that could be challenging to navigate. In some cases, it was an unexpected role reversal. A few couples were blindsided when the significantly younger partner had a stroke; the older partner never expected to be the one in the caregiver role as they aged. In another instance, a stroke patient said:

> When we first started dating, his back was out, and he had back surgery. And then he had his fifth back surgery, like a month before COVID hit. And he was bedridden for, I would say nine months out of the year prior to that. And so like, while we've been dating and married, there's always been, you know, those pockets of really bad moments and like—but it's always been me taking care of him. So we've been through this sort of thing before, quite a lot. Just not with me. (stroke, White, female, inpatient)

In addition to shifting the dynamics of care and dependency, injury often changed household divisions of labor. In some cases, the injured partner was now doing more work in the home than ever before; Ellis, for instance, was used to working long hours outside the home while his wife ran the household and took care of the children. Post-stroke, he was physically mobile, but he was still on leave from work while he continued day rehab, so he was trying to contribute to the household in new ways.

Other patients, however, were more cognitively or physically restricted. These patients were often concerned about a spouse having to take on a disproportionate share of household labor or childcare and worried their partner would feel overburdened or cheated out of the expected dividends of partnership. In some cases, uninjured partners were called upon to take on a superhuman level of responsibility, for the foreseeable future. As a patient explained:

> [My wife is] also doing all the work. So she's like a single parent. I mean, she's got to take care of the house. She's taking care of all the bills, taking care of the kids, you know, when they get sick, when they're not sick. And her [paid] work [outside the home]. So it's—I can only imagine how stressed she is … I'm sure there are some resentments that she has about it. So we'll have to talk those over. (TBI, Hispanic, male, inpatient)

While patients appreciated (and in many cases felt guilty about) all their partners took on, this new dynamic could leave patients feeling deprioritized or like one of many demands on their partner's time. Patients didn't want to feel like their care was one task among many their partner was attempting to juggle.

Some couples lamented the loss of the complementary partnership they had come to rely on. As a patient's wife explained: "I think we were—we've been a good team. Like, you're different personalities. He's very outgoing. I'm more like, reserved, introverted" (wife of TBI patient). This "team" dynamic could be disrupted if the more gregarious partner was no longer able to speak or, for any number of reasons, was now reluctant to engage socially. Complementarity also came into play in division of labor.

People in longstanding partnerships often had specialized tasks (i.e., one partner always handled X and the other dealt with Y), and when one partner was temporarily or permanently unable to handle their customary duties, the other could be left scrambling, as one patient's wife described:

> I think the biggest area of concern I have—the most worry about from a home life [perspective] is financials. [That] scares me a little bit. I mean, taxes hadn't been put in in April because of the extension that we all got. [My husband] has been doing them all. And he's got some of his own files. Many of our accounts are shared, but some aren't. So he's got security on those accounts. I'm having to go in and figure that out. I'm trying to keep up with the statements and the letters, and I don't know what he wants to do about this investment or not.… It's not like I'm stupid to it. Because he always brought me in on it. But when you're not the one actually doing it—and it takes time. And I don't even have the brainwaves, let alone time to figure all this out [right now]. (wife of stroke patient)

This woman's husband had profound aphasia, so he wasn't able to walk her through what to do or provide any information to help her access their accounts. In a parallel scenario, Cleè was trying to sort out her household's finances from the hospital because her husband didn't know when or how certain bills were paid. To make matters worse, staff were now telling Cleè she shouldn't manage their finances or sort their medications without supervision because of her cognitive changes, and she rankled at the implication that she couldn't handle tasks that had always been her responsibility.

Many patients talked about their concerns about partners or adult children taking on jobs they took pride in doing (or doubted someone else could adequately perform). Even if the patient could still manage, their partner might try to take over because it was more convenient. In some cases, patients had to set boundaries around what they wanted to do and how they wanted to contribute to the household:

> And [the patient] kind of spoke with her spouse as to what she wants to be responsible for and what she wants to take ownership for and take the time to do—because [those tasks are] going to take longer—and what she's okay with her spouse, you know, having that responsibility. So she devised like, a set list of things that she will do, and that her spouse

> needs to give her the time to do, and the things that her spouse is responsible for. (staff, outpatient)

For some people, a changed division of labor could feel like a violation of established gender roles. Men especially could experience guilt and shame at perceived failure to perform masculine-coded jobs. As one patient's wife reported, her husband was dejected to learn she had removed their window air conditioning unit for the autumn on her own. "You shouldn't have had to do that," he said.

As I will discuss in Chapter Five (Re-Constructing Identity), several patients experienced their changed bodies, lives, and relationships as a threat to their masculinity. As one patient told me:

> I've been short[-tempered with my girlfriend]. You know. I'm probably not fun to live with right now. I try to be, but—it's um—you know, it's difficult. You know, until I start feeling like a man again. You know. I don't feel like a man anymore. (TBI, White, male outpatient)

These emotional responses could strain relationships, but beyond that, couples had to renegotiate roles and alter established routines. As one patient's wife explained, he was always the one who drove when they went anywhere together, and she wasn't sure how he would react to having to be in the passenger seat when driving or in their life, in general:

> It's sort of a different dynamic for me to be the one [who is] kind of the leader, sort of the in-charge person. Maybe that's not the right way to describe it. But he's typically kind of the decision maker or the—he kind of usually takes the upper hand in a lot of this stuff.… And even silly things like, I don't ever really tell [him] what to do. You know, like, he's a grown man with kind of firm opinions about things. So having to tell him like, "You can't put your leg like that" or "No, I don't think you can hop to the toilet [just] because you're right there. Like, can you maybe do this instead?" (wife of TBI patient)

This wasn't exclusively a gendered issue—women also valued their independence and pushed back against caregivers' advice and restrictions. But in more traditionally gendered relationships, undermined masculinity added another element of strain.

Another woman also described her husband as an “in-charge kind of guy” (wife of TBI patient). As she put it, “I hadn't paid a check in thirty years.” In the aftermath of his injury, she experienced “a reversal of roles.” In the end, she felt she was more permanently changed than he was. “I guess I'm not as dependent as I was before. Because I—now I know how to write the checks,” she said.

Patients, on the other hand, often felt increasingly dependent on their partners, which could lead to fears of overburdening or overcrowding their partner. Patients often expressed qualms that their care needs would be “too much” for their partners and/or that their partners would feel smothered. As Luke said:

> I'm used to being independent. I'm [a] veteran. I've been a lot of places, done a lot of stuff. I've never been needy. Well, my wife say I'm needy. (stroke, Black, male, inpatient)

In part because of his confusion and disorientation, Luke was anxious when separated from his wife, Sarah. One day, I was visiting him when Sarah was due to arrive. He fretted that she was late and worried she wouldn’t come or that something had happened to her. When she arrived and had to run back downstairs to sort out the parking situation, his distress increased. “Sarah!” he called out in agony, every few minutes. He told me people need space in relationships, but now he couldn’t give her any space because he needed her too much. He worried it would drive her away, perhaps even into the arms of another man. “See how I am?” he said. “If she messed around, I’d be devastated … I want to talk to her, see her. I get nervous. Pitiful.”

Some patients were worried their care needs and/or perceived vulnerability would circumscribe their partners’ lives, leading to resentment. As George said:

> I want to be independent. And don't—don't misinterpret that. It's not—that's not ego-centered on me. That's a duality. I want to be independent enough that [my wife] is satisfied that she doesn't—that she can go on a trip with her friends. And I'm qualified to be at home alone for that period of time. (TBI, White, male outpatient)

He was acutely aware of how his wife's concern for his safety caused her to forego recreation and socialization that once brought her joy.

Some patients were more comfortable slipping into a dependent role, to the point that their partners and staff worried about their self-efficacy. In some male patients, I noticed a tendency to default to "ask my wife." They didn't always pay attention to the specifics of their medical care because they assumed their partner would handle it. As a patient said, "Like, if I have to take medication when I leave here on my own, you know—which I told them, "I don't! I'm married. My wife does that. You know, she'll give me the pills'" (TBI, Hispanic, male, inpatient).

A few patients' partners were alarmed by what they saw as a worrying shift toward anxious codependence. In some cases, the issue was at least partly neurological. For instance, one patient became confused and belligerent when his wife left him alone with visiting friends. In other cases, the situation was more complicated. One patient told me, with a tone of satisfaction, that his wife would be in control when they returned home:

> I already know what's going to happen. I know her. I'm not going to be able to lift a finger or do a thing. If I go upstairs or take a shower, I'm going to have one of my friends standing there. Or her. I'm not going to be able to do a thing for the next month … she's already got it mapped out. I'm just- I'm not gonna say, "What are we doing in a week?" She's got us mapped out … I'm going to let her lead this for a long time. (TBI, White, male, inpatient)

His partner, on the other hand, was concerned by his growing reliance and wanted to make sure he was challenged to be more independent going forward. As she said:

> So a little bit of codependence with—that would probably be a "big" not a little bit. He's codependent on me now.... The nurses would come into the room, and they'd say, "We're gonna give you a shot." And he'd look at me and say, "Is that okay?"… I think that's important for him to have his independence and a feeling of worth. (wife of TBI patient)

He thought she would be hovering over him every step of the way, but she was intent on making sure he did as much as he could on his own. As roles and in/dependence dynamics shifted, some people resisted, some negotiated or adapted, and some seemed to relish the sense of being cared for and protected, and couples weren’t always on the same page.

Boundaries between Caring and Intimacy

Some patients’ new care needs involved highly intimate tasks, from washing and grooming to assistance with toileting. Staff reported that some spouses “jump in and say, ‘Yep, I can do this.’ And other people go, ‘Woah, I cannot change my wife's diaper. That's just not something that is in the realm of possibility for me,’ and that is not a facet they can take on.” While some patients were more comfortable allowing a partner to help them with intimate care tasks than they were accepting help from staff, many people struggled to accept this new and unwelcome change in their spousal relationship, as a therapist described:

> And it's just very tough like, because you're training family on how I can help them change their brief from the bed, and the patient really doesn't want them to be doing that. So it can be very touchy. Especially [with] locked-in patients because they're fully aware of what's going on. They're fully aware that their husband is changing their diaper, and they're not okay with it. The last girl I had, it took us—we did a family training every single week. But we couldn't do changing her brief because she would get so emotional during it until the very last week before she left. (staff, inpatient)

Patients and partners struggled to establish boundaries between caregiving and intimacy. As one patient’s wife said:

> I hate being called his caretaker. I hate it so much. But I am his full-time caretaker. But more so I'm his wife. You know, so when I'm referred to as that, I correct very quickly and say that I'm his wife, not his caretaker. I'm his wife. [tearful] (wife of stroke patient)

It was both an identity problem and an interactional challenge. Couples tried to maintain the distinction between a romantic mode and a functional and efficient caregiving mode, particularly when the patient required assistance with hygiene and toileting. As another patient’s wife explained, it could be difficult to transition from one register to the next, especially if there was no spatial and temporal separation between one mode and the other. As she explained:

> It can be hard when, let's say it's shower night. And the shower is a whole routine. And it's a lot of work, especially now that he's not using the shower chair. And we're like actually transferring him to a shower bench. And I'm doing it, and it's exhausting. It's a lot of work. It's kind of frustrating at times. Because he's wet, and it's like hard to make everything go smoothly … it's hard to go from the transition of caregiver, like immediately into bed as wife. That's a tough transition where I wish I had more space, like maybe more physical space, but also more time space in between the two. Where I'm like, I wish I could get [him] into bed, let him chill out there for a little bit. And I wish I had a room where I could go so I could like decompress. And sort of switch modes. Because I'm finding it's just difficult for me. (wife of stroke patient)

At the time, they were still in the hospital, so time and space were in short supply: she had no room of her own to retreat to, and they had a limited window in which they were ensured privacy for nonsexual intimacy. But even in their own homes, couples had to work to create separation between roles. Likewise, patients could struggle to feel attractive or romantic when their spouse was helping them with tasks that could be exhausting and frustrating, and potentially made the patient feel humiliated or disempowered, especially in the early stages of adjustment.

Sexual intimacy presented its own set of dilemmas, from issues of consent for patients with cognitive changes to problems with self-esteem and self-consciousness about appearance or ability to maintain one's preferred standard of hygiene and beauty. Unfortunately, I cannot cover these complexities in any depth here, and in fact, they were often glossed over or avoided in the rehab context. Staff said they didn't address sexuality because patients generally didn't bring it up. Some staff members said it was an important topic but tended to "fall off the plate" in rehab because of more pressing concerns and lack of time. PTs and especially OTs agreed that as an "activity of daily living," sex was within their scope of practice, but most weren't experienced with addressing the subject. As an OT reported one day: *I need to talk to [a patient] about sex positions. I remember* *it's in our textbook, but I've never discussed it with a patient. We had a couple lectures, but it was more like "this is something you should address."*

They had been taught sexuality was important and should be addressed, but not necessarily how to broach the issue. Inpatient staff often assumed sexuality was discussed at the outpatient level, when patients tended to focus on longer-term concerns, but outpatient therapists gave similar reports—sex generally didn't get discussed because patients didn't bring it up. A few patients or partners had questions about sexual intimacy but were unsure whether it was appropriate to ask for advice from therapists or doctors.

Many patients and their partners wanted to regain sexual intimacy. It was central to many couples' feeling that their relationship was "the same." Of course, couples also missed nonsexual forms of intimacy (e.g., a patient with sensory changes might miss the ability to feel a partner's touch or embrace). As one patient's partner described, sexual intimacy was an important part of their relationship, but she also missed the ways communication facilitated emotional intimacy:

> If he's going to be a quadriplegic or if he's going to be wheelchair bound, I can learn how to adapt to that new life. I think I can learn to adapt to anything. But I think if he had his voice, and if he could speak freely, then we could return to who we were as a couple more easily.... We always have been good communicators with each other. And we are—we have a lot of inside jokes. And, you know, we have, like a pretty particular sense of humor. So, to be able to be witty and fast and make comebacks with each other, I think, is a quality that we share. (wife of stroke patient)

Disability could alter many aspects of the companionate, romantic, and sexual components of intimacy, and couples often struggled to recapture what felt like the core components of their relationship and who they were to each other.

Wanting to Be the Same

In some cases, non-injured partners felt the person their partner had been was permanently lost, to one degree or another. As I'll discuss at length in Chapter Six (Brain, Body, and Mind) behavioral and personality changes could be especially devastating to partners. As a staff member recounted:

> And you see a lot of people who are devastated by that and view that individual as no longer the person that they married. There's actually a very famous quote from one of the founding members of the Brain Injury Association of America whose husband had a severe brain injury. She said, she thinks in the United States that if your spouse has a brain injury you should get an automatic divorce and should be able to decide whether you want to remarry this new person. Because it's essentially a different human being. It's not in sickness and in health, the way it would be, if they had cancer, if they had an amputation. That your brain is who you are, and if your brain is altered, you're a different person … so that sense that, you know, I have lost not only my husband, lost the person all together, but it would be easier if they died because now there's this other person in their place that I am responsible for. (staff, inpatient)

Even when the patient didn't have cognitive or behavioral changes, physical change could cause a seismic shift in a couple's life together and modes of interaction. To an extent, even patients who weren't "behavioral" in the neurological sense might act very differently because of changes in mood or routine. As one patient's wife said:

> Other than our wedding photos and pictures of [our son], I actually took down every picture in our house. I had an entire gallery wall on one of our walls. And about two months before he came home, I took everything off the wall. And I haven't put them back up. [tearful] Because um, it's kind of hard to see what we—I would get upset. I would get mad. But not at him. Mad at why this happened. (wife of stroke patient)

Regardless of cause, it could be wrenchingly painful to be reminded of the contrast between one's current and former life and relationship.

At the same time, many patients desperately wanted to remain the same person their spouse loved. They wanted to be loved and lovable, valued and valuable in the ways they always had been. As one patient said, "I feel like, who would want to be with me, you know? [tearful] My husband didn't sign up for this. A half-crippled wife” (stroke, White, female, outpatient). Patients who sensed their spouse’s behavior and feelings toward them had changed tried to restore what they feared had been lost:

> I've been trying very hard to please her. And I bring her a latte to her bedside every morning with *The New York Times*, and I make a chocolate croissant for her to have … I'm trying to go on long walks with her, now that I'm walking better. But she said to me, you know, “This thing happened. My life is over. I'm never—I'm not having a life like I had before”… I mean, she's just so angry all the time about her life now. And I've been trying to do everything I can to make it normal or make it be as normal as she would like … That's the most devastating part of my life as a result of this [TBI]. I mean, sure the memory [change] is frustrating, but I'm not [working] anymore. And it's not as acute. Financially, we had great insurance, and we're pretty well off. And so that was not a problem. All those things. But that's the part of my life that that is the most upsetting to me is what it's done to our relationship. (TBI, White, male, outpatient)

Some patients had to find new ways to be what they were to their partner. If they couldn’t perform the same acts of service, they had to find new ways to be supportive. As one patient said:

> I always asked her "can I do anything for you?" Now she does everything for me. I can't really—I can't get her a glass of water. I can't give her a massage. So now, I focus on being an emotional support. Because that's what I can do. (stroke, White, male, inpatient)

One patient and his wife were separated for their anniversary: at that point in the pandemic, hospital policy required her to quarantine for two weeks before being allowed to see him. His mobility and communication were limited, but he arranged to surprise her with roses, wine, cookies, and a gift certificate for pizza sent to her hotel room.

Extended Family and Friends

Sources of Support

In the future, I hope to write more about friendship, mutual support, and caregiving, but in my sample, most patients were counting on partners, parents, or children for support. However, many patients talked about their extended social networks and their plans (and concerns) surrounding these relationships. At the time of my research, COVID-19 had already substantially changed people's social lives, and many patients were even more careful about social distancing after injury. As Hayden's wife pointed out:

> Hayden has so many friends … but unfortunately, I have limited visitors to solely family because very early on it was explained how—I mean it could be fatal. Even a common cold could be fatal to Hayden. Even still, at this point. (wife of stroke patient)

Post-injury social interaction was restricted to an unusual extent, but patients talked about many issues that weren't pandemic-related.

Some patients felt touched by the "outpouring of love" (stroke, Black, male TBI) from their extended family, friends, and communities. Patients talked about having heard from people they hadn't been in touch with for years. Other patients felt abandoned or let down by people they expected to show more concern or offer more assistance. One patient's wife reported:

> His brother's been very involved in helping me. So they're probably closer even than they were. You find out who your friends are and who aren't. Because some people that should have definitely contacted us have not said a word. And that's pretty scary. So how do you handle that when you see them out in public, you know? (wife of TBI patient)

For many patients and partners, seeing who reached out (or failed to come through) in their time of need prompted them to reevaluate relationships.

Some patients felt hurt or disillusioned when, as time went on, people who had rallied around them in the immediate aftermath of the injury were no longer as attentive. Families and friends found it difficult to sustain the level of support they were able to offer during the period of acute crisis, but patients often faced months of rehabilitation and, in many cases, permanent disability. They felt the support and care available to them tapered off, but their needs remained.

Sources of Stress

In several cases, patients were called upon to mediate conflicts among family members. Mariah, a TBI patient, recounted that groups of opposing family members sat on different ends of the hospital waiting room when she was in the ICU. Afterward, she went home with her brother and his family, and her father and his camp refused to talk to her because she "sided" with her brother. Naomi told me she had to set boundaries with her family. She was recovering from a stroke, and she was aware that stress was a stroke risk factor. Her mother kept coming into the hospital complaining about Naomi's husband, claiming he excluded her from a family meeting and telling Naomi her pastor was worried about Naomi being in an "unequally yoked" relationship because Naomi's husband wasn't Christian. Naomi eventually had to tell her mother, *I would love to have you visit, but I don't want to hear gossip or negativity or complaints about my husband, so don't come if that's what you're going to do.*

Other patients, although touched by people's support and concern, were overwhelmed by the volume of calls, texts, and emails. In some cases, a designated family member acted as a gatekeeper, keeping interested parties involved but asking (on the patient's behalf) that people refrain from calling. Many patients were easily mentally and physically fatigued, and they talked about how much effort it required to reply to well-meaning messages.

Many patients and families kept extended networks informed through social media or sites such as CaringBridge. These forums allowed people to relay messages of support to and from the patient, and in some cases, crowdfund and/or mobilize and organize community support and resources (e.g., visits, rides, meals, childcare, etc.). They were also an efficient means of disseminating information: social media and text and email groups allowed patients and family to keep loved ones in the loop but restrict the number of people directly contacting them without being rude or dismissive.

Treating the Patient the Same

Some patients cherished relationships with friends and extended family who treated them the same as they had before the injury. One patient explained how he preferred people to interact with him:

> I just don't want them to be, you know, “Oh well, he had a stroke, so you know, we're gonna do this for him.” I just don't want them to look—I want them to see me, when I come back, how they saw me before. Even if I am a little slower. But that would be my concern. Like, you know, “Don't baby me”… and I didn't want to be catered to like, you know, “Oh, well, you're disabled now.” And my one friend in [another city], that's how he is: he doesn't—he'll ask, “How you doing? How are you feeling? How's your legs and your arm?” And then the subject is changed to something else. He shows his concern and then it gets changed to, “Let me tell you about this, tell you about this happened or this happening. Now what are you going to do for this? Or what are your plans for that?” (stroke, Hispanic, male, outpatient)

Patients appreciated people who helped them preserve a sense of continuity by acting as they normally would and de-emphasizing the changes in the patient. In some ways, friends and extended family could be more valuable in this way than close family and partners who had stepped in to help with care. Caroline, for instance, had a highly contentious relationship with her mother, in part because she was living with her mother, and she felt her mother was treating her like a child and preventing her from returning to her former lifestyle.

Caroline spoke fondly of a friend who would occasionally pick her up and take her out. These visits were the only bright spot in her life that Caroline mentioned. I asked what they did when they were out together, and Caroline said, “Movies. Basketball at the park. A little wine coolers, a little—you know, when you go out and kick it with your girl” (TBI, Black, female, outpatient). Her relationship with this friend was untainted by the pressures and tensions of caregiving and cohabiting. The friend wasn't hectoring Caroline about her sleep or her smoking. When she was with her friend, she could return to a version of who she was before.

Dealing with Dependency

Loss of Independence and Self-Determination

Desire for independence and frustration with dependence were at the center of most patients' post-injury relationships. Some patients discharged from inpatient and immediately returned to living on their own (two in my interview sample), but it was unusual. Many patients were worried about becoming a "burden" to their caregivers. At the same time, patients were concerned about being "at their mercy" or dependent on others for support (stroke, Black, male, inpatient).

Many patients—especially those who were permanently or temporarily unable to drive—felt isolated and bored at home. People often had to rely on family or expensive or unreliable paid forms of transportation, and it made many patients feel under-stimulated and socially limited. Lack of accessible transportation was also a common issue, as a patient's wife explained:

> We recently, two weeks ago, purchased a wheelchair van, as well. [Before that] we were very tied down to our transportation company … [we] literally have been tied to the house since January, other than doctor's appointments and therapy. (wife of stroke patient)

Often, patients felt restricted to the home but also constrained *within* the home. Patients with mobility limitations often expressed frustration at having to constantly ask family members for help. Patients had to carefully weigh their desires—wanting a glass of water or wanting to take a shower—against their concern about asking too much of their caregiver. Even when caregivers were both available and willing to help, patients were aggravated that they had to involve someone else in the first place. Before, they could do what they wanted; now they tried to limit their requests to what they absolutely needed. As a patient said, “In the beginning, I noticed I was just more quiet. Trying to stay out the way. Didn't want to bother anybody” (stroke, Black, female, outpatient).

In some cases, people reported a sense of diminished control over their environment and routine. If their space wasn’t as they preferred it, they didn’t necessarily feel entitled to express a preference. In particular, patients who lived with adult children made comments like:

> And we have a large house. And it's not the way I kept it. (stroke, White, female, inpatient)

> And we got cleaning people. I never had that. I never wanted that. But they decided to get cleaning people that come in every other week. So. (stroke, White, female, outpatient)

Generally, patients weren’t resentful about these changes: they understood that caregivers were busy and doing the best they could manage, and they didn’t want to quibble. But patients expressed a sense of loss—they were no longer taking care of housekeeping, so they didn’t have the same degree of control over how the house was “kept.” As another patient put it: “So I kind of pulled back from [complaining about messes like dirty dishes] because I don't want them to get all mad at me about it” (stroke, White, female, outpatient). Patients had to adjust their thresholds of what annoyed them.

One of the above patients was also wistful about a time when she was able to shape her space in accord with her aesthetic preferences and pride:

> Well, you know the TV in the living room, which I never allowed all the years the kids were growing up. “No, I don't want TV in the living room!” Now it's there. Ugly as hell. It is! It's a—all these wires coming out of it, and we have to have the TV in the middle of the living room. So when you walk in, you see this thing with these wires coming out of it … I did consider myself a designer of the house … and I've done it all on just small amounts of money and furniture that I picked up at garage sales and stuff. (stroke, White, female, inpatient)

This lack of aesthetic control could extend to the patient’s own body. As another patient pointed out, if someone else was picking out your clothes and helping you dress, it was hard to tell them you didn’t like the sweater they chose and ask them to go find a different one. In many ways, learning to adapt to needing assistance required learning to accept support in whatever form it was offered or figuring out to what extent you were willing to make waves, to assert your own preferences. As another patient reported:

> And [my family] want to bring somebody in [to help care for me]. A stranger. I don't know how I feel about that. I don't want anybody else showering me. But then I also don't want to be selfish. It would be easier for them, I think, if we brought somebody else in. So it's not about me really, it's got to be about them. (stroke, White, female, outpatient)

As this patient saw it, this significant decision about her care wasn’t ultimately “about” her, despite her discomfort. She needed and appreciated her family’s help and support, so she didn’t feel entitled to dictate how it was provided.

Feeling Controlled and Surveilled

A few patients expressed appreciation for the supervisory measures their caregivers put in place. These patients were highly anxious about reinjuring themselves and had come to doubt their own judgment. As one patient explained, he was glad his wife put a lock on their basement door and the door to the second floor—he didn’t trust himself not to try to use the stairs. He also appreciatively reported that his family placed security cameras outside the house, as he put it, “So nobody will mess with me when I'm home. And if the wife or kids see me outside, they're gonna get home and straighten me out” (TBI, White, male, inpatient).

As another patient put it, he readily accepted staff’s supervision recommendations because:

> I don't want to go home and mess this up. I got told [that] a lot of people go home and make a mistake because they think it's you know, “I'm cured. It's party time!” This is a lifetime injury. With your brain rattling. It'll come back in a couple years. But you'll ruin it if you go home too soon. And when they tell me that stuff, I listen. (TBI, White, male, inpatient)

He felt safe in the hospital, and he was wary of going home and reinjuring himself, so he wanted to feel people were keeping an eye on him.

In contrast, many patients balked at the implication that they couldn’t be trusted and at the lack of privacy and solitude that came with supervision. And of course, some patients felt their family was overbearing in their attempts to ensure safety. Patients often felt hovered over and excessively monitored, and certain safety precautions could feel humiliating. Ellis, a relatively young stroke patient who until recently had been the breadwinner for his wife and children, reported that they gave him what he called a “grandpa fell over and he needs help” medical alert button (stroke, White, male, outpatient). In other cases, patients were annoyed when caregivers tried to help them with tasks they could accomplish on their own. As one patient said:

> I'm like, “Stop babying me!” You know, my aunt—I'm very close to my aunt. And my girlfriend she—you know, gonna put a shirt on for me, she holds it up like you're a little kid. I say, “Give me the fucking shirt!” [laughs] “Okay? I can put a shirt on.” And they're just trying—they're trying to help me and stuff. So I try not to get too angry at it. (TBI, White, male, outpatient)

He recognized their kind and helpful intentions, but he had no mobility problems with his upper body, so he felt belittled by their ministrations.

Patients were also annoyed when caregivers tried to restrict their choices on the grounds that their preferences were unhealthy or unsafe. One patient was unhappy with the hospital food, and she asked her husband to bring her certain preferred snacks. ut she was diabetic, so he refused to bring food that might spike her blood sugar. Another patient reported:

> I was having something to drink, and [my daughter] goes, “That's got caffeine in it!” I'm thinking, “How many cups of coffee do *you* have a day?”… I had takeout. She'd look through it because she knew what I had ordered and what I took home. I—even with my ex-husband, I would never have thought of going through his takeout. (stroke, White, female, outpatient)

Until recently, patients had been permitted to make their own decisions based on their own assessment of risk and reward. It was frustrating to be disallowed from making “bad” decisions that non-disabled adults would be free to make.

Similarly, many patients struggled to adjust to suddenly having to be accountable to someone else, especially when they previously lived alone or with roommates and were now living with concerned and vigilant caregivers. As one patient explained, in his pre-injury life he never had to tell anyone where he was going, what his plans were, or whether he remembered to charge his cell phone, but now he was living with one of his sisters. On the one hand, he appreciated what his sisters did for him—he jokingly told me he had “workers” now. But the support and surveillance went hand in hand. As he explained:

> Only thing I don't like about it is, in point of them being my workers, they turned into a mama figure. Oh man !... [my sister] makes [her youngest daughter] watch me. And [the daughter] tells her mama everything … man, [my niece] reports on if I drunk water, what I'm doing right now, who I was talking to. (TBI, Black, male, outpatient)

Many patients missed not only their freedom to make their own choices without interference but also their sense of privacy, as a patient explained: “I am never alone. I always have someone with me. And have them watching me do things … someone's always just there, staring at me” (stroke, White, female, outpatient). As another patient explained, the feeling of being constantly observed could create emotional inhibitions. He felt he hadn’t really had a chance yet to weep or otherwise cope with the trauma of his accident and what followed because he hadn’t had any true alone time. Patients grieved the loss of solitude. A patient described how she missed being by herself:

> And one thing I didn't realize is that you can never be alone again, you can never be alone. I used to like to be alone. When I'd come home from work, if I saw my husband's car wasn't there, I'd be like, “Oh, thank God, he's not home.” So I could just be by myself. (stroke, White, female, outpatient)

Often, patients felt not only controlled and surveilled but also deprived of time alone in their own space.

Managing Emotions

Patients often felt guilty about their frustrations. They were grateful for their family's help and wary of imposing. They struggled to balance this sense of obligation and gratitude with the frustrations and indignities of having to rely on others for the fulfillment of their needs and desires. Factors like pain, fatigue, and sensory sensitivities also frayed tempers, so some patients had to work hard to manage their emotions, so they weren't "cranky at the wrong people" (TBI, Hispanic, male, inpatient).

Reciprocally, caregivers also struggled to remain serene through the stresses of caregiving. They didn't want to snap at their loved one, and they wanted to avoid displaying annoyance that might make the patient feel guilty for requiring care. As one patient's daughter explained, she missed "having my mom get on my nerves and not feeling bad that, 'Oh, like, here I am, I'm mad at someone who had a stroke.'" Having one party reliant on the other for care shifted relational dynamics, as did the sense that one party was responsible and in control and the other party was vulnerable.

In some ways, patients felt they needed to manage not only their own emotions but also the emotions of those around them; they were cognizant of caregivers' anxieties surrounding the transition home and the provision of care. Patients did their best to minimize the stress of those around them, in part by keeping their own anxieties and frustrations to themselves. One patient described how he tried to mitigate his family's stress:

> I feel like [the transition home] was a kind of a moment of—a little bit of unraveling, you know … I felt like I was—I just kind of had to be quiet. And just watch… I was not trying

> to—I feel like—I felt I was the cause of all of it. So I was trying to not cause anyone any more stress. (TBI, Black, male, outpatient)

Patients often expressed guilt about what they "put their family through." With TBI in particular, patients might have no memory of the acute phase of their hospital stay. They often talked about how their loved ones had been, in a sense, left behind to cope with the medical emergency (and the possibility of their death) when they were in a coma or medically sedated. This guilt was compounded by lengthy hospital stays, during which family members often had to commute long distances to visit. A patient's wife described this period of emotional trauma:

> So, like, for example, I'd just stand over the bed for four hours and cry. There's—there's nothing else you can do. You know, and say, like, "Fight! Stay strong. I need you. Don't leave me. You've got this. We can do this," over and over again … And then his sons were just—even though I prepared them, and I told them visually, everything—I mean, I said, "Visualize. There's a bolt in his head. Go down. He's bruised. His eyes are bruised. He has facial fractures. His ears are bruised. His face is swollen … he won't respond to you … they said that it just was horrifying for them to go there. And they're in their thirties. Big, huge guys, six foot four, you know, 280 pounds. And they're just sobbing. (wife of TBI patient)
>
> Her husband said: "I told her, when I get home, we got to heal *you*" (TBI, white, male, inpatient).

In a few cases, patients felt their family members blamed them for their injury. One stroke patient was heartbroken because his early-teenage daughter was angry with him. He called her his "natural" —of his children, she was the one most like him, with the most affinity and the closest relationship. But she Googled "stroke" and found a list of risk factors—"smoking, overweight, stressful job" —that fit her father's circumstances, and she got angry. She wouldn't pick up his calls. She also told him that talking to him "brought her down." Her attitude hurt him, frustrated him, and exacerbated his own sense that he was at least partly responsible for his stroke.

Learning How to Help and Be Helped

Staff emphasized the importance of letting patients do as much as possible on their own. They encouraged family to at least let patients attempt a task before stepping in and doing it for them. In some cases, staff reported, patients regressed in their recovery after returning home because overly solicitous caregivers weren't allowing them to practice. Connor's wife, Emilia, described how he had to set boundaries with his parents:

> And he said, like, "I am your son, but I'm not your child, and you need to realize that"... because he doesn't want anyone to help him. He wants to do it himself. But when he's struggling to take off his shirt, and his dad's in the room, his dad's gonna be up immediately like hovering, like, "How can I help you? What can you need? What do you need?" You know, trying to do it for him. And he had like, a really straightforward conversation with them where he said, "I'm going to do everything on my own first. I will ask for help. So stop asking if you can help me." (wife of stroke patient)

The wife and her husband both understood where the parents were coming from: they wanted to be helpful, and it was painful and sometimes uncomfortable to watch someone struggle without assistance. But in the end, helping too much was counterproductive and not what the patient wanted.

In other cases, caregivers jumped in because it was simply easier. Patients and caregivers had to adapt to a disability timescale—patients might take longer now to communicate and/or perform certain actions. All parties involved had to learn to be patient and plan ahead, but time pressures could still lead to tension and resentment. As patients and caregivers learned, navigating the world with disability required planning.

Often, patients felt self-consciousness and guilt about the degree of coordination required for their care. As a patient explained:

> [My family] always have to plan. They'll say you know, "I want to go out Tuesday night. Is that okay?" They have to work among themselves and make sure somebody is always gonna be home. For me. Even if it's for a half hour, they can't just leave me there. Because if I have to go the bathroom or something, you know. (stroke, White, female, outpatient)

Although most patients understood the importance of practicing their skills and, in many cases, felt frustrated and even infantilized when caregivers tried to do everything for them, they were often anxious about holding people up. In many instances, it felt easier to just go with the flow and not complain.

At the same time, patients' care needs evolved with their abilities, and both patients and caregivers had to adapt. Caregivers had to learn when their intervention was no longer needed. As Emilia recounted:

> I think, just as [Connor's] parents need to revise how they interact with [him], I think I will, too. Because the rate at which he's progressing means that I need to keep up with him … so I think I need to really be aware of truly where [he's] at and that today might be different than yesterday. So I just need to make sure I'm reading him and communicating with him. And recognizing, like, if I overstep or if I do something the old way, I need to just say, "Look, I'm sorry, I did it the old way. I'm going to get to the new way, you know, just give me some time." (wife of stroke patient)

Patients' relationships shifted as they learned to deal with dependency post-injury, and they had to continue to be fluid and adaptive as recovery progressed.

Caregivers

In some cases, a patients' caregivers pulled together well. One patient, for instance, described her daughters as a dream team: not only did they have solid and loving relationships with their mother and with each other, but each had a relevant skillset (medicine, law, financial planning, etc.). Another patient told me he felt his parents' relationship had actually improved following his injury because his mother was touched and impressed by how capable and devoted his father was in their son's time of need.

But of course, conflict among caregivers was fairly common. Families were in high-pressure situations that often caused relationships to crack along existing fault lines. To give an example, Jasper’s mother was overseeing his care while her ex-husband took her to court to try to renegotiate their years-old divorce settlement because he was trying to finalize his retirement and was having financial trouble. At the same time, two of Jasper’s siblings were harboring resentment because of a disagreement about how the funds raised for Jasper (through online crowdfunding) would be spent. The mother spent every day in the hospital, but due to the contentiousness between them, her ex-husband didn’t want her to be present when he visited. She was frustrated that he visited Jasper so infrequently and seemed to assume she would be the default caregiver, unless he wanted to drop in without warning and kick her out of the room for an hour or two. But at the same time, she tried to shield her son from any stress that might hinder his recovery.

There were a few common issues that complicated caregiver dynamics, including differing medical beliefs. One patient’s son was chronically frustrated that while his siblings refused to read any of the research he found on stroke recovery, his sister pushed alternative medicine. Perhaps the most common complaint was that other family members weren’t pulling their weight, and tensions were particularly high if the less hands-on family members were opinionated and exacting.

One patient’s granddaughter explained that her parents and she were responsible for the majority of her grandmother’s care because her grandmother’s other children lived out of state. But one of the less involved children had a habit of critiquing the caregiving sibling’s decisions and also seemed to stir up the patient’s anxieties by asking probing questions about whether she would be safe at home. As the granddaughter explained, “On the one hand, I think [the patient’s daughter] would like to be in control of everything. But on the other hand, she doesn't want to come here and do that” (granddaughter of TBI patient).

In many cases, caregivers felt unprepared to take on their new role and the responsibilities that came with it. A lot had changed quite abruptly, as a patient's wife explained:

> Literally, everything in my life before this has crumbled to the ground. Disintegrated … I was going to start a master's program. That's on hold. I have been involved in a lot of things that I've had to cancel or resign from or not do anymore, at least for the time being … I've been thrown into this. And this is going to sound really cold, but it's not—I didn't really have a choice. Like, as the wife, as the partner, this is what you do. You help. You jump in. You take care of. You care-give, right? (wife of stroke patient)

She'd had to quit her job, and her husband and she moved out of their apartment and were considering relocating to another state to be closer to his family for support. Needless to say, she felt a bit unmoored.

And not everyone felt suited to be a caregiver. As a patient's wife lamented:

> Oh my God, I've never been a caretaker. I've never—I've been the worker, you know? I'm the worker. I go to work. I'm a moneymaker. I am not a caregiver. So this is killing me, you know? (wife of stroke patient)

Another patient's wife described how hopeless she felt when it seemed like her husband would remain profoundly cognitively disabled:

> I wanted to kill myself. I thought, "Oh my god, this is my life" ... I mean, this idea of caring for somebody. I mean, if I wanted to care for somebody, I would have gone to medical school, but I do not have those skills. I mean, these people are heroic in the way they take care of people. But I am—I am not a compassionate person. And I don't want to be … I thought at one time that I would have to take him to a nursing home. And I couldn't leave him. I mean, I would have to leave him, but I couldn't leave and go live my life. (wife of TBI patient)

As these partners expressed, they felt they were in an inescapable bind. They felt responsible for their husbands, and they would feel immense guilt if they left them. But at the same time, this wasn't what they had chosen for their lives, and they didn't see themselves as natural or even willing nurturers.

Even less ambivalent caregivers struggled to cope with the way their lives, their relationships, and their identities were changing. Caregiving often demanded an extraordinary degree of selflessness and a willingness to put another person's needs before one's own. As a patient's wife explained:

> What I want is to be able to wake up and have a cup of coffee, and read a book, and eat my breakfast totally unencumbered. But I can't. I can't do that. Like, I have to wake up and shower myself first so that I can get [my husband] out of bed and help him get dressed. And help him with getting his day started. And my stuff, even though it's a cup of coffee, and a book, and breakfast, those are my things. They are not the priority right now. So I understand that this is temporary. It will not always be like this. I'm living with it for right now. Because that's just what the environment and the situation dictates. (wife of stroke patient)

On one side of the dynamic, patients were frustrated at not being able to do what they wanted to do, when they wanted to do it—at having to wait for help and/or restrict their requests to the bare essentials. On the other side, caregivers sometimes felt their own needs took a backseat. They couldn't go about their day according to their own preferences and at their own pace because they knew someone else was relying on them, and in many cases, the patient's needs felt more pressing.

Caregivers talked about not wanting to be "consumed" by the caregiving role, and they often stated they knew the patient wouldn't want that for them either. A patient's wife explained:

> I'm very scared about losing myself. And I'm not going to … I am not going to just become [my husband's] caretaker. We have to figure something out that provides him a valuable life, but also me. Because he wouldn't want that for me, and it will take a big chunk of me away…. But I'm going to be working really hard on maintaining a balance in my life and finding how to better create what I'm going to call an effort to set some boundaries and practice more mindfulness, so that I can stay healthy. Because I think the last four months has been so stressful, that I'm not quite taking care of myself. (wife of stroke patient)

In many cases, caregivers asserted that the patient's needs were paramount at the moment. But like the patients, they were hoping for recovery, and they were hoping that once they were out of crisis mode they could once again prioritize their own health, careers, and desires.

Although there were caregiver support resources available through the rehab facilities, caregivers were often unaware of them and reported that services were never offered. As a patient's wife described, even when they were offered, they might not amount to much:

> They give you the list. We have twelve people on the list, and here, you can call somebody. See if you can get an appointment.… And they don't—they don't call you back. They just don't call you back. And so if you were suicidal, and you were told to call this number to get some counseling, you could have killed yourself ten, twelve times by the time—I mean, they're not going to call you back. (wife of TBI patient)

Like the patients, caregivers tended to suffer from the social worker shortage. No one was available to offer much guidance or hand-holding.

Broadly speaking, caregivers had an easier time accepting their new role when their relationship with the patient was strong to begin with and they felt (or knew) the patient would reciprocate their devotion, if given the chance. For instance, one patient had been by his wife's side through nearly a decade of kidney failure and dialysis. Another patient's niece said she was happy to support her aunt because her aunt was "a good egg" who had been there for her through her mother's end of life care.

Even hypothetical reciprocity could go a long way toward easing the discomfort for both parties. As Connor's wife, Emilia, said:

> Anytime that I might feel bothered or frustrated or impatient with a request of his, I remember that if the roles were reversed, if I were the one who had the stroke, and Connor was the one who was helping me, he would never, I know without a doubt he would never bat an eye. He would never complain, he would never, you know, show any signs of exasperation. He would always gladly say, "Yes." Because that's just who he is. And that's who he is with me … and, you know, sometimes he's a little embarrassed, you know, he's like, "I wish you didn't have to do this for me," or "You shouldn't have to do this." And I think he gets a little down sometimes. And I'm like, "Hey. I know without a doubt that if the roles were reversed you would—no questions asked, no hesitation, help me." He's like, "You're right. I would." I'm like, "So anytime you feel bad, remember what you would do for me. And know that I'm doing that for you." So I think that helps. (wife of stroke patient)

Patients and caregivers were thrust into the world of disability precipitously and often unprepared. Providing and accepting care altered relationships in myriad uncomfortable ways. Patients and caregivers struggled to shield each other from unpleasant emotions, even as they dealt with the realities of shifting division of labor, reduced privacy, and the need to adapt and evolve along with changing abilities and circumstances. Although, in some cases, a crisis brought people closer together, in most cases, close relationships with open channels of communication and a deep store of mutual good will were best equipped to weather the storm.

In many ways, changes in relationships had a substantial impact on caregivers' and patients' identities. Caregivers might balk at taking on the nurturer role and/or worry about having to submerge their own desires, put other priorities on hold, and potentially become "consumed." At the same time, patients faced fears of rejection, anxieties about becoming a "burden," and threats to central identity characteristics. What did it mean to be a father if your child was frightened of you or if you could no longer fulfill an idealized parental role? What did it mean to be a spouse if you feared you were no longer attractive to your partner or capable of reciprocating your partner's support? And what did it mean to still be *you* if everyone was treating you differently?

Speech: Severe Aphasia

Image 9: A set of communication aids, prepared for a patient
Source: Photo by Author

Andy knows I'm a terrible driver, SLP Zara joked, as she pushed his wheelchair into her office. Andy, a Black man, in his early sixties, was in day rehab following a stroke. He was dressed in a bright teal jacket with a towel tucked in the front of his shirt.

Is Maddy here with you today? Zara asked him. Maddy, Andy's paid caregiver, generally accompanied him to therapy. Zara wrote out yes and no and then two sentence alternatives—"Maddy is here" and "Maddy is not here." He pointed to "Maddy is not here," and she circled his response. As Zara later explained to me, she wrote out full sentences because Andy sometimes exhibited yes/no confusion.

Hmm. It's the first day Maddy or your wife isn't here. Let me just quickly email who you have next to make sure they know Maddy isn't with you today, Zara said.

Andy, you sound like you have a lot of saliva going on. Let me see if I can clear that off for you. I'm going to just take your mask off. She wiped his mouth, replaced his mask, and told him she'd get him a fresh mask at the end of the session. Saliva had started to soak through his current mask.

Last time I saw you, you were working with the iPad. I'll give you two choices. Is it here or not here with you, today?

Andy pointed to "not here."

Have you had a chance to use it over the weekend?

An assistive communication specialist had issued Andy an iPad to test , so they were working on getting him used to it. *But we'll have to do without it today. Let's see. Some non-device things we can do,* Zara said.

"You're getting really good at naming things," she told him. *We're going to start off with some naming of objects and then what they do.*

Zara laid out a picture of a towel.

Let me give you three choices. Clock, towel, cup. Zara wrote out the options.

What do you think? A towel! Very nice.

Zara selected a photo of a knife cutting butter.

Knife, bread, or hammer?

Andy indicated bread.

I threw in a trick there, right? Because this is a term related to bread. But do you see any bread in this picture? Not a bad choice though. I also think about bread when I see this picture. Let me cross that one out.

Andy selected knife.

You got it! A knife.

The next one, he got right the first time.

Beautiful! It is a cup. Awesome, awesome, awesome. You're doing an awesome job identifying pictures based on three choices.

Andy looked distressed.

You okay, Andy?

He lifted a hand, in an "it's fine" gesture.

Is your leg okay?

Again, he waved the question away.

They moved on to the next exercise. Zara wrote "drink water," and Andy was supposed to select which of three photos (a sock, a key, a glass) related to that function. He pointed to a photo of a sock.

"That's a good guess," she said. *Let me show you what I mean*.

Zara Googled an image of water being poured into a glass and showed him the image on her phone. When asked again which object he would use to drink water, Andy pointed to the photo on Zara's phone, and finally to the picture of the empty glass on the card.

As they continued, Zara gave effusive feedback.

"Nice! You use a toothbrush to brush your teeth. Beautiful job, Andy. Let's keep up the good work." *Which object would you use to take pills?*

Andy started to point to a picture of a key, but then hesitated.

I liked that you checked, Zara said. *I like that you selected and then were like "Is this right?" Do you use a key to take your meds? Does another one of these look like a container for medication?*

He pointed to the pill bottle.

I know Maddy and your wife help you take your meds, but if you're ever in pain or want to ask for your meds, this way you know the symbol.

Andy kicked his foot off the wheelchair footrest.

I see something's going on with your foot, Zara said. She leaned under the desk to get a better look, but Andy had already lifted his foot back on. She asked if the foot was all right, and he indicated, *fine, fine*.

Andy was breathing heavily, in short puffs.

What's going on Andy? What's going on? You're getting real fidgety, Zara asked.

Maddy arrived. The car was low on gas, so she dropped Andy off first and went to fill it. She had all his accoutrements with her, including the iPad. The device was already on the emotions screen, so Zara used it to question Andy further about his agitation. The screen offered options for emotions and sensations, like cold, pain, and pain in leg.

Are you feeling one of these, right now? Zara asked.

Immediately, Andy pressed “angry.”

Well, you did a good job expressing yourself. Why are you angry? Is it pain, uncomfortable, because this is hard, or something else?

Zara wrote out the choices. He tapped “hard,” and she circled it to confirm.

Yeah, he agreed.

Oh, Andy! You’re doing such a good job with this. “This is some of your best work.” *I know this is really hard though. And it’s something new. We’re doing object-function matching today.*

Once again, his breath came short and fast.

I notice you’re fidgeting. Is your leg okay?

Do you need to be moved, Andy? Maddy asked.

Do you want to show me on the iPad? I’m sorry, Andy, Zara said.

Again, he tapped “angry.”

So you’re angry. Is it okay if we keep working on this? I’m sorry it’s hard, Zara said.

She still seemed to think his leg might be troubling him.

I’m going to ask a question, she said. Zara touched the “my leg hurts” icon on the iPad.

Again, he said no.

Is there anything I can do? I’m sorry. I don’t want to make you angry. Your leg is hanging off the rest. Do you want it to hang off? Are you just stretching it?

He indicated it was fine. Zara didn’t seem to know what to do, so she moved on.

If I say “Who is your wife,” is there an icon that says the name of your wife?

Andy tapped the correct icon. Zara explained they could customize the app, adding tabs for family, friends, extended family, as well as photos. She added Maddy's name to the app.

Andy was puffing again.

Are you breathing okay? Maddy asked.

Yeah. Are you in pain? I noticed that too, Zara said.

One of the nurses came in, asking if she could steal Andy away for an appointment with the day rehab physician.

Of course! Zara said. *His wife knows he has the appointment today, and she asked if you could call her, so she could listen in. She has her own doctor's appointment, starting at two, but if she's not in that yet, she'll be available. We were just noticing Andy was getting a little fidgety. Maybe some leg pain? Getting fidgety is pretty common in our sessions though*, Zara told the nurse. *Okay! Let me know if I can help with communication.*

Clearly Andy had an ongoing problem with leg pain. "Pain in leg" was its own separate icon on the iPad. But Andy repeated over and over that "anger" was bothering him, not leg pain. When Andy left for his appointment, I asked Zara about Andy's history.

He had a stroke about nine months before. He subsequently received therapy, but he was hospitalized again in May and discharged to a facility where he wasn't getting therapy. When he finally arrived at day rehab, he was nonverbal, except for yes and no, and he had been given no tools for communication. He spent several months virtually unable to express his thoughts and feelings. Andy was supposed to be at day rehab for only four weeks, with an emphasis on caregiver education and providing communication tools, rather than recovery. He was nine months out from his stroke, and he wasn't able to participate productively in therapy.

He makes it through the three hours, but it's not always a productive three hours, Zara said. *He's not a great fit for rehab. He fatigues easily.*

Zara also reported that Andy broke down in tears in about half their sessions. It's possible the emotional lability had a neurological cause, but from the session I observed, frustration at his circumstances also played a role. Nine months before, his life had been entirely different. Now he was being praised for identifying a picture of a toothbrush.

There was a time I was trying to probe more for verbal expression, but that would cause frustration and tears, so I stopped, Zara said.

Naomi, Caroline, Jada, and Aliana

Naomi

Naomi, a Black woman in her thirties, had recently given birth to her second child. She was also recovering from a tubal ligation, and her husband and she were taking turns with the overnight infant care. So when she woke up with a terrible headache, she wasn't immediately alarmed. She decided to take ZzzQuil and get some rest, but the headache didn't abate, and when she started vomiting, she asked her husband to call an ambulance. At this point, her symptoms became frightening, as she described:

> I'm just not feeling good. I'm really not feeling good. And he was trying to get me to stand up so he can clean me up and put on a new gown, so when the ambulance came, I would be okay. I would be dressed up and everything. I could not stand, for the life of me. I looked down and I saw my foot was turned backwards … and I'm like what's going on with me?

When the ambulance arrived, the paramedics asked what medications she had taken, and her husband explained she had taken a narcotic, as prescribed, for post-operative pain. At that point, they seemingly decided Naomi was overdosing. Naomi's husband had recently pulled a ligament, and he was struggling to juggle their crying infant and help Naomi stand. The paramedics reproached Naomi for being uncooperative. As Naomi recalled:

> And they were like, well, you're being very selfish. Because you—see, he over there with a newborn baby, and you're not trying to help us. You're not trying to stand up. And I say, I can't! If I could stand up, I would … I was trying to get my husband to take me to the bathroom, and he didn't, and I messed the stretcher too.

In the midst of this chaos and the humiliation of losing continence, Naomi heard the paramedic say they were calling Naomi in as a drug overdose. Naomi tried to contradict them, explaining she took the narcotic as prescribed, but Naomi remembered the paramedic telling her "You knew exactly what you were doing." Naomi's husband reported:

> But you know, I just feel, personally, that the projection of those EMTs was not professional. It was not compassionate, or considerate. The way they came in, they automatically were like, "ah okay, they're in the ghetto"… Then the fact, on top of the area we in, as soon as they came in to see "oh, it's a Black couple, okay. There's got to be drugs, you know?" And that's what they wrote it down as [on her medical paperwork].

He remembered the paramedics criticizing his wife for forcing her husband to deal with their children. As he pointed out, even if she hadn't been in the midst of a medical crisis, she was still recovering from recent childbirth and surgery, so their harsh criticisms seemed callous.

Naomi was taken to the nearest hospital, but fortunately, her husband called the hospital where she had just given birth, and she was transferred. At the second hospital, they diagnosed her with a postpartum stroke. It wasn't until she got to inpatient rehab that staff started mentioning the cause of her stroke: pre-eclampsia. As her husband recalled, they never heard the term "pre-eclampsia" from any of the medical personnel they encountered throughout her pregnancy and delivery and acute stroke treatment. Naomi and her husband pointed out that Naomi's was a high-risk pregnancy. As Naomi explained:

> What's mind boggling is—like when you get into the late like seven months of your pregnancy, I believe it is, you have to visit the doctor every two weeks…. When you make

> your nine months, you go every week. I'm wondering, did this pre-eclampsia—was it already a pre-existing condition? Or was it—was it overlooked?

Naomi had never been diagnosed with high blood pressure prior to her stroke, but she wondered now whether the signs of pre-eclampsia should have been caught prior to her delivery or in the aftermath. But instead, Naomi ended up going home, undiagnosed, and having a life-threatening brain bleed. She was hospitalized for an extended period of time, separated from her young children while her husband battled to keep their life together at home.

Despite everything she endured, Naomi was upbeat when I saw her again, on her day rehab discharge day. She was walking again, and she was driving. The driving was particularly important to her because she worked for a rideshare service to augment the family income, in addition to her primary job.

Caroline

When I met Caroline, I asked how her Thanksgiving was. She immediately burst into tears. Thanksgiving was supposed to be a big spread of food and all your family, but she had no food and no family this Thanksgiving. She seemed distraught, punching out at the air and sobbing. *I'm trying to "let go and let God." But I was a good person! Why did this happen to me?* she said.

Caroline, a Black woman in her forties, looked like a bedraggled Barbie doll. She was exceptionally tall and strikingly pretty, and you could tell she put effort into pulling together an outfit. Her nails were painted hot pink with rhinestones, and she was dressed in a jumpsuit and bolero jacket, with jewelry to accessorize and a bow in her hair. But her wig was askew, and she had hospital ID bracelets on both wrists. Her fingers were constantly in motion, clenching and flexing spastically.

She said the day rehab staff were the only support she had, but even they didn't understand what this was like. *But I always do more, work harder than they ask*, she said.

Caroline was living with her mother, and it infuriated her that her mother restricted her freedoms, wouldn't let her do "basic things." *I have a car, but she won't let me drive!* Caroline said. Caroline insisted she was capable of driving, but it seemed highly unlikely she could. It was terrifying to watch her walk. She lacked motor control, and the walker juddered along the floor as she moved. Even with a staff member's hands hovering around her waist for stability, it looked like she could topple at any second.

When a PT arrived to begin Caroline's session, the PT briefly let Caroline vent and then sympathetically said, "family, right?" and immediately pivoted to business. *Are you ready to work?*

As they practiced walking, Caroline was sporadically tearful. "Gotta do the hard stuff, right? Take your time," the PT said, encouraging but not leaving space for a breakdown that might derail the session.

Afterward, I tentatively asked Caroline if she was willing to schedule an interview with me. I fully expected her to say she couldn't or didn't want to, but she jumped at the offer. She begged me to call her mother and request a later pickup. Caroline was insistent: she didn't want to go home.

Caroline's story was tragic and complicated. She was hit by a car, over a year prior, and she was initially discharged from acute with just orthopedic follow-up, no ongoing neurological care. When she was readmitted for a surgery, about ten months later, they recognized that she could benefit from neurorehabilitation for her TBI, and she was sent to inpatient rehab and, after discharge, to day rehab.

In the time between her accident and starting rehab, her life had fallen apart. Her husband filed for divorce, and she was living with her mother and niece. Unfortunately, Caroline and her mother didn't have a strong relationship prior to her injury, and Caroline bridled at her mother's attempts to control her behavior, as Caroline explained:

> I don't need [my mother] to tell me a motherfucking thing. You ain't tell me nothing, my whole life. Why you trying to tell me now I'm [in my forties]? Where the fuck was you when I was 11, 10, 9, 8, 7, 6? Where was you? You didn't tell me nothing before, what are you trying to tell me now? I'm [in my forties]. I'm grown now … because I've lived my whole life without listening to you. I've done good. I went to college. I've done everything without you, mama.

Now, her mother was back in her life and telling her to sleep, eat, go to therapy. She was trying to prohibit Caroline from smoking, which made Caroline irate. Caroline owned a home that was currently rented to tenants, and she believed she was capable of living there independently, but as she told it, her mother wouldn't let her. And Caroline's niece was driving Caroline's car, without Caroline's permission. The disagreement over the car escalated to the point that Caroline called the police. Caroline said the police got her niece to agree to drive Caroline around, in exchange for use of the car, but Caroline said the niece still wouldn't agree to take her anywhere.

"I want to leave. Now! You are *using* me. I want to leave. You are using me for my car!" Caroline seethed.

Caroline told me she had no way to contact anyone because her cell phone broke, and her mother wouldn't replace it. She was awarded a small settlement following her accident, but her mother controlled the funds and spent them as she saw fit. The picture Caroline painted was one of control and possibly even neglect. She was desperately unhappy with her circumstances. But at the same time, it was hard not to question elements of Caroline's account. To begin with, it seemed entirely possible that at least some of Caroline's mother's domineering behavior was out of concern for Caroline's safety. I could easily believe that Caroline *couldn't* live independently or control her own finances. But that didn't necessarily mean Caroline's mother wasn't *also* abusing her power. And undeniably, Caroline was in acute emotional distress.

Caroline presented a dilemma for the medical staff at day rehab. Her mother had been calling them, complaining that Caroline was abusive and aggressive. But the mother's reports didn't correspond with what staff saw at day rehab.

How can she be so fine here, but so … aggressive, at home? the nurse asked.

But the mother says she's so violent, not eating, smoking cigarettes, the doctor said.

None of that contradicted what Caroline told me herself. Caroline even described an incident in which she broke her mother's TV because her mother wasn't allowing her to watch it. It was entirely possible Caroline presented a different face at home.

The staff wasn't sure how to proceed. As far as the nurse recalled, Caroline was a Medicaid patient, so her insurance wouldn't cover psych sessions. And when they reached out to the facility psychologist, she didn't want to get involved in Caroline's case. She gave the nurse a pamphlet for inpatient behavioral health facilities, but she said day rehab psych wouldn't do Caroline any good when clearly so much more was needed.

The doctor and nurse dove in themselves, trying their best to figure out what they could possibly do to help. But to complicate matters, the facility didn't have a social worker,[16] at the moment. The social worker assigned to two other facilities was allocating one day a week to the North and South sites, but as she told me, "If it was one of my facilities, I would be making direct phone calls, but I'm only helping, so they have to deal with most of it and I just give my advice."

She also explained that North and South were relatively large facilities, but they still shared a social worker between them, and the previous social worker in that position hadn't even been

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[16] See Chapter Three: The Transition Home.

full time, so best-case scenario, North and South each had only about two days of dedicated social worker time per week to assist patients with highly complex needs.

The doctor called Caroline's mother and asked to speak to Caroline directly. As the doctor later explained, she asked Caroline if she was in a position to speak freely, and Caroline said she could only answer yes or no because her mother was listening. Caroline was immediately agreeable to the idea of family counseling, and the doctor told Caroline an SLP would work with her to set up that appointment during Caroline's next speech session. The doctor suggested a mood stabilizer or antidepressant, but Caroline didn't want to be medicated.

When the doctor talked to Caroline's mother, however, the mother doubted Caroline would truly go along with family therapy. She said there was no one in the family who Caroline hadn't "abused," so she wasn't sure who Caroline would agree to go with. The mother said she'd had to call 911 in the past in response to Caroline's outbursts.

The doctor hoped family therapy might help mediate the ongoing disputes and teach the family techniques for managing someone with a brain injury—what to say and not say, how to avoid or—failing that—calm a negative reaction.

But a week later, they received word that Caroline would be absent from therapy. She was inpatient, following a suicide attempt, and she was refusing to let her mother see her.

The medical staff were in a quandary. Caroline's alleged aggressive behavior was a possible effect of the frontal brain injury she sustained, so part of the problem was likely neurological. But, as the nurse pointed out, Caroline's medical records didn't report combative behavior during her hospital stay, so part of the issue was likely the toxic relationship between Caroline and her mother triggering reactions that were now harder for Caroline to keep in check due to her brain injury. Both Caroline's claims and her mother's claims could be true: Caroline's mother could be struggling to deal with Caroline’s temper, but it was also possible she wasn’t providing a healthy or even adequate environment, and even taking advantage of her injured daughter. At the very least, it seemed clear Caroline’s reactivity stemmed, in part, from understandable frustration at her situation; she was an adult, and she had been happy with herself and her life before her injury, but now she felt diminished, infantilized, and surveilled. But it looked like her mother might be her only option. She didn’t have anyone else.

Jada

A couple of weeks after Jada’s partner was killed, Jada was injured as a passenger in a car accident. Jada was a Black woman in her thirties. She had young children at home, and no partner to look after them while she was hospitalized. She had sustained serious injuries, including a severe TBI, and her doctors urged her to enter the inpatient rehab program. She needed continued medical care and intensive therapy.

But while Jada was in the acute hospital, her mother was caring for her children, and Jada didn’t feel she could leave her kids with her mom any longer. As she explained:

> [My mother’s] not used to kids. So she can't really do it…. She don't really know everything to do. She don't know—she don't have the patience. And then, I don't want my children to feel uncomfortable with somebody else. Because, you know, kids understand what's going on, if a person is irritated with them or anything like that. And that's—they're used to—they have a home to go to. So I want them to be comfortable.

So against medical advice, she went home to care for her children, on her own, even though Jada herself was in need of ongoing care. She didn’t have any help at home, so as she said, “I had to basically force myself to be strong and work extra harder.” She was still experiencing ongoing TBI symptoms, including extreme head pain, but she tried her best not to let her children see her suffering. To compound the situation, she had lingering mobility and cognitive changes. It took her several weeks to begin day rehab because, as she explained:

> I had to make sure my children are all right and able to get back and forth to school. Then I had to find out how the transportation system worked … because I'm not remembering everything. And my speech was way worser than this. So half the time on the phone, people—nobody understand what I was saying. So I'm getting irritated. I'm like, "Oh my god, how am I gonna do all of this?"

When she left the hospital, she was supposed to see several specialists to follow-up on the neurological and physical damage from the accident, including a urologist, a neurologist, an ophthalmologist, and a hearing specialist, but her PCP stopped accepting her insurance. As she said:

> So I had to find a new doctor out here. And I just wanted to check to see if my bleeding all the way stopped, on my brain. Is it completely stopped? Is it all the way back to where it was? Like, is it normal?

Jada was also anxious to get back to work to support her family. Before the pandemic, she worked two jobs—at a factory and a nursing home. But when schools closed, she had to quit her jobs to take care of her children. They were managing financially because she was collecting unemployment, and she started her own small business buying clothes wholesale and reselling them online. Before her accident, her children were about to return to in-person school, so she was gearing up to return to working outside the home. With her partner's death, she was the sole breadwinner. But then the accident happened. And now, she was anxious about getting back into the job market with a new set of disabilities, including problems with vision, hearing, cognition, and communication.

Due to the social worker shortage, no one at day rehab had managed to discuss disability or social security with Jada. She owned her home, and she had SNAP to feed the children, so she was scraping by, but barely. Jada did her best to remain optimistic:

> But I don't know, maybe this was God's plan. And I'm a—I believe in God. And I know every—sometimes, something happens for a reason. So I'm just being patient. And, you know, I'm still blessed. I might not be able to have all the money I want and buy things. But I have a roof over my head. I'm able to feed my children. So I'm grateful for that.

When we last spoke, Jada was working out a plan to put off a couple of utility bills to allow her to buy a present for each of her children for Christmas.

Aliana

Decades ago, Aliana was shot in the head in a domestic violence incident. Her sister's abusive partner showed up at her mother's home, and Aliana stepped outside to try to talk him down. That was her first neurological injury. Following the gunshot wound, she had a grand mal seizure. After that, she changed careers, leaving her job as a financial aid director to secure more comprehensive healthcare coverage.

A few years later, she fell and sustained a concussion. After the doctors read her imaging, they called her back in to the hospital: they found a tumor in her skull. She had gamma knife radiation surgery to reduce the tumor, but she was instructed to come back at regular intervals for imaging to monitor tumor regrowth.

Unfortunately, she was going through a tumultuous period of her life. She was raising a young daughter, her only child, and Aliana moved them out of the home they shared with Aliana's fiancé. "He had anger management problems. I didn't want my daughter raised around something like that," Aliana said. They were on their own, but so far, Aliana had been able to manage. She was working as a teacher, so she had a solid income.

But then her supportive boss left the school and was replaced by a principal who refused to accommodate Aliana's ongoing disabilities caused by the gunshot, the seizure, the concussion, and the tumor. Aliana had trouble with organization and executive function. As she explained:

> And once technology came into the classroom, I couldn't seem to keep up with all the reporting data that was needed. The individualized IEP plans, the various meetings, you know, the differentiated teaching to students, new input of training that would only be about two days at tops, but no manuals given out where you can reread the material or highlight it. So needless to say, I was having a hard time trying to keep up with the new age that was coming into the school.

When the new principal came in, “He immediately started trying to pull apart the various things [the previous principal] had put together to support me.” There was no existing Americans with Disabilities Act policy in place, so Aliana had to write her own proposal. She got approval through the ADA to have a teaching assistant. The assistant was supposed to escort Aliana’s students between classes to give Aliana a chance to collect herself and prep for the next period. But the principal wasn’t satisfied with the arrangement, and Aliana was one of longest serving (and therefore highest paid) teachers. Eventually, he told Aliana she could either take voluntary leave or they would terminate her.

Aliana had a child to support, so she took medical leave and then went on short-term disability. Short-term disability carried her for three months, but her long-term disability application was denied for lack of documentation, despite her long and checkered medical history.

In the interim, Aliana and her daughter were evicted. As Aliana described:

> What it was doing to my credit history you can imagine, being evicted. A teacher at your top pay grade. Now you're homeless, you're going to pantries, you're going to [a local organization] for medication. You're getting public aid for food stamps, called SNAP now…. So my daughter now, when we both stay at these various homes with various people, we can at least barter the sleeping arrangements with the food arrangements.

Aliana’s daughter’s school tried to push her out because she no longer lived in the catchment area, so Aliana fought the district to allow her daughter to finish out high school at her current school. Aliana was concerned about her daughter’s mental health—she had become withdrawn, self-conscious about her friends finding out her family’s situation—so Aliana found a way to get her into counseling. In the meantime, Aliana didn’t have insurance, so she wasn’t attending her neurological follow-ups.

Then, Aliana fell and hit her head again. When she contacted her neurosurgeon, he suggested a CT scan to check for further damage, but without insurance, it was going to cost her $10,000. That was out of the question, so Aliana went without. But her neurological symptoms worsened, and she began to experience intense pain on one side of her face. It was later discovered that the tumor had begun to grow, pressing on a nerve, causing trigeminal neuralgia. Aliana reported, “So I couldn't eat, I couldn't drink, I couldn't sleep, I couldn't take a shower, couldn't brush my teeth.” At the time, Aliana didn’t know about the tumor regrowth, but she suspected the pain was neurological.

She consulted a primary care physician, but he tried to prescribe her Norco, a combination acetaminophen and hydrocodone. She didn’t want to be on an opioid, and a friend had told her about gabapentin, a non-opioid, targeted specifically at nerve pain. Aliana was frustrated. Her doctor was trying to put her on an addictive painkiller, seemingly ignoring her concerns about the underlying cause of the pain and her preferences for treatment.

Eventually, she was able to return to the neurosurgeon, and they found “a walnut-sized tumor.” She had a surgical decompression and resection, but she awakened with additional neurological symptoms, including double-vision, mobility and balance issues, and cognitive changes. She went to inpatient rehab, but she feared there was an unresolved issue. She complained of feeling cold, but her concerns were dismissed. At her neurosurgical follow-up, the doctor was alarmed; he sent her to the emergency room. Eleven hours or so later, they decided to admit her, following some bureaucratic wrangling, as she reported:

> I was eavesdropping—I'm gonna be honest with you, Virginia. It sounded like there was a discussion about who was going to take responsibility for me because I was at [inpatient

> rehab] when I came to [the acute hospital] for the post-op … But because the neurosurgeon had sent me to the emergency room and they needed to admit me, that meant that, who was going to admit me and who was going to discharge me?

As it turned out, Aliana had a double pulmonary embolism. Aliana's daughter was enrolled in college, but she came home to help care for her mother. Staff at inpatient rehab felt Aliana couldn't manage on her own at home given her balance and mobility issues. Aliana felt guilty about relying on her daughter, so she was determined to recover as quickly and completely as possible. Together, they were doing what they could to keep their household afloat.

Weeks later, Aliana was at day rehab, working toward recovery, but she was aggravated and worn down by a lifetime of coping with disability and barriers to access. At every point, Aliana felt she was forced to look out for herself in an overly complicated and, at times, uncaring system:

> When you advocate for yourself, then people think you're being too wordy, and too mouthy, and too know-it-all, and you won't take professionals' advice. But then if you don't speak up, then you get what they give you…. So you know, I'll ask questions. I have to, you know, because I've had people who want to write me up for MRIs, and I'm like, I can't have MRIs. Have you checked my record? I've got a bullet in my head. I can't have an MRI, I got metal in my head.

She had seen her medical records, and she knew she had been recorded as "combative." But at every turn, being willing to push and persevere in asking questions had been her saving grace. Over the years, lack of access to medical treatment and disability accommodations precipitated a downward spiral, as Aliana described:

> Well, you got to remember, I wasn't always broke. I was a person who was doing pretty well in life, you know? But I paid for that by getting my education and doing everything else I had to sacrifice.

Aliana felt she had done everything right, everything she could. But here she was, despite her best efforts.

Chapter Five: Re-Constructing Identity

As discussed in Chapter One (Goals Over Time, Goals in Conflict), “return to Self” was a primary objective for most patients. When I asked patients to tell me more about what it meant for them to get back to “normal” or get back to “being me,” a central theme emerged: desire to maintain identity characteristics and social roles that were particularly salient to their sense of Self. Twinned with these hopes were anxieties about what it would mean and how they would cope if the desired “return” was incomplete.

In this chapter, I will discuss how patients' experiences with and attitudes towards re-constructing identity in the aftermath of injury shifted over time as they transitioned from inpatient to outpatient settings. In the months following injury, patients took their idealized past Selves as their primary reference points, but they also reshaped their identities in interaction with other patients and with (often stigmatized) images of disability available to them in the rehab context and in their broader social worlds. I will examine how patients discussed their sense of who they were and wanted to be, particularly with respect to significant areas like dis/ability, health, and professional status and important traits like independence and intelligence.

Inpatient Rehab

As previously discussed, some stroke and TBI patients (especially in the immediate aftermath of injury) had problems with insight, making it difficult for them to perceive changes that might otherwise have been deeply troubling to them. Patients who lacked insight might be troubled for other reasons (e.g., they are furious at being kept in the hospital under what they deem false pretenses), but they were often unconcerned about questions like "Will I be able to return to my job?" or "Will I still be able to pursue hobbies that give my life meaning?" Some believed the only obstacle keeping them from joining a conference call or heading back to their construction site was the unreasonable intransigence of the staff.

The Self in Suspense

But for patients who were largely aware of post-injury changes, their initial reaction was often shock at the suddenness of it all. For most stroke and TBI patients, the life-changing medical event happened without warning, with no opportunity to prepare. Patients talked about the stark contrast between their present condition and who they had been, until very recently. One stroke patient emphasized, "The day before ... I was at the gym for almost two hours, like doing a hard workout" (stroke, White, female, inpatient). Stroke patients, in particular, often arrived at inpatient rehab within days of their initial hospitalization. Their sense of Self was still very much anchored by recent memories of life-as-usual, if not robust gym-honed health. The suddenness of the change was disorienting, and it contributed to a sense of unreality. Patients talked about the abruptness with which their lives (and their bodies and minds) had changed.

> [The stroke] stopped me in my tracks. I mean, it's like you're going along in life and all of a sudden, a door slams right in your face. And I'm like, oh my god. Really? You never—you never think. [tearful] (stroke, White, female, inpatient)

> It's just very surreal. It was for me. It felt like it came out of nowhere. You know, it's like, I just kind of woke up in a hospital and I was like, what happened? It was bizarre. (stroke, White, female, outpatient)

As discussed in Chapter Two (Managing Expectations), staff members were reticent about offering concrete predictions. The "no promises, no limits" framing many staff members adopted could leave patients feeling at sea, as though no one could (or was willing to) tell them what to expect:

> It was scary. I was confused as to how this happened. Worried about my job ... although they was telling me, you know, you're gonna do rehab, you know, things are gonna get

> better. We can't promise you 100 percent ... it depends on you. And things can—things can get back. It was like, they didn't make any promises. So in the beginning, hearing that, it was still confusing. (stroke, Black, female, outpatient)

As discussed in Chapter One (Goals Over Time, Goals in Conflict), inpatients were often vague in describing their goals, and many of them reported actively avoiding thinking about the future, preferring to focus on the rigors of rehab and put as much energy as possible into recovery. Recovery was treated as a crucial variable: patients saw their present post-injury Self as (hopefully) temporary. They bracketed the question of who they were now and would be in the future until they were further along in recovery. The inpatient Self was a Self in Suspense. When asked about future plans, hopes, anxieties, and anticipated changes, many patients responded with some version of "it's too soon to tell." When asked what they had been like before and how they perceived themselves now, many inpatients responded as follows:

> Interviewer: Has anything changed about the way you would describe yourself?
>
> Patient: I don't think so. But I need to see how my recovery goes. (TBI, White, female, inpatient)
>
> No, I don't think that'll change. I hope not, anyway. But it's early too. So. We don't know. Nobody knows. [tearful] (stroke, White, female, inpatient)
>
> Interviewer: So how would you describe yourself now?
>
> Patient: I'll tell you in a week. (stroke, White, male inpatient)

So much had changed in so short a time that patients (and families) felt their lives and their Selves were in a state of flux. As one family member put it:

> I hope we truly get to a place where we can be independent and go back to living our lives. Like, I feel right now things are suspended in air. So I'd really like to find a place to land for a little bit and arrive, I guess. I feel like we're working on arriving. We haven't arrived yet. So I'd like to arrive. (wife of stroke patient)

It was difficult to envision and plan for the future with so many remaining unknowns. Recovery itself was foremost among these unknowns: while still in the process of rehab, patients and their families felt they couldn't truly know what they were dealing with.

Fighting for Return

Their hope, of course, was that when they "landed" they'd be back essentially where they started, and their sojourn in the land of disability would be temporary. But at the very least, they felt they needed to get closer to a definitive (or at least stable) version of themselves before they could pause, reflect, and plan, as this patient and his wife suggested:

> Interviewer: What do you want most in all of this right now? What are you working toward?
>
> Patient: Some place and point where I think, okay, this is where I'm at, and this is what I can do. And I can manage all right. But everybody wants that when their life is in flux. (TBI, White, male, inpatient)
>
> I know it's going to impact our life. I just don't know how much yet. You know, I really don't know. Because it's hard to tell, especially while he's still recovering. And—I know our life will be different. I just don't know by how much. (wife of TBI patient)

Many inpatients were hoping for an almost complete return to their previous life and mental/physical status. They were willing to entertain the possibility of a nominal change, one that wouldn’t substantially alter their life circumstances or force them to permanently reconstruct their sense of Self. One common refrain was, "I don't know if I'll be there 100 percent. I'll hopefully at least be there 90 percent" (stroke, White, female, inpatient). This new terrain of disability was disorienting, and the "normal" Self felt so near and so recent. In many ways, patients thought of themselves not as passively waiting to find out how they would be, but as actively fighting for a return to the normal Self and against their present state.

> But if I'm still in this condition, I see us figuring out how to basically survive this and dealing with that, working with that. I mean now, I feel like I'm fighting it. Because I don't want that. (stroke, White, male, inpatient)
>
> I don't like to talk about what I'm like now. Because I'm not finished. Just a little pause, until I get well. Cause I'm gonna get well again. If you don't believe that, then all I can say is, well, you don't know me. I've got this to prove to myself. I'm going to do it. (stroke, Black, male, inpatient)

As these two statements reflect, many patients spoke defiantly, highlighting their determination to recover as fully as possible. They were "not finished"—both in the sense that they didn't feel they were done fighting and in the sense that the present Self was (hopefully) in progress toward a desired endpoint.

Patients emphasized their determination and self-belief. Many of them admitted the possibility that their lives might change, but as in the following example, they hoped it would not be in unacceptable ways:

> I believe in my strength as a person; I believe in my body, which is going to figure it out somehow. And I believe in me, that I will be doing what is needed to get better. So what else can I do? So I expect my life not changing dramatically. I may be able to adjust some things, but it's not going to—I'm not—never going to be a burden to my husband or to my children. It's not in my plan. (TBI, White, female, inpatient)

Inpatients often felt their lives, bodies, and minds had been thrown into chaos, and they experienced the full range of emotion one might expect in response. They were stunned, frightened, anxious, at times deeply dejected. But on the whole, they were inclined toward optimism that recovery would bring back most of what felt lost. The social environment of the hospital contributed to this tendency.

The Hospital as Cocoon

As discussed in Chapter Two (Managing Expectations), staff made considerable effort to preserve patients' motivation and avoid “crushing hope.” Even if staff thought a patient’s hopes were unrealistic, it was seen as counterproductive to give them a brutally honest prediction and potentially dampen their motivation. The inpatient rehab environment also removed patients from their usual contexts and insulated them from many of their outside responsibilities, contributing to the sense of suspense, of existing in carved-out time, dedicated to advancing as far as possible in recovery before having to consider the permanency of any changes.

If patients were overly focused on outside concerns (e.g., trying to check work email), staff encouraged them to focus only on getting better. In many cases, staff and family also tried to prevent patients from working or engaging with other complex responsibilities. Staff genuinely believed that patients should carve out time to focus on recovery, but this advice served a dual purpose as a face-saving fiction. It insulated patients from the potentially painful truth that they might not currently be capable of doing their job, and perhaps never would be again. Being told to focus on recovery preserved motivation both by reinforcing the Work Hard and Get as Much Back as Possible ethos and by helping bracket longer term questions about how their lives and Selves might be changed.

Not (Yet) Disabled

In keeping with the Self in Suspense/Self in Recovery framing, very few patients self-identified as disabled, particularly in the early stages. "Disability” and related terms were seldom used by staff in conversation with the patients. Patients themselves brought up disability almost exclusively in terms of repudiation:

> I want my life to function like it did before the accident. I don't think that's going to happen with how many bones were broken and pins are probably gonna be in there. But I don't want to be disabled. I want to be able to do my job and keep a job, because I love to work. (TBI, White, male, inpatient)

> I don't want to feel like I'm a handicapped, you know. That'll prevent me from doing all those things: hiking, biking, skiing. I don't want to lose it. (TBI, White, female, inpatient)

Disability identity was present primarily as a threat or stigma. Some patients were utterly deflated by the prospect of lasting disability:

> And before this happened, I was a normal person just like you. And then I wake up and I can't do anything ... it's really—it's like I died. That's what I feel like sometimes. I say, I died. They gotta drag my body around. Except I can keep talking. But they got to keep moving me out of the way, one place to—yeah, it's crazy. I can't recover fast enough. (stroke, White, female, outpatient)

In statements like this, patients expressed feeling trapped inside a disabled body. They disliked depending on family for assistance with basic tasks. To them, to remain disabled was to feel helpless and burdensome. Patients on the whole had internalized a great deal of disability stigma. Most patients avoided self-identifying as disabled and were concerned about being identified as such by others. As one patient put it, "I'm ashamed a little bit because I don't want to be looked at as being handicapped" (stroke, Black, female, outpatient). Patients paired terms like disabled or "handicapped" with descriptors like "weak."

Patients at this stage were likely to react against anything that hinted at permanent adaptation to ongoing disability, as opposed to return to normal. Patients and family associated disability with incapacity, even with loss of Self, as this family member's comment suggests:

> It's kind of funny because she'll forget something once in a while, but so do I. So it's not like she's disabled, or it—now maybe they have a different medical perception of what's going on with her brain. I don't know. But to me, she's fine. I mean, we, I—in one of the emails I wrote to somebody, I said, “We've had fun conversations and fun reminiscing.” (TBI patient's niece)

On the whole, patients and family saw disability as incompatible with continuing to pursue the same goals and passions in life, or with remaining fundamentally the same person. As such, patients often rejected proposed accommodations they associated with disability and incomplete recovery. Therapists wanted to sustain hope, and they wanted their sessions to go as smoothly as possible; to that end, they carefully skirted discussions that could provoke negative emotional responses in patients. For instance, as described in Chapter Two (Managing Expectations), if a patient was reluctant to learn how to use a wheelchair because they were determined to walk again, a therapist might frame the wheelchair as a temporary expediency, a stepping stone toward more complete recovery.

A young, male stroke patient, for instance, shut down a discussion about adaptive sports when his medical team brought up the option of setting up an appointment. He wanted to focus on rehab and get back to playing his chosen sport in the way he always had. In another instance, a young, female stroke patient described a conflict with her husband:

> There was one particular time [my husband] got frustrated, because he came up here and he said, “Oh, I forgot they got to give me a handicap sticker for your car.” And I say, a handicap? I don't want no handicap sticker! I'm not handicap, you know. And he [said], “Well, no, no, no, you need to stop thinking like that and start thinking about it for the greater good. We could use the sticker”.... He was just thinking about—telling me [to] think about it in a good way. Like, you can have the parking pass, and we'll pull up to grocery stores and stuff, then we get right in the front. Like, why are you looking at stuff like a negative? (stroke, Black, female, inpatient)

Patients didn't feel ready to accept adaptations. At this stage, accepting accommodations felt too much like taking on a disability identity and accepting a permanently changed Self. Most patients were hoping to get back to the pre-injury Self, with which they still predominantly identified.

All of this is not to say that patients were universally optimistic. Mood and attitude toward recovery depended on a variety of factors,[1] including the extent of the injury that occurred.

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[1] Patients could request or be referred to psychology and psychiatry treatment if they exhibited or expressed signs of depressed mood. Rehab psychologists explained that they have an intentionally narrow scope of practice, in large part because even if a patient’s insurance will pay for psych visits, psychologists generally only get to see a patient a handful of times over a period of weeks (or in day rehab, a few months). They refer patients to outside psychologists and psychiatrists for long-term, in-depth treatment. Within the rehab context, their primary goal was essentially triage—making sure the patient's mental state didn’t prevent them from actively participating in therapy and making progress toward recovery.

Certainly, patients whose bodies and minds were more profoundly affected had a harder time envisioning themselves "getting back to 100 percent."

Some patients reported having experienced a period of sadness early in their inpatient stay, but they generally framed it as an obstacle they had to overcome in their efforts to recover. I spoke to patients who were very emotional for a variety of reasons. I didn't interview any patients in acute despair, but staff told stories about such patients. Two nursing staff members separately brought up their experience with "voluntarily incontinent" patients, patients who appeared to have no cognitive or physical impediments preventing them from getting to the toilet but who were routinely incontinent. The nurses theorized that these patients were perhaps in such abject despair about their condition that, "maybe they're saying FU to the world. Maybe they're depressed, maybe they're like—it's just a point of like, I don't care or, you know, like, kind of learned helplessness" (staff, inpatient).

A lot of patients expressed frustrations at being in the hospital, some more vociferously than others. One Black male stroke patient described his hospital stay and the experience of being dependent on others as "a horrible ordeal." This patient was consistently resistant to therapies, and due to his stroke, he was often disoriented and frustrated with staff, so he was by no means a model rehab patient. But even he, like most inpatients, was overall optimistic about himself and his prospects to repair what he felt he had (hopefully temporarily) lost.

Outpatient

Emerging from the Cocoon, Emerging Concerns

In the longer term, as patients were discharged from inpatient rehab and continued to outpatient day rehab, a new set of concerns arose. To some extent, patients expressed these anxieties at the inpatient stage, but for many patients, worries begin to crop up in earnest once they left the hospital, returned to their routines and social contexts, and began to contemplate the possibility that "return to normal" may be more complicated a goal than they initially conceived.

I first interviewed Scott (a White, male stroke patient, in his thirties) when he was an inpatient. His stroke was caused by an arteriovenous malformation (AVM) rupture, and he was otherwise in very good health, so he was expected to recover well. He participated enthusiastically in therapy, receiving excellent feedback from his therapists, and he left inpatient rehab earlier than expected and on a positive note. As discharge approached, he was pleased with the trajectory he was on and excited to go home to his young family. I ran into him a few months later, at one of the day rehabs, so I had the opportunity to re-interview him and catch up on his outpatient experience. As it turned out, he struggled with the outpatient transition far more than anyone (himself included) anticipated. On the ride home from the hospital, he suffered overwhelming motion sickness, and his experience was more or less downhill from there:

> It was very hard. I got pretty depressed because it just felt like, every other day I was learning a new thing that either I lost or was affected from the stroke. And just the constant loss just really got to me. It just felt like—at inpatient I felt like I had a really tremendous experience. It was great. I was really happy with that. And then the ride home, feeling sick, and then getting home and constantly like having new obstacles that I didn't realize I would have, it just felt like I was just going down, down, down. Like it was just incredibly depressing and like I just sunk into this terrible, terrible depression. I just was crying all the time. I couldn't—I felt like I couldn't get out of it. And sometimes it'd be like for simple things that would trigger. And then just knowing that I kept getting that kind of sad, without like being able to control it. Just felt like I was trapped in that mindset. And just felt like I wouldn't be able to get up naturally like so, yeah, getting home—to me, I felt like it was, it was probably the worst day I've had. One of the worst days I've had since the stroke. I was expecting it to be my best day because I was—that's what I was working for, getting home, because I hated being in the hospital. (stroke, White, male, inpatient/outpatient)

Scott had seen himself as one of the "good patients," a hard worker, previously healthy, with no stroke risk factors, on track to return more or less to his previous life and Self. Once outside the controlled environment of the hospital, however, Scott became increasingly aware of the discrepancies between his pre- and post-stroke Selves, and less certain that he would manage to fully return to before. The contrast between his imagined triumphant return home and the reality of his struggles heightened his despair.

Still Counting on Return

At the day rehab stage, some patients still saw themselves as just passing through disability, on the way to recovery. The single-minded determination and refusal to accept the possibility of defeat many inpatients exhibited were still very much in evidence in day rehab. Alan was a Black, male stroke patient, in his fifties, and he described his stroke and rehab as "just something that I'm going through, and I'm gonna get through, and I'm gonna look back on and be like, ‘Man, that happened to me.’" Like the inpatients who distanced themselves from disability by resisting accessibility adaptations, Alan staunchly rejected the recommended safety modifications to his home and lifestyle:

> I didn't make no changes to my house because I wanted everything to stay normal … because I can't see on my left side. So I have to scan the room. And I have to watch where I'm walking. And then, I've had some incidents. I've had some incidents. It's all—it's all trial and error with me! [laugh] I'll tell you, I built—before this happened to me, I built a fire pit in my backyard, right? I done walked into—it's brick. I done walked into the fire pit and I'm on blood thinners, so my knee swoll up like a balloon and I was on my—on my leg. My dog was laying up under me. I didn't see my dog. Tripped over my dog and fell on the arm of the couch ... and when you touch the couch, it feels all soft and nice. Boy, when you in my situation—and see like, when *you* fall, you throw your arm up and brace yourself? You know what I'm saying? Or something like that. Yeah. And when I fell, I fell like a ton of bricks. Because at the time, I had no motion in this arm. So when I fell, boom. It bruised my ribs. Um, I was cooking dinner for my wife. And I was cutting vegetables. And I almost sliced my finger off. So it's all been like trial and error. [laugh] (stroke, Black, male, outpatient)

Even though the stroke affected Alan's mobility and awareness of obstacles in his surroundings, Alan was unwilling to make compromises. He wanted his life to be normal, and despite his series of mishaps, he behaved as if he could will himself to overcome the changes to his perception and mobility. Despite this stoicism, Alan broke down in tears during our interview, talking about his drive to get better and his fears that he would remain in his present condition:

> It's hard. It really is hard. Because—wait a minute. [tearful] Because you want to be yourself. And I'm not. You know? As much as I try. [sobbing] As much as I try, I'm not me. It's hard. It's hard. It's so hard. (stroke, Black, male, outpatient)

As much as he tried to maintain the belief that this present version of Self was temporary and he would soon return to the "me" he truly felt himself to be, his confidence wavered.

Confronting the Possibility of Incomplete Return

For the majority of outpatients, it became progressively harder to maintain the Self in Suspense as time went on. This was in part because recovery often started to plateau, as patients were warned it likely would. The day rehab psychologists reported that as progress began to taper off, patients often became frustrated and worried. Patients became more acutely aware of the remaining gap between the present Self and "normal" Self, the standard to which many of them still held themselves. As one patient put it:

> I'm worried about never getting back to normal, so to speak. Never being able just to—just to be a regular person. I worry about that. Just never getting back myself. (stroke, White, female, outpatient)

As progress slowed, many patients became anxious about time running out. Patients were often told by staff (or learned from family or through online research) some version of the recovery timeline:

> There's a point of no ret—there's a ceiling effect on recovery, right? So like, the most important time is, you know, two to four months after, you know? The most significant progress happens two months after your stroke, and then you still make progress for the next two years, but it's not as quick. (staff, inpatient)

> It's at least a two-year rehabilitation. And usually at the one-year mark is when we have a better idea of—they're going to be closer to their new baseline. And then after a year they make progress, but it's much slower. (staff, inpatient)

When staff delivered this information, it was often with the objective of encouraging patients to work as hard as they could during the early window of optimal recovery, and/or to highlight that recovery was “a marathon, not a sprint.” Recovery was expected to happen over a longer time horizon than patients generally anticipated when they first arrived at inpatient. While it might be comforting, initially, for patients to hear they would continue to make gains after inpatient discharge, patients often began to fixate on perceived “deadlines” as time went on. With a significant date looming (two months, three months, a year), patients began to worry that they wouldn’t actually get as close to the pre-injury Self as they hoped.

The Closing Window

Staff tried to deliver these timelines with caveats: every patient is different; you can still continue to recover beyond the optimal window, but you'll progress more slowly; once neurological recovery has stalled, you can continue to make "functional" improvements by modifying your environment and learning adaptive strategies. But patients tended to reify the recovery timeframe, treating it as a closing window of opportunity. The "window" initially fostered hope, helping inpatients accept the fact that neuro-recovery happens on a longer timescale than recovery from appendicitis or a broken ankle. But as time passed, the ticking clock created a sense of urgency. And as the "window" closed, it could provoke despair. Alan spoke to that sense of urgency, here:

> They said, your first—you get your first—let me say—let me say this right ... um, your most strength and your most—I want to say your most advancement—your most stuff you get back come within your first six months. And I'm like four months now! So I got two more months. I need to go! I gotta go. (stroke, Black, male, outpatient)

This attitude could also lead to self-recrimination, especially among patients who, for whatever reason, hadn't worked as hard as they might have during their inpatient stay. Some patients felt they hadn't fully appreciated the value of therapy and/or the importance of making the most of their window of optimal recovery. Patients also reported that during their inpatient stay, they were fatigued, in pain, demoralized, disoriented, etc. and consequently hadn't taken full advantage of the time and resources available. As one patient explained:

> [When I was inpatient], I was devastated. I felt—what the hell happened to me? You know, why am I in here? I wish I would have fully taken advantage of being there. Like okay, I'm here to do physical therapy. All right! Let's go! All I could concentrate on was getting back into bed. I just wanted to get back to bed, you know. I was hurting, so I didn't take full advantage of being there. I wish I would have. I didn't really understand where I was at. And what was happening. Yeah. I just wish I had fully understood how important the therapy was to recovery. You know, I would have gone full force into it. I don't think I gave my best effort, let's say, when I was [inpatient]. I probably could have done more. You know, I could have done more at home too. When I went home. (stroke, White, female, outpatient)

Day rehab patients also worried they were *currently* squandering valuable recovery time. Some patients fixated on the quality of the therapy they felt they were receiving in day rehab. If they believed their window was closing, it became increasingly important to wring out whatever gains they could in the remaining time. Inpatient therapy took place six days a week, but patients generally spent only two to three half-days a week at day rehab. Staff explained that the model of day rehab was different: patients (and caregivers) were expected to be self-sufficient enough to take what they learn in day rehab and continue practicing on their own, between sessions. But some patients fretted over the decline in intensity.

Inpatient rehab sessions were more often conducted one-on-one, and patients could be dismayed to arrive at day rehab and find themselves frequently in group sessions. The shift toward group therapy was, in part, due to staffing considerations. Staff might also group patients to maximize the number of visits a patient's insurance would provide; under some plans, a group session was billed at a lower rate, so therapists could provide longer term care for patients by grouping patients and draining the "bucket" of funds afforded by insurance more slowly. Therapists also took patient acuity into account. For a variety of reasons, inpatients were often not "group-able." A patient might require too much physical assistance for a PT to supervise other patients simultaneously, for instance, or a patient might be too disoriented or agitated to participate in group activities.

Often, by the time patients arrived at day rehab, however, they had improved to the point that not only were they “group-able,” but interaction with other patients in group sessions was integral to their treatment plan. For the most part, patients weren’t privy to all these considerations, so the increase in group sessions sometimes frustrated them and contributed to their concern that they weren’t making the most of their precious recovery window. Scott was concerned about what he felt was a decline in therapy quality in day rehab, particularly the shift from individualized attention to group sessions. He described the feeling that his optimal recovery was retreating from his grasp:

> I think I was just so stubborn about the idea of, “I needed to make a full recovery, like 100 percent recovery.” And with my—the way my sessions were going, I was thinking, you know, if you thought of it like a game or something, like the percentage was going down every session. Like in my mind, like, “Agh, okay, at this rate, I'm lucky if I get like an 80 percent recovery.” But my mind was stuck on the finish line. And so I just couldn't focus on the quick wins, you know? ... and anything that felt like it was obstructing, like, as much work towards recovery as possible—like just the tiniest bit of slowdown felt like I was watching my full recovery go away.... And after a while, I started seeing, instead, the short wins, like focusing on short goals, like instead of having my sight on full recovery at the end of the line. (stroke, White, male, inpatient/outpatient)

Patients' ticking clock anxiety was exacerbated by the reality that they generally had a finite number of visits covered by insurance. Therapists tried to strategize and advocate for the patients they felt needed longer-term treatment, but they could only do so much. In some cases, patients who weren't aware of the rules could fall afoul of insurance regulations. Isobel, a woman in her thirties had been a language teacher, but her stroke caused aphasia. She was determined to return to her profession, but as her discharge date approached, she increasingly began to doubt her goal could be achieved. At the beginning of her time in day rehab, she asked to double up on speech sessions; her physical symptoms were far less pronounced, so it seemed to make sense to prioritize speech over OT and PT. At the time, she didn't understand that she had a limited number of visits in each category. Isobel later regretted burning through her speech therapy allotment, unknowingly hastening her discharge date.

Dealing with Discharge

Discharge from inpatient therapy was often fraught, but inpatients were generally tired of being in the hospital and eager to return home. And staff explained that inpatient therapy was only the beginning, and patients would continue to progress in day rehab. Unfortunately, when patients were approaching discharge from day rehab and weren't "fully recovered," it could be harder to cushion the blow. Staff reported that patients and family sometimes felt staff were "giving up on them." For some patients, day rehab wasn't the end of the line, and they would be continuing long-term outpatient therapy in at least one therapy discipline, so the outpatient referral could ease the day rehab discharge anxiety:

> Especially here, it's easy to say, "Well, you don't need the whole team approach anymore." Because at day rehab, not only do you have the therapists, but you have nurses, you have the doctor, you have the voc[ational] therapist, you have the psychologist. And you might not need that whole team anymore. So maybe you just need some more physical therapy, and you're going to get that. We're going to refer you for, you know, outpatient physical therapy. (staff, day rehab)

But long-term outpatient therapy was the end of the road, so it was harder to explain to patients why long-term outpatient therapy needed to end, as one inpatient physician with an outpatient practice explained:

> So, families want indefinite therapy, and we have to sort of explain that no, the concept of therapy is to have an intense therapy intervention, but then to learn a home exercise program.... And trying to explain sort of the indication for therapy versus just ongoing exercise and that home program can be kind of challenging conversations to have. (staff, inpatient/outpatient)

In long-term outpatient therapy, the emphasis shifted somewhat, away from neurological recovery. Therapists at the long-term outpatient level were more likely to focus on “functional” goals or adapting to living with disability. They still helped patients work toward recovery, but as rehab ended, it was important to equip patients with the strategies they currently needed (and might need indefinitely), to operate in their daily lives. For instance, an OT might focus on teaching a patient to use an arm with limited mobility as a "stabilizer" to help the other arm maneuver objects. But this shift in focus, coupled with the looming end of rehab, could be unsettling to patients and could force them to confront the reality of what staff called "the new normal." As one long-term outpatient therapist put it, "[in outpatient therapy], I do think there's an acknowledgment of like, if they still continue to have some weakness or some changes, that that might be something that's going to be ongoing, and recognizing that."

The New Normal

Patients in day rehab and long-term outpatient rehab were in various stages of the process of recognizing and accepting that they were likely *not* on a temporary hiatus from a Self to which they would eventually return. One TBI patient told me:

> This thing [brain injury], ain't no time limit. Ain't—this is not even guaranteed to change. Chances is, this how I am. You know, chances is, I take the good with the bad. I'm lucky to be alive, from everything the doctors were saying. Everybody kept saying.... Now, I can't see like I used to. I be struggling with my speech a lot. Saying words. What else be aggravating? My memory, short-term memory and right-before-it-happened memory.... (TBI, Black, male, outpatient)

In outpatient rehab, this patient and others accepted that certain changes to their bodies and minds would likely endure. Arriving at the "new normal" entailed finding a way to accept that elements of the previous Self were irreparably changed, discerning how to preserve what could be salvaged and re-building from there. A stroke patient described the process of developing strategies to cope with ongoing disabilities:

> I've gone to therapy. What else can I do? To get better? I don't know ... I mean, I'm trying to figure out my new normal, you know, and I think I'm doing that. Like different things like ... so I have [a reusable grocery bag] in the kitchen and up the stairs. This way, what I want to take up to the upstairs, I put in there and I carry it up. Same thing going down. So little stuff like that, you know, like making things easier for myself. Just figuring out my new normal ... taking this gait belt everywhere. You know, stuff like that. Stuff I didn't do [before]. I have my bag. I have pants in there, in case I have an accident. So just figuring out what I have to do to be normal. Again. (stroke, White, female, outpatient)

Some of these adaptations (such as getting used to carrying a spare set of pants in case of incontinence) might have felt unthinkable immediately post-stroke. This woman and other patients were in the process of learning to do "stuff I didn't do" in order to continue on with essential elements of their lives and preserve central components of their identities. Carrying a gait belt to allow other people to assist with mobility and balance wasn't ideal, it wasn't a complete return to "normal," but it meant the patient could get out of the house and return to an active life.

In some cases, the new normal involved painful sacrifice, accepting the loss or alteration of central components of identity, as Isobel described:

> When I met with my neurologist on Monday and he was helping me fill out my long-term disability papers, he said you know you—if your speech does not improve, [you] won't be able to teach anymore. We had that discussion. We—he brought it up. And I'm glad that he did, right? You know, we're filling out this paper and he says—it says mental impairments, and it says patient is unable to engage in stressful situations, engage in interpersonal relationship—relations. Marked limitations. That's what he signed for me. And in—my speech is not as well as it should be. I couldn't be a teacher. So I guess when we left the appointment—I didn't think about it until now. I'm always like, keep fighting, keep fighting, keep going, keep going. And I was like, I never thought that I wouldn't go back into the classroom. And I'm glad he brought it up. You know, he's like, "You may not recover." It was a good and bad reality, right? Sometimes, you know, it's not like—you

> need it. You need bolting. I'm still going forward and trying my hardest, but if my brain doesn't cooperate or doesn't heal, I need to know that I may not go back into the classroom. So that was really hard to think about and process and—well, maybe I can't go back to the classroom and maybe just, I don't know if I will be disabled for the rest of my life. (stroke, Hispanic, female, outpatient)

When patients reached the point of accepting the previously unthinkable or unacceptable, they were encouraged not only to adapt and find a "new normal" but also to find a way to derive meaning from the experience. As one stroke patient's wife put it, it was important for her husband to find a way to "have a life that feels valued and valuable," even if it was going to be drastically different from the life he had known and the future he envisioned. One young TBI patient said she was in the process of

> trying to get comfortable with myself. Trying to derive meaning—in the beginning, I got depressed. With the trach and not being able to walk or move. But now, it's better. I get out. I watch TV, I listen to my music. I'm eating. I use my cane to get around. I try to exercise, stretch more. I cook, sometimes. I talk with my brother every day, almost every day. I still have some insecurities and [am] just trying to accept my new life. I'm getting more comfortable with myself.... My cousin is a writer for a company. So she's helping me write a journal. Yeah, I'm gonna make a journal because—I don't know, I just—I want people to find a way to learn how to deal with this life-altering trauma, you know? And accepting things we cannot change. So I'm working on that. (TBI, Black, female, outpatient)

From the inpatient Self in Suspense—waiting to see what the future would hold—patients worked through a process of coming to terms with the parts of their lives, their bodies, and their minds that would remain changed. Leaving the hospital tended to highlight complications that hadn't been apparent until the patients returned to their familiar environments. And as patients felt the urgency of the closing window of neurological recovery, they began to confront the gap between their expectation of return to previous Self and their present condition. In the process of constructing a “new normal,” patients began to reconcile themselves to loss and change. They learned to adapt in order to preserve what was most essential to them, define and shape meaningful lives, and in some cases, derive meaning from the trials of recovery

Other Patients as Reference Points

Wanting to Serve as a Positive Example

Identity reconstruction also took place in interaction with other patients and with patients' ideas and perceptions of their fellow patients. Patients imagined themselves through the eyes of other patients. Some patients saw themselves as positive models to other patients. They often hoped their gains would provide hope or inspiration for patients at earlier stages of recovery. Some patients also believed they could set a good example for other patients with their positivity, perseverance, motivation, and assiduous participation in therapy. They were particularly proud of (and derived a sense of purpose from) helping to encourage other patients.

A TBI inpatient's wife described her husband as "trying to make [other patients'] lives better" by coaxing smiles, providing encouragement in group sessions, and promoting levity during Friday dance parties. Her husband was a highly social man who had been feeling a bit stir crazy in the hospital. He had a prior diagnosis of ADHD, and since his brain injury, he had only become more easily bored and less able to sit still. Getting to know the other patients and "trying to make their lives better" distracted him and gave him a sense of satisfaction and purpose.

Patients also told stories about noticing others struggling in ways they themselves had struggled until recently. The ability to jump in and offer advice or commiseration made patients feel helpful. By adopting the part of role model and experienced, old hand, they occupied a privileged position even as they confronted the frustrations and anxieties of rehab. A day rehab stroke patient explained his impulse to reach out to a man he saw using a familiar therapy device: "I wanted to tell him, ‘Look, that thing is silly. But trust me, it works’" (stroke, Hispanic, male, outpatient). He recalled a similarly rewarding experience from his inpatient stay:

> Over there, it was a lot of stroke patients, and it was a lot of older stroke patients. And I kind of pepped them up a little bit cuz like I said, you could see that they were depressed,

> like *This happened to me. Great. I'm going to be like this for the rest of my life. Nursing home, here I*—you could just pick up on it.... This one gentleman in particular, he had came in, and he had a massive stroke. He had no use in his left side. And he was just there in a wheelchair ... and he was really, you know, he just looked like, *Whatever. I'll never walk again. I'll never use my arm*…. And, you know, I would mess with him. “Hey, come on, let's go race.” You know, I was just starting to walk with a walker. And I'm like, “Come on, let's go race.” And he was like, *I can't walk*. And I'm like, “Let me tell you something— "I was like, ‘I couldn't either.’ But these little baby steps. They'll get your confidence back, that you can walk.” So the one day they took me in another gym that had the harness and the ceiling track. And he came in there. And I looked at him, and I really didn't want to be like intimidating to him because here I am doing like, you know, obstacle courses, lifting my legs and getting over things. And I don't want to be like, “Hey, look how fast I went.” And then they put him in a harness. And they're like, “Okay, this is what we're gonna do.” And here he is slowly walking. And I just look. Like, I told him this was going to happen. And there was a point where my track met with his track, and we were side by side. And I told him, “Come on, let's race.” And he kind of laughed. And I told him, I said, “It's a lot of therapy. And it's a lot on our bodies. But it's worth it.” I was like, “Just do what they tell you. Keep doing it. Because it's going to help you.” And for me to see, like, his progress … I was like, “I wish I could just stay here and watch him.” (stroke, Hispanic, male, outpatient).

As this passage illustrates, patients wanted to think of themselves as proof to other patients that the rigors of therapy pay off and that good things come from cooperating with therapeutic regimens. Patients felt pride and satisfaction when it seemed their encouragement and example contributed to someone else's progress. In some cases, patients remembered a significant encounter earlier in their own recovery in which a former patient inspired them by telling their own recovery story:

> I was walking down the street yesterday. I saw a guy. He just stopped and said, “Hey, I was like that six months ago.” And he was looking really good. And it was such an inspiration to me. That was like an angel … and I stopped and looked at him. That guy's walking the street like normal. That was a tremendous boost. That made me work even harder. (stroke, Black, male, inpatient)
>
> And [the stranger in the store] was like, “Man, what's wrong with you?” And I told him. I said, “I had a stroke.” And he said, “I had a stroke too.” And had he not said that, I would have never knew it. He told me he had left neglect, just like I got. And he was in the store working. You know? So stuff like that is encouraging to me, let me know there's gonna be a life after—there's gonna be, you know, a future after this. (stroke, Black, male, outpatient)

When patients told these stories, they often highlighted how "normal" the other person seemed, how difficult it was to discern that they had ever been a patient. These encounters were cherished as evidence that complete return to "normal" was possible. Having been marked out by these strangers as *like them*, as having a shared recovery potential, patients could hope their rehabilitation would proceed along a parallel trajectory. Patients who remembered these moments as turning points in their own recovery often hoped to pay the kindness forward by inspiring other patients in turn.

Reclaiming Pre-injury Roles and Traits

For some patients, this role as motivator and inspirator felt like a continuation of a previous social role. For patients who saw themselves as extroverted people, accustomed to making connections and elevating the mood of social gatherings, it could feel important to express this aspect of themselves, to continue to be the social butterfly in the rehab setting. One patient who identified as "definitely a people person" said, "That was me prior to the accident, but even more so now" (TBI, White, male, inpatient). By engaging with staff and patients and trying to bolster collective spirits, he emphasized the continuity between pre- and post-injury Self.

Other patients described how their support of other patients was an extension of prior caring or nurturing roles. One patient, Father Will (as staff called him), framed his attempts to motivate others as an extension of his calling:

> Even, you know, as a priest, I try to encourage people. My role as a priest continues here. So what I try and do, I try to encourage people in the gym. That's where all the activity takes place. And I say, “Hey, you're doing great. Keep up the good work.” So it's a—I continue my priesthood that way. And you never stop being a priest ... so I take—I take on that role. I don't see too many other patients taking on that role. [laugh] The therapists sometimes ... so my role is to encourage everybody. So that's why I'm kind of well-liked here. [laugh] They'd probably have me keep—stay around a few more weeks. (stroke, White, male, inpatient)

He preserved his identification with one of the primary facets of his sense of Self, his profession as a priest. Seeing himself as ministering to other patients not only gave him a sense of purpose but also allowed him to, in a way, align himself with the therapists, with the healers, rather than the sick and disabled people in need of help. Father Will told me about the positive feedback he received from staff, including the physician who discharged him from the acute ward:

> But the last time I saw him, he says, “Father Will, you look great.” And he says, “You're gonna improve tremendously at [inpatient rehab].” And he was right. So I mean, I didn't know I looked great. But this is the doctor. He said, “I also want to tell you, it's a pretty big floor of patients. You have the fewest deficits to work on of anybody on this floor.” So that—so you know, those words of encouragement are crucial. (stroke, White, male, inpatient)

Like Father Will, many patients treasured this kind of affirmation. Not only did it augur well for their recovery but it positioned them at the top of the patient hierarchy, among the nearly normal. Patients appreciated this image of themselves as not really like the unfortunate, other patients who were clearly disabled and likely to remain so.

Other Patients as Negative Counterfactuals

In other cases, patients who saw themselves as more fortunate than other patients were concerned their presence might have a demoralizing effect. Referring back to the patient's story about challenging a dejected patient to a race, note that the storyteller also said he "didn't want to be, like, intimidating to [the other patient] because here I am doing like, you know, obstacle courses, lifting my legs and getting over things. And I don't want to be like, ‘Hey, look how fast I went.’" Patients who saw themselves as exemplars expressed concern that other patients might see them not as a motivating example but as an unattainable standard. One TBI patient was frustrated that staff limited the amount of time he could spend at the windows in the hallway after therapy, but he justified it to himself as necessary because, in his telling, "There's a lot of people in here that's not able to do that on this floor. And they don't want me to make them people feel bad, obviously. Which I understand that. And I respect that" (TBI, White, male, inpatient).

Some patients who believed themselves to be better off than others said they felt a duty to show compassion for less fortunate patients whose agonies put their own suffering in perspective. As one TBI patient put it, “[Seeing other patients] gave me a gauge of just where I sit on the severity scale." This perspective prompted him to "reach out to them and to make a difference for them, in whatever way I can. Maybe it's just a pat on the back or a kind word sometimes" (TBI, White, male, outpatient). Another TBI patient explained:

> You'll see people that'll never get out of a chair. So I'm not running around here floating that I'm leaving. I'm just—I saw two of my buddies coming downstairs and I said, “Hang in there. Give it—give it a chance. This place does work.” I'm giving them hope, you know? (TBI, White, male, inpatient).

Through this sympathetic response, patients acknowledged their own relative good fortune and set themselves apart from the unfortunate patients who will "never get out of a chair."

Many patients framed other patients as negative counterfactuals for their own circumstances. Patients pointed to others who went through a similar experience but came out much worse than they did:

> I just—I'm humbled in how soon I healed. Everyone said I'm one of the low percentages that are moving on…. It's humbled me that I'm going home and some of these guys won't. I mean, I've seen a guy move his hands, but they'll never move their feet or their legs…. But I know what I looked like when I came in here. And for some reason I came out of it. (TBI, White, male, inpatient)

> The people I've met, they tell me how lucky I am ... some of them won't get their walking back. And some of them can't even eat normal meals. And so it's a lot that I learned with them. Like, even though I went through all of this, some of these people will never have maybe the life that I'll be able to go back to. But they're really nice people, you know? (TBI, Black, female, outpatient)

As I will discuss at greater length in Chapter Seven (Understanding and Finding Meaning), patients were often preoccupied with questions about why the stroke or TBI happened. Focusing on other patients who were more adversely affected allowed them to reframe these questions away from "Why did this awful thing happen to me?" to "Why was I spared a worse fate?" By dwelling on comparisons to patients they viewed as tragic, some patients could cast their own narrative in a more triumphant light. On the other hand, some patients felt they had to stifle their own complaints because, in comparison to many other patients, they were well off. As one stroke patient's daughter recounted:

> She sees people in the gym. And she'll be like, “I'm so upset and angry about [my stroke]. But I see what could have happened.” And so then she feels more like a jerk … I told her yesterday, I was like, “Mom, things can always be worse. Someone is always going to have it worse than you. Even if you have it the worst. But that doesn't mean you don't get to feel however you're feeling.” You're still going through this. "Eh." [laughs] (daughter of stroke patient)

Identifying as one of the lucky ones allowed some patients to maintain positivity in the face of sudden and disturbing change. But in framing themselves as fortunate, patients also limited their ability to raise complaints about their own condition or circumstances. It was hard to justify their own negative emotions when they were hyperaware that other patients had it worse.

Accepting or Rejecting Group Identity

Interacting with other patients was also an opportunity to either form or reject a group identity. Some of the staff (particularly a psychologist at one of the day rehabs) actively created groups where patients could share their experiences, commiserate, and "cheer each other on." As one staff member framed it:

> I've heard many stories, you know. I have some skills because of that, but I do not understand. But the group members do get it. They're in the same boat. They might have different injuries, but they understand. Patients will say, you know, “My spouse doesn't get

> it, my friends don't get it, my kids don't get it, like nobody understands." And I say, "No, nobody understands, but in the group settings they do." (staff, outpatient)

Some patients felt a sense of kinship and appreciated these opportunities to socialize and bond. They echoed staff's belief that similar experiences and circumstances created affinity. For patients who had retreated socially (for reasons ranging from self-consciousness to lack of transportation), day rehab often provided one of few opportunities to socialize in an environment where disability was understood and accommodated:

> And I just don't like being around people no more. [laugh] Because people don't understand what I'm going through, you know? And then my family is really judgmental. It's really terrible with them. I had—I tried to talk to them, though, about things. But. Even coming here, it helps me because it helps me get out the house and be able to be around people and communicate with people that really understand what I have going on. (TBI, Black, female, outpatient)

For some patients, the appeal was more the ability to get out of the house in a supportive, disability-informed environment than the opportunity to bond with other patients, but some patients specifically referenced interactions with other patients who made them feel heard and understood. They remarked on the specificity of the experiences and feelings they shared, and they appreciated the license other patients gave them to talk about topics that might be unacceptable in other contexts. Patients who felt family and friends were tired of hearing about their medical traumas or were uncomfortable discussing disability or preferred to hear only positivity from the patient, felt relief in interacting with other patients:

> Like this woman that was sitting here, I was in a speech [therapy session] with her the other day. And she's like, you know, "I don't feel like doing any Christmas stuff or anything like that." And I told her, you know, "I'm glad that you said that because I feel the same way. And I thought I was the only one." And she, you know, she was happy that she helped somebody. So I think that helps, you know, like, having a discussion with people that are in the same situation, strokes or whatever. (stroke, White, female, outpatient)

Some patients, however, felt a sense of alienation from other patients. They felt isolated by what they saw as a disconnect between their experience and that of others who were supposed to be their peers. Certain patients felt like outliers either because their medical condition was unusual or because they were significantly younger than most other patients. Connor, for instance, was both young and had a rare diagnosis of locked-in syndrome:

> I felt alone. I am always unique. I know. For me to have a stroke that is so different. Nobody could help me. I was trapped with my thoughts. I remember when I came here they had a seminar on TV about stroke. And none of it applied to me…. Usually I'm healthy. Don't smoke. I don't smoke. You know? I felt alone. Because everyone else who has a stroke is different. That was supposed to be helpful. But it wasn't. It only made me feel worse. (stroke, White, male, inpatient)

Scott, another demographic outlier as a young stroke patient, also felt a sense of remove from other patients. Like most young patients, Scott expected a more or less complete return to his pre-stroke self, and he was frustrated to find himself grouped with patients who seemed to be in a different prognostic boat. Not only did he feel he didn't have much in common with them, but he also felt they were unevenly matched in terms of ability to actively participate in therapy:

> I didn't feel like I was getting much out of [the group sessions]. Because, again, I was grouped with older people that were like cognitively, I felt like, much further behind, understandably. But like, you know, we'd be working out a puzzle together. And in my head, I'd be figuring out them like, really fast. But everyone else would be having trouble, and I would feel like I shouldn't answer them out loud. Because I don't want to like ruin their recovery by being the young guy that's answering all the questions. (stroke, White, male, inpatient/outpatient)

Part of his alienation stemmed from annoyance at feeling like he was grouped with patients who weren't able to move at the same pace and who were, to an extent, holding back his own therapy. But here, Scott demonstrated another common element in reactions to fellow patients:

> I was having group sessions with, like, 80-year-olds that were like, drooling and stuff. And that was discouraging. I was, like, “Is this where they see me?” Like, I'm at the same level as, like, an 80-year-old who's practically having dementia next to me? Like yeah, that was scary to me. And maybe I was there because, you know, I had memory problems. And, you know, I had brain damage. So like, I wasn't where I am now, then. So. But at the time, I was like, “I don't understand why I keep having like, group sessions with like, old people.” (stroke, White, male, inpatient/outpatient)

Like many others, Scott was discomfited by the implication that he might have something in common with stigmatized others, in particular, patients he saw as obviously and profoundly debilitated. As Scott acknowledged, he was also a stroke patient, and he was *also* working on memory-related therapy. But he recoiled from self-identifying (or being identified by the staff) with patients he associated with aging and disability. Scott was markedly dissimilar from many of the other patients in both age and the extent of his recovery. But some patients who were concerned about being tainted by the stigma they associated with other patients had more in common than they realized, as one staff member described:

> And this guy pulls me aside after group and goes, “I think we need to kick [this other patient] out of the group.” And I'm like, “Well why?” He goes, “Well, he's rude to you, I see him talking bad to a therapist. Like, he's not appropriate for group. You need to get rid of him.” I'm like, “Do you remember?” “Oh no, I was never that bad.” (staff, day rehab)

As the staff member told me, this patient was also disinhibited and socially inappropriate when he first joined the group, but he didn’t remember having been “that bad.” It wasn't uncommon for patients to express a stronger identification with therapists and other staff than with fellow patients. Until quite recently, they had been among the non-sick, and they hoped soon to return to that status.

Some patients associated the others with what they saw as the depressing atmosphere of a healthcare setting. They didn't want to be in a place associated with illness, surrounded by sick people. Bennett, for instance, was a stroke patient in his seventies who was very eager to get out of the hospital, in part because he found the overall environment, and particularly the other patients, "depressing." When I was interviewing him, we occasionally heard moans and other sounds of distress from patients down the hall. Bennett stopped to listen, indicated the sound, and told me it was disturbing. "I want to get out of here," he said. Like Scott, Bennett disliked being grouped in therapies with other patients who weren't "at the same advancement," as Bennett put it:

> And [staff is] amazed at my aptitude. One lady told me, “Man, for your age” ... and I hate group therapy. Group therapy, I've just realized, just makes—if one person's doing good, like I am—I'm a very hard worker. Then a guy that's debilitated more than me. Where do his aspirations go? You know, he says—and they probably think that it motivates, but it doesn't. It works opposite. So they should put people of the same temperament together. But they don't. You've got one guy there, he couldn't move, and I saw him look at me, and I'm walking. Man, it makes me depressed. Don't put me with this guy. And don't put him with me. (stroke, Black, male, inpatient)

Again, we see a patient imagining himself through the eyes of another patient, as an unattainable standard. At the same time, patients like Bennett were distressed by the physical and social proximity of patients with whom they preferred not to associate.

Inspirational Figures and Stories

Patients also had an ambivalent relationship to "inspirational" figures and narratives. Some staff shared stories and images of past patients who they saw as models, assuming these stories would motivate and inspire current patients:

> On my phone I have a video. One of our locked-in patients came back to visit. She came to visit [her doctor] downstairs in outpatient. She came upstairs, and she was walking with a walker. And we were like—people were crying, we were like freaking out.… So I said, “Do you mind if I video you?” And I took a little video, and I've showed that to like three or four other locked-in patients. And I'm like, “This girl could not do anything but move her eyelids when she got here. Her eyes. And now like, she—” ... but she's at home, she's independent, she's living with her boyfriend and her son, like she's doing a lot better. So she's not where she was 100 percent. But given what happened. (staff, inpatient)

Other staff members were more wary of the complex reactions such comparisons could evoke. At one point, there were two locked-in patients on the ward at the same time, and I asked their physician whether he ever offered patients the chance to be introduced to each other, if both consented. He told me these dynamics weren't always straightforward. In some cases, patients appreciated the chance to commiserate with someone who shared the same rare experience. But a sense of competitiveness and invidious comparison could also develop because patients didn't recover at the same rate or to the same extent.

Some patients and family sought out and treasured success stories, citing people they read about who, after similar injuries, achieved extraordinary recovery. Other people, however, avoided getting their hopes up:

> And you know, early on when [my husband] was in the ICU, I didn't want to research anything about this. And his family would find videos of, you know, people who have recovered from locked-in and were running 5Ks and all this. And I just didn't want it because I was so afraid that I would get my hopes up. That I would get my expectation to be like, "Okay, so [he] can run a 5k in a year," you know, when he's like, on a ventilator, and like, can't move anything but his eyeballs. So there was a part of me that like, truly did not want to have that connection with anyone else because I was afraid that it would set me up for more grief and heartbreak. (wife of stroke patient)

Staff also occasionally misjudged the type of example a patient might find comforting or inspiring. In some cases, for instance, staff offered stories of remarkable adaptation to long-term disability to a patient who was still bent on making a complete or near-complete recovery. Ellis was a stroke patient in his forties. He was otherwise healthy, and prior to his stroke, he worked a high-stress office job, providing the primary income for his family. His stroke caused aphasia, affecting his ability to communicate, but he was determined to return to his career as soon as possible. The rehab set him up with a former aphasia patient, and the encounter was unsuccessful, to say the least:

> And I'm like, "Oh, geez. I'm like, I want to talk to somebody who—myself who's younger and had a stroke and goes back to work. That's, that's what I want to hear about. But what I'm finding more is most people who do have a stroke, like my—that has—aphasia, that doesn't always go back to work … and it scared me, hearing this woman that she was gonna take five years to get back to work, and then she decided to go work somewhere else because it wasn't going to work for her. And I'm like, "Oh shit, this scares the hell me" ... and now I stay away from like, [the rehab's] like a, like a groat—groot—*group*. They're aphasia, and they all—there was some of them there that couldn't talk or very much for for years. And it scared the shit out of me. That I'm like, "Oh my god, am I gonna be like this forever?" And so then I decided, I don't want to talk to any other peoples unless unless it's a po—it's going to be a positive thing…. But unlike, um, you know, I'm old—I'm young,

> I was pretty smart. This was—my brain—I didn't have any other problems, I didn't have these other things, you know, my brain or my heart. And so hopefully it should everywhere I need to be. Just may take some time. (stroke, White, male, outpatient)

The former patient Ellis met hadn't been as successful in her return to work as Ellis still hoped to be. She tried to return to her previous job in journalism, but she struggled and ultimately left the job. Many years out from her stroke, she wasn't yet where Ellis hoped he would be very soon. Ellis also opted to stay away from an aphasia group organized by the rehab staff because associating himself with people he saw as severely impaired scared him and shook his faith in his ability to return to his career within a few months. In cases like Ellis's, patients rejected "inspirational" stories if they portrayed the wrong sort of success: not return to normal, but adjustment to disability.

In some cases, patients appreciated opportunities to socialize, exchange information, and identify with other patients. But particularly in the early stages of recovery, patients were perhaps more likely to distance themselves from identification with other patients if they saw them as objects of pity, depressing unfortunates, or troubling mirrors showing a version of themselves they rejected.

Disability Identity

Avoiding a Stigmatized Identity

As previously described, patients (inpatients, particularly) tended to regard disability as a stigmatized identity they hoped to avoid. By the outpatient stage, some patients were beginning to confront the possibility of long-term, significant change in their bodies and/or minds, but many were still determined to avoid ongoing disability. Alan described an encounter with a disabled person in public:

> We went out to dinner for my birthday.... So there was this guy who was our waiter. He only had one arm … shoot. He can get a job, I know I can get a job. I got both my arms. And he was waiting on us with one arm, you know? That's just—the endurance that people have, you know? You—you adapt. but I just want God to heal me, man. I don't want to be like this ... I got to deal with it. Get stronger. Get better. And see what life—life happens. It didn't kill me. So what don't kill you oughta make you stronger. (stroke, Black, male, outpatient)

Patients were aware of examples of successful adaptation to disability, but like Alan, many patients rejected this kind of "strength" and hoped instead for a return to their former able status.

Few patients were experienced with disability. One patient stood out because she had struggled with chronic illness for years before her stroke, and consequently, she already had well-developed systems and strategies for coping with "bad days" (Charmaz 1991):

> I mean, the only thing I can do is pace myself ... when, you know, it's happening, you know, I can't do anything important. You know, actually, in a lot of ways—okay, I—usually, the first thing in the morning, I'm kind of tired, and you know, I perk up and I would prefer to be getting housework or something done. But I do mental things, I mean, that’s going to take concentration. Because that's when I'm most alert. And before I had the stroke, every morning I would do Sudoku. The first thing. And it could kind of tell me how I'm gonna do the rest of the day. If I zipped through them, it's like, “Oh. Well!” And if it's like a really hard time ... I knew the brain wasn't the same. So I just wouldn't take on a task that was really important. (stroke, White, female, outpatient)

But for the most part, patients were just beginning to figure out how to navigate disability.

Non-accessible Spaces

When they talked about getting back to life, many of them worried about as-yet-unimagined logistical obstacles to navigating environments and situations not built to accommodate disability. During my fieldwork, COVID-19 was still preventing many patients (and much of the population at-large) from resuming in-person social life. But patients commonly worried that resuming routine activities would be fraught with unforeseen complications. A day rehab stroke patient described encountering one such obstacle:

> So we went to Costco like the week before. And I was just, “We gotta get out of here.” [My husband was] like, “What's wrong?” I was like all these voices are driving me nuts. I can hear these conversations, and then we're talking to our daughter and trying to do, you know, our task. And he's like, “You have a lot of sensory overload. You need to try step by step including things to help you be aware of that”.... But the sensory thing was really hard for me because I didn't know what was happening. I didn't know it was my brain saying, “Too much! Too much! Too many people talking!” (stroke, Hispanic, female, outpatient)

Other patients were coping with accident-related trauma reactions. One TBI patient described having to work her way up to crossing the street again after having been hit by a car in a crosswalk. For some patients, day rehab was a respite—a controlled, safe environment where they didn't have to worry about finding a wheelchair-accessible bathroom or navigating curbs. Patients who lived in suburban and rural communities could be particularly limited by the absence of accessible public transit or rideshare services.

Visible Disability

Patients also talked about anticipating or experiencing being visibly disabled. Inpatients were often apprehensive about going out in public in a physically altered body. As one stroke patient explained: "Um, I- I- I care a lot about what people think of me. Like how I look in public or something. So I'm sort of embarrassed about how I walk now" (stroke, White, male, inpatient). Patients were often self-conscious about using assistive devices. They were eager to graduate from one device to the next. As a TBI patient described:

> I totally understand why they needed me in the wheelchair when I first got here. But it was kind of a—it was a little bit of a mental blow to me. And it—I don't know, it just, it didn't make me feel super great. Like being in that chair. So I think mentally it helped me, using a walker and being out of the chair. (TBI, White, female, inpatient)

Many patients strongly associated wheelchairs with disability stigma. Staff reported that patients commonly resisted wheelchair training, hoping instead to recover enough to walk unassisted or at least with a less obtrusive and less stigmatized device.

Patients talked about dreading (and in some cases, actively avoiding) encounters with acquaintances who knew them prior to injury. Some people explained that they were tired of talking about *what happened*, but they knew acquaintances would be curious or would feel obliged to ask. In a few cases, patients said they didn't want to relive traumatic memories for the sake of politely answering questions.

Some patients didn't feel ready for people to see their present body—they wanted to preserve a prior image of themselves from contamination by their current embodied reality. Many patients were not prepared to identify as (or be identified as) disabled, so they avoided situations where they felt that label would be applied. As Mariah, a TBI patient, articulated, she particularly hoped to avoid being perceived as disabled by people who knew her before:

> I don't want nobody from [my previous neighborhood] to see me. When I go out, I'm embarrassed because people see me, they stare, they're whispering, you know? It's just awkward. Because I'm so used to being the person who saw somebody, maybe glanced at them or stared for a little bit. To now, being that person that people are glancing at or staring at. It's me. So dealing with that is hard. I never really—only two people from [my old neighborhood] know what I'm like. Only two. And those are two people I trust. But the only people that have saw me is my brother's wife's family. That's because I'm comfortable. I'm not worried about them trying to take pictures of me, you know, trying to see what I look like, trying to tell other people. They don't talk about me. They don't judge me. They make me feel comfortable because they look at me and they treat me as if I was the same ... because [people from my old neighborhood] are used to the old me. And they're expecting the old me. And I'm just not ready to share me, and who I am today, with anybody from the past, my old life. (TBI, Black, female, outpatient)

Like Mariah, patients expressed concern about leaving the hospital because people in the hospital understood their "context." Inpatient staff and trusted family knew what happened, understood the process of rehab, and knew what the patient still hoped to achieve. Like Mariah, they were concerned people with limited context might regard them and treat them as they currently presented, as a disabled person. Without context, people might reduce them to a stereotyped disability identity, not understanding they were *still the same me*, or in the process of *getting back* *to normal.* Former acquaintances, in particular, might painfully highlight the discrepancy between the pre-injury Self and the current Self.

Mariah also drew attention to fear of conspicuousness, another common concern. She was acutely aware that she now inhabited the sort of body she herself might once have stared at. Another patient described feeling "miserable" at a recent social event because "I always feel like people are watching me. If I get up and walk from one table to the next, I feel like everyone's staring at me, like, watching me walk. Am I gonna make it, you know?" (stroke, White, female, outpatient). Patients imagined themselves in the position of the conspicuous, stigmatized other:

> But I've always wondered, like, what it was to be like, on the other end, because you see, you always see like, the person—like when you're passing a hospital, or like a homeless person who's like, clearly got some disability. And they—you don't mean to, but then you actually give them like, like the side-eye. Like, not in any rude way. Just out of like pure curiosity. (stroke, White, male, inpatient)

In these imagined encounters, visible disability was often associated with other stigmatized qualities or identities, like illness or homelessness. Patients mentally rehearsed what they might do if confronted with rude questions or blatant stares. They imagined congenially explaining what happened to them, calling out discourtesy, or deflecting intrusive questions with humor. One patient mused:

> Either, I'll say [it was] alligators or like black ice or something. [laughs] Just have to make up a story. But yeah, that's—I've been dreading that. I don't want to just stand in the street and tell someone this long story. (TBI, Black, male, outpatient)

People also had different relationships to conspicuousness to begin with. One younger, highly extroverted TBI patient with relatively mild physical and cognitive changes expected to confront stares with genial openness and a willingness to share his story. But not everyone was as comfortable with the idea of standing out, as one patient explained:

> I am trying so hard to fit myself in. Number one, I am a foreigner. Number two, I came here a little bit, to United States, late. I do not have the knowledge as everybody. I do not

> have the support like everybody have a family here. I don't have nobody here. I don't have no family. So I'm try to fit in, try so hard to fit in, in every single thing that I do in my life, and fight for it as much as I can. I try to fit into [my profession] ... it's a work field made not for a foreigner like me, for example. But here I am. I am fighting myself through … after I did all what I did in my life here in United States. I've been here for over [X] years. Now I got a stroke and I cannot even move anymore. How do you think this is hard, Virginia? After all what I fight for, all this time. Here I am, I cannot even move. (stroke, Middle Eastern, male, outpatient)

Intersectional identities complicate and compound the stigma of disability, and patients were well aware of the additional liabilities associated with being, for instance, elderly and Black and disabled, or fat and disabled, or non-native and disabled.

Mariah and others were also concerned about being targeted by people who perceived them as vulnerable marks. One recently widowed stroke patient said she was hesitant to date because she heard "horror stories" about widows being taken advantage of, and she wasn't feeling cognitively at her best. Mariah reported a similar sentiment: “Because before this, I was sharp. Now, I'm not as sharp. And I get worried because people will take advantage. And I don't want nobody to take advantage of me while I'm vulnerable." Patients were also afraid of being physically vulnerable, less able to run away from danger or defend themselves, and a tempting target for crime.

Along with unwanted visibility, many inpatients anticipated (and experienced) other unpleasant elements of the social experience of disability, such as being the target of unwelcome sympathy. Patients talked about receiving patronizing praise or condescending solicitude. One stroke patient recounted:

> And my daughter was getting married on that Saturday. So they let me out on that Friday.... But it was you know—so every time I would stand up or something, everybody was [clapping] like if I was paralyzed forever, you know. And it was kind of getting annoying, after a while. You know, every time I moved, they were clapping. Like it was a miracle that I was walking. (stroke, White, female, outpatient)

Patients generally didn't want to rebuff social gestures they understood to be well-intentioned, but they were often discomfited by displays of sympathetic attention. As the above quote suggests, these sorts of interactions often made patients feel disabled, as opposed to temporarily inconvenienced and on the way to recovery. This patient didn't want people clapping "like if I was paralyzed forever" or indeed, calling attention to her at all. Outsized acclamation for relatively simple acts not only felt patronizing but also highlighted the gap between the post-injury Self and the pre-injury Self for whom getting up from a chair wouldn’t have been noteworthy.

Related to concerns about condescension, some patients were also wary of and frustrated by feeling infantilized. Locked-in patients and other patients with similar physical disabilities were especially subject to the tendency to treat visibly disabled people as though they were also cognitively impaired. As one patient's wife explained, this kind of behavior wasn't limited to laypeople:

> And then I think the ignorance of people in the medical profession who [tearful] don't take the time to read charts or fully understand [his] prognosis is probably one of the biggest medical frustrations we've come into, you know. He went to the doctor, and again they see “TBI, traumatic brain injury,” and they see that he's essentially fully paralyzed, and they speak as if he's a five-year-old child. Right out the gate. Just literally speak to him, as if he's a child ... you know, and he keeps his head down kind of low too, so that also kind of gives them an indicator, you know. And that is very, very frustrating. And he obviously will never speak up. You know, I'll have to say, you know, “You can talk to him like he's [a man in his thirties] that never—like this never happened. You can talk to him. He understands.” [wife of locked-in syndrome patient]

Medical professionals who weren't rehab specialists or otherwise disability-literate could make insulting and humiliating assumptions that alienated their patients. In medical and nonmedical contexts, patients had to learn how to negotiate other people's ableist assumptions and social fumbling. In the course of my research, I had my own moments of awkwardness and incompetence.

When I was interviewing the patient described above, he asked for a drink. I filled the Styrofoam cup on his tray, but I couldn't figure out how to position the cup correctly or understand what he wanted me to do. He explained that he needed a straw (of course! I felt like an idiot), and I couldn't find any in the room, so I offered to run out and find one. He said it was okay, but I thought he might just be saying that because he didn't want to inconvenience me, and I didn't want to leave him parched. I found a nurse and procured a straw. But then it took me a few adjustments to figure out how to position the straw suitably and how to hand him the cup. I probably apologized far more times than was comfortable for either of us. It was a humbling reminder that as patients are learning how to maneuver their own changed bodies, they're also learning how to interact with people who have even less experience with disability and with their particular needs and preferences.

Some patients defused awkwardness with humor or were preemptively self-deprecating, signaling to others that they were not looking for pity and were able to joke about themselves. One TBI patient lost an eye and was using an electric wheelchair. He joked that his friends all tell him he's *more* handsome now. "Busting each other's balls" had been a prominent part of his dynamic with his friends. By giving himself nicknames like Cyclops or Robocop, he signaled that he was still the same friend as before, and they should continue to banter with him as usual.

Invisible Disability

In contrast to figuring out how to interact socially in a visible disabled body, some of the patients were learning the pitfalls of managing *invisible* disability. In some cases, lingering symptoms weren’t readily apparent at a glance or in casual interaction. Patients were concerned about being perceived as rude or stupid by people who didn’t know about their stroke or TBI. Alan recounted a few uncomfortable incidents:

> I noticed that you can't tell something’s wrong with my eyes because there's nothing wrong with my eyes. It's wrong with my brain connecting to my eyes. So you look at it—you're

> looking at me looking at you like I'm looking at you normally. But I'm not seeing normally, and you don't know that ... so like people be like, if I don't see them, they [get upset]. I had one guy—I was out with one of my buddies. And he was like, "I thought you were gonna move out of my way." I wasn't! Because I don't see you. [laugh].... You know, I'm not trying to be rude ... I had one guy—I was walking across the parking lot. And he was driving. And he blew his horn at me. And as I went by, he was like, "You were looking the other way." And was like—I had told him, "I had a stroke, man" ... but it's really not their fault. Because you know, I'm walking around trying to look normal ... you know, I'm not walking around limping and struggling. No, I'm trying to walk normally. (stroke, Black, male, outpatient)

In Alan's case, the desire to minimize visible disability by "trying to walk normally" laid him open to the hazards of invisible disability, such as being perceived as rude or even antagonistic. Staff were particularly concerned about patients' struggles with invisible disability in the context of return to work. If coworkers and managers thought the patient seemed fine, even "back to normal," they might suspect them of having falsely claimed medical or disability leave. They might also be less willing to provide crucial accommodations or less tolerant about symptoms like fatigue or difficulty concentrating.

Staff and family also worried about patients with stroke- or TBI-related difficulties interpreting body language, reading social cues, or judging appropriate behavior. Although rehab staff were understanding about brain injury-related inappropriateness, they were cognizant that many people in the outside world wouldn't be, particularly if they were unaware of the patient's medical condition. One staff member described one such scenario:

> We actually had a patient recently who kind of had a crush on a therapist and was doing really inappropriate things like bringing flowers, and just not really treating her with respect and like the professional that she is ... I was like, "Listen, you're gonna have to have this awkward conversation." But I always say like, we don't do patients favors by like trying to be nice and polite and not really critique that type of behavior. Because in the real world, if you did that at work you're going to get fired or get a sexual harassment suit. You might get slapped if you do it on the street. (staff, outpatient)

In many ways, day rehab was a kind of soft landing following inpatient discharge. As patients adapted to disability, they also had to figure out how to navigate the social world as a visibly or invisibly disabled person, whether or not patients themselves self-identified as disabled. Some patients wanted to avoid being perceived as disabled (and all that perception entailed) by avoiding social interaction entirely, until they achieved some desired level of recovery. In many cases, patients expected to graduate from using a particular assistive device. If, for instance, they were currently using a wheelchair but were hoping to transition to a walker or cane in the coming weeks or months, they might say they were waiting to go out or see friends until they were out of the wheelchair. As one stroke patient explained:

> Just getting out in society. It's more of being embarrassed, with me. Because I was an—because I wasn't a great athlete, but I was an athlete in college. So it's sort of embarrassing to be stumbling out in public, if you understand what I mean. So I'll be more of a sort of a homebody now. Until I get better. (stroke, White, male, inpatient)

For some patients, this sort of plan was more realistic than for others both in terms of the speed and extent of recovery expected and the logistical ability to minimize going out in public. Other patients were beginning to contemplate the prospect of long-term or permanent disability, forcing them to re-imagine the future. One stroke patient talked about second-guessing the plans her husband and she were making for their retirement:

> I always had thoughts of being able to go outside, and it'd be like 100 degrees out in Florida, and just laying in my pool listening to music or whatever. And I don't see that happening now. I think that's all changed. But he still wants to go there. And I'm like, ugh. So I just get to be handicapped in Florida where my family is not at, my kids aren't there. You know, if we have to go—if I have to be dragged to—in a car, to go to a store, it'll be 1000 degrees outside? I'm not looking forward to that. Like I was before I was handicapped. (stroke, White, female, outpatient)

Disability had not featured in any patient's plan for the future. When disability began to seem like a likely reality (at least for the foreseeable future), patients had to contend with what it meant for their relationships and their ability to perform cherished social roles. Patients identified a wide variety of roles and characteristics that were central to their identities—both how others perceived them and how they perceived themselves. In the aftermath of injury and facing the likelihood of prolonged disability, patients felt these central aspects of themselves were under siege.

Self-Presentation

Patients were often anxious about alterations to aspects of their appearance and self-presentation, particularly when those changes made them self-conscious about social interaction or otherwise made it difficult to pursue their accustomed social life. Elderly patients were especially likely to highlight the importance of chatting with friends on the phone or joining in group outings with an extended social network. And people of all ages who thought of themselves as highly social and personable were particularly concerned about loss of ease with and/or pleasure in social interactions.

Understandably, people who had problems with continence and/or toileting logistics were often very concerned about managing these issues in public settings. Day rehab nurses reported that some patients avoided taking medications that increased urinary frequency or urgency before coming to day rehab because they worried about incontinence or having to ask for assistance in the bathroom.

As much as patients generally hated needing family or staff to help with toileting, they were even more self-conscious about potentially having to involve friends in the process. Ideally, they didn't even want to make people aware that continence or toileting was a problem for them. One patient explained that because she required help in the bathroom, she had been avoiding going out with friends. One of her daughters offered to come out with her and sit in a separate area of the restaurant to be on hand for bathroom assistance, but the woman felt guilty at putting her daughter to this trouble, and she was self-conscious about having to publicly accept this sort of assistance.

Many patients were concerned about eating in social settings, particularly because so many social events revolve around collectively eating or drinking. The act of sharing a meal could be a minefield. Some patients were on specialized diets (or required tube feeding) because they had difficulty swallowing and/or were at risk of aspirating food or liquid. Patients with dietary restrictions wanted to return to unrestricted eating and drinking for a number of reasons (e.g., missing the pleasure of certain foods; finding pureed food disgusting), not least of which was their desire to eat "normally" in social settings.

For some patients, muscular weakness or paralysis in the face and/or throat caused drooling or made it difficult to keep food from falling from the mouth. In certain cases, the combination of hemineglect and problems with facial muscles meant someone could accrete dropped food on one side of their face or body without realizing it. For patients who were aware of these issues, it could be a paramount concern. At one point, a patient who was finishing his lunch while talking to me paused our interview to say, "When I'm eating, I hope to *god* I'm not showing you my food." Patients were often horrified at the prospect of violating eating etiquette and inspiring disgust.

Grooming and Appearance

On the whole, grooming, appearance, and physical attractiveness were low priorities for inpatients considering the obstacles to maintaining hygiene and beauty routines in the hospital. But several people (both inpatient and outpatient) did raise the issue. As previously noted, many patients were self-conscious about gait changes or being seen using a wheelchair or other assistive device or wearing a brace. One woman commented, "I would say [I want to get back to] dating, but I'm so far from that. I mean, who would want me? I can't even walk" (stroke, White, female, outpatient). Another stroke patient repeatedly emphasized that improving his walking and losing his facial droop were "the most important thing" to him. He felt he couldn't date until he looked "normal" again, "because who would think you're attractive?" (stroke, White, male, inpatient).

Several female patients brought up body image and discomfort with aspects of their appearance:

> Interviewer: So what do you think you'll be like a year down the road?
>
> Patient: Ten times better. Cause this ain't me. This ain't me.
>
> Interviewer: So tell me—because, you know, I didn't know you before—what's different? You said this isn't you? What *is* you?
>
> Patient: My hair's all grey right now. Which makes me look five times older. I mean, [if] you look good, you feel good. You know, your hair is done, your face is on, your makeup's done, you feel better. Not looking like this. This is sad. So sad. (stroke, White, female, inpatient)
>
> So this is so cruel. Because on top of everything else, I have to wear a belt around my stomach, my fat stomach. I have to wear a belt. A gait belt ... and I have no hair. That's okay, though. I don't care that much about that. I don't have to do my hair every day. That's nice. But. yeah, I don't know. I always cared about the way I looked. Even though I didn't like the way I looked. You know? But I'd always try at least. Put some makeup on. Now I'm like, what's the point? You know, that's why I'm glad we have masks that cover half my face. (stroke, White, female, outpatient)
>
> Right now, it's surreal to me. I never wore glasses in my life. I'm wearing glasses. I watch videos and look at pictures of who I was before this. So. I'm struggling with my looks. My scars are very, very—really only my neck scar is very surreal to me. I have a lot of new clothes and shoes, but I don't wear them because I'm not walking, so I don't feel comfortable. My left arm is—well, it's coming back slowly but surely. But it's not working how I want it to work.... I take pictures and videos of myself. To look at and see and try to feel comfortable. But I—the one thing I would say is acceptance is very hard to deal with. (TBI, Black, female, outpatient)

As these passages suggest, some patients were unhappy with the unfamiliar features they saw in the mirror. And especially for some women, maintaining a certain standard of grooming and feeling *put together* contributed to feeling *like me*. To see a familiar face in recent photos, to feel the habitual physical sensations associated with personal grooming rituals, and to present what felt like an acceptable face to the social world were all important to sense of Self.

Communication

Any patient who had difficulty communicating expressed some degree of general frustration. But in addition to the annoyance of struggling to make oneself understood, patients also felt socially wrong-footed. Patients who thought of themselves as particularly “verbal” were especially focused on regaining this element of themselves. One patient's daughter characterized her mom as "very overly talky ... and she likes to talk about everything ... she likes to be the center of conversation.” She described the pain they both felt because her mother's aphasia was inhibiting her self-expression. I wasn't able to interview inpatients with severe aphasia, but by the time I met Ellis in day rehab, he had recovered considerably. He spoke at length about the impact his more labored communication had on him, as someone who saw himself as a people person and used to take pleasure in conversing:

> You know, now I'm, you know, the guy who's gotta remember to do words and speech and, you know, little things that are, you know, email or texts. Now those are, you know, that's a, that's a big deal now ... I mean, you know, I was a, you know, I used to talk people all the time, and, you know, talk people, and now I don't want to go to talk people unless I need to. Because I don't really, like I used to be. So it's, it sucks. (stroke, White, male, outpatient)

At a basic level, being unable to convey one's preferences and needs could be agonizing. Patients who had since regained the ability to communicate recalled their irritation and anger, and many staff members pointed out how acutely frustrating communication disruptions could be:

> I think one of the reasons is that patients who are cognitively intact but don't have the ability to verbally communicate and also don't have the ability to just write and communicate—I've seen patients become very frustrated, because they know exactly what they want to say. And despite our, you know, communication book and multiple choice, we're just not able to figure out what they're trying to tell us. (staff, inpatient)

Other patients had difficulty speaking loudly and clearly enough to make themselves understood. Beyond the inconvenience and awkwardness of having to repeat oneself and strain to be heard, patients often reported that problems "phonating" (in rehab parlance) affected their ability and desire to resume their social lives. One patent explained:

> [Going out to see people is] miserable. I don't have a good time. I mean, I try. You know, people can't really understand me that well, especially when we're all wearing masks. I can't enunciate. I have a problem. I don't know what's going on. I got to get that checked out. I always got like a frog in my throat. And when that happens, I can't project and then people—I have to keep repeating myself. And it's annoying. It's tiring. (stroke, White, female, outpatient)

Another woman reported that due to her professional role and her accent when speaking English, she was especially invested in regaining her ability to project her voice:

> I need to conduct a lot of meetings. And in the meetings, I need to be clearly understood. English is my second language. I already have a barrier. So I need to compensate [for] it with the clear voice, and volume. (TBI, White, female, inpatient)

Some patients who struggled with volume and clarity of speech found themselves either avoiding certain social situations or socially withdrawing when in a setting with substantial ambient noise. As one might imagine, this limitation could be difficult for people who enjoyed live music, bars and restaurants, or any number of social activities that take place in crowded or noisy venues. Patients found themselves retreating inward, reticent to contribute to conversation as they once did because making themselves understood was exhausting and, at times, demoralizing. For some patients, straining to be understood was coupled with the feeling that other people were struggling to understand you. They were concerned conversation would be stilted and unnatural, potentially even unpleasant for or an imposition on one's listener.

Speech therapists reminded patients to use the "strategies" they learned, such as the acronym SLOB (slow, loud, over-enunciate, breathe) or the tactic of circumlocuting to avoid words they were struggling to recall. Some patients found it uncomfortable to use these adaptations. Similar to patients who were offered a walker but just wanted to "walk normally" again, these patients didn't want to have to speak in a way that was unusual for them and would mark them out as different. As one speech therapist explained:

> [They say], you know I don't want to have to use my strategy because it's not gonna sound normal or like, it's gonna be—people are gonna think it's weird that I'm talking slow. So some of those modifications we give people to be more clearly understood might change the naturalness, but I always tell people you want to be understood first and then as you get better, you know, hopefully that naturalness comes back. Sometimes people are hesitant to even use word finding strategies. Like we'll tell people to describe something. "Well, like if I describe it, they're going to know I forgot the word." It's like, well yeah, they probably will. But you're at least communicating, and so maybe you just do that in a safe space, I don't know. But we do get that hesitation a lot. (staff, outpatient)

For some patients, speech was so laborious that it had to be restricted to the essentials. Connor recalled that when he was in the early stages of recovery, he had to whittle his thoughts down to the bare bones. His wife, Emilia, agreed—his sentences were along the lines of "Need urinal! Hurry!" Now, Emilia said, it was more like, "Emilia, could you please pass me the urinal? Thank you!"

In many ways, Conner was a fascinating case study of language and the presentation of Self. I interviewed him at two points in his recovery, and he asked to see the transcripts. We both marveled at how, when his speech began to improve, his use of filler words started to return. The second interview read as a much more "natural" dialogue. The first time, he had to choose each word carefully because every word required a deep breath to produce.

Connor reported another frustrating effect of his hampered speech:

> I also really try to be very polite. And now it is hard for me. So I can't really say [plugs nose] "Yes, please." And so I say, "Yeah." I don't feel like that is as polite as I want to be. (stroke, White, male, inpatient)

As Connor's speech improved, he appreciated his renewed ability to observe the rules of courtesy. He was uncomfortable when he was forced to essentially issue demands, like "need urinal," even though all the others involved—staff and close family—fully understood his circumstances.

Humor was another central facet of Connor's sense of who he was and how he presented socially. He was an engaging and funny conversationalist, but post-stroke he realized how much humor (and his style of humor, in particular) relied on timing and inflection, both of which were now a problem for him. Connor felt that these subtleties of verbal expression were crucial to "letting people know who I am." When he had to communicate through an eye gaze device and later when his speech was labored, he said, "I tried to make jokes, and they would fall flat because the moment had passed." As time went on, however, not only did Connor's speech improve, but his most frequent conversational partners got better at leaving space and recognizing when Connor had something to say. For unfamiliar people, however, the problem to some extent remained: if you didn't know Connor, his speech patterns, or his sense of humor, you might not realize he was being sarcastic or that he wanted to interject with a joke.

Even after his ability to speak in more complex sentences returned, Connor's inflection was still diminished, and he worried about appearing to take an impolite tone or coming across as rude or blunt. As Emilia reported:

> And, you know, he doesn't want to upset anybody. So, you know, he's like, kind of trying to think of strategies about how to be, I guess, upfront with people or like, tell them, like, “Hey, I'm sorry. I know that came out wrong.” Or I think he's worried about sometimes he still laughs randomly, when he doesn't find anything funny. Or he might not have the same filter as he used to have. So I think he's worried about like those like social dynamics and social cues. And so he'll have to develop strategies like, “Hey, I'm sorry, I don't mean to laugh at you. It's nothing personal, you know, I just do that sometimes.” (wife of stroke patient)

Like Connor, many patients considered how they might preempt or attempt to explain this sort of misinterpretation. The situation was in some ways analogous to the problem of invisible disability. Although Connor was visibly disabled, people unfamiliar with him and his condition might not realize his flattened inflection had anything to do with his being in a wheelchair or having limited motor control. And people who didn't know him before the stroke wouldn't have a prior image of him as a thoughtful and polite person, so they wouldn't necessarily give him the benefit of the doubt if he came across as flat or terse.

Non-Verbal Communication

Emilia's quote draws attention to another significant element of self-presentation: as she stated, Connor's stroke caused him to laugh uncontrollably at times, and he was concerned about laughing in socially inappropriate contexts (and being presumed to have done so intentionally). As described in Chapter Four (Shifting Relationships), many patients, especially older men, noted that they were more “emotional” than they had ever been before. It wasn't always clear whether this increased emotionality was a neurological symptom (like Connor's laughter), a response to their circumstances, or some combination of factors.

They talked about crying more, and even crying in front of loved ones and staff, in a way that would have been unthinkable for them before. Some were embarrassed by this development and saw it as an unwelcome change in their self-presentation, but some thought it might be, to some extent, a positive change, as increased openness brought them closer to loved ones. In the next chapter, I’ll discuss the unsettling experience of feeling more emotionally labile and wondering whether the feelings are “genuine” or are an artifact of the injured brain. But from an interactional standpoint, patients often found heightened emotionality embarrassing, especially when it didn't seem to be in reaction to any particular social stimulus.

Some patients were unable to smile in the way they had before, and varying degrees of facial paralysis could drastically alter people's non-verbal self-expression. People felt hampered in their ability to convey nuance, or felt they had to overcompensate for flattened vocal affect by doing more "work" with their face.

Conversational Partners Unaccustomed to Disability

Some patients said they withdrew socially because they felt people had withdrawn from *them,* or they felt people were uninterested in hearing about neurorehabilitation and other central concerns of their lives. As one patient speculated:

> I always had a conversation for you, but now it's like sometimes I just don't feel like talking. I do more listening than adding to the conversation.... Sometimes I feel like, well, I don't want to burden anyone with—because all my conversation's about now is this. My body. What I'm going through, what I've discovered today, as opposed to yesterday, or what I've just—the difference between in the beginning when this first happened up until now. Or how much therapy has really impacted me or, you know, made me better. That's what my conversation is nowadays. And I don't know. Sometimes I feel like, you know, people don't really want to hear that. (stroke, Black, female, outpatient)

Whether or not family and friends were truly avoiding conversations about therapy and recovery, if a patient felt this to be the case, they could feel not only hurt and rejected but uninteresting and self-conscious, as though their world had narrowed, and they were no longer as engaging as they had been. Often, other peopled lacked familiarity with patients' preferred modes of communication, or with supportive communication in general. It could be hard for patients to direct someone who had no background knowledge, as I learned from experience.

Hayden had a tracheostomy, so air escaped as he spoke, making his voice faint and his speech arduous. Early in our interview, he asked me to get a sanitary glove from the container by the door and cover his trach dressing with my hand, to help prevent air leakage and strengthen his voice. It's a common method, but I was entirely uninitiated, so it took a while for him to convey what he was asking. When I figured it out, I was happy to help in any way I could, but I was also scared to hurt him. I had no idea how hard I was supposed to press or what it might feel like for him. I pressed on my own throat in the same place with equivalent pressure, and it was certainly uncomfortable. As I increased the pressure on his throat, at his instruction, it was hard to suppress the fear that I was choking him.

On that day, we spoke for about an hour, and I occasionally had to change my glove and switch hands, as one arm got tired. I can only speculate on what the experience was like for him because eventually I stopped myself from compulsively asking whether he was still comfortable. I also didn't want the interview to become entirely about the process of communication itself. I can only imagine what it's like to have to request that a virtual stranger invade your personal space, and to wonder how the person will respond. What if you asked someone to help occlude your trach and they said they weren't comfortable touching you? Or touching the trach dressing? In a medical setting, it's a reasonable bet that even an outside researcher will be comfortable and willing to oblige (especially if you're the one doing her a favor by agreeing to an interview), but in other social settings, it might be a tricky social calculus to decide if it's worth it to ask. You might weigh the greater ease of communication and the ability to get your point across against whether you want this person pressing on your throat.

Patients often felt people didn't have the patience required to communicate with them. Even the medical team didn't always take the time to optimally communicate with Hayden. They could have pulled up a chair for a minute so they could hear him better or they could have asked if he wanted them to occlude his trach, but they tended to take a got-the-gist-of-it attitude. One stroke patient with aphasia explained that when she got stuck on a word, "People get a little bit impatient, right? And kind of move on. Because they really don't know what aphasia is and how it affects people" (stroke, Hispanic, female, outpatient). Patients often felt self-conscious when they perceived that people were becoming impatient with them, and ultimately this sense of being a conversational burden could lead to withdrawal.

Patients themselves had to cultivate a great deal of forbearance, as this excerpt from my first interview with Connor demonstrates. At the time, Connor occasionally used a letter board. If someone couldn't understand a word, he could point to letters.

Connor: So when the ambulance came, they actually thought I was on drugs.

Interview: They thought you were?

Connor: On drugs.

[Interviewer is silent]

[Connor uses letter board]

Interviewer: D-R- Oh, they thought you were drunk?

Connor: No. [spells again]

Interviewer: Oh! Drugs!

Connor: They thought I overdosed.

For the first interview, Connor talked to me for over an hour and a half, over the course of two sessions. We were both doing our best, but I wouldn't have blamed him if he had gotten frustrated. He was admirably calm and gracious throughout.

Cumulatively, all these changes in patients' ability to present themselves in social interaction in their accustomed ways could lead to social anxiety and withdrawal and threaten patients' perceptions of themselves. Hayden's wife articulated her pain at seeing him retreat:

> [Hayden] has always been a social butterfly. I'm the introvert … [Hayden] has been the light of the party. [tearful] Always would talk to anybody. Everyone would say he'd talk to a wall if he could. He just loved to talk. He loved people. He never judged anyone. To know [Hayden] is to love [Hayden]. [tearful] And to have that voice taken away from him.

Another patient talked about how she had been a business professional and later a fitness instructor with a lot of social contacts. She described her loss of social confidence:

> And I didn't want to go [to the party] because I felt like there's so many things wrong with me. I got to walk around that woman's house with a cane, you know ... you know, I was like, I can't communicate with these sophisticated women, you know, with this stroke and everything. But I did. And I was glad that I went because, you know, you feel like you have no confidence in yourself. (stroke, White, female, outpatient)

For some patients, social grace and polished self-presentation were essential to their professional roles. Ellis, for instance, was a sales and marketing executive, and his living depended on being personable and highly proficient at verbal self-presentation. Even though he had come a long way in recovering from aphasia and could now make himself understood fairly effectively, he was facing the possibility that he might never again be able to speak in a manner suitable for a client presentation, for instance. He was also used to holding himself to a high standard of verbal ability:

> And, you know, having that I had, you know, I couldn't talk too very good. My words were pretty, pretty bad ... and try to get to where I need to—what I used to have. And you know, talking people, and you know, like my writing isn't the best. For sentence—sentences aren't the best because my brain doesn't know to say that. Like it used to ... because what I did before was quite a bit talking. And speeching was quite a bit, you know, I was doing pre- or press the arrest or pre-senting, like, of people's in, you know, under all the time or, you know, a couple hundred people here, that was part of my, my work. And now I'm, you know, doing, like you just saw, consider the word when I can't think of what to say. (stroke, White, male, outpatient)

In the next section, I'll discuss loss of or changes to professional roles and identities. For someone like Ellis, the recovery stakes were high not only because of the prospect of losing income, security, status, and prestige, but also because he was losing something he was good at, was valued for, and had taken pride in. Something he had done with ease and pleasure was now effortful and stressful.

At a more basic level, patients were also hoping to regain their ability to accurately portray themselves to their loved ones and to the social world. One patient described what she experienced as a troubling disconnect—when she spoke or read stories to her children, her voice was like a "runaway train," flat and unexpressive. She didn't feel like herself, and she felt cut off from her ability to connect her inner life to the world outside:

> So I think like, I had all of these like thoughts or like things, but it wasn't, I wasn't able to get them out. And the voice, the connotation of my voice and that runaway train was like, was very awkward. Because like, that's how you portray who you are. That's how you connect with other people ... I could talk but it was like, it was just like, no spirit, nothing was behind it ... so I felt a little lost in that way.... The muscle disconnect and stuff wasn't really, I mean, that was more secondary … I don't think that controls who I am or like, you know, my characteristics. It's just like a part of my body. (stroke, White, female, inpatient)

Later, she experienced heightened physical symptoms, but those changes, while troubling, didn't seem as integrally connected to her sense of Self and her ability to convey that Self to others. As much as it was important to her to be able to play with her children, give piggyback rides, and work on ambitious art projects, she was most deeply unsettled when it felt like she was cut off from her own voice.

Return to Work

As discussed in Chapter 1, most inpatients weren't focused on returning to their jobs yet, but work was often still at the forefront of people's minds, and as one physician put it:

> I'd say, you know, the minute people are able to do most of their day-to-day routine and are not seeing major impairments, work is always at the top of the list of what they want to do. They really are always eager to kind of get back into that environment (staff, inpatient).

Even patients who were currently prioritizing shorter-term goals often talked about their jobs, and many of them were anxious about being away for so long. Some of the more disoriented patients were focused on work, in part, because they weren't able to remember where they were and why. As one staff member reported:

> I'm just thinking of someone that we actually have right now who is retired. And he's planning on going back to work! And now, after his brain injury, he's—I mean, he thinks he's—you know, should be going back to work, but he actually has been retired for a couple years. Still in [post-traumatic amnesia]! But no, don't worry, you don't have to go back to work. You're already retired. You don't have to worry about that. It's like, *I gotta get back to the office!* (staff, inpatient)

A patient's wife told a similar story about the period of time after her husband regained consciousness but before he was out of post-traumatic amnesia:

> He asked a lot of questions at first because things didn't make sense. He would ask, "Am I in trouble. What happened? Are you calling me in? Does my work know I'm here?" You know, things like that. You know, at first, he was very concerned. And now he kind of is just—it's taken a lot of me and his friends and whatever, just to say, you know what, you need to focus on you for the next year. (wife of TBI patient)

The patient in question was horribly injured in a workplace accident and nearly died, but in his confused and disoriented state, he was still concerned about whether his job knew he wasn't coming in for the day. Other patients tried to sneakily work from the hospital. In most cases, these patients either had minimal cognitive changes (so wanted to check in with work between PT and OT sessions) or were severely cognitively affected and didn't realize they weren't capable of working, at the moment.[2]

The significance of work came up frequently in my interviews and observations. In some cases, when asked what they were like before injury, patients talked first and foremost about their

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[2] Staff sometimes had to find creative ways to redirect these impulses for patients with poor insight. I ran into one patient several times on the brain injury ward. He would accost anyone willing to listen and vehemently insist he had to get out of here tomorrow because he had a business to run; another common refrain was that he was only here working as a contractor, and the hospital hadn't paid his bill yet. The next time I saw him, someone had given him one of the measuring wheels the PTs used to track distance for walking tests. He was very contentedly going around measuring the hallways and telling everyone he encountered that he was checking for mold, and we should all be aware that the hospital was riddled with it.

earning ability and how much time they used to spend working. Some patients were strongly identified with a particular profession or deeply invested in a career path, but for many people, to be hard-working and a provider were equally and sometimes more important than their specific profession.

Several patients talked about wanting to be "useful" or not wanting to feel "useless." This exchange is a striking example:

> Interviewer: So how do you think about yourself now? How would you describe yourself now?
>
> Patient: Useless.
>
> Interviewer: Useless?
>
> Patient: Yeah, useless. I *am* fucking useless. I'm not a productive—I'm not a productive—of society. I'm not pro-ducting anything. Productive in anything. I'm just living life, going through the motions now. Wait for the next step, right? (TBI, White, male, outpatient)

Usefulness and productivity were nearly always closely identified with labor, paid labor in particular, but some patients talked about trying to do more around the home to compensate for being out of the workforce. This trend was, perhaps, unsurprising, given American cultural valorization of productivity, tendency to equate productive use of time with labor, and privileging of paid labor over other forms (Stone 2007). Many patients also stressed the importance of being a provider, especially for one's children. Patients with children often said something along the lines of, "I always took care of my kids no matter what. And if they needed anything, I'd give it to them" (TBI, White, male, inpatient).

Breadwinner/Provider Status

Being a provider or a breadwinner was strongly identified with masculinity. One patient who talked about work a great deal said, "[Work] was a massive part of my life before the surgery.

You know, I was the breadwinner for my family. I spent a ton of time working" (TBI, White, male, inpatient). The way he framed it, I assumed his wife was a stay-at-home mom, but when I interviewed her, I learned she was actually a working speech-language pathologist. Men often talked about wanting to provide for their wives, even if their wives also worked. As Alan told me:

> So my wife, you know, has really picked up the slack. But don't no man want their wife in that position, you know? I want to provide for my household. My wife also provides for my household, but I used to be—to do things for my household. You know, it was a team effort. You know, and now I have no income, you know. My bills didn't stop, you know, and they still want the mortgage for our house. You know, they still want my car note. So it's a drastic change. And, you know, that's another motivation to keep—for me to get better. Because I'm not a lazy person. (stroke, Black, male, outpatient)

Like Alan, a lot of patients, especially low-SES patients and perhaps low-SES Black patients most of all, emphatically stated that they wanted to return to work and were not "lazy." The stigma of reliance on disability was, in some cases, explicitly referenced.

Being a provider was essential to masculinity in a way it wasn't for femininity, but women were just as likely to focus on getting back to work; loss of workforce participation was essential to other aspects of their identity, if not their gender performance. For some women (especially younger women), sharing financial responsibility with their partner was an important value, as Isobel explained:

> So I'm very independent, but also like very strongheaded. I'm also—I'm also like, I want to contribute to what we're doing at [home]. For example, like when we got a new stove, I'm like, okay, I pay half, you pay half, right? We got a new washer-dryer, I pay half, you pay half, you know? I'm always trying to be equal partners, right? On what—in what we're doing and how we're doing—how we're raising our child and finances, too. So my husband makes a lot more money than I do ... I probably won't make money as much as he would. But like, I'm trying to contribute. (stroke, Hispanic, female, outpatient).

Professional Status

Isobel, the aphasic language teacher, identified as an accomplished, educated, professional. She described her process of coming to terms, first with not returning to her job right away, and then with the possibility she might never return. She recently had a frank—and not entirely optimistic—conversation with her neurologist about her professional future.

She was worried about finances and about contributing equally to the household, so she started trying to think about a backup plan, what her options might be if she couldn't be a classroom teacher. Beyond financial considerations, Isobel was concerned about loss of her profession:

> But you—you lose part of your identity, right? As—you know, as a professional ... unfortunately, our lives are—revolve our—our life revolve [around] our profession right now. Right? You know, for me in my thirties, right? (stroke, Hispanic, female, outpatient)

Like many patients, her specific profession mattered to her, but it was also important to be *a professional*. She had gone to grad school and invested in her career over more than a decade. When asked how her life had changed, she noted, "But my—you know, all my friends are working professionals and, you know, it's not like anyone's hanging around during the day, right?" She didn't want to be the sort of person who had nothing going on, who wouldn't have anything to say when asked about her profession in a social setting.

She was also starting to feel out of the loop with her colleagues; when she joined them for a social gathering, they talked about students she didn't know and situations she wasn't aware of. Like many patients, she missed both her work and her workplace, as she explained:

> The profession part kind of kills me. Because I miss it. Really do miss it. While it's stressful, right—it's still work, right? But when you see your students achieve and grow with their knowledge and do really well or, you know, see them playing their sports. And I teach AP, and my last class did really well on their AP scores. So when I went to talk to my boss about—after my stroke, he was going through my scores, and I did so—I'd like surpassed state and national standards. And how well—the students did well, you know. A lot of it is professional pride, right? And in how my students achieve, right?... So part of it—it's gone right now. Or on hold, I guess, is what I want to say. (stroke, Hispanic, female, outpatient)

For Isobel, and for many other patients, a job was not just something you *do* but something you *are*. At this point in her recovery, she was having to consider what it would mean to do something else, to no longer be a teacher.

Pushes and Pulls

Not all patients were equally eager to return to work or return to their particular profession or position. A number of factors pushed and pulled patients toward or away from return to work. A patient's physical and cognitive constraints were an obvious limiting factor. One stroke patient, Valerie, outlined some of her own considerations. Of her previous job she said, "I would love to go back there if I could because it's a great company." But she was also confident that given her skillset, work history, and interviewing ability, she wouldn't have much trouble finding another job. In fact, she had just applied for a new job near her home. The first consideration was salary; given her work experience, she didn't want to take a substantial pay cut. The other concerns were logistical. She had lost the use of one arm, so while she had always been an excellent typist, she would now need some kind of adaptive system. And she was concerned about going back to an in-person work environment for a number of reasons:

> [My] main concerns are, can I make it through the day without having to take a nap? Can I make it through the day without peeing myself? Because I know I have to go to the bathroom, but sometimes like, if I think, "Oh, I have to go to the bathroom," I stand up and just—gravity takes over. So you know, walking to the bathroom, am I gonna make it? Who's going to help me if I pee all over my pants at work, you know? And then just emotionally, can I deal with everything? [tearful] Like in an office environment. I'm just more concerned about that ... like I said, if I can do something remote it's going to be a heck of a lot easier for me. So that's what I'm looking to do…. And especially in the winter, I can't imagine me standing outside, waiting for a train in the snow, in the rain, you know, and then getting off the train and getting on a bus ... I can't see commuting in snow in this condition. In snow and all those people, being around all those people. Someone knocks me over, I could hit my head on the ground and cause more damage, you know?... I'm not—I can't do the wheelchair. That would be ridiculous too. Cause like, I'm not one of those

> people who like—I only have one arm, so it's not like I can—you know, you see some of these people in the wheelchairs and they're running around. You know? I got one arm, so it's kind of hard to do a wheelchair. Can't move fast. (stroke, White, female, outpatient)

Valerie's changes were primarily physical, although she was experiencing emotional lability and fatigue. She knew her skillset was valuable, so the primary obstacle was to find an employer that would accommodate her need to work from home. She might also benefit from a gradual start or flexible hours to cope with the fatigue, but she felt she was currently capable of doing the work.

In many cases, however, patients and/or family and staff were concerned about the consequences of jumping the gun with return to work. Many staff members told me some variation of: "Because the truth is there's not a lot of protections, once you go back into the workforce, if you're not performing, many—I've seen many people lose their job" (staff, inpatient). A vocational specialist explained that vocational therapy won't sign off on a patient's return to work until they're confident the patient will be successful. If a physician signed off instead and the patient went back and failed to perform, the company could fire them. They would lose both their job and their ability to apply for disability benefits because a medical provider had approved them to work.

Staff members warned patients about this potential outcome, but some patients were already fully aware of the risk. Rowan was one such patient. He was injured at work when a piece of heavy machinery fell over and pinned him. Rowan had been working alone on the graveyard shift, even though the company wasn't supposed to schedule people to work solo. He told me, "I'm afraid of losing my job when I finally go back to work," (TBI, White, male, outpatient). He had seen it happen before: people came back, couldn't do the job, and were let go.

Staff had plenty of cautionary tales. One vocational specialist recounted:

> I had a client who was post-COVID. And he had a stroke, while—because of the COVID. Stroke caused physical, cognitive impairments, along with a loss of vision. He was participating in the day rehab program. The therapy team did not recommend that he return to work. Because of all of his limitations. They didn't say that it was like a permanent don't

> return to work, it just—you still had a lot of areas of improvement. He did have long term disability available to him. But that was only based on his salary. And his position paid commission. So family really wanted him to go back to work. There was a family meeting where family was—and the client was in agreement with the family ... they thought that the employer was going to be extremely accommodating. They also came and said that the employer has unlimited PTO. I tried to explain to them that the only way that an employer has unlimited PTO is if the demands of the job are being met. You know, an employer doesn't care if you take time off, if you're doing everything that you need to do. But they were adamant that he's got unlimited PTO, so just release him to return to work. And he could use his PTO to continue with therapy. I tried to, you know, talk to them about what was more than likely going to happen. Well, his—we did not release him to return to work. His neurologist released him to return to work ... so the client goes back to work, he tries to take some time off for PTO to go to therapy, and the employer told him that he was off work too long and couldn't take PTO for a while. So about six months later, I get a referral from another physician for this individual to be seen by voc rehab, which could only mean that he's having difficulties on the job. (staff, outpatient)

As with many contentious decisions, at the end of the day all staff could do was warn the patient and family and then document their recommendation and that the patient was choosing to ignore it. As the above story highlighted, family pressure was another major factor. Family pressure could be applied in either direction, for or against rapid return to work. But in many cases, the family was anxious to get the patient back to work because they depended on their income.

Ellis was another example of this particular bind. He had two teenage children, and his wife was a stay-at-home mom. His family relied on the sizable salary he brought in, and staff reported that the family was applying pressure. Ellis was ambivalent about returning to work, or at least to his particular job. Before he had his stroke, he was considering starting a job search. In fact, he largely attributed the stroke to the colossal stress of his current job. As far as staff were concerned, it didn't seem likely Ellis *could* return to this job, or even a similar job, in the near future. He was able to get his point across, but he hadn't fully recovered from his aphasia, and his job demanded a certain amount of verbal polish. But Ellis was feeling the pressure to provide for his family:

> I got to worry about my kids, you know? Luckily, I've been—the word that I work—you know, paid until this point to January. Then they'll pay with part of it, but still not where I ... you know, my or my bonus and other things, and you know, it's a lot of money and I

> don't want to lose these things. Because I figure, I did it, you know, did all the work. And I don't want to lose all this extra money. And—but I need to get better. So it's kind of, it's kind of tough because I want to get better, but I don't want to lose a bunch of money at the same time. (stroke, White, male, outpatient)

Some families were applying pressure in the opposite direction: they wanted the patient to take it easy, continue their recovery, and safeguard their health, and/or they didn't think the patient was ready to return. In some cases, they were pressing the patient to retire, but the patient was resistant. Rowan, for instance, was currently in conflict with his wife.

As previously mentioned, his work situation was complicated. He was injured on the job, and he was collecting worker's comp. So far, the company seemed supportive, telling him they'd make every accommodation necessary to bring him back, but Rowan was aware he could be fired if he returned too soon. His job demanded heavy, manual labor. As he put it, "And hell, they got starters that weigh 80 pounds. You know what I—I don't think I can even hold a starter up to put the bolts in. They got hydraulic pumps that weigh over 100 pounds, you know?" And because of the damage to his spinal cord, Rowan had trouble standing for too long.

Even if he tried to move into a supervisory role, he said, workplaces had changed. Companies expected a supervisor to not only deal with timecards, ordering, invoicing, organizing the shop, and keeping the work flowing, but they want the supervisor doing the same physical labor as everyone else. And he didn't necessarily have the "computer skills" a younger, less experienced supervisor candidate might bring to the job. He had been working in this field for over forty years. Rowan said, "I loved what I was doing. I was good at it." Ideally, he wanted to go back to the same role, but he was willing to take any job they would give him.

His wife, however, wanted him to retire and collect disability; she said he was getting too old for the work, and she didn't want to see him get hurt again. But he was a few years away from being able to collect a pension or social security, and he was adamant that he wanted to provide for his family. His adult children already had to stepped in a couple of times, after his accident, to help him make the mortgage or car payment. "My wife would live on $10 a week," he said. But for Rowan, it was a matter of principle:

> I just want to go back to work, man. I want to be able to provide for my family. The way they deserve ... so I can take care of [my wife] the way she needs to be taken care of. I can't take care of her on disability, can't give her what she needs.... How ‘bout the house payment? And clothes? She got my grandkids' cars on my name. You know? And I gotta—sometimes I got to kick in the money for it, you know? Right now we're making it. But by pennies. Before, we made it. I was making three grand a week. You know? Disability ain't paying me that. I'm only making like, 750 a week in workman's comp. (TBI, White, male, outpatient)

Beyond the push and pull of family preferences, Rowan's story drew attention to one of the weightiest factors at play in many return-to-work discussions. In some instances, both incomes in the family were affected by the injury. In Hayden and Katie's case, for instance, Katie had to quit her job to provide medical care for Hayden. They were both invested in making sure he had the best possible chance at recovery; insurance provided either day rehab *or* home care, so they opted for day rehab to ensure he would continue intensive therapy. He still needed round the clock care, especially when he was initially discharged from inpatient rehab and required frequent trach suctioning, so Katie left her career and learned how to be a home nurse.

Connor and Emilia were in a similar position, at least for the immediate future. They had been living in another state when Connor had his stroke, but they knew they needed to go where the best possible care was available for Connor's rare condition. There was no way of knowing how long he would be in intensive rehab, and Emilia wanted to be with him and wanted to make sure she was there to advocate for him and learn the ins and out of his care, so she left her job behind. They had been saving to buy a home, and now they were living on that nest egg.

Other patients were in a similar bind, for different reasons. While Valerie was going through stroke rehab, Valerie's husband developed a debilitating chronic condition; he had been through numerous specialist appointments and a taxing battery of tests, but so far, they hadn't been able to pinpoint the cause or find a treatment. Valerie said:

> And he's just tired all the time. And he's a person who's like, always like a go-getter. You know, he's always doing something, tons of energy. And so now he's getting depressed because he's not working. I'm not working. I—finances are not looking good right now ... so we've already got all the help we can get. I mean, my family's helped us. My friends have helped us. My sister did a GoFundMe for like, in the beginning, you know, with the medical bills and stuff. But so I'm waiting for my social security disability. Because when that comes, I'll get back pay. But I don't know. So I've been waiting. We started the process [9-10 months ago]. And I just found out last week, that they finally made a decision on my case, but it had to go to quality assurance. So now it's going to take another two to three weeks because somebody has to like, you know, just check it out.... One thing we had to do is we got our mortgage deferred.... We would be in bankruptcy right now if we had to make that mortgage payment. There's no way. I mean, I only get $3,000 a month. And we don't qualify for like food stamps or any financial aid, because the $3,000 is too high.... I'm trying every avenue you know, like we're going to food pantries. I even went to try and donate plasma. Well, after two-and-a-half hours, they tell you that, well if you had a brain aneurysm you can never donate plasma. I'm like, I went through this whole thing of all these different questions. Sixty questions and talking to this guy and blood pressure and all these other things. And now you tell me that. So it just seems like I keep getting the door slammed in my face over and over again. [tearful] (stroke, White, female, outpatient)

As previously explained, Valerie had a valuable professional skillset and had been working for a major corporation. They went from being a dual income household to trying to sell plasma.

For other patients, the need to sustain insurance coverage compounded the return-to-work urgency and, in many cases, complicated people's lives considerably. Becca, her husband, and her adult son were all hospitalized simultaneously with COVID-19. Becca had a stroke, and her husband died in the hospital. Their adult son had a developmental disorder, and Becca and he were both on her husband's insurance. When her husband died, the insurance was abruptly cut off, but their son was on a ventilator and needed to transition to a long-term acute facility for continued care.

Because of his disability, he qualified for Medicaid, but as Becca (only recently post-COVID and a stroke patient herself) worked with the hospital social worker to find somewhere to move him, she learned that few of these facilities took Medicaid. In the end, an administrator at one facility had a personal affinity for people with Becca's son's disability, so she pulled strings to get him in. Unfortunately, the facility was about an hour's drive each way from their home, and because of her stroke, Becca had to find someone to drive her. She wanted to make sure someone was always there with him because he wasn't very verbal, and the nurses had a hard time understanding him.

Degree of Commitment to a Specific Job or Profession

Physical and cognitive changes, availability of accommodations, family pressure, finances, and insurance influenced whether patients prioritized return to work, and with what degree of urgency. Among people who prioritized return to work, I noted degrees of identification with a specific job or career. Some patients wanted to return to paid employment but weren’t strongly identified with a particular profession. Generally, they wanted a job that paid just as well at their most recent job or a job with similar characteristics (e.g., a desk job, not a job that required them to be on their feet all day). But the important thing was to return to supporting oneself and one’s family and returning to a sense of status and independence.

Patients also talked about missing how work structured their day, challenged them, or provided camaraderie and social engagement. But many were flexible about the job itself, as long as it fulfilled the basic parameters. Staff could cite examples of people who successfully switched careers to something more suitable post-injury (e.g., from a high-pressure CPA job to a lower stress accounting clerk position). But career change presented its own challenges. It was often difficult to go back on the job market after an extended medical leave, without experience in the role for which you were applying, and potentially, with disabilities that required accommodations.

In some cases, patients wanted to stay within the same company but understood they probably wouldn't be able to perform the same job, so they were hoping the organization might find them something new. But depending on a patient's skillset and current limitations, it wasn't always a viable option. One patient had worked as a mechanic; post-TBI, he couldn't do that job anymore, but he described himself as "devoted" to the company and hoped they might find him something in management. His wife, however, also worked for the company in a different capacity, and while she didn't want to crush his spirits, she didn't feel his hopes were realistic:

> He has comprehended he probably will not do that job that he is doing again. He goes, “Well, maybe they'll give me a desk job.” You know, we don't even talk about it. I'm just like, “Well, maybe. Well, let's just worry about that when we get down the road” ... I just want him to focus on recovery, recovery, recovery ... [But he] will never work there again. (wife of TBI patient)

Based on what was expected for his recovery, what she knew of the company (and their concern about safety and liability), and his age and educational background, she thought his hopes would meet with disappointment, at least when it came to that particular organization.

Other patients wanted to return to their specific job (or to the same role, at another company). These patients cared about the same factors that mattered to the previous group (being able to support themselves, enjoying the status of “provider,” etc.), but they had additional reasons for wanting to return to the same position. Scott, for instance, returned to his job as a software engineer. Being a software engineer wasn’t particularly central to his sense of self; it wasn't necessarily his life's passion. But he felt he was good at it, it was a reliable means of providing for his family, and his employers valued his abilities and were very supportive during his recovery and transition back to work, so he had ample reason to want to stay.

As one might expect, if a patient had a specialized, in-demand, and hard to replace skillset, and if the patient was expected to recover to the point that they could still do the job, many companies were accommodating. And patients who felt their companies valued them and were eager to have them back were often loyal and highly motivated to stay. At the same time, one patient who enjoyed her job and worked there for over ten years felt slighted that her coworkers and supervisor hadn't reached out to her more in the aftermath of her injury. She began to feel lukewarm about the job, even as she prepared to return.

The smallest but perhaps most vocal group of patients were those who were highly passionate about their profession itself. They derived a great deal of enjoyment from their work, and it was at the core of how they saw themselves and wanted to be seen. One of these patients was technically retired, but as a priest, his primary goal was to regain mobility so he could stand to say Mass. Another patient, Hassan, prioritized returning to work as a commercial scuba diver above all else. He couldn’t begin to envision a life without diving. At the end of an interview in which we talked predominantly about diving, I tried to branch out to other areas of his life:

> Interviewer: So aside from diving, what else do you want to get back to?
>
> Patient: Diving. [laugh]
>
> Interviewer: Just diving?
>
> Patient: Just diving. It's the best thing that's ever happened to any human being, to be honest with you ... and I love my work so much. I try to be as much effective in my work as much as I can. So.
>
> Interviewer: Is there any future in which you don't go back to diving or?
>
> Patient: Well in the condition that I am in, I don't think that I will be able to go back to diving, in general. Which is breaking my heart so badly. But in the meantime, I try so hard to work everything out so I can be back again healthy, as much as I can. So I can be able to get back to diving. (stroke, Middle Eastern, male, outpatient)

In Becca's case, she was hoping to reclaim her fitness instruction business. While in the hospital, she gifted all of her equipment and her established contracts to her night instructor. She believed she would never be capable of teaching again. When she was stronger and further along in her recovery, she regretted having made that decision while she was cognitively "foggy." Even though teaching wasn’t a financial necessity for her, she loved it, and she lamented losing the enjoyment and social outlet the job provided. Now that she was back home and looking for distraction and stimulation, she was trying to figure out how to get back to it.

In some cases, people knew they would never be able to go back to a beloved job, but they hoped they could find another job that would be similarly meaningful. One law enforcement officer corrected me when I referred to his job as his "former" profession. He said he would always have the community and identity, even if he couldn't work in that capacity anymore. He would always be part of the brotherhood, but he would miss being on the job. He hoped to find another career that would give him a sense that he was contributing to his community and serving people.

Patients Already in Transition

Some patients were already in a transitional phase before their injury. A handful of patients were pursuing higher education, and they hoped to continue their studies, although perhaps with a different emphasis. A vocational therapist reported that universities, on the whole, were very willing to work with vocational therapy to arrange accommodations for returning students; sometimes, however, patients had to reconsider their major, taking into account whether they would be able to find work in their chosen field with their current cognitive and physical changes.

Several patients were between jobs at the time of injury, including a few whose jobs were affected by the pandemic. One woman worked at a senior center for ten years and was laid off when it closed down. Another woman, Jada, had to leave work when her children's schools shifted to remote learning. Her partner had recently died, so she was parenting on her own. She explained:

> I'm ready to try to get back—I need to go back to work because I'm barely getting by with trying to raise my children. That's my main goal, I want to be able to provide for my children again. (TBI, Black, female, outpatient)

But post-TBI, she had changes in her vision and hearing, she had difficulty speaking, and she was struggling with memory impairment. She was concerned about entering the workforce again with all of these new disabilities, so she was hoping to make major strides in rehab before trying to find work. At the same time, she was hoping to make a change in her professional trajectory:

> I've been thinking. Because I feel like I'm [in my thirties], and I just don't want to work a regular job, I want to go after a career job because I feel like I'm at the edge that—so I need to think about—I need to work, go back to school. I've been thinking about what kind of work is it that I want to do. So the job that I picked, it was kind of—I only wanted to pick it because I saw a lot of women starting to do it now. CDL truck driving. Because it was shocking to me, when I was on Facebook, I started seeing a lot of women starting to do it now. And they make a nice amount of money. But with that, I have to make sure my vision and my hearing is all the way well, because they're gonna test you on those things. So this a career job. They pay like $30 an hour. So I was like, that would help me be able to save up and take care of my children. I gotta think about, you know, I just can't take any job and it's not able to pay the bills or do this and do that. So I'm just trying to really do something better now. But I got to get myself back together first, so I do the kind of work that I want to do. And I gotta figure out, what kind of work do I want to do? (TBI, Black, female, outpatient)

Without much support and with a lot of potential barriers, Jada was hoping to recover fully enough to embark on a new, more lucrative career and support her children. Other patients were under less financial pressure and had more family support but had been struggling to find work that suited them and felt meaningful prior to their injury. One patient had worked as a programmer for many years before getting laid off. He decided he didn't want to work a desk job anymore, and he didn't want to work for someone else, so he started his own handyman business. But following a slide into alcoholism, his relationship with his wife deteriorated and she moved out of the house.

When he sustained his TBI, he was in a deep depression, drinking "all day every day" (TBI, Hispanic, male, inpatient), picking up jobs occasionally, and living on investment income and savings. After his accident, his wife and he hoped for a new start. Her income was enough to support them, but they both hoped he would find something to structure his days and provide purpose. Patients in this position tended to frame their injury as a reset, a turning point that altered their outlook and wiped the slate clean, leaving them open to career possibilities.

Retired Patients

Several patients were already retired, so they were primarily focused on getting back to recreational pursuits, preserving their independence and significant relationships, and minimizing disruption to their retirement plans. In some cases, patients had retired quite recently and felt they were only just on the verge of enjoying the life they planned when medical catastrophe struck.

Many patients were about to retire or nearing retirement age within the next several years. Some of these patients felt ready to retire. Luke, for instance, had never been particularly invested in his job as a janitor—it was important to him to bring home an income, but as his partner Sarah framed it, he could have done something else. He wanted a job he could forget about at the end of the day. Before the stroke, Luke was within striking distance of retirement, and now he was happy to turn in his paperwork a bit earlier than planned. Sarah questioned if it might be better for him to have the job to go back to as an incentive to get the most out of his recovery, but for the most part, they were ready to accelerate his retirement, even as Sarah planned to work for several more years.

Others had planned to continue working indefinitely and now felt they were in a bind. It could be difficult to find a new job so close to retirement age. And in some cases, people were disappointed that they might not be able to finish their career on their own terms. According to staff, some patients talked about wanting to be remembered as they were before the stroke or TBI: they didn't want to come back for six months or a year and limp across the finish line. Other patients wanted to prolong their careers post-injury so they could finish strong, rather than retiring unexpectedly due to illness.

Shifting Priorities

In several cases, patients were inspired to downshift or re-order their priorities. Prior to injury, they had no plans to change their work life, but now they were talking about focusing on family and enjoyment of life, over career building and financial gain. These patients tended to be older, but not close to retirement age, so they were hoping to continue working. But before, they worked multiple jobs and/or picked up as much overtime as possible, and now they hoped to make a change:

> I don't know if I'm ever going back to work. If I do, that's fine, but it would be a different job. No more run and gun, you know, up at four in the morning, home at eight at night. I don't know. We'll see. We'll see ... I wouldn't go back to what I was doing. I would switch jobs and just go pick up a lumber truck and deliver lumber. The getting up at five in the morning, standing in a foot of concrete and mud, and pouring concrete till seven o'clock at night. It's just—the run—the run and go lifestyle is for a younger man ... I mean, I was always making big money and providing for my kids. And I just—I know now there's more to life than making 100,000 a year and staying out till sixteen hours every day making money. I mean, it put all three kids through high school, but it cost me a marriage. The ex-wife said I was never home, and she was right. Because I was always providing … that's all I knew. My father did it. My brothers all did it. I figured going to work and working your butt off and earning the ultimate buck was it. Well, I get this handed to me and you realize that not everything's about a paycheck. (TBI, White, male, inpatient)

Another patient was in his seventies and still working, plus promoting concerts on the side. He was used to burning the candle at both ends, but he was contemplating a change. He said:

> All the money I made, I'm gonna have to spread. [laugh] So it's not really worth it. Yeah. The quality of life is better than all this ... so I got to think about what I want to do, jobwise. If I'm going to retire. Or If I'm gonna—see, I was waiting for them to give me a buyout. There was some talk of that. And then the pandemic hit. So we'll see. I'm not gonna leave any money on the table.... But if I work again, I'd go back inside and do a less strenuous job, physically strenuous, less strenuous job. (stroke, Black, male, inpatient)

Patients were hoping to be strategic about their finances. Few people were in a position to have absolutely no regard for money, so patients carefully considered their retirement savings, pension options, and access to various income streams. But some patients were comfortable enough to consider accepting a drop in income, and in the aftermath of a life-threatening medical event, these patients often talked about shifting focus away from maximizing their earning potential.

Active, Capable, and Independent

Many patients identified strongly with the idea of being active people—outdoorsy, energetic, good with their hands, and dedicated to athletic and adventurous hobbies. Hayden and his wife, Katie, always described themselves as “not couch-sitting people.” Hayden had no sedentary hobbies and no desire to be the sort of person who did. He spoke fondly of a time in his life, during his military career, when he would jump in a helicopter and go somewhere at a moment's notice. When asked to describe himself, he said, "Ready for anything. Really fun. Adventurous. I build in family time. But I still make time for friends. Thrill seeker." His post-military profession required skill, willingness to travel frequently, and a significant measure of physical courage.

Locked-in syndrome changed their lives dramatically. I asked Hayden whether he had developed any new hobbies and what he did now to occupy his time, and he said, aside from time with family, his energies were entirely devoted to recovery. Between outpatient PT sessions, they had a physical therapist come to the house. Katie described how Hayden used to love to be outside, riding his dirt bike, working around their extensive property, or playing with their son. Now they were forced to "turn into couch-sitting people." He told me, "Right now, I see myself as weak and handicapped. In this chair."

Katie struggled to coax him outside. It was painful for him to sit and survey the projects he had to shelve, the tasks someone else had to take over, the beloved hobbies now on hold, and the tools he couldn't currently use, and perhaps would never be able to use again. And most of all, it was heartbreaking to sit on the sidelines and watch his son play.

At one point, I asked Hayden "When you're not able to be active, and you're just kind of left to your own devices, what do you think about?" He said, "Sometimes I wonder what I could have done different. [tearful] And a lot of the time, I think about all the projects I wanted to do on the house and how like we wanted to do new windows upstairs, sanding the new deck ... all stuff normally I would have done."

Hayden is an extreme example, both in terms of degree of identification with an active, adventurous life, and the extent to which his life changed post-injury. But a lot of the elements present in his story were echoed by other patients. In Chapter Four (Shifting Relationships), I discussed how loss of independence altered relationship dynamics. Independence was also a central theme in patients' discussions of who they were, as people.

Independence

One daughter talked about how her "super independent" mom would rather change her mind and deny she wanted something than admit that she needed help. Another patient said:

> I am very much a do-it-myself person, which is why I chose the career that I did. If you ask any of the therapists here, or nurses, or PCTs, you'll know that, you know, I tell them when they say, Can I help you? I say, “No, I got it.” That should be my name ... I've been very independent. I don't like anybody to do anything for me. (TBI, White, male, inpatient)

Beyond loss of independence, many patients were thrown by the loss of *being depended on*. As one TBI patient framed it, "It's like things—everything's swapped. Because I'm used to being the caretaker, and now I'm not. That's so-o-o! Depressing. Demoralizing" (TBI, Black, male, outpatient). Patients enumerated their litany of responsibilities, all the ways people used to depend on them, and the things that made them indispensable, in control, and of service to their loved ones:

> I was in control of everything. I worked hard, made the most money in the family, took care of all the bills, took care of the kids, took care of the house, took care of all the cooking, shopping. I did everything. I was in control. [tearful] And that's the hardest part for me, is I have to ask somebody if I want a glass of water, you know? I have to ask somebody if I have to go to the bathroom. (stroke, White, female, outpatient)

> I mean, I was extremely active like you know, just be pushing, pushing, pushing, pushing, constantly. Just whatever like, between work and just things, needed to be done, like around the house. I'd be doing all the yardwork, housework. I would, you know—I cook more than my wife, so I'd cook as many meals as I could. I'd help family members. You know, just always pushing stuff ... helping my mom out with her things. She was—you know, my dad passed away, so you know, she had some issues kind of with being—life on her own. And some financial things. So taking care of her. Like, taking care of a lot of people, a lot of things And work.... (stroke, White, male, outpatient)

Patients who felt they had been essential to their families, communities, and employers and/or who felt highly prized for their competence and ability to juggle tasks were dismayed to feel at loose ends, or see others take on their responsibilities. Some patients, such as Father Will, put *doing for others* at the center of their identity. As one stay-at-home mom said, "I never ask people to do things for me. I always do everything for everyone else. Like, before they even think about it." Like Father Will, she was having a hard time being “waited on.” Some patients, such as the man above who described himself as having been "pushing, pushing, pushing, pushing, constantly" began to consider whether they had been spreading themselves too thin. At the same time, he tried to find ways to stay occupied and be "helpful" around the house, such as making sure he always walked the dog, to take that task off the family plate.

The Fixer and Masculinity

A lot of patients, particularly male patients, were strongly invested in being a person who “fixed things” for other people, the type of highly capable person you would call to help you install a hot water heater. As one man put it, "I've just-—always been a fixer. I've always been a provider. And this I couldn't fix. It's very humbling" (TBI, White, male, inpatient). Some patients talked about projects they left unfinished. Rowan described himself as, "Very active. Very active. Always moving. Always doing something," (TBI, White, male, outpatient). When he was hospitalized, he was working on repairing a car, one of many sideline jobs he took on. He was frustrated that his son had to come in and finish the job for him, but he was gratified that his son had to call him in the hospital for technical pointers. Several men talked about working with their hands, in both a professional and recreational capacity, "get[ting] down and dirty and greasy" (stroke, Hispanic, male, outpatient), as one man put it.

Alan, for instance, worked as a contractor, and he was also very self-reliant, the type of person who would never think of calling a plumber but would roll up his sleeves and do the job himself. Despite his post-stroke changes in mobility, he had recently taken up some damaged flooring in his basement. But he couldn't yet reinstall the new flooring because the task required two hands. He said, "So that was me. That was the kind of stuff that I did, and I enjoyed doing it. I'm looking forward to getting back to it. I just—I just know right now—it's just like, sometimes doubt set in (stroke, Black, male, outpatient). In his moments of doubt, he wasn't sure he was going to be able to get back to the sorts of jobs that were essential to his work, his free time, and his sense of identity.

Alongside the loss of the "fixer" role, many male patients talked about feeling a loss of masculinity. They talked about having been "truly the big man on campus" (stroke, Black, male, inpatient) or being someone others respected and envied. Luke described himself pre-stroke as "athletic, aggressive ... a leader." When asked to talk about himself now, he said: "Half the man I was. Still a good man, but half the man I was" (stroke, Black, male, inpatient). To some extent, he was able to frame the struggles of recovery as a noble fight, a proving ground. He spoke to old friends about the rehab process, and he said, "Man, we gladiators don't give up. [tearful] I'm not. I'm trying not to. A gladiator fights. Until there's no more air in his body. That's how I want to be. A fighter, till a fighter go home. A fighter." He found the stroke and the dependent position into which he had been forced demoralizing and emasculating, but he tried to think of himself as someone strong, determined to fight to his last breath.

During one interview, my subject was a bit taciturn. He was an ironworker, not the type to talk about his emotions with a stranger. His responses were straight and to the point:

> Interviewer: So what do you think it would take to feel "normal" again?
>
> Patient: Oh, obviously just like I said. Being a man. Getting strong again. And, you know, being productive. You know, me being productive was work, you know? That was—that was kind of like, my hobby was work.
>
> Interviewer: This might be a stupid question, but having never been a man, what does it mean to be a man?
>
> Patient: Well, you know, I mean—I mean, you know, you know, what do you want me to say? You're weak, you know what I mean? You're—you're not—you know, you just can't jump up and run out the door. You can't, you know, lift stuff. And you know, I mean, everything's just like—everything takes so much more time now. Even going to the bathroom in the morning. You got to put this on, you got to put that on. You know, takes you fifteen minutes to go to the bathroom. To get into the bathroom. Everything's a lot more time consuming. To go do something. (TBI, White, male, outpatient)

For him and for many patients, masculinity was bound up with physical strength, independence, the ability to work and be "productive," and freedom of movement, the ability to do what you choose, without a great deal of fuss.

Active Lifestyle

Both male and female patients brought up a desire to be productive, to feel useful, and to spend one's time doing something stimulating, or at least doing *something.* As one patient told me, "I've been working forty-two years and I never had any—been working since I was in grade school ...[now] I don't do nothing. I just sit at home. I wish I was more active, you know?" (TBI, White, male, outpatient). A lot of patients talked about missing active hobbies and pursuits. Some of them had been highly athletic, performing at an elite level, like the patient who was under contract to drive a race car in the coming year, or like the woman who was once a semi-pro basketball player. She seemed to respond to every third question with some variation on, *I just want to play basketball again*. Some people were mourning the loss of themselves at peak performance, missing their finely tuned abilities, their lifetime passion, or simply the image of themselves as an athlete.

But even people who were decidedly hobbyists still emphasized the importance of an active lifestyle. One patient was injured on a hiking trip in a national park with her husband. The life they led, and the eventual retirement they envisioned, involved hiking, biking, downhill and cross-country skiing, and other active pastimes. Her "relationship to my body," as she put it, had always been solid. She was a highly educated person who worked a desk job and was edging toward retirement age, but she stressed the importance of her sense of herself as someone strong, active, flexible, and healthy. She was still in a lot of pain, and she was deeply concerned about losing her active lifestyle and her reliable, uncomplicated relationship with her physicality. She said the possibility of living with debilitating chronic pain was "probably the only thing that scares me. Because I want to be dancing. I want to be skiing. I don't want to feel like I'm a handicapped, you know? That'll prevent me from doing all those things. Hiking, biking, skiing. I don't want to lose it" (TBI, White, female, inpatient).

As another patient described, a large part of what people meant by "active" had to do with spontaneity and freedom of movement:

> We were really active ... I mean, we were going every day somewhere, doing something. Walking on the lakefront. Going for a picnic. Going here, going there. Driving. You know, I would make him drive all the way out to Bolingbrook just to take me to Cracker Barrel. Things like that. We always—if he didn't think of it, I did. And we did it. You know if somebody—his best friend lives in Indiana. And if he would say to him, you know, what are you and [Cleè] up to? I'd say, well, why don't we go? (stroke, White, female, inpatient)

For this patient and others, disability meant forfeiting a measure of freedom. A patient might have lost the ability to drive and might struggle to arrange transportation. Patients had to consider logistical factors they never had to before. Outings required more planning, forethought, and prep time.

Active hobbies were also tied to significant relationships. As discussed in Chapter Four (Shifting Relationships), people with young children talked about wanting to be physically active with their kids. In many cases, particular hobbies were important components of relationships with adult children or with friends. People didn't want to lose the opportunities to bond while golfing, fishing, or traveling together.

It should go without saying that being active and seeing oneself as an "active person" was also very important for elderly patients, many of whom were very invested in a lifestyle that revolved around a variety of outings and activities and an image of themselves as always having been an active, independent person. They talked about an active social calendar, retirement plans, and traveling to visit family. Some of them were part of a mutually reliant community, trading off driving and organizing social events with friends around their age. One woman wanted to get back to visiting her nieces around the country, driving to Costco, going to "luncheons," and baking for friends and acquaintances. A couple of neighbors helped clear her snow in the winter, and she made sure to reward them with baked goods.

Many people planned to travel in their retirement, and the potential change in plans could be devastating, especially for people who had family abroad and/or planned to spend more time in their country of origin. As an interpreter pointed out, some of the Latin American immigrants she worked with owned property in their countries of origin and had been building towards splitting their time between countries someday. Others had family members who couldn't visit them here because of immigration restrictions, so losing one's ability to travel could mean not only forfeiting the transnational retirement they always envisioned but losing the ability to see family and friends.

Changes that struck at people's ability to feel active and capable or independent/depended on could be devastating. In some cases, however, patients were able to adapt to a new pace of life:

> I still have my—my joy, I guess you could say. You know, holidays are coming in, and as you can tell and heard, you know, my Christmas decorations are up. And I started buying stuff for like Thanksgiving dinner and stuff like that. Because I do have Thanksgiving dinner at my house.... For the most part, I just feel—I feel like I'm myself. And I think it's pretty much because I can still do some of the same things I was doing before. Doing my laundry, cooking, and whatnot, stuff around the house and decorating and things like that. I think if this would have been worse, and I couldn't do some of those things I may have—I may look at it differently. Like, this *has* really affected me. I can't decorate the house for the holidays like I usually would do. Now, that makes me feel some kind of way. But the fact that I can still do it, even though it's a slower process and it's taken me a couple of days to get things done—I could still do it. So when I see it done, it's like, hey, I can still do it, it's just moving slower at it. (stroke, Hispanic, male, outpatient)

As this patient pointed out, his ability to adjust could be, in part, attributed to the fact that he recovered well. He could still do most of the activities that gave him joy and preserved his independence, even if they took him longer and perhaps couldn't be completed in the same way or to the same standard. Despite his significant recovery, coping with these adaptations demanded considerable resilience. For someone like Hayden who hadn't made the gains he hoped for, it could feel like life had ground to a halt entirely.

Health and Youth

In the aftermath of stroke and TBI, patients of all ages experienced an unaccustomed sense of vulnerability. Most patients hadn't previously given much thought to the possibility of serious illness. One patient said he preferred to tell people he had a "cardiovascular event," rather than a stroke. Stroke sounded like something that happened to elderly people. It sounded like a disabling, life-changing condition. For many people, any medical incidents in the past had followed a consistent pattern: illness followed by recovery. The flu cleared up, the broken bone healed, they took your appendix out and you came home and recuperated. In many ways, patients hadn't seen themselves as the sort of people disability happened to.

Patients talked about how they never smoked, drank only in moderation, and exercised regularly. People who saw themselves as especially fit or hardy could feel particularly blind-sided, almost betrayed by the body they treated so well. One female patient told me, "The day before, I was doing like sixty push-ups and planks, and like, you know, like, a solid arm and ab workout. And like, I wanted to get a butt, so I was like working on my legs, you know?" (stroke, White, female, inpatient). Katie, Hayden's wife, said:

> Hayden, ironically enough, broke his foot taking the dirt bike off the back of the truck the year prior. Two months before our wedding, and [he] was in a boot. And never took pain medicine. Hayden had 20/20 vision. [tearful] He was just healthier than a horse, and now going to all this medication and things like that.

It was difficult to imagine this happening to someone so robust. For some patients, their body always seemed reliable. They were naturally athletic, physically adept. As one woman explained:

> See, my whole life when I was younger, anything I tried was—came easy to me. I could do it. I was a gymnast. I'd do whatever, you know. And I was always good at stuff. Now I'm not good at this. I'm not good at having a stroke! Or recovering from a stroke. And that bothers me. (stroke, White, female, outpatient)

The body had been a lifelong partner, responsive, there when you needed it. It had rewarded investment. It had been, on the balance, a source of satisfaction and pride. Many patients were able to live their lives, up to this point, without giving much thought to the inevitability of physical decline. As one psychologist put it, stroke or TBI caused patients to lose the "healthy denial" that permits us to proceed through life without being paralyzed by anxieties about the many ways any one of us could become ill or injured.

Feeling Vulnerable, Feeling Old

After injury, some patients began to worry about physical vulnerability, especially in environments less carefully controlled than the hospital setting. Some TBI patients, in particular, were worried about jarring or jostling the brain and setting back recovery or compounding their injury. Certainly a few patients*,* like Alan for instance, were far *less* cautious about the potential for falling than might have been warranted, but others showed a significant uptick in concern about accidents. Post-injury, the body felt at risk, in ways it hadn't before.

Several patients in their sixties or seventies who had, prior to stroke or TBI, lived active lives and thought of themselves as “healthy people” talked about feeling old, overnight. Milestone birthdays and other major life events (e.g., retirement; the birth of grandchildren; the death of parents) may have led people to reflect on their own mortality, but for the most part, these patients previously experienced aging as incremental. The self at sixty-five felt essentially the same as the self at sixty-four, and so on. Now, age seemed to have ambushed them and a lifestyle that revolved around a variety of outings and activities

One patient, Rose, had a history of serious health problems, including cancer, but when she described herself, she said:

> My main thing is walking my four miles a day. It's my biggest thing.... So you know, I had to close my watch rings. My kids bought this [smart watch] two years ago, and I know they regret it. Because I'm so addicted to it that I've got to do everything that watch tells me. If it's time to stand, I'm standing no matter where I am. (stroke, White, female, inpatient)

Her daughter mentioned the watch in her interview too. "And her Apple Watch is like the boss of her. And if she doesn't get her rings, it's stressful for her. And everyone knows that about her." Rose led a very active retirement, playing cards and bingo, going to dinner and the theater, and of course, organizing her daily walking group. Her daughter explained:

> She does not want to be viewed as, like not—I don't even want to say not healthy because everybody knows what she's been through. But she never wants that to be defining. You know, she's the one who walks. And that's what's really hard, I think, for her is because everybody in her building, everyone in our lives knows her as she walks, and she walks, and she walks.

As she saw herself and wanted to be seen by others, she was fit and healthy, not the kind of person who had a stroke. She lived in a building with a lot of elderly residents, and as an exercise-focused woman in her early seventies, a lot of her neighbors were not nearly as young, active, and spry. Among her peers, she saw herself as the healthy one, despite years of chemotherapy. Her daughter said, "She's mad [about the stroke]. You know, she—at first and probably still, she wants to know why this happened. Because this doesn't happen to her. This happens to like, the woman in [room] 207."

“Feeling old” to these patients had a lot to do with sudden change in their sense of bodily integrity and physical vulnerability. People also reacted to feeling that their choices and abilities were abruptly circumscribed (i.e., to be “old” was not just to be X years old but to be X years old and no longer in control of the conditions of your life). Their focus was drawn more tightly into the body. Options that previously felt available were suddenly foreclosed. Peyton, a TBI patient's wife, stated:

> It's almost like one day you're, you know, sort of this active retirement kind of thing. And you're playing golf and you're doing whatever you want to do, and everything is fine. And the next day you wake up, and you're old. You know, you're old. You're thinking about your health all the time. You're going to the doctor. Every conversation is about peeing or, you know, some—you know. And so you got old, almost overnight. And that's—you're not prepared for it.

Her husband, George, brought up similar concerns in his interview. He described incredible trips they had taken together and with their adult children and grandchildren. They were adventurous travelers, planning trips that covered considerable ground and spanned weeks at a time. They were financially secure. The life they planned, the life they were living, involved extensive travel, both together and independently. George spent time abroad to accelerate his study of a foreign language. Toward the end of his extended trip, Peyton joined him, and they explored the country together. They hadn't felt old when they were living that life, but now their plans were on hold and their interests were eclipsed by matters that felt both pressing and painfully mundane. The body imposed itself on them, and "almost overnight" they were visiting doctors and talking about urination.

In some cases, the circumstances of the accident heightened this sense of insecurity. One woman sustained a TBI in a car accident when, after a long day of hiking, her husband fell asleep at the wheel. He told me:

> If another car hits you, like in car accident, nothing you can do about it. But for that one, whatever happens, it was 100 percent preventable. So it should not happen. So now I actually—I think I—I become much more—much smarter, and pay attention [to] what your body is saying. And I think [my wife] has the same—I think that's a big change in point of view, and because—well, I am [in my late sixties], so I'm not young anymore, but in mind, it's hard to accept that actually, you know, you can't do the same thing as you used to. But it looks like, not really. So you need to be more careful. (husband of TBI patient)

Neither of them had been concerned about driving back to their hotel after a long day. It was the sort of thing they had always done. The accident made them both more aware of their age, and more concerned about the limitations that might come with it that had already caught up with them.

Similarly, George and Peyton were unsettled by their recent trauma. They both still hoped their life would return to something approximating what it had been before George's TBI, but George felt Peyton had become skittish about leaving him home alone. She was out of town when his accident occurred, so it seemed now like she was frightened to travel without him but also frightened to travel *with* him. George worried that she saw him as fragile, liable to hurt himself or get dangerously and inconveniently sick on an overseas trip. But as ardently as he wanted their lives to get back to normal, he was also more aware of his body's limits and liabilities than he had ever been before:

> I don't know how normal I'm going to be. And given the amount of damage that was done to my body, it's hard for me to say that I'm just going to go smooth over the next twenty years and not have other catastrophes, not other accidents or other things that I do. (TBI, White, male, outpatient)

Given the damage that had been done in the accident, he knew his body couldn't absorb the sorts of routine minor injuries that are unavoidably part of an active life. He remembered falls he had taken in the past, while biking for instance, and he wondered what the repercussions might be if the same incidents happened to his present body. After telling me about one of their most memorable trips, he said:

> That's—that was our world. And I—I'm just not seeing that world anymore. It goes back to what Peyton has said several times. My life is over. And what she really has said is, the world the way we lived it and that I existed is not here anymore. (TBI, White, male, outpatient)

To George and Peyton and other patients of their age who experienced the sudden shock of stroke or TBI, it felt like old age had crept up on them. It threw their lives and bodies into chaos and destabilized the relationship they maintained with their bodies up to that point.

The Oldest Patients

Without meaning to imply that it *wasn't* tragic when elderly people were injured, staff often talked about how shocking and/or tragic it was when a young person was disabled by stroke or TBI in contrast to older patients in their late eighties and nineties. Staff avoided explicitly saying it mattered less if the same event happened to someone older, but many staff members told me some variant of, *the young ones are really tragic—not that that the older patients aren't tragic, but….* Several younger patients also seemed to feel that stroke especially was more "expected" for older people. As one younger patient said:

> You know, just not having to spend the next forty or fifty years needing a wheelchair or needing a seat in the shower, or, you know, being able to like braid my own hair, or brush my teeth with my left hand again, you know, like, little things like that. Like, if I was eighty or ninety, I think it'd be, you know, I'd be more accepting of stuff like that. (stroke, White, female, inpatient)

Given the attitudes of patients I interviewed who *were* in their eighties or nineties, it's entirely possible that she would not, in fact, be "more accepting."

Among the elderly patients I talked to, very few had an attitude of resignation or seemed to feel prepared for loss of mobility and physical decline. It feels like I'm stating the obvious, but people struggled to adjust to disability, at any age. Young and old, patients were concerned about loss of independence and dignity, loss of significant parts of identity, and the prospect of having to rethink life plans.

I interviewed three women in their nineties, one who had a stroke, and two who fell and sustained TBIs. All three of them were very strongly invested in getting back to who they were prior to hospitalization, and they certainly still thought of themselves as independent and, up until that point, healthy. They made it to their nineties, after all.

None of them felt prepared for or resigned to disability; they all, in some way, felt the whiplash effect of sudden medical trauma. One woman was hospitalized following a fall; her niece described her as "a very young [ninety+]." The niece reported:

> Prior to this, she was very active. So this is driving her nuts ... her shock at this happening to her, you know, is—because she'll say, "Did you ever think this would happen? Did you ever think this would happen to you? Did you ever think that just hit your head and this could happen to you, did ya?"

As Inez, a stroke patient in her nineties put it:

> And I have been a very—I didn't really realize, a very, very healthy lady for [over ninety] years. So that's probably really hard to take. When you—you don't have any health problems. I mean, I've had little surgeries—not surgeries that are little, but they pass. But this did—is not going away. And I guess it's not going to go away ... I have to depend on somebody helping me and I have never had anybody help me. So I don't like that .... [over ninety]. So that's a long, long time.... And I was very active, and I was an athletic person, and everything is haywire. (stroke, White, female, inpatient)

One might assume that a long life gives you time to prepare for disability and reconcile yourself to an eventual loss of independence, but to the contrary, as Inez pointed out, a long, generally healthy life also represents many years of precedent for a body that does what it's told and is dependably there when you need it. Inez and her two coevals were not at all prepared for their bodies to go "haywire."

Two of the women were still living alone, albeit with the support of friends and family. It isn't as though people fail to realize that disability will eventually come to us all unless we die first, but the women I spoke to were by no means willing to surrender their independence yet. If anything, independence was particularly significant to them because they knew its value, and in some ways, had fought to preserve it. Many people in their seventies and up were themselves depended upon by elderly friends. Kathy, for instance, still drove, so she was a linchpin of her social group.

For these women, aging happened slowly and then all of a sudden. Their bodies and lives had been changing incrementally, and they acknowledged that. Inez said, "You know, I'm really not—running around all the time anymore at all. Which is not me. Not me at all" (stroke, White, female, inpatient). When I asked her what had been challenging for her, since her stroke, she said:

> Just accepting the fact that I am not the same [Inez] anymore. I am not. This is a new person that has evolved out of this body. And I'm never gonna be like I was. And that's very challenging for me ... everything has changed, and it's stuff I never thought about. (stroke, White, female, inpatient)

When I probed a bit more about her saying she wasn't "the same Inez anymore," she explained that

> Oh, I don't think I'm a new [Inez]. I'm the same [Inez] I was. And everybody—nobody has said, “Mom, you're so different.” Or anything like that. It's just I'm not sprouting out the door doing this and doing that. I'm not—and I can't get up off the couch. (stroke, White, female, inpatient)

What I took her to mean was that she both was and wasn't the same person, like a human Ship of Theseus. She knew she was still Inez. No one else had said she was acting differently. But at the same time, certain aspects of herself that seemed fundamental had been chipped away over the years. She had been the sort of person who was always up to something, and in recent years, she became more of a homebody—partly because of her age, but partly because her finances were tighter, and more recently because COVID-19 had largely curtailed her social life. Most of the younger patients hoped to return to their pre-stroke or TBI Selves. For the three ninety+-year-olds, it was more complicated. They wanted to get back to pre-stroke or TBI levels of independence, but to some extent, their sense of Self was still anchored to a version of themselves before they began to feel old, a Self they knew was never coming back. They all talked about death, in one way or another. Kathy talked about things she knew she would never do again, places she knew she had seen for the last time.

Inez said, "It is scary. Because for [over ninety] years, I've been a very stable, individual person. And then to be stricken down like this. I don't like it. But we all go. [laugh]" (stroke, White, female, inpatient). She acknowledged mortality and spoke somewhat wistfully about missing previous versions of herself. But she wasn't by any means ready for or accepting of disability and dependence. She felt her physical peak was behind her, but she still wanted to fight her way back from her recent, precipitous decline.

Intelligence and Cognitive Ability

Feeling Foggy

A lot of patients perceived and complained of changes in cognitive performance. What they noticed and how they described it varied, but the central throughline was that they felt diminished. As Inez put it, "Oh god. My—my brain has been lessened, since this happened" (stroke, White, female, inpatient). Patients talked about feeling slow or foggy or having difficulty concentrating. Ellis described a period of about two-and-a-half months in which he felt "like a zombie":

> I didn't know what the hell was going on. Was this my right? Or who is this? Or, you know, am I writing this? Or is this, you know, I'm cooking; is this warm? Is this hot? Because your brain just, it's, it's, it's the weirdest thing you've ever seen. And now I feel a little bit better than it used to be ... and I call it the zombie is what I felt like, because I was—I was really scared about myself. I'm like, oh my god, oh my god, I don't believe my brain—what they're saying is correct. You know, I didn't know if I was right or wrong, or it was very—it was very scary. (stroke, White, male, outpatient)

He still didn't feel back to his old Self, and that bothered him immensely, but at least he was past the zombie phase when he feared he might walk around in a daze for the rest of his life. For many patients, their cognitive changes were thrown into relief when they attempted to return to routine tasks:

> I mean, my mind has been so foggy. Ever since this COVID. I mean, I used to be sharp, you know, I used to be real sharp. Now? I just, I can't concentrate. I'm having problems

> with balancing my checkbook and just stuff like that, you know, stuff with numbers and stuff like that. So I mean, it's getting a little better, but from being what I was to being now is just depressing. (stroke, White, female, outpatient)
>
> And plus the tiredness, which is more than I am used to, and the tiredness comes from, not just physical therapy, but from focusing. Which is much worse. Because if I focus on something, one thing, like, I start responding to emails, and I'm writing long emails, and I do it for half of the day, I'm exhausted for the rest of the day. Because it's just too much focusing. So that's what I noticed, which is a little bit frightening, obviously. (TBI, White, female, inpatient)

It was frightening and demoralizing, to go from feeling "sharp" (and seeing oneself as sharp) to struggling with tasks that always seemed simple before. Patients commonly reported fatigue, and relatively short periods of focus or mental exertion caused them to feel drained.

Prizing Cognitive Performance

For some people, cognitive performance was central to how they measured their value as a person and to what they felt others valued, appreciated, and respected about them. Understandably, they were very focused on identifying cognitive differences and recovering to the fullest extent possible. For many patients, cognitive performance was crucial to their ability to perform their professional roles. These patients were often in the unfortunate position of being deeply invested in their careers and returning to their former standards of performance, but also having to meet a very high benchmark to successfully do so. As one physician stated:

> So certainly, anybody who's had a very high level, cognitive component to their job, those are always the most challenging. Because many of our patients may have some long-standing cognitive problems. Fatigue is a huge problem that we see long term, attention, concentration problems, so they just—they can do some of the same things, but they just can't function quite at that same level or they fatigue very early. (staff, inpatient)

This physician cited CEOs as an example of people for whom return to work was both fervently desired and, in some cases, next to impossible. Certainly, CEOs tend to be highly career-driven (and likely invested in returning to their specific company). But it's a role that requires not only cognitive skill but also the ability to inspire confidence in one's capacity to perform. They couldn't afford to leave any doubt as to their complete recovery.

For some of the patients I met, they were concerned not only about meeting their employers' performance metrics but also about satisfying their own internal standards. Scott went back to work in his old job, and he had been performing well. His employers were supportive; he was able to resume working a full schedule slowly and work from home. But even though he could accomplish the required tasks, he was moving slower than he had pre-stroke. He prided himself on how he worked before—effectively and quickly—and he found this change discouraging, even though he achieved his return-to-work goal.

Isobel, as previously discussed, was starting to grapple with the possibility that she wouldn't return to her job as a Spanish teacher:

> [My job requires] a lot of word retrieval, grammar and syntax, not only verbally, but on paper. Let's see, my oral reading in Spanish is really slow. I'm still working on higher level cognitive abilities. As a teacher, I make very quick decisions, very fast, with high school students. And pivoting and, you know, pivoting a lesson or trying something else. And I'm just not there yet. And not only do I need it in English, I need to do it in Spanish. (stroke, Hispanic, female, outpatient)

As Isobel's fine-grained sense of what she needed to regain illustrates, the experience of neuro-recovery and particularly speech therapy, compelled patients to break their jobs down into cognitive components and think critically about all the ways in which it was possible to cognitively fall short. Patients practiced tasks like inputting detailed information into a spreadsheet while responding to distractions at random intervals. As you can see from the following examples, therapists helped patients map out all the different types of tasks they were called upon to perform and the skills required to do so successfully.

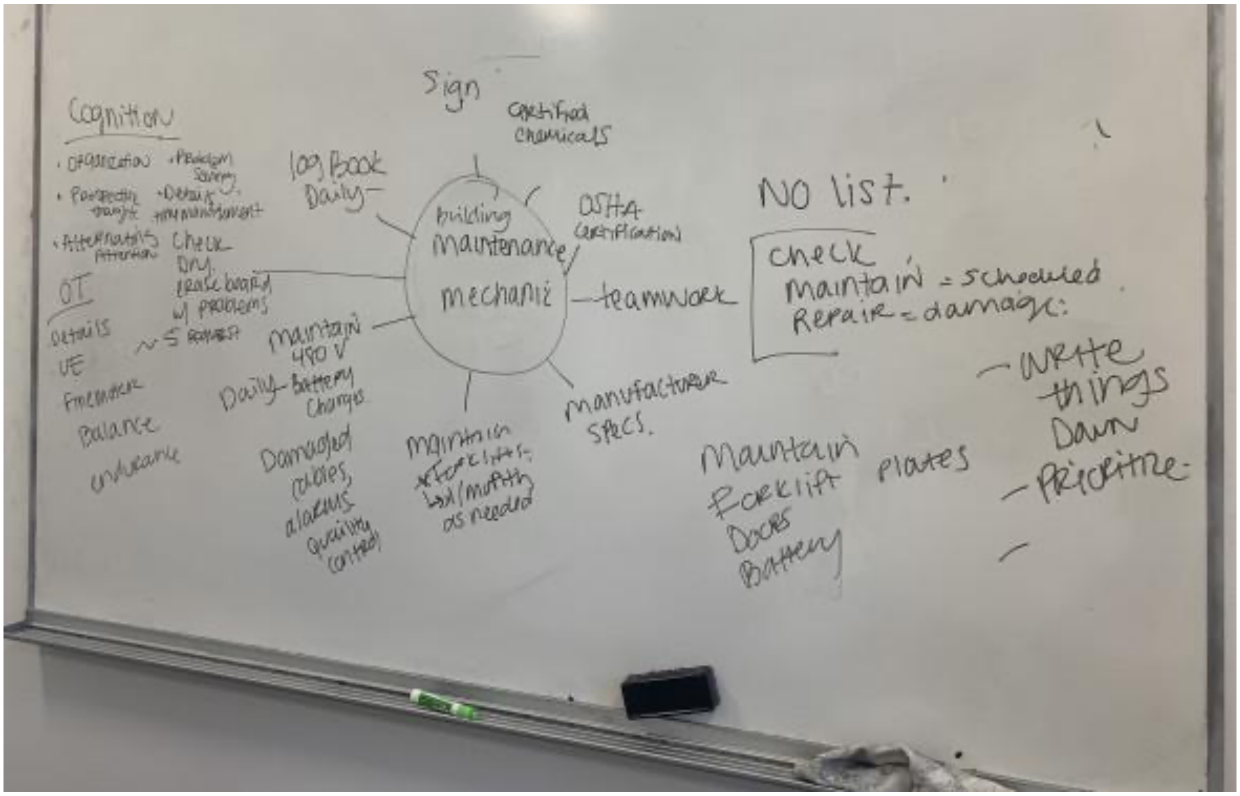

Image 10: Return to work group whiteboard
Source: Photo by Author

Intellectual Hobbies

Beyond cognitive abilities required for job performance, many patients talked about significant hobbies and pastimes that were now more difficult for them to engage with and enjoy. One patient's granddaughter said the 90+-year-old had been taking cultural studies classes through a community college lecture series; she read "hefty nonfiction books," pored over two different newspapers, and did crossword puzzles. It was hard to imagine how she would entertain herself if she couldn't concentrate. Scott and his wife both told me that beyond the cognitive demands of his job, most of his hobbies (aside from playing with his kids) drew on skills like math, short-term memory, critical thinking, and quick and flexible thought. His wife said, "He's a very intellectual thinker. So this is—he's like one of the worst people this could happen to because his passion is like coding and researching."

George expressed his frustration at how cognitive changes affected his ability to enjoy theatre:

> George: Well, last week we went to—see now, here's a memory problem. Don't tell me. It'll come to me in a minute. The play. The Shakespeare play? Don't tell me what it is. Oh, god, I've seen this play two or three times. Oh, God. "Both Ways" or something. "See It Both Ways?" Or—is that it?
>
> Interviewer: *As You Like It*?
>
> George: *As You Like It*! See, is that an example or not?... The plot is very difficult to follow. And when you're seeing it with actors-—and [in this production], every now and then they'd break off into a Beatles song. It's really hard to tell who—which actor, I mean, the cast, the characters, you know, they're all sisters, and brothers and nephews and nieces and all of that stuff. And to remember the names of each and who announced that—but now she's here and now she's in love with him. But wait a minute, he loves her! And now she's going back ... but isn't that amazing? I couldn't remember the name of that play. *As You Like It*. (TBI, White, Male, outpatient)

Not only was it frustrating to struggle to follow a complex plot, but it was all the more disconcerting because he'd seen the show before, and he knew he enjoyed it in the past. To George, it was a clear demonstration of the gap between his current brain and his brain pre-TBI.

Several patients talked about reading as a beloved pastime that was now tainted by difficulty with memory and concentration. For patients who struggled with cognitive endurance, reading transformed from an immersive, enjoyable, and relaxing experience to an onerous slog. Not only was it difficult to lose a significant hobby and a pleasant form of entertainment, but for some, being a reader was a central part of their identity and perhaps also a status marker. George, for instance explained:

> I do not like to watch television. There's hardly anything on TV that I find enjoyable or whatever ... I'm just forcing myself to start reading books again ... been trying to read newspapers. We get *The New York Times* and *The Financial Times of London* on our door every morning.... I still—I mean I subscribe to *The Economist* magazine I subscribe to—

> we get *The New Yorker* and all that. So I try to read a lot of those interesting things but it's nothing like it was before. I'm kind of embarrassed that I've got all this time in my life and I'm not reading. (TBI, White, male, outpatient)

It was important to get back to doing what he enjoyed, but it was also important to be the sort of person who subscribed to *The Economist* and *The New Yorker* and who could talk compellingly about the book he was currently reading, in social settings. Cognitive changes could threaten cultural capital, and in some ways social capital as well if you felt the people in your network would no longer want to associate with you if you couldn't generate interesting and intelligent conversation.

A "Smart" Person

For many patients, however, concerns about cognitive change were about more than a desire to return to professional roles and forms of recreation that required cognitive skills. Feeling "smart," (and appearing so to others) was significant, in and of itself. Ellis recounted:

> I'll never forget, there was one day—my wife was trying—I was doing some words, and they're really easy, easy words. And I looked at my wife, and I was almost crying because I'm like, you know, I used to be a smart guy ... and now I don't, I don't feel like I'm very smart ... and I mean, people think I'm just, you know—and I have gotten better. But, you know, hopefully it gets better to where I have—to where I was, at least. Because I used to move real fast. Now I got to move kind of slows. (stroke, White, male, outpatient)

This perceived loss of intelligence could strike a considerable blow to self-esteem. It was also acutely embarrassing to struggle with basic tasks in front of other people, particularly people who regarded them as intelligent and perhaps valued them for that reason. Many patients were not satisfied with "functional improvements," in part because managing to adequately perform tasks wasn't entirely the point. Certainly, patients wanted to arrive on-time to appointments and manage their own schedules. But keeping track of appointments by adopting a system of notetaking and memory strategies felt like a partial victory. The situation was analogous to patients who didn't want to learn to use a wheelchair because they just wanted to work on getting back to walking. Some patients were frustrated because they wanted speech therapy to focus on getting their cognition back to the way it was before, not just teaching them ways to compensate.

Speech therapists often pointed out that *everyone* uses cognitive strategies in some form or another: we keep a calendar, we doublecheck our work, we enlist proofreaders, we take a photo of where we parked. And to some extent, patients were able to accept this normalization of cognitive strategies. But as one patient explained:

> Being able to be as effective and be as accurate as I was before. Being able to do ten things at one time, without even thinking about it. Being able to complete a task without thinking if I did it right. I don't want to be able to second guess—I mean, I know that's like, sometimes we do. Because we want to make sure. But I don't want to do—I don't want that to be a part of the new [Me]. You know, always second guessing or like, you know, having to—I just want to be—I just want to be good at whatever I do. Because I was before. and I know you always have to allow room for mistakes. But I'm talking about the things that you normally do without even thinking about. I just want to be able to do all of those things that I was able to do before. (stroke, Black, female, outpatient)

Patients were aware of the extent to which they relied on strategies before, so that was their benchmark. They wanted to return to the same level of confidence and ease. They wanted the same sense of pride and mastery, not just to be able to perform the same tasks.

Several patients were also worried about the degree to which cognitive performance was linked to status markers, like educational attainment and professional achievement. Patients who were proud of their professional or educational bonafides worried that their high status would become less socially legible. Connor was an interesting case study in this respect, too. He hadn't experienced any cognitive changes, but when it was difficult for him to communicate, he still took pains to avoid being misperceived as unintelligent or uneducated.

His family and he joked that when he was using an eye gaze device they expected him to use the simplest sentences possible because the device was so laborious to use. But not Connor.

He capitalized. He punctuated. And if he made a mistake, he would go back and correct it. His dad joked, *If Connor missed a comma, he would backspace, backspace, backspace*.

Connor said he's like that with texting too, even though it's now difficult because he doesn't have much fine motor control. But why? If the purpose is quick and functional communication, why would Connor capitalize while using an eye gaze device? Especially when communicating with people who knew him and understood the context of his stroke; they knew perfectly well he was "still there" cognitively, and they knew him to be an intelligent, educated person who understood the rules of grammar. Beyond habituation or perfectionism, there was likely at least some element of social performance. Connor was concerned about continuing to be perceived as a certain kind of person.

Wanting to Be Exceptional

Some patients held their cognition to a particularly high standard. Staff talked about the problem of not knowing a patient's baseline. To some extent, it was impossible to know exactly what had changed and to what degree because no patient had been through a full battery of neurocognitive testing prior to stroke or TBI. Staff relied on a combination of patient self-report (if available and reliable), family accounts, and proxy measures (e.g., if you were a software engineer before, we know you probably have above-average quantitative skills).

But some patients complained that although cognitive testing showed they were performing at average or above average levels, they weren't in fact "recovered" to an acceptable degree because they had been extraordinary in these areas prior to injury. One patient talked about his frustration when testing was used to suggest there was nothing wrong with him, but he still felt very impaired:

> I couldn't work because my job is very, you know, very high level and a lot of stuff going on. And reading and writing is like, the very basics of things. So it was just—it was tough,

> and frustrating. And I had a neuropsych exam, and it was like, well, you're still showing above normal with your cognitive function overall, but I'm like, well, there's no baseline before that. And you're in a clinical setting [rather than a chaotic real-life environment, when you're taking the exam]. (stroke, White, male, outpatient)

Some patients felt they were expected to accept (and even be grateful for) a cognitive recovery that fell far short of their personal standards. They were not used to being "average," so average did not feel normal to them. To some extent, average felt like a threat to their sense of Self. George, for instance, explained that he was used to being superlative. At every stage of his life and career he excelled, and he identified strongly with excellence. For him, sufficiency felt insufficient.

His wife, Peyton, described him as, "a very intelligent, competent, intense person who was very hard on himself, really had high expectations of himself and everybody else." She said his drive and exacting standards probably contributed to his recovery, but it also made it hard for him to appreciate what he regained. George told me he felt he had only gotten back about 30 percent of his cognitive ability. When I asked Peyton what she thought of this estimate, she said, "Oh, that's ridiculous." She thought he was far closer to his previous benchmark. But George, like some other patients, was highly self-analytical and self-critical, and of course, he was able to observe every little mistake and lapse he made, moments that others would never notice.

In some social milieus, cognitive ability is treated as something to be obsessively quantified and even optimized. For patients who were highly invested in their cognitive performance, and used to noticing fine gradations of difference, it could be hard not to obsess about test results and what they signified in terms of recovery.

For people who were strongly identified with cognitive performance and how they stacked up against other people, it could be excruciating to see concrete evidence of brain damage (e.g., images showing the areas of the brain that had “died”) or to think about missed opportunities to preserve as much of the brain as possible. Some patients agonized about what might have happened if they had made it to the hospital or gotten the right diagnosis sooner or if they had been given a particular medical intervention at the right time. How much better off would they be now? How much of their brain, how many cells, how many neural connections had been lost that might have been preserved?

Ellis talked about how bizarre it was to see images of his brain:

> Ellis: Pretty—it did take quite a bit. But when it hit me, the stroke, you know, it showed the picture and I looked at it and I'm like, that's, that's, it's gone. I mean, it is gone, but it is there, you know, but they got me pretty, pretty good…. But here, I'll show you the picture. Because I was like, holy shit. And my—and I had to realize that you know, once once it's gone, that's all she wrote ... it is what it is. And you could see mine. So that's my brain.
>
> Interviewer: Oh wow! So that bright spot? That's the area that was affected?
>
> Ellis: Yes. Yeah. Yeah. And that was just—so now the question I worry about, did I did I have the stroke while I was sleeping? Which is possible. We don't know. (stroke, White, male, outpatient).

It could be unnerving to look at an image of your brain and see clear, physical evidence of what had been lost. A spot on an MRI might represent the precise extent of what was now gone. It could bring home to patients the frightening possibility of permanence: this fogginess wasn't the same as the fogginess you might feel if someone accidentally gave you decaf coffee or if you were jet-lagged, ill, or sleep deprived. This sense of difference could be imaged and examined, traced back to a clear source. For some patients, it was profoundly strange to associate the loss they felt with the death of brain matter in a specific location.

Not Wanting to Be "Stupid"

So far, I've focused on patients who were highly identified with intelligence, but there were other patients for whom cognitive performance was less salient, and there were several people who said they weren't really concerned about cognitive change. They said they hadn't thought of themselves as the “smartest” people before, and they didn't expect to be now. Some patients were more strongly identified with, and more concerned about, regaining physical abilities. As one patient explained, "I'm more of a physical person than a mental person. You know, I don't sit behind a desk and fill out paperwork. I'm the person that's in the field you know, doing the labor you know, stuff like that" (stroke, Black, male, outpatient).

The same attitude comes across in this excerpt:

> Interviewer: So what were you like before all this happened?
>
> Patient: Special ed. [laughs]
>
> Interviewer: [laughs] What does that mean?
>
> Patient: Just [people in my profession] just—our brains doesn't work like everybody else. You know? Just—how do you say it? Just, you know, some of us had a chance at schooling and this and that. We just didn't take advantage of it ... I mean, some of us are smarter than others, but we're basically mentally retarded. [laughs] I don't mean nothin' bad because it's not nice to say that, but yeah, I mean, I mean, I was a foreman for years, I heard every excuse in the book. It's a trade where you can do what you want. Let's put it that way. So you can tell your boss to go fuck themselves today. And you could have a job tomorrow somewhere else. (TBI, White, male, outpatient)

When talking about his job, he downplayed the cognitive skills involved (although he did concede it required mechanical and spatial intelligence), and he instead highlighted physical prowess and maverick spirit.

But crucially, while not everyone was strongly invested in feeling or being perceived as highly intelligent, no one wanted to feel or look “stupid.” The patient above told me at several points that he wasn't concerned about speech therapy and cognition, but his speech therapist told me she had tried to discharge him several times, and he opted to continue.[3] I was present for one such discussion. She explained that as far as she was concerned, he had met his cognitive goals. He could opt to spend more of his day rehab time in OT or PT. But just as he had every time she

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[3] See *Three Day Rehab Discharges.*

offered this option before, he chose to keep attending speech. Even though he said he disliked the sessions themselves, and he wasn't so concerned about cognition.

As previously discussed, part of the delicacy of navigating interactional dynamics in speech therapy was in trying to correct errors on cognitive tasks without making the patient feel stupid. Perhaps more so in speech than anywhere else, the difference between concern about not appearing intelligent and concern about appearing stupid was readily apparent. Patients might insist that they weren't a "mental" sort of person, but they would tell stories about how humiliating it was to lose their train of thought when talking to friends and emphasize how much they wanted to work on improving their memory.

Most adults are not accustomed to struggling cognitively in front of other people. Usually, if we're not adept at a particular task, we structure our lives to avoid it or we use compensatory strategies or we make excuses or make light of it. Speech therapy requires patients to confront cognitive shortcomings head on, in front of an audience. As one patient explained:

> Speech is harder because, you know, she do the—I have a memory problem. I can't remember a lot of stuff ... and then when she reads to me and she asks me to remember it's like, it just irritates me that I'm not able to remember certain stuff that a person read right in my face ... I just get frustrated when I can't get things right. [laugh] That's what it is with me. Yeah. I'm not used to somebody reads something I can't remember that quick. (TBI, Black, female, outpatient)

In many cases, patients used face-saving strategies to mitigate both the stigma of cognitive change and the potential damage to their sense of Self. They often made excuses, arguing that the instructions were unclear or pointing out distractions. Patients also questioned the validity of tasks, calling them pointless or saying this wasn't the sort of thing they would ever have done before or would ever do again.

Speech therapy often brought to light changes that hadn't been obvious to patients before, and they responded in a variety of ways. Rose's daughter talked about an instance where a speech session threw her mom into a bit of a spiral:

> She said, the other day, that sometimes she can't like remember words. But I haven't really noticed anything. But I know that like speech did this test with her. You know, like, you see all these pictures. That really stressed her out because she couldn't remember some of the names of the objects that were on the picture. But she knew what they were, you know? And, you know, she was just like, *they just keep testing me*. And it's like, timed, and it's—one of the things was you had to say all the words you could remember that start with M in a certain amount of time. But not knowing like, it would be normal if you could get twenty or thirty or forty or whatever the benchmark is. So then she was like, *Well, I don't even know if I met it*! So I think that was just like—she so doesn't want to be—have a deficit. Because then she was timing me. And I was doing the M. I'm like, "Mom, I can't think of anything else." So yeah, I think she's just really fearful of having deficits. And then when you're timed, it's just that much worse. (daughter of stroke patient)

In other cases, rather than responding with anxiety, patients got angry or defensive. Staff reported that patients who were highly accomplished and strongly identified with their cognition could be especially combative when it seemed their intelligence was being impugned. They might begin listing their credentials or question the therapist's expertise. Speech therapists were careful to manage this sense of threat by drawing a distinction between performance on specific cognitive tasks and overall intelligence. Buffering threats to patients' self-image was a routine part of their job. Some patients were more closely identified with exceptional intelligence, but no one wanted to appear stupid.

The Most Important Part

When interviewing patients, I asked them what was most important to them about themselves. I didn't have high hopes for this question. I assumed some people would find it vague or too difficult to answer, so I placed it towards the end of the interview guide, where it might not help but it probably wouldn't hurt to throw it in.

As it turned out, there were a wide variety of answers to this question, as one might expect. But one theme emerged: what's most important to you often depends on what you currently feel you lack. Connor, for instance, said: "I think that before this, if I was asked that question, I don't know what I would say, but I think it would have to do with my brain. Now, I am—now I talk a lot about walking" (stroke, White, male, inpatient). Connor had always been a cerebral person, but having experienced locked-in syndrome, he gained a keen appreciation for all that having control over one's body means.

Similarly, a woman in her nineties who was highly educated and a prolific reader said, "Everything's important. But at least my brainpower. I don't know! But everything's important" (TBI, White, female, inpatient). In many cases, people who experienced the disruption of disability were loath to leave anything on the table. It was hard to hierarchize one part of the Self over others when you had experienced the threat of loss.

What Hadn’t Changed

People often talked about relational characteristics, such as kindness, caring, generosity, or love for family and friends as being especially important to them. Patients and family also seemed to view these characteristics as being least vulnerable to damage or subject to change. In many cases, there were significant physical and cognitive differences in a patient, pre- and post-injury. But when asked to talk about what *hadn't* changed, patients and family often gave answers that closely resembled their responses to the "most important" question.

People emphasized the endurance of their relationships with loved ones, but they also talked about empathy and kindness, more generally. As these examples illustrate:

> What is most essential to who I am as a person? To be more independent than I am now. And to always have companionship, not to be alone ... and to be in touch with my family. That might be the most important. (TBI, White, female, inpatient)
>
> So I think just my personality, you know, my outgoingness my caring-ness, my love for life itself and the people around me have all stayed the same. For sure. (TBI, White, male, inpatient)
>
> The most important part of me is to be the same as I was, as far as people. I love people. I respect—you give me respect, you get it back, you know? And be nice as possible to people. And that's the way I've been. So I want to improve that, just a little bit more. I want to do more for people, you know? And help them. (TBI, White, male, inpatient)

Family members mentioned generosity quite a bit when asked what hadn't changed in patients, but it seemed like the examples of generosity they mentioned were, at least in part, brought out by the uncomfortable interactional dynamics inherent to hospital life. As previously discussed, patients generally weren't used to having to rely on people for assistance, especially with tasks like eating, bathing, dressing, and toileting. The relationship between patients and staff was necessarily non-reciprocal. Staff did quite a lot for patients, including tasks patients regarded as highly distasteful. And even though staff and family frequently reiterated that staff were just doing their jobs, many patients felt as though they couldn't possibly thank staff enough, even when they were occasionally frustrated with staff members for a variety of reasons.

Patients weren't used to being "waited on," and it felt odd to be cared for, without expectation or possibility of return. Some patients wanted to show their gratitude by making sure everyone who helped them left their room with a piece of candy. In other cases, the generous impulse was more extreme and perhaps less realistic. As the wife of a TBI patient put it, "He wanted to take everybody at [the previous hospital] out to dinner, all the ones that took care of him. Like, [Jeff], we'd be broke If we did that." Another TBI patient's wife told me her husband was a sneaker aficionado, so he kept wanting to buy shoes for various staff members who helped him.

More than any other trait, however, family members pointed to humor as a sign of continuity. When asked what hadn't changed, I often heard responses like the following:

> And I think that personality is still there. He is quite a jokester. He's so incredibly funny. Especially with the doctors, and his therapists. I love the playful banter they have. And I love that that's still there for him. (wife of stroke patient)

> Interviewer: So can you tell me about how [he] has changed since his injury, if at all?

> Wife: He's got the same personality. He's got the same sense of humor. (wife of TBI patient)

> I think his joking personality. It's still the same. (wife of TBI patient)

In patients who came through periods of confusion, agitation, or minimal consciousness, humor was often noted by family as an early sign that a patient was "coming back." Even for aphasia patients who were very limited in their ability to verbally express themselves, a loved one might point to humor as indicative that the person they loved was still present and fundamentally themselves. A word or phrase or look or tone could be framed as characteristic of that person's comedic sensibility. A person's sense of humor can be highly idiosyncratic, and loved ones often have a shared humor repertoire that is easy to shorthand and readily recognizable to someone in the know. It makes sense that humor might be noted as an early signal that something distinctly tied to the patient was still present.

Humor was often coupled with what you might call feistiness or spiritedness. When I asked one stroke patient if anything had changed about her personality, she said:

> I don't think so. No, I don't think so. I don't—I think I'm still the same person. Just can't do the things I used to be able to do. [tearful] I mean, even my sister said, you know, even when I was kind of like out of it, she said, "You'd still like crack jokes and stuff." I do remember one thing where like, I was with the nurse ... there was a nurse and I reached back like this [to scratch myself]. And she started scratching [for me]. I said, "I can scratch my own ass, you know!" But yeah, so I think I'm still the same person inside. (stroke, White, female, outpatient)

A stroke patient's father told me:

> I mean, the most challenging thing before we got here was just being terrified he was going to die at the hospital ... I mean it was—I stayed up for thirty-six hours ... and then the next kind of big hard thing was if it was still going to be him when he came out of it, you know? How much of his cognition and personality was going to be affected with the midline shift and the swelling. And that was a huge relief the first time he took his limp arm and did this to me and gave me the finger. So it was like, "Yay, my son just gave me the finger! That's so awesome!" So that was, you know, that was like a sentinel moment, you know, that his humor was intact. (father of stroke patient)

It wasn't a stereotypically heartwarming scene, but what it signaled was monumentally important to everyone involved. Family members often seemed heartened that patients could display humor in the midst of such somber events. Several patients mentioned feeling responsible for puncturing emotional tension and helping quell family members' anxieties on their behalf.

Still the Same?

Ultimately, many patients were ambivalent about whether they were fundamentally the same or fundamentally different post-injury. It's fair to say that most patients felt they were the same person, in essence, although often a great deal *about them* had changed. And in many cases, the things that changed were highly salient aspects of their identities, even parts of the Self they might previously have regarded as essential. In the two instances below, the patients quoted seemed to feel there was very little that they valued about themselves left:

> Patient: I was always the loudest person in the room, you know? At get togethers or whenever. I was outgoing ... I love sports. I love to watch sports. Now I can't pay atten—I can't follow sports anymore. I get confused. I try to watch football and then I'm like who's got the ball—I can't? And I used to know all that stuff. And I can't follow anything anymore. So I don't know. I wasn't any big deal before. [laugh] But I could get around. And I don't know, I think for my age I was doing okay. You know?
>
> Interviewer: So how would you describe yourself now?
>
> Patient: Now I'm completely dependent, you know? And I'm afraid to do stuff. Which I never was before.... You know, I would try something. Now I—now I'm hesitant, because now I realize that stuff can really happen. You know, I'm not immune to it, to bad things happening to—so I guess it's changed a lot. (stroke, White, female, outpatient)

> So how would you describe yourself now?
>
> Nothing. nothing. [tearful] I guess I'm just waiting. I'm just waiting before I die. I don't want to feel like that. I don't want to feel like that. But that's how I feel. I'm just waiting. Every day that goes by, it's just another day that I don't have to—you know, that is down. And I don't want to feel like that. I got all these kids and my son. If something happened to me, my son would just go crazy. But that's how I feel. I just don't feel like anything. I don't feel like myself. I just feel like nothing. [tearful] I feel like I can't carry on a conversation with people. I don't—I can't exercise. You know, exercise is such a big thing. And when I exercise, I feel good. You know, it gets your endorphins going. And just I feel good about it, you know, and I can't do it. (stroke, White, female, outpatient)

Becca, the woman in the second excerpt, had lost her husband around the same time she had her stroke. She was grieving her partner, and she was grieving herself, and she was trying to figure out how to go on with what was left. To some extent, the woman in the first excerpt seemed to be grieving too: she was mourning a lot of what she most valued about herself.

A lot of patients told me something along the lines of "I'm still the same person" (stroke, Black, male, inpatient) or "I'm myself" (TBI, White, female, inpatient). Regardless of what had changed, people generally felt something important and irreducibly Them remained. At the same time, patients were understandably concerned about regaining the identity characteristics they had lost. They focused on getting back as much of themselves as they could in the course of recovery.

Scott's Disappointing Near-Complete Recovery

Scott was a young, White man whose stroke was caused by an arteriovenous malformation. As an inpatient, he had every reason to be optimistic. As his therapists pointed out, he was young and otherwise healthy, and he worked hard in therapy. Scott fully expected to return to work, and he hoped he would soon be back to running around with his young children. When I interviewed him during his inpatient stay, he reported some physical discomfort, but at the time, he had reason to expect it was, if anything, a positive sign:

> The left side of my chest is still very numb. All my shoulder muscles are still numb. But from all the therapy, it sounds like it's starting to all awaken again. So it's all just super tingly at this point…. But as far as any other lingering things, no, just the numbness and waiting for the feelings to come back. I'm starting to feel temperatures a lot more than I used to. So like, I feel heat way more than I did, when this all first started. I couldn't feel literally anything at first…. When I feel something cold, my sensations tend to just flare … but it sounds like it's all coming back. So I guess that's a good thing.

I was on rounds with Scott's medical team one morning when the resident got a page: Scott was reporting a tingling sensation. The doctor told the resident it wasn't a concern. "Subjective sensation changes mean nothing unless you see an objective change," the doctor explained. If you performed a pinprick test to assess sensation and the patient could feel it yesterday but not today, the doctor would recommend imaging, but he didn't worry about subjective reports of tingling. The doctor conveyed a similar message to Scott, telling him the tingling was just the brain trying to figure things out, looking for sensory pathways that worked. If Scott suddenly lost strength or had a headache, that could be cause for concern, but tingling might actually be a positive sign of neuro-recovery.

While Scott noticed the tingling and temperature sensitivity, as an inpatient, he was encouraged to frame them as evidence his body was doing its work to re-wire itself and restore mobility and sensation. As Scott told me when I ran into him at day rehab, he was discharged early from inpatient rehab because he was progressing so well. As he explained:

> My sessions were just always very positive, very reassuring. They kept saying like, "man, you're gonna make a full recovery like—and you're progressing like way faster than is expected" … I just felt like I was ready … so I was just feeling really good about the fact that I was able to go home earlier.

By the time I caught up with him at day rehab, he had already achieved many patients' highest aspirations: he was walking without the aid of any assistive device, he had returned to his job, and he had been cleared to drive. Staff didn't consider his recovery shocking; they expected him to do well. But they certainly saw him as a success story and encouraged him to consider himself fortunate. Scott was acutely aware that in comparison to the vast majority of his fellow patients, he was “lucky” to have recovered to such an extent and was expected to feel grateful for his gains.

But even though he was back to work and his company had been supportive, he was still coping with fatigue, and he was frustrated at being unable to work as quickly and efficiently as before. Perhaps more troubling still, he was experiencing ongoing, debilitating nerve pain. He realized in retrospect that the uncomfortable “tingling” he noticed in the hospital was the beginning of this nerve pain and hypersensitivity, but at the time, it was framed as “a sign your nerves are growing.” But the painful and disorienting sensations didn’t abate. As he described them:

> I was having some interruption with my nerve to my foot…. I kept thinking my foot was twisted. Like facing me or just like instead of being flat on the ground, I kept thinking it was like twisted sideways. And I would imagine the kind of pain and discomfort that would come with that. My muscles would even like start like contracting as if they were twisted, and then I'd look down and my foot was flat on the floor. So I guess there was some like interruption between my brain and my foot. And eventually that got better.

But as the weather changed, the hypersensitivity to cold became more intrusive. Scott was able to take his oldest child trick-or-treating for one block, which felt like a personal victory. But walking in the wind was agonizing. As usual, his foot felt like it was clenching painfully, and then after a while, it felt like an electric shock was running down his foot.

After he returned home, Scott fell into a depression. He couldn’t yet drive, and post-stroke, he was experiencing severe carsickness as a passenger, so he felt isolated and trapped. In the hospital, he longed to see his kids again, but when he returned home, he found he was sensitive to overstimulation, so it was difficult to bear the noise and activity of young children. And of course, there was the pain. It felt like holding snow in his hand, for too long. Before the stroke, Scott had envisioned his future as an active parent. He always pictured teaching his children to play soccer and racing around the yard with them. Even after the stroke, he was initially confident he would get back to that version of himself, but doubt was beginning to intrude, with the ever-present nerve pain.

He was in his thirties, watching his imagined life recede from his grasp and imagining a new life adapting to disability. Scott didn’t want to be ungrateful: he knew many other patients would envy his recovery. But he still felt cheated of his expected return to normal. And for him, normal was living in a healthy body, a body that didn’t get in the way, that did everything he expected it to do. As Scott said:

> And that made me depressed because [the pain] was constant. And then I was having constant neck pain and back pain because I was always stressed. And so it just felt like my body was falling apart.

Ultimately, Scott and his wife had a difficult but constructive conversation:

> My wife's like, look, it's not going anywhere. Like you still have to recover, you're still in the early stages of your recovery. And it takes a while, takes a long time for your nerves to regrow. This is gonna be a problem for at least a few months. You need to move on from it. And accept that it's your new norm for now.

Scott still hoped for a complete recovery, but in the meantime, he was doing his best to adjust to a new normal. He started taking gabapentin, a medication targeted to nerve pain specifically, and it made the pain “possible to tolerate.” But Scott didn’t want to be on medication. The lingering fallout from his stroke raised the unwelcome possibility that he might not make it “back to 100 percent.” Scott grappled with the disappointment of having to revise his expectations for the future. Taking his past Self as a reference point, Scott felt depressed and frustrated with his recovery, but taking his fellow patients as a reference point, he felt guilty for not adequately appreciating his near-complete recovery.

Mark Returns to Work[4]

Mark was a return-to-work success story. Following his stroke, he ultimately went back to his old job as a banking compliance analyst. He started back to work in stages, initially working three days a week and attending day rehab two days. But a couple of weeks in, he was having a rough time.

His lack of obvious, external changes was a pitfall. As he put it, “People have certain expectations of how you used to do things,” and because Mark didn’t seem any different now, his colleagues didn’t understand “the challenges that are still beneath the surface.”

Mark’s speech had improved considerably. As he explained one day in speech therapy*, I start talking, and the words come out of my mouth, and they kind of make sense.* But he still had to be careful when writing. He was prone to missing connecting words, so he had to go back over his work, checking closely. As he pointed out, in his field, if you meant to put the word “not” in a sentence but left it out, it could be a really big deal. He could do the job, but it took longer.

He also had a harder time with what speech therapists called “alternating attention.” In the past, he was able to jump from task to task, but now switching back and forth between roles that required “different mindsets” was difficult. His work required him to read pages upon pages of dense material, compile notes, write memos, and also attend meetings and be ready to answer questions on the spot.

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[4] The return-to-work process is a fascinating subject, in and of itself. I shadowed vocational rehab therapists and observed a regularly scheduled day rehab speech and OT group dedicated to helping ease the transition back to work. Patients set up elaborate role-play scenarios to help each other prepare to return to jobs such as pharmacist or high school Spanish teacher. I wish I had space here to cover this topic at greater length. How patients navigate the process of getting back to their careers after stroke or TBI would be a worthwhile area for future work.

His working memory and short-term memory weren't what they had been. As Mark explained, "Things I did 2005 I can tell you a lot better about than what I did eight hours ago."

As he readjusted at work, he wanted to focus on his areas of strength. In a speech session I observed, the therapist told him, *As you keep progressing, it will get easier. I'm not saying you won't go back, in that capacity, at that efficiency. But you have to build back up*.

The greatest obstacle was his boss. Mark described his boss as a nice, well-intentioned guy who was "kind of all over the place." He tended to give his employees a direction and then, in the next conversation, set an entirely different priority, a new "flavor of the week." The boss had always been like that, and in fact, Mark had been looking at moving into a new role prior to his stroke, but following the stroke, he had to remove himself from consideration. He was back to working with the same disorganized boss, but since his stroke, it was much harder for Mark to cope with this scattered management style.

Instead of directing Mark to work on X, and then Y, and then Z and checking back as Mark progressed on these assignments, the boss seemed to forget, from conversation to conversation, what he asked Mark to do. When Mark tried to remind him, the boss would say, "yeah, yeah, yeah—well, this came up!"

When Mark came back to work, he tried to remind his boss that, post-stroke, he needed to focus on one objective at a time, and that it was harder for him to multi-task. Using the strategies he learned in speech therapy, Mark wrote down talking points to make sure he got his point across, but as he explained, his boss was the kind of person who let you get five words in and then was already glossing over, not listening, and telling you not to worry about it.

Before his start date, vocational therapy at the day rehab worked with Mark's company's HR department. The day rehab submitted a letter outlining the supports Mark would need while transitioning back to work, but in the email HR sent to Mark's boss, they only included the part about Mark's staged return. Mark said, "So it hit me yesterday, if he only saw like, just this ramp up schedule, he thinks everything else is fine, regardless of what I say, verbally. Because [the email from HR] is what he's going to look at."

Mark sent an email to HR asking them why they hadn't informed his boss of the other agreed-upon accommodations. He made it clear he wasn't saying he couldn't do his job, but he needed time to ease back in, and he needed his boss to understand his lingering cognitive changes.

Twenty-plus years into his career in the banking industry, Mark was also ready to reorder his priorities. Before the stroke, he worked 60 to 80 hours a week, sometimes seven days a week. He was used to "pushing for that next level," but his recent experiences changed his perspective. Mark wanted to safeguard his health. He was reluctant to return to the "pressure cooker" lifestyle he had before, and he hoped to shift to more of a mentorship role and take less on his own shoulders.

Speech: Cognition

Image 11: Speech therapist's office
Source: Photo by Author

In addition to working on speaking and swallowing, speech also dealt with cognition, which presented a particular set of interactional challenges. With cognitive tasks, success or failure often wasn't immediately self-evident to the patient. Even patients who lacked insight could generally tell if they were unsuccessful in putting a clothespin on a line or using a walker to stand, but it was harder to recognize errors in a logic puzzle or comprehension task. SLPs working on cognition had to find ways to point out errors and provide positive feedback without coming across as patronizing or condescending and embarrassing or angering the patient.

Geraldine

A speech therapist was concluding her session with a long-term outpatient, Geraldine, a Black woman in her fifties. For their final exercise, the SLP pulled out a worksheet with a sample prescription label and a series of questions pertaining to the information on the label.

Can you read the first sentence? the SLP asked. *What does "dosage" mean?*

You can only give so much, Geraldine replied.

So is this the dosage? the SLP pointed to a serial number.

Yes.

Hmm. Dosage lets me learn how many times a day you take something. Do you see that anywhere? the SLP probed. She gave Geraldine a second to think, and then asked, *How many pills should be taken in a day?*

Two times? No.

The SLP repeated the question.

Five-hundred milligram, Geraldine said.

Think about how many times you take it each day and how many pills you take each time, the SLP suggested.

Oh. Two times, Geraldine said. *Because I do mine with breakfast, lunch, and dinner.*

So at the END of the day. How many will you have taken? the SLP prompted.

It depends on how many times you take it, Geraldine said.

How many pills though?

This says two times, Geraldine said.

But how many do you take in a day? If you take one pill, two times a day?

Four.

Mmmm? the SLP said, dubiously.

That's four. Or two, four, six, eight.

You're so close! So that's one capsule, two times a day, the SLP said.

Four!
The SLP wrote it out on the page. *One at this time, and one later. One and one is?*

Two, Geraldine answered.

Does that make sense? the SLP asked.

No. Because lunch too.

Well, he only has to take it twice a day, the SLP explained.

Huh. That's just me that has to take it at lunch then.

Geraldine got the next two answers quickly: the name of the prescribing doctor and whether there were refills available. But she got stuck on the question about whether there were any special instructions.

I think maybe the special part is "with food," the SLP suggested.

But Geraldine kept getting hung up on other parts of the label. *Two times a day?* she said.

So the SPECIAL instructions, the SLP emphasized. Geraldine was still distracted by other potential answers. *Mmm. I think I would just put "with food,"* the SLP said.

Geraldine pointed out a line prohibiting sharing of medications.

I see why you think that. Because it says warning. But I think they just want- that's just reminding people you should never share your medications, the SLP explained.

Pete

Pete, a White TBI patient in his fifties, had just finished a scheduling puzzle task, and Molly, the SLP, was debriefing him.

Perfect! How did you feel about that task? How do you think you did? she asked.

Just gotta read it and try to detail it in my head more. Maybe it's an attention span thing. Or maybe I'm just dumb, Pete said.

You are definitely NOT dumb. Please don't say that. I think you did a great job of going back and checking your work and staying organized, circling ones to come back to and checking off the ones the ones you had already done. And you did a great job of questioning yourself, going back and picking up on errors and making changes. That's that thought flexibility!

Yeah. I guess sometimes I'm just impatient, he said*. I get frustrated, and then it messes up my thinking. Maybe it frustrates me that sometimes you can see it easier than me.*

I've done this so many times! Don't compare yourself to anyone else. You did great! With these skills, I don't want you to think about whether you can do this puzzle. You did, and you can. The purpose is to use these skills outside. Like, if you're scheduling a doctor's appointment, can you schedule it so that it doesn't conflict, build in time to get there, and make sure you have transportation? Scheduling is a big deduction puzzle, Molly explained.

Molly highlighted the connection between the cognition exercise, the skills it was supposed to train, and the real-world applications for these skills. Performing well on an exercise in speech therapy wasn’t a goal, in and of itself. The idea was to equip patients with the skills they needed in their daily lives, and as Molly pointed out, Pete was managing these sorts of tasks perfectly well.

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How does an adult tell another adult they failed to accurately answer a reading comprehension question or tally up a simple restaurant bill? How would you delicately explain to someone exactly what mistake they made and how they should go about avoiding the mistake in the future? Patients often got frustrated because they saw certain tasks as elementary, something they learned to do as children or would have done easily, prior to injury. Failing made them feel “stupid,” and having their failures pointed out could come across as having their intelligence called into question. In other cases, patients became frustrated and insisted the exercise was pointless: this wasn’t the sort of thing they would have done before, so it was a waste of their time.

The social script we have for “teaching” (especially basic skills) generally involves an adult and a child, so some patients found the experience of being quizzed and corrected infantilizing. It didn’t help that most of the SLPs were young women, and many of the patients were older. Several patients mentioned disliking speech therapy in particular. They took pains to say they appreciated the speech therapists and the work they were doing, but they made comments like:

> At first, I hated [speech]. I hated it because it's all this thinking … I felt like I was back in school. If you were one way before, you know, and then you're not as smart as you were—and then you've got these young girls who are teaching you. It's like—I don't want to say embarrassing. It's just—you know, it's like—you feel like, “I know that I'm way past where you are.” (stroke, White, female, outpatient)
>
> So it's like you're back in second grade again. You know? (TBI, White, male, outpatient)
>
> Sometimes [the speech therapist] can treat you like a little kid ... it’s just the way she is. She talks—there's a couple of them I don't like because they talk to you like you're a kid. You know what I mean? But you're not a kid. But I don't say nothing because I know that eventually, they're doing the right thing…. You remember your kindergarten teacher talking to you? ... It just feels like they're not addressing you as an adult, they're addressing you as a child. (TBI, White, male, outpatient)

Speech therapists were cognizant of the delicacy of the situation, as one therapist explained:

> You don't want to call the person out and make them feel bad…. First of all, there's a stigma when it comes to cognition…. I think it's more frowned upon by people—not by people, but by that person—than changes physically. (staff, inpatient)

Many staff members acknowledged that patients could find cognitive changes especially discrediting. Therapists had to strike a careful balance. They didn't want to sound harsh, but they also didn't want to praise in a way that came off as condescending. The problem wasn't unique to speech therapy. In other disciplines, praise for activities like successfully transferring to the toilet, for instance, could also unpleasantly highlight the difference between a patient's present Self and the Self prior to injury. But when working with cognition, speech therapists had to be particularly careful not to either criticize or compliment in a way that called attention to either the contrast between therapist and patient (e.g., I find it easy to complete this scheduling task, but you're clearly struggling) or between the patient's past and present Selves.

Speech: Pragmatics

I first met Silas, a Black man, in his early thirties, when he was an inpatient. His speech therapist led him through a session with an expiratory muscle strength trainer (EMST). The device was designed to build breath support, and a set of exercises should have taken no more than 15 minutes, but with Silas, it absorbed the entire session. He was diligent and driven, intent on doing the best he could, but his post-stroke cognitive changes made it difficult for him to recall and execute a simple sequence of actions, such as: *Exhale through the device. Wait ten seconds. Repeat (exhale and wait) four more times. Then rest for one minute and begin again.*

About six months prior, Silas had COVID and a stroke. At the time, Silas didn't receive inpatient rehab. He was in a long-term acute care facility, followed by skilled nursing. Finally, at a medical appointment, he was referred to inpatient rehab, but as a therapist explained, he should have received intensive rehab sooner.

Silas struggled with initiation. If you put a tray of food down in front of him, he would likely stare at it, until prompted to eat. His primary speech therapist asked the PCTs to have Silas eat his meals in the hallway, so they could supervise him, but Silas also had trouble filtering stimuli. He found being out in the hallway too distracting.

He also had long response latency. He understood what people asked him, but it often took him a while to reply. As a therapist joked, *I would say something at the end of a session, and then hear him respond when I was out the door, down the hall. I had to learn to let him process.*

Silas had an almost eerie presence. He made unflinching eye contact, and he spoke with a flattened affect. *His pragmatic skills are really reduced*, his SLP explained. In speech therapy, "pragmatics" essentially meant what a layperson might refer to as social skills—subtle, often non-verbal elements of communication. A patient struggling with pragmatics might interrupt or fail to respond, laugh inappropriately or neglect to laugh politely at a joke, avoid eye contact or stare into your soul.

Pragmatics patients couldn't always judge appropriate topics of conversation. They might make hurtful comments or, as in one speech session I observed, tell an off-putting anecdote about growing up near a slaughterhouse. Patients who previously worked client-facing jobs and were champion networkers might lose the art of making small talk. In other cases, patients struggled to distinguish between literal and figurative language or to interpret tone and body language. Speech therapists worked on training turn-taking in conversations, both for patients who dominated discussions and for patients who failed to reciprocate conversational gambits and sat in silence.

I encountered Silas again at day rehab, and I had a chance to observe a speech session that incorporated pragmatics. Before his therapist arrived, I greeted him and asked what he was working on in speech.

"Comprehension and attention to detail," he said flatly, with no further response. He tended to speak in precise, no-frills sentences.

The speech session began with a judgment exercise. The SLP posed a series of scenarios, and Silas had to tell her what he would do in the given situation.

How do you get a piece of bread from a toaster? she asked. *What would you do if your older child left toys with small pieces out where your younger child could get them? What would you do if you noticed your medication had expired?*

If the doorbell rings and your cane isn't nearby, what would you do? the SLP asked. *Why are you smiling?*

Because I was thinking of a silly, dangerous response, Silas said.

What's that?

Hop.

Please don't tell me you've been hopping! You're not wrong. But you could fall!

No. I was just trying to be funny, he said.

I love that! Not hopping to the door. But making a joke.

She remarked to him that he was "adding more of your personality back in." *Because of where your stroke was*, she explained*, we've talked a lot about social skills. Verbal and nonverbal communication, turn-taking, intonation, or even—right there! You're nodding your head, giving me feedback that you're with me, instead of not reacting at all.*

The SLP also explained that Silas should acknowledge other people's attempts at humor. *Even if you don't think it's funny! It's just a social skill. Just a giggle or a laugh. Unless we're offended. Then we don't laugh. Does that make sense? Any questions about social skills?*

Next, the SLP set Silas a scanning task. He was supposed to skim through columns of words and circle every instance of a chosen word. When he was finished with the task, he sat in silence, and the SLP let the quiet drag out for a moment or two.

Are you done with the task? she asked. *When you're done, I want you to practice initiating. That's why I sat here. Next round, just be thinking about that initiation piece.*

She also gave him feedback on the word-hunting. He began his search at a seemingly random point on the page and jumped around, unsystematically. She explained that his post-stroke brain made him more distractible.

"Because your brain's going to do that to you," she said, "and you're going to have five half-done things." *So if you spot a word somewhere else, don't jump to it. Just keep going through the rows. A strategy is only good if you're consistent with it. Your brain is going to tell you "Oh, I have to do this, I have to do this."*

After the next round, he told her he was finished, and she complimented his initiation.

At the end of the session, she reviewed the skills they covered: comprehension, attention to detail, and organization, along with pragmatics. *And I did note your eye contact! You're doing a lot better. Does it feel like you're doing better?* she asked.

Yes.

"You're retraining your brain," she said. *You're telling it, if someone's talking, I need to show I'm listening.*

After the session, the therapist told me Silas was “so interesting because he looks so much lower level than he actually is.” As she explained, his cognition had improved considerably, but because of his flat affect and terse phrasing, he could come across as if he didn’t comprehend what a person was saying.

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As speech therapists explained, teaching pragmatics could be challenging for a number of reasons. To begin with, patients who had problems in pragmatics often had problems with insight. If a patient didn’t recognize they were boorishly monopolizing conversation or speaking at an inappropriate volume in a quiet place, how could you teach them not to? “Good pragmatics” required a person to have a firm grasp of interactional norms, but it also depended on accurate self-perception and an understanding of how one was being perceived by others.

To further complicate matters, these social rules weren’t always clear and ironclad. It could be a matter of personal judgment whether a comment or behavior was appropriate, inappropriate, or perhaps subtly “off.” Speech therapy, in some cases, required therapists to tease apart unspoken social rules and attempt to train patients in strategies to help them abide by these rules. Therapists might work with patients on pausing to think before speaking or trying to imagine the perspectives of others.

This process could be awkward, on many levels. Therapists were asking people to interrogate taken-for-granted aspects of communication. And of course, as with teaching cognition, therapists had to tread carefully to avoid causing offense or hurting a patient’s feelings. As an SLP explained, “There are times where I do feel a little bit bad just because—you know, nobody wants to be like, quote unquote, weird or wrong in a social setting, right?” Teaching pragmatics, itself, required the breaching of norms: therapists had to directly confront and call attention to another person's *faux pas*.

Chapter Six: Brain, Body, and Mind

As discussed in the previous chapter, brain injury threatened patients' identities—the relationships, social roles, and personal characteristics they valued (and believed others valued them for). Perhaps even more unsettling for patients, however, were the ways in which brain injury could threaten the basic components of Self—not only what patients could do or who they felt they were (to themselves and to others), but their connection to their own bodies and minds, their perceptions, their memories, and their sense of Self.

In the next chapter (Chapter Seven: Understanding and Finding Meaning), I will discuss patients' understandings of what exactly happened to their brains in greater detail. In this chapter, I will explore challenges patients experienced in coping with changes to perception, sensation, memory, judgment, emotion, and behavior—characteristics all but inextricable from sense of Self, but emanating from a bodily organ.

Conceptualizing the Injured Brain

Stroke and TBI patients often experienced perceptual changes, memory changes, and numerous other cognitive and behavioral changes. Patients were encouraged to connect their symptoms to the damage that occurred in their brains, as I will discuss at greater length in Chapter 7 (Understanding and Finding Meaning). Many patients learned to talk about their brains as being at the root of their problems, even if they didn't fully understand the neuroanatomic details of what had happened and why. As one patient characterized it, "My brain got all reorganized and restructured so to speak" (stroke, Black, male, inpatient). He didn't have a clear sense of what areas of the brain had been affected and how injury to these regions mapped onto his symptoms, but he was well aware that what he was experiencing mentally and physically was attributable to physical changes in his brain.

Due to this awareness, patients often expressed a newfound sense of the brain as a point of vulnerability, especially if there were still diagnostic unknowns or unresolved medical issues (such as an arteriovenous malformation that would require future surgical intervention). As one TBI patient explained:

> I think the biggest concern I have is, I want to make sure everything up here in my head is working. And I know that they—I was told that, you know, I didn't have any—there was no bleeding. There was no swelling of the brain. There was none of that. But it still scares me just because I don't—I don't—I'm not familiar with everything up there.... So I think that's probably my biggest point of anxiety is, is everything in my head okay? Like physically. (TBI, White, female, inpatient)

Aside from what could be seen through brain imaging, it was hard for patients to get a sense of how the brain was healing, of what was going on "up here in my head." In some cases, a patient had recently learned that a hidden defect, like an aneurysm or arteriovenous malformation, had been lurking in their brain for a while, and they had been entirely unaware of its presence until it caused a stroke. It was difficult to return to their previous sense of security knowing now that a life-threatening issue could fly under the radar.

Patients, family, and staff alike tended to talk about the brain as though it were, to some extent, a separate entity, with its own agency. The brain could harbor unknown problems. The brain could have its own agenda. Patients used metaphors that attributed emotion to the brain:

> And one nurse told me that the reason I have the headaches is because the brain is angry. The brain don't like blood, so this is blood sitting on there, and so there's tension in between the blood and the brain. So that's what a nurse over at [the previous hospital] explained to me. (stroke, Black, female, inpatient)

The brain, figuratively, had its own preferences, could be angered or placated. As one staff member put it, the brain could even intervene to soothe itself:

> It's amazing how the brain starts to reach its goal of being calm.... I have noticed that [patients] become very fidgety and wiggling in their chair. And it's because the brain is looking for a way to calm it, but the person itself doesn't know. (staff, inpatient)

In this case, the brain was represented as exercising a kind of benign intuition, but the brain could also be conceived of as adversarial. Serena and her husband Shane, for instance, spoke at length about trying to wrap their minds around the relationship between body, mind, and brain. Shane and Serena (White, female, inpatient) had both been hospitalized for COVID-19, but Shane recovered, and Serena suffered a stroke. Shane had a way of speaking as though her brain's willfulness was the primary obstacle to her recovery, as he suggested here: "Doctor said, if you can pull her finger and rub her elbow and she feels that, there's a feeling there. He says, ‘The brain's gotta tell [the mobility] to come back’" (husband of stroke patient).

Serena attributed her continued left-sided paralysis to her brain's intransigence. She said the brain would let her do some things, but not others. In Shane's telling:

> It's all in the brain. Whatever that stroke hit that brain. That's what it's telling her. Like, yeah honey, if the brain would tell me to do it, I would do it. Like you're telling me, Yeah, move my left leg. Okay! Move my left ankle. Okay! Move my toes. Okay! Can you feel me rubbing your knee? Yeah! Okay, push back. She pushes back. Okay, well, lift your arm. The brain's not telling me to do that, she said. She's like, the brain is like dead. On that. For the hand. Isn't that weird? (husband of stroke patient)

In their narrative, the brain was a capricious dictator. Serena might want to move her arm, but it wouldn't happen until her brain was ready to give the order. What she *was* able to do—move her left ankle, move her toes, etc. —happened only with the brain's sufferance.

In neurorehabilitation, patients became minutely aware of the myriad functions and sensations controlled by the brain: everything from loss of balance to uncontrollable bursts of emotion could be caused by damage to this single organ. The brain was the fount of consciousness and awareness, as patients whose brain damage had caused periods of unwakefulness and disorientation were acutely aware. But at the same time, patients rhetorically separated the Self from the brain.

As one patient described his situation: "I guess I know what it means to have the trauma brain. It's still a bowl of jelly, and it's in there jiggling around" (TBI, White, male, inpatient). It was, in many ways, surreal to connect such profound, life-altering physical and mental changes to a damaged organ. What did it mean to think of one’s brain as both the source of cognition and sensation and also “in there jiggling around?” It's hard to conceive of the Self as dwelling in a physical object, a mass of tissue that can swell and bleed, and (hopefully) heal.

Bodily Change

Insight

Some patients believed they had no (or minimal) cognitive symptoms and were focused on regaining strength and mobility, but staff and family members often noticed cognitive changes of which patients were unaware. Hassan was an extreme example,[21] but I met several other patients (particularly young male patients) who downplayed or didn’t recognize cognitive or behavioral changes that were apparent to those around them. When I interviewed one such patient, I didn't notice any obvious signs of cognitive impairment; I was inclined to take him at his word that his symptoms were almost entirely physical. But when I observed him in a PT session,[22] I was surprised to find that his cognitive symptoms were more pronounced than he (or I) had acknowledged. He had a hard time remembering where he left his wheelchair after taking a lap around the gym. He had to be prompted to face forward on the treadmill. The PT later explained that some patients are “sneakily coggy”—they tend not to recognize their cognitive symptoms,

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[21] See *Does Hassan Have Hemi-Neglect?*

[22] See *PT: Sneakily Coggy.*

and the cognitive components of their disability only become apparent in extended interaction or in a context in which particular skills are tested.

Patients often had less of a problem with insight into physical changes. It was easier for patients to observe and acknowledge physical differences[23] (e.g., easier to notice and harder to deny that your right leg is weak than that you're having trouble concentrating). When patients were disoriented (still experiencing post-traumatic amnesia, for instance) and denying that anything had happened to them or that they were (or needed to be) in a hospital, staff sometimes pointed to visible injuries or deficits as undeniable proof. For instance, staff would point out a broken limb or a motor difficulty to prove to the patient that *something* had clearly happened and to help anchor the patient in the consensus reality. As discussed in Chapter Five (Re-Constructing Identity), these changes could be frightening and frustrating. Particularly for patients (of any age) who were strongly invested in the idea of themselves as healthy and active, these bodily changes might be experienced both as a shock and as a betrayal—the body had never let them down before, had always been able to do whatever was called for, and now it had suddenly absented itself.

The "Not Right" Body

Stroke patients often reported that a vague sense of unease and subtle bodily dysfunction were the first signs of trouble. They felt strange, but at first, they weren't sure why; exactly what felt different could be hard to pinpoint. For a lot of stroke patients, their initial symptoms didn't mirror the signs people typically associate with stroke, such as facial drooping or pronounced weakness on one side. Patient after patient told their stroke story in similar terms:

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[23] The obvious exception was in cases of hemineglect (also called hemi-inattention), which could cause patients to "forget" about parts of their own body on the affected side.

> And then I called the office and said, I'm not feeling good. They said, well, go home now. It was a Tuesday, and I went home and later I said, gee, I really feel funny. So I lay down in the bed and watched the basketball game, the finals. And after that, I thought I could sleep it off. So as long as I laid down, I thought it'd be all right. So I watched the game. And then the next morning, I woke up. I thought, gee, I don't think I can come to work today. And nothing was hurting. It was just, I felt real wobbly. (stroke, Black, male, inpatient)

> I went in for a routine iron infusion. And the girl you know, she goes through her little list of questions. And she said, how you feeling today, [Cleè]? And I said, you know, I'm not really feeling Me. I said, I got a headache. I was ready to leave the house, when I told [my husband] to drive me. So you knew something was up, right there, that I wasn't taking myself to the hospital. And I said I just don't feel right. (stroke, White, female, inpatient)

As in these examples, patients often said they "felt funny" or "didn't really feel like Me." Many patients thought they were coming down with a flu or perhaps hadn't slept well. In retrospect, and after explanations by doctors, all the symptoms became intelligible, but as it was happening, most patients just felt “off” in an indefinable way.

Sometimes, the patient wasn't even the first to become truly alarmed, as Nico, a stroke patient, recounted:

> Tuesday, I woke up. Going downstairs, bonk bonk bonk, into the right wall. But I thought I was just sleepy. Made my coffee. And I always spill my coffee. However, I spilled it into the wall ... I go like, that's really weird. When have I ever spilled coffee on a wall? Sat down at my desk and started typing and noticed that I was making tons of typos.... And now I'm like, maybe I didn't get enough sleep. So I start working. First up, I grab a client that needs help, and I'm talking to him. And I swear to that man, I don't know how he got through the call. But he said like, I'm sorry, I didn't understand. I'm sorry, you broke up. Oh, I'm sorry. Your phone's kind of goofy. Like a thousand times throughout the call. Me, I'm thinking everything is normal. But something's strange. It's actually kind of hard to talk. I stopped, got another cup of coffee. Sat outside for a few minutes. Went back and sat down. And I see that one of my brothers called, so I pick up and I'm talking to him. He's like, dude, have you been drinking? Like, and it was nine in the morning. I'm like, what the hell are you talking about? He goes, are you drunk right now? And I said what are you asking me that for? Like, I didn't know what he was talking about. But I felt it difficult to talk in terms of like, effort. I didn't even notice the slur. (stroke, White, male, inpatient)

For more than a day, Nico noticed what seemed, at the time, like minor incidents and trivial physical differences, all of which he felt had a relatively benign explanation. His working theory was that he hadn't been taking care of himself lately—it was some combination of insufficient sleep, overwork, dehydration, and poor nutrition. Unfortunately, one of his symptoms was an impairment in judgment and self-awareness, so he wasn't well-positioned to put the pieces of the puzzle together and recognize that he urgently needed help. As he pointed out, his client and his brother heard him slurring his speech, but at the time, Nico himself didn't notice a difference in his voice. All he noticed was that, like everything else that morning, speaking seemed unaccountably difficult. His body felt odd, uncooperative, but he lacked awareness of how he was presenting to others.

Other patients followed a similar trajectory. As this patient explained, it only became clear to him that he was having a stroke when medical imaging discovered the physical evidence in his brain:

> I was out to dinner. And I had a headache. So I went home, took a couple Tylenol and went to sleep. And I actually slept through my stroke. I woke up during it and went right back to sleep. And then I woke up the next day, thinking I had like the flu or something. And—but I just didn't feel right all day. And I worked from home. And then I woke up on Wednesday, and I went to go to the bathroom, and I fell down ... my left side of my body did not want to cooperate ... I mean, it was just off. I was off. You ever felt off? ... [Once I was in the hospital], I knew something was wrong. I didn't know the severity of it. Until they started doing all the MRIs and the different tests. And then they told me that I had it in the lower part of my brain. (stroke, White, male, inpatient)

Until his diagnosis, he just felt "off." What he experienced wasn't yet identifiable as a serious medical event. It was confusing but, conceivably, within the bounds of "normal" dysfunction. Many patients initially tried to respond by taking the day off work, going to sleep, and hoping for improvement. In some cases, the strangeness reached an undeniable and terrifying crescendo, as Naomi described:[24]

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[24] See *Naomi, Caroline, Jada, and Aliana.*

> So I say, we got to call an ambulance. I'm just not feeling good. I'm really not feeling good ... I could not stand for the life of me. I looked down and I saw my foot was turned backwards. And I said like, this look like a scene from a horror movie where somebody's feet are backwards and they're about to run, like some *Paranormal Activity* stuff. (stroke, Black, female, inpatient)

As she explained, there was an element of body horror in her experience—a body that suddenly refused to cooperate and was unable to keep track of the position of its limbs. Whether the experience was one of terror and abrupt bodily alienation or one of diffuse, inarticulable strangeness, many patients didn't realize what was happening until a diagnostic label was applied.

Bodily Alienation

In many ways, the bizarre sense of bodily alienation lingered, as patients proceeded through rehab. Patients whose bodies and appearances had changed found that the intimately familiar was made strange. Some patients lacked self-awareness; staff reported that they could look in a mirror and appear not to notice or be concerned by visible changes. But other stroke and TBI patients, especially at later stages when awareness had returned, were disturbed by the stranger in the mirror. Patients might have new scars, shaved hair, eye patches, drooping facial muscles, any number of newfound differences.

In some cases, patients could no longer form the same facial expressions due to facial paralysis. Their emotions were harder to externalize, and didn't seem to translate as they once had. The face they saw didn't look like their face, and it no longer seemed to accurately reflect their interiority or their desired self-presentation. Patients whose voices changed reported similar dissonance between self-image and self-perception. As one patient put it, "But it's like, I'm going—like I'm gone. Like, where'd I go? I don't even sound the same. My voice isn't even the same" (stroke, White, female, outpatient). Another patient elaborated:

> I still have paralysis on the left side of my face. And my throat. Like [my voice] sounds breathy, and it sounds raspy. So this isn't my natural voice ... I don't like the way I speak. I don't like the way I sound. Just because I've lived with myself for you know, thirty-something years. And this is not me, you know? The me that I know, was who I was, that's what I want to get back to. (TBI, Hispanic, male, inpatient)

Patients found it difficult to adjust to the discrepancies between the voice, face, and body they had known (and were used to presenting to the world) and the new version that, in some ways, seemed to belong to a stranger. In other cases, patients themselves didn't recognize a change, but from feedback they received from others, they gathered that something was noticeably different, as this patient recounted:

> I didn't feel as if there was something so significant that was obvious to people, but they all would come up and say, today you sound really great. So I don't really—I don't really know what that means. But that's what they would all say … to have it done by one person would be "okay." To have it consistently done by everyone? It's quite "Yeah. Oookay" ... I didn't feel like there was any significant shift that was outwardly visible. But apparently there was. (stroke, Black, female, outpatient)

When people repeatedly complimented her on how much better she sounded, it became clear there was a difference in her voice apparent to others and not to her. These comments were seemingly intended as validation, but in fact, they destabilized her sense that she could accurately perceive her own voice while highlighting the difference between her pre- and post-injury Self.

Some patients also had to negotiate a degree of ambiguity as to the origins of particular symptoms. For TBI patients who had been in accidents, it could be difficult to tell whether pain or numbness were the result of bodily injuries (broken bones, healing wounds, etc.), neurological damage, or some combination of the two. Patients who experienced nerve pain had to grapple with the fact that their nervous system was essentially misreporting distress—a limb might be excruciatingly sensitive to cold or might feel like it was twisted into an uncomfortable position despite being visibly unharmed, as Scott described:[25]

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[25] See *Scott's Disappointing Near-Complete Recovery*.

> My foot—I was having like some interruption with my, my nerve to my foot ... I kept thinking my foot was twisted. Like facing me or just like, instead of being flat on the ground, I kept thinking it was like twisted sideways and I would imagine the kind of pain and discomfort that would come with that. My muscles would even like start like contracting as if they were twisted. And then I'd look down, and my foot was flat on the floor. But so I guess there was some like interruption between my brain and my foot and eventually that got better. (stroke, White, male, inpatient/outpatient)

The disconnect between brain and body caused the body to become an inaccurate reporter, signaling distress when the patient knew there was no underlying external stimulus. The sensation felt entirely real, but it also seemed to be disconnected from reality. Hemineglect or hemi-inattention represented a more extreme version of this alienation. Hemineglect could involve a variety of perceptual changes—a patient might not notice people standing to their left and/or might skip over words on the left side of the page when reading, for instance. But hemineglect also often involved inattention to one’s own body parts. A patient might let their left arm slip off the armrest onto the floor repeatedly and express confusion when a staff member pointed out the forgotten limb, as in these examples with Luke:

> An OT is working with Luke. He keeps trying to remind Luke to pay attention to the positioning of his left arm, but the arm keeps trailing behind or falling limp.
>
> OT: *Where’s your arm?*
>
> Luke: *You think about that arm more than me!*
>
> OT: *I do! And that’s why we’re trying to work on it.*

***

> The nurse and PCT are hooking Luke up to IV meds—they’re trying to keep the arm with the port propped up on a pillow on his lap or on the tray in front of him, but the arm keeps sliding off, and Luke never notices. They point out that it has fallen again, and he says “Did it? I can’t keep up with this arm.”

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> Nursing staff report that Luke has been urinating on himself the last several days. The medical student talked to him to try to figure out what's been going wrong. Sometimes

> Luke doesn’t realize the call button is there because it’s positioned on his left. He’s been instructed to use his urinal, but sometimes he forgets about it or can't find it.

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> Luke had a fall overnight. *Heard you took a little tumble*, the doctor says to him. *Things aren’t what they were before*, the doctor says. *You need to remember your left side. Your brain is different. It’s hard to keep in mind, but it’s very important, and you can do it.*

In a way, patients weren't aware of what they were missing—they simply "forgot" about the affected limb. But especially as rehab proceeded and patients were repeatedly reminded of their hemineglect, patients often became aware of this gap in awareness, at least sporadically. They might not *always* remember the neglected limb, but they were generally aware they had an awareness problem, as these patients articulated:

> I forget about my arm and my leg sometimes, if that makes sense. Like going down the stairs, you know, my left arm would kind of like drag behind me. And I'd, you know, be like, four flights up, and I would forget to bring it with me. Now I'm able to like hold on with that hand and, and have it just kind of go along as I go down. So I'm remembering about my limbs a little bit more. But it's very weird. You forget that you actually have an arm, or you forget that you have a foot. So like, I would roll over my foot all the time, like in the wheelchair. (stroke, White, female, inpatient)

> I might not be wording it correctly, but [they told me to] try not to allow my brain to forget that my right hand needs to work again. So whatever I was able to do, slowly, but surely, even if it was just holding the towel with my right hand. Just to remind myself that, you know, don't forget about this hand. Or, like, you know, if I was washing my face or whatever, instead of allowing my right hand to just lay off to the side, put my hand on the counter, so that my—so that my right hand can be visible. My therapist told me that, because some people just, you know, can be sitting on their hand and not even realize it. (stroke, Black, female, inpatient)

When patients were prompted to notice the forgotten limb, the situation could feel surreal: until I was reminded, there was part of Me that I didn’t remember or acknowledge. Hemineglect could also be a serious safety hazard, contributing to falls and other accidents. And as the second quote suggested, hemi-inattention could be a barrier to rehab. It could be hard to consistently exercise and work on rehabilitating a body part of which you were only sporadically aware.

Beyond hemineglect, patients might have other lapses in self-perception. Patients reported feeling they could no longer trust that their sense of their body was accurate. They used a variety of vivid descriptors for changes in bodily sensation, including:

> "This is the good foot, but this one feels like it's stuck in a sausage or something...it feels like a wax figure" (stroke, Black, male, inpatient)
>
> "[It's like] I've got a boxing mitt on, and I'm trying to type." (stroke, White, male, inpatient)

Limbs might feel leaden, unresponsive, or deadened, as if wrapped in a layer of foreign matter. Changes in mobility often accompanied these changes in sensation. A body part might both feel and behave as if it were disconnected from the person, refusing to move when asked or moving unbidden, as this exchange from an OT session illustrates:

> Connor's shoulders are moving, jerking up and down.
>
> OT: *Are you shrugging your shoulders on purpose?*
>
> Connor: *No.*
>
> OT: *Okay. Just wanted to check.*

Some patients, like Connor had bodies that moved on their own, without being asked, even as they refused to move when bidden. Staff normalized unintentional movement. In this interaction, the OT checked in with Connor to verify that his shoulder movement wasn't deliberate, and then when he confirmed that the motion was due to spasticity, she didn't comment on it any further and returned to the task at hand.

Loss of Automaticity

Although not as complete as in locked-in syndrome, many stroke and TBI patients experienced diminished bodily control, and with it, a loss of the taken-for-granted body. Actions patients were used to accomplishing without a second thought became suddenly effortful or impossible. Some patients talked about gaining a greater appreciation for their body, and for all the things it once allowed them to do with ease, as this patient suggested:

> It definitely makes you more thankful. Like, that's for sure. Like, I didn't realize how nice it was to be able to pick up a guitar and strum it whenever I wanted. Until I couldn't. (stroke, White, male, inpatient)

Patients also complained of a loss of automaticity. They never previously thought about walking or swallowing as processes that could be broken down into biomechanical components. Now, every action was dissected into stages; every step was conscious, effortful, and subject to endless repetition. Walking was no longer a unified, natural action. Patients had to remember to work on, for instance, locking and unlocking a knee or making sure a foot wasn't turning too far outward or inward.

Patients lost the ability to perform an action without conscious thought. To walk or swallow or grab again, they had to learn to deconstruct and reconstruct deceptively simple movements. As one patient put it, "People don't think about that. Just because, walking is walking" (TBI, Hispanic, male, inpatient). Until walking becomes difficult, "walking is walking," and its component parts go unexamined. Staff helped patients parse out the sequential stages of basic actions. Connor, for instance, explained that he now had to think about things like tongue positioning when he spoke and locking and unlocking his knees when he walked. This excerpt from a PT session describes the process of reverse engineering one's walking:

> Connor is on a treadmill, hoisted up by a harness. A PT and a PT in training sit on the edges of the treadmill, on either side of him, coaching him along and helping move his legs. *Kick, straighten, squeeze*! the trainee prompts. "Do everything, [Connor]!" the PT jokes. Connor is supposed to focus on a lot at once: flinging his leg forward, straightening his knee, and then locking the knee into place so it can hold weight. Then he has to think about unlocking his opposite knee and repeating the process on the other side. *Try—I know it's hard with the timing, but as soon as you unlock your leg, try to swing it forward*, the PT says.

> As Connor walks, one toe gets caught and drags his foot back along the treadmill. *Think about picking your toes up*, the PT instructs. The PT gives the trainee instructions on how to help Connor move. *Push behind the knee to make it buckle, and then help him advance*, she explains. For each stride on her side, the trainee helps unlock Connor's knee, pull his foot forward, and lock the knee again.
>
> Connor is starting to get some movement in his ankle back. *Now that we know the ankle moves, try to pick your toes up, or at least think about it. And try to plant your heel*, the PT instructs.

Despite never having thought about the mechanics of simple actions before, patients were now forced to break down and focus on each minute detail. Picking up your toes and planting your heel. Unlocking and locking your knees. As Alan put it:

> You know, you take for granted that you can walk. You never think you have to learn how to walk again. Learning how to walk again is a hard process. Who thinks heel to toe, you know, heel toe, heel toe? Who thinks that? ... But once you lose it, you know, your brain forgets or loses all that information and you have to relearn it. (stroke, Black, male, outpatient)

The whole process made patients hyperaware of their bodies. Patients thought about how they moved their arms. They observed how others did. When observing others, they thought about what it had been like to move in such an unstudied way, swinging one's arms and putting down one's feet without effort or conscious awareness of the particulars of the process. What they could once allow to happen passively, on autopilot, could no longer be accomplished uncritically.

Many patients reported that everyday activities were now onerous and required strategic planning, in ways they hadn't before. As these patients described:

> I mean, you don't even think of the little things like, my earbuds were all tangled up. Right? Try and untangle your—try and put a bra on with one hand. I dare ya. It's not easy. I've done it. So things like, you don't even think about. Like everyday, you know, things that you would do. Try even just putting a coat on or something. It's just hard. Everything's just hard. [tearful] (stroke, White, female, outpatient)
>
> Even now, I'm using my skills, my new talking skills ... first, going slow. Second, I'm loud. I'm like shouting at you. And when I shout at you it actually is easier to grab the consonants and avoid that [makes slurring noise].... It's like, I can overcome the deficit with a little

> effort. Because it hurts. It's draining to talk with you. It's more effort than normal to talk. I never thought that you could wear yourself out talking. (stroke, White, male, inpatient)

Acting or speaking required considerable effort. Additionally, patients had to keep the strategies they were taught in therapy at the forefront of their minds, adding a layer of cognitive burden to basic tasks. It was exhausting to speak as loudly as possible and to overenunciate, but it was also mentally taxing to remind oneself to slow down, speak up, etc. Many patients also talked about the oddness of having to relearn activities they couldn't remember having learned to do to begin with. Patients talked about feeling like they were back at square one, having to work on skills they had acquired as children.[26] They also pointed out that as children, they had probably learned through trial and error, rather than thinking about and practicing each discrete component of a movement. They hadn't been taught to walk by being told to unlock one knee, advance the leg, pick up the toe, plant the heel, and so on.

Some patients felt themselves reduced to relearning essential bodily functions. As one patient described:

> So like, it was kind of like, my body was like out for a while. But like, everything had to relearn and re—like I had to build the total basics of life. Kind of that's what it felt like, for the first week. I had to, like, start over again with life. Like learning how to live. Learning how to go number two, learning how to go number one, which was really hard, really hard.... So after that first week, then I felt like I was ready to like start with rehab start to, you know, practice things and build things ... then I felt like I could actually be a person, you know, like in the most basic sense. (stroke, White, female, inpatient)

Patients had to relearn their bodies, how they moved, the signals they sent, and whether these signals could be relied upon. As in the example above, patients even had to relearn "the total basics of life," like how to recognize a full bladder. In the process, patients were also confronted with the reality of a body that, at times, felt alien. Their voice might sound wrong, or their arm

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[26] See *Keira Cries in OT.*

might feel "like a wax figure." In many ways, the intimately familiar was made strange as they used these new bodies to pick apart and put back together previously unexamined movements.

The Uncooperative Body

Previously, there had been no gap between the desire to reach out and grab a cup and the action of grabbing it. Now, patients found themselves concentrating all their mental energy on a single movement, trying to "tell" the limb to move, as this patient reported:

> For whatever reason, I can like open and close like individual fingers and stuff. But once there's something in my hand, it refuses to drop it.... But like, I'll pick up like, a, like, toothbrush that they hand me. Just like, for practice of picking up things. And they'll say drop it, and then I'll put so much focus into it. I'll get like a couple fingers off. But I can't drop it. I don't know. Like, sometimes I'm stuck there like with just one finger on it. But the finger just refused to release. (stroke, White, male, inpatient)

In some cases, limbs behaved as if willful. It seemed like body parts were able to "refuse" commands from the Self when they had once been an unquestioned part of the Self. Patients experienced an unsettling sense of disconnect from recalcitrant or unresponsive body parts, as reflected in the way they talked:

> Interviewer: And what do you think you'll be like, a year from now?
>
> Patient: Hopefully, this dead foot and my busted arm, you know, are just gonna stop being a hindrance to me. Where I don't have to drag them around. (TBI, Hispanic, male, inpatient)
>
> At first, I had like a lazy leg you could say. It would—I had—I didn't have control of it. (stroke, White, male, inpatient)
>
> Twice, the patient's left arm slides off the arm rest, and his wife goes over and lifts it back on.
>
> Patient: *It has a mind of its own.*

Patients referred to affected limbs like they were separate entities, calling them "this thing" or "that leg." As the above examples demonstrate, patients talked about their limbs as not under their control, as having a mind of their own, and as having to be dragged around. One of the most commonly used framings was that the body "does not want to cooperate," and patients and staff often used phrasing that suggested a willful, oppositional body.

Like Serena and her husband Shane who marveled at how Serena's brain was "telling [her] no," many patients struggled to conceptualize this mind-body disconnect. Other patients framed the body, not the brain, as the holdout: "My brain is ready to do something. But my body isn't" (TBI, Hispanic, male, inpatient). Either the body or the brain was refusing to cooperate with the Self and the mind, declining to do what the patient wanted. For some people, the experience concretized their abstract understanding of the nervous system's "wiring":

> I learned a lot about just my body. And basically, you know, if I tell myself I can do it, I'm sending those signals to my brain, which is—my body is reacting to whatever I'm telling my brain to do. And, I mean, you learn that in school, but in a different way. But when something traumatic like this happens, it means more. It's almost like, I can show you better than I can tell you. (stroke, Black, female, outpatient)

As in this statement, many patients appeared to think of the brain, body, and Self as distinct entities: there is a brain, a body, and an "I" trying to corral them. In the process of neurorehabilitation, patients were forced to think about what exactly was getting lost in translation and how. "I" might tell my brain to do something, but the brain may or may not relay the message to the body, and the body may or may not choose to respond. They knew the brain and muscles sent signals back and forth and that these messages could be disrupted. But it also seemed clear that some thinking and experiencing Me was at the helm, giving orders that the uncooperative brain or body might "choose" to countermand.

Some patients talked about their body as untrustworthy, as these examples illustrate:

> I do everything on my right side. So then my right side starts to hurt. You know, because I'm—I guess my mind doesn't trust my left side yet. So I'm told. (stroke, White, female, outpatient)

> A therapist is explaining to Naomi that she needs assistance with standing and transfers. She shouldn't attempt them on her own.
>
> “Y’all don’t trust me,” Naomi says.
>
> “Ehhh, we don’t trust your *body,*” the therapist says.
>
> "Just kidding—this side [of my body] can’t be trusted,” Naomi says.

In the latter example, the gap between Self and body was used to save face—it wasn't that staff didn't trust Naomi to do things for herself; it was her body that was the problem. In this formulation, the brain-body connection couldn’t be relied upon, either to respond when needed or, as previously described, to accurately report back to the Self. As this patient described:

> Right after the stroke, my mind would think, Hey, move your foot. And my mind would think it, and I would look at my foot, and as much as I wanted to it wouldn't move ... it was like no matter how much you try, you just can't do it. So it's like your mind is there telling it, hey, this is what you need to do. But there's no connection between the nerves and the muscles like, Okay, do it ... you can think it, and you can think you want to do it, and there were a couple of times where I thought I was doing it. And then I would look down and it was like, no, your foot's not doing anything. And it was kind of like mind-boggling because my mind is saying to do it and I felt like I was doing it, but then I physically was not doing it. (stroke, Hispanic, male, outpatient)

As these examples suggest, some patients could no longer rely on their body's perceptions, even as far as accurately reporting what the body was or wasn't doing at the moment. And as the exchange with Naomi suggests, other people could also begin to treat the patient’s body as unreliable. Patients were often frustrated by the restrictions staff imposed to prevent unobserved falls. In many cases, patients felt they could get around their rooms well enough without assistance, but staff disagreed. Even if the patient felt their self-assessment of their body could be trusted, others had lost faith in both their body and their ability to judge its level of functioning.

The Body as Unreliable Witness

Inpatient staff rules for working with locked-in patients presented an interesting case study in how institutional policy could encode the body as an unreliable reporter. The floor that accepted locked-in syndrome patients had a rule that nursing staff had to work with LIS patients in pairs when performing personal care tasks. Staff told me this rule was put in place after an LIS patient reported that she had been touched inappropriately by a staff member. The staff didn't believe abuse had occurred, in that case, but the incident contributed to a policy change. Staff said it was important to be cautious (and have a witness present) when working with LIS patients because it was difficult for LIS patients to tell what was happening to their bodies, and it was possible for them to mis-perceive what staff were doing. As one staff member explained:

> [LIS patients] can't see what's going on, on their body, and they may not know—like, if you don't explain everything that you're doing, they may not know why you're doing that and why.... But you just need to make sure there's like two people and that's for, you know, if you are accused you can say, well, so and so was there too. But mostly I think it's mainly for the patients just to feel like ... cuz I can't imagine, you know, it's like, having no control of your body but still able to feel everything. (staff, inpatient)

Staff didn't think these sorts of presumed misreports were malicious or intentional. There was a disjunct between what patients experienced and what staff perceived as reality. For a number of reasons, including changes in sensation and bodily self-perception and an inability to turn their heads to see what was happening around them, it could be hard for LIS patients to interpret what was happening around them or to them. LIS patients were (generally) cognitively unchanged, but staff regarded them as potentially unreliable historians because their bodies were prone to giving them false or incomplete information.

Locked-in syndrome represented an extreme example of bodily alienation. As the name implies, patients could experience their body as a cage, in which they were effectively trapped. As they improved, patients regained some degree of control of their movement, but especially in the beginning, it could feel like they were trapped, fully conscious and aware, in an unresponsive body. As Connor described:

> Connor: And every time I wanted to ask for help there was nothing I could do. I just had to wait for someone to notice. So one time I was laying like this [slumped to the side] for a long time. Someone even came and talked to me and gave me breathing treatment.
>
> Interviewer: But they just kept you all slumped over and didn't notice?
>
> Connor: Yeah. And I couldn't ask them to bring me up. (stroke, White, male, inpatient)

The loss of control was comprehensive: Connor couldn't move or even signal his desire to be moved. He felt captive within his own body. For patients, locked-in and otherwise, who couldn't communicate or act for themselves, family members sometimes acted as translators and were relied upon to perceive and communicate the patient's needs. A family member could become tantamount to an adaptive device, a necessary appendage, helping bridge the gap between the patient and staff members who didn't know the patient well and couldn't interpret subtle signals or intuit preferences.

The Body as Medical Object

The hospital context was another major factor in the ways patients experienced bodily change. The experience of being treated as a medical object could be alienating in and of itself. As in many teaching hospitals, during daily rounds, doctors and students crowded into patients' rooms, sometimes with only a token knock to announce themselves. On the whole, physicians and other staff members endeavored to treat patients and their bodies with respect. But at the same time, rounds tended to be quick, since many physicians were scheduled to begin their outpatient clinics immediately afterward, and patients were starting therapies for the day. In the process, interactional corners were often cut. Staff didn't always take the time to introduce everyone entering the patient's room, and some patients and family members were frustrated by this brusque approach. It contributed to the sense of becoming a medical object, a case being monitored and displayed, rather than a person with whom the norms of courtesy must be observed.

The medical team might discuss the patient's case within earshot of the patient, but without directly addressing the patient, in a way that suggested the patient was being talked *about* rather than *to*. Generally, this discussion involved technical matters (e.g., lab results), but it could also cover topics a patient might conceivably want to weigh in on. And in some cases, staff discussed patients in a way that came across as insensitive, as this exchange illustrates:

> The nurse practitioner says their next patient has a right basal ganglia. “Yeah, she’s really slow too,” the doctor says audibly, right outside the patient’s open door.

It wasn’t always clear exactly how much a confused or aphasic patient was able to understand. Staff clearly didn't think they were having sensitive discussions in front of people who could hear and understand them. But the practice of assuming patients were unaware (regardless of to what extent they actually were) contributed to the objectification.

Staff didn’t always take the time to try to involve ambiguously aware patients in discussions. And in some cases (e.g., Conner’s conflict with Isabelle)[27] staff members acted in a way that presumed a patient had limited awareness, even when that was not at all the case. On the brain floors, a lot of discussion occurred outside the patient’s closed door before and after going in to see the patient, particularly if the patient was seen as disoriented, confused, or difficult to rouse. But in some cases, discussion continued outside an open door or at a patient’s bedside. The following example highlights some of the interactional complexities:

> When the team arrives for morning rounds, Mr. H is still asleep. He's often lethargic and confused, in the mornings. The bed enclosure and his hemineglect also make it difficult for him to tell who's coming into the room. The doctor greets Mr. H and says, *Tell us, how was your therapy yesterday*?

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[27] See *Three Perspectives.*

> Mr. H doesn't respond. He's still groggy, barely acknowledging that the medical team is here.
>
> *Well, you need your sleep. Sorry to wake you*, the doctor says. The doctor makes sure Mr. H’s call button is on the inside of the bed enclosure, in case he needs it. He says the original bed enclosures didn’t have a slit for the call remote to go through, so you used to have to leave it partially unzipped. The resident asks if patients used to get out that way. *Oh, sure*, the doctor says.
>
> We’re still bedside, but Mr. H doesn’t seem aware. The doctor asks the medical student if he’s heard of the agitated behavior scale. He suggests the medical student report on it for his next informal presentation during rounds.

In many ways, the physician was scrupulously courteous. He spoke to Mr. H as though Mr. H was party to the discussion, even though Mr. H didn't appear to be paying any attention. But as was routinely the case, the discussion continued at Mr. H's bedside, after the discussion with Mr. H had concluded. Nothing they discussed was necessarily inappropriate for Mr. H to hear, and Mr. H seemed to be dozing (or at least ignoring them), but in discussing the logistics of behavior management at the bedside, they had switched to a backstage conversational register, behaving as though Mr. H was no longer present.

Attending physicians have a duty to train residents and medical students, and information conveyed on rounds was a substantial part of that training. At times, however, the need to educate contributed to the sense that patients were on display, as these incidents illustrate:

> The resident asks what happened to Mrs. G's hand. Is it a new bruise? The doctor takes the opportunity to explain that the greenish color of the bruising on the back of her hand indicates that it’s older bruising. He points out a black, newer bruise on her arm. She confirms that the bruise on her hand is from blood draws. As the doctor is pointing out the color, he keeps rubbing his finger across the bruising on the back of her hand, in a way that makes me cringe. The way he’s touching it looks painful. He tells the students that color and location of a bruise can be an indicator in the ER (e.g., if a child comes in and the parent says the bruises are from a fresh injury, you should pay attention to the color of the bruise and to where the bruises are located. Are the bruises in unusual places where kids don’t tend to fall?). Mrs. G asks if they’re talking about her, and the doctor quips that they’re talking about child abuse, not elder abuse.

***

> We’ve made our way to the gym where Mr. S is on a treadmill. The doctor asks the team why Mr. S has a weight on one ankle. Mr. S jokes that it’s because he’s “practicing for the Olympics." The PT says “S, I don’t think that was a question for you. You’re off the hook on this one.”

In many cases, staff made an effort to acknowledge patients as more than demonstration objects for medical education. For instance, they would ask patients for their consent before inviting students to listen to a patient's heart or lungs. But the way interactions are structured in a teaching hospital tends to frame patients on rounds as subjects in one moment and teaching aids in others.

The Body as Worksite and Workload

Another major factor in bodily objectification is that patients' bodies become part of the workload, for the nursing staff in particular. In some cases, the pace of hospital workflow contributed to a sense that patients’ bodies were being “handled” without acknowledgment of their personhood or preferences. Under time pressure and juggling multiple patients who all needed to be ready for therapy around the same time, staff might rush through, getting the job done and not taking time to acknowledge and involve patients, as they ideally might.

This issue was perhaps most pronounced for disorders of consciousness (DOC) patients who were immobile, uncommunicative, and ambiguously aware of their surroundings and therefore unable to speak up or push back. DOC patients were unable to speak for themselves, but Dani, the partner of one DOC patient called Owen, spoke at length about how some staff members treated Owen with respect and others manipulated his body as though he wasn’t “in there.” She appreciated when staff gave a running commentary, speaking to him about what they were going to do or where they were going to touch him or what kind of sensations he could expect rather than presuming he had no awareness whatsoever. Rather than, for instance, jabbing a needle into his arm without warning, some staff members interacted with him as an experiencing subject rather than a medical object. Dani described her frustration at finding Owen left in uncomfortable and undignified positions:

> And as great as some of the nurses and techs are, they don't love him like I do. And like this morning, I walked in—and he's supposed to have pillows underneath to prevent pressure sores, and he doesn't support his head, as you saw. And so, I walked in and he didn't have a single pillow underneath him. He was at an almost upward angle, and he had a puddle of drool on his chest. And I don't know how long he was sitting like that. His [tube-fed] food had exploded, and it was like sopping wet all over his gown. And just the fact that no one has a close enough eye on him to realize that. And to me that's just disrespectful to him. He deserves all the dignity in the world. He's still a grown man, and he's still a human being. And so, days like that, that's why I'm here all the time because I know if someone's not watching, no one's watching really (partner of TBI patient).

Dani didn't want to come across as "pushy or disrespectful," and she didn't want staff to get frustrated with her, let alone with Owen. But she felt that at times, Owen was treated as an empty body rather than a person. She felt that had they seen him as someone with preferences, capable of experiencing discomfort in the same way as everyone else, they never would have left him in uncomfortable and undignified positions. I saw analogous situations myself, including this interaction on rounds one morning:

> The next patient has a brain stem injury. He’s in the minimally conscious program. He’s in his wheelchair, outside his room, and as soon as the team arrives, the doctor notices that the patient has slid down in his chair and his leg straps are digging in, cutting off circulation to his legs. The doctor starts trying to fix the patient's positioning. He points out that this patient can't complain about the discomfort, so especially when a patient is out in the hallway, visible to anyone coming by, staff should make it a point to notice whether he looks comfortable or not. The doctor flags down a PT as she’s coming by. She looks at the patient and says, “oh, buddy!” She says nursing keeps putting him in the chair wrong; the straps shouldn’t be there. She tells the doctor he can continue on his rounds because she can finish repositioning the patient herself.

Dani talked about her appreciation for staff members who interacted with Owen like he was a person and not just a malfunctioning body. Many family members, of course, believed that patients were more aware than they appeared to be, both of their bodies and their surroundings. And certainly, family members were very attuned to subtle signals that could indicate discomfort or agitation. Dani, for instance, talked about staff members failing to recognize signs that their activities were disturbing Owen:

> Especially at night. Like, it was a couple of nights ago where like he had just fallen asleep, and I told the nurse that, and she came back ten minutes later and was like slamming cabinets. So I stopped her, and I said loud noises startle him, whether it's middle of the night or during the day, loud noises startle him. He can't see where you're at. And he woke up immediately and started posturing.[28] (partner of TBI patient)

In some cases, staff members proceeded with their jobs as though certain patients were inanimate objects in the room who wouldn't be disturbed by an unexpected presence or jarring sounds. In many cases, it was difficult to know how aware patients truly were of their surroundings. But more than once, patients at later stages of recovery reported having memories of how they were treated when minimally conscious. As one patient said:

> [I remember] different bits and pieces. But, you know, telling me—like she told me she was going to shave me and asked me how I was doing this morning and stuff like that. She was real gentle. I remember she was real gentle. (TBI, White, male, outpatient)

This discussion also highlights the vital importance of inpatient staffing, both in terms of ensuring that staff isn’t stretched too thin to provide optimal care and in retaining skilled and experienced workers. As staff, family, and patients all made clear, taking care of this patient population required not only medical skill but also interactional finesse. Certain interactional techniques were very much appreciated by patients and families, such as when staff narrated what they were doing to a patient’s body as they went, helping patients understand where they were about to be touched and for what purpose. Experienced and skilled nursing staff also tried to be aware of a patient’s field of vision, especially if it was restricted. They tried to stay on the “good side” of a patient’s visual field. They remembered to announce their presence, introducing themselves, and explaining what

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[28] In this context, posturing refers to rigid and abnormal body positioning, indicative of distress.

they were there to do when entering the room, knowing that patients might be discomfited if they could hear movement but had no way of seeing or asking who was there.

Some staff also tried to err on the side of caution, defaulting to acting as though patients were part of every conversation, even if they were ambiguously aware. As a nurse explained:

> A lot of staff have gotten into trouble because they would come into a room and just start talking to the family member. This person is aware! So I always try to include them. You have to be like, you know, I'm talking, I know you're in there, I'm talking to you, too. If I'm talking to the family member, I'm like acknowledging [the patient]. So I'm not—you can't treat them like they're not there. You can't treat patients like they're not there. They're there. Even when I'm talking to the family. They're asking me questions and the patient's like just like, seems like they're zoned out. I always tried to be like, you know, refer to them like, Yes, you're here, I'm talking to you too. (staff, inpatient).

To many staff members, it was important to treat all patients as experiencing subjects, even in cases of ambiguous awareness or when patients were conscious and oriented but appeared not to be paying attention. But in some cases, staff members made assumptions that alienated patients from staff and, in some ways, complicated patients' relationships to their own bodies. Locked-in syndrome patients and other patients with severe mobility disorders often had problems seeing and/or feeling what was being done to their bodies, and it was difficult if not impossible for them to assist in or direct their care. It was particularly important for these patients to feel that staff were not just plowing ahead with a routine, as if the patient’s body were uninhabited.

This interaction illustrates how staff could try to involve patients in their care, and highlight, for everyone involved, that the patient isn't being treated as a piece of furniture to be moved and manipulated, without their participation or input:

> Connor, his wife Emilia, and Connor's mom have an education session scheduled with a PT. To get in and out of bed and his wheelchair, Connor uses a harness and lift. The harness has to be positioned correctly under him and attached to the electric lift, and then someone has to operate the lift controls to raise, lower, and move Connor. Up to this point, these transfers were performed by staff, but if family members are trained, demonstrate their understanding, and have a staff member sign off, they can assist Connor with transfers themselves, which would mean Connor wouldn't have to ask for (and wait for) staff

> assistance as frequently. Both Connor's mom and Emilia are eager to learn and help, but there is a note of tension in the room. No one wants to hurt Connor, and it's a new and somewhat complex skill.
>
> Emilia and Connor's mom both love him deeply and are abundantly aware that Connor is "present" and fully aware, but in the tension of learning the maneuver, even Connor's mom has a moment or two of accidentally interacting with him like an object they're carefully trying to shift. "Watch the head!" she instructs Emilia, sounding for a second like someone moving a piece of fine statuary. Both Connor's mom and Emilia, however, try to make it clear they regard Connor as a full participant. They ask him which way he prefers to roll, when they need to slide the harness under him; they ask if he feels centered and secure once the harness is positioned.
>
> The PT repeatedly finds ways to emphasize Connor's involvement, pointing out that Connor can remind Emilia and his mom about crucial steps, since he's done this more than any of them. The PT says, *Get used to having the power wheelchair off for transfers. It isn't off, but it's too tilted to move right now. It can be up to you to pay attention too, Connor. Now that you've been turning the chair off yourself, before transfers.*
>
> She suggests they have Connor hold and operate the controls, even though it's difficult for him to maintain pressure on the button. Emilia and Connor's mom complete two transfers independently, and the PT signs off. She says, *When they print out the mobility sheet that hangs up there, it will say you're clear to transfer. If at least one of you is here, you can supervise an untrained person. Like dad. And it's your job too, Connor, to say something if it's not right. Of everyone, you've done the most of these.*

As this scene makes clear, thoughtful gestures by staff can ameliorate patients' sense of objectification. When the PT suggested that Connor operate the controls, for instance, she modeled the idea that efficiency shouldn't override the importance of giving Connor a sense of control and allowing Connor to challenge himself and practice his skills. Unfortunately, the structure of the hospital workday often meant that nursing staff couldn't take the time to let patients direct and/or participate in their care. On the whole, patients understood that staff were often under immense time pressure, but patients and family appreciated interactional strategies that emphasized patients' personhood and dignity.

Loss of Pride in Bodily Adornment and Pleasure in Bodily Comfort

Hygiene and physical care were another significant element of comfort and dignity, especially given that patients were at the inpatient rehab for an average of three weeks and had often been in an acute facility for a week or more before that. It was a long time to go without feeling properly clean and comfortable.

At a basic level, patients who needed assistance with showering and grooming didn't have a great deal of control over when and how hygiene activities occurred. Each patient had three scheduled shower days a week. If a patient declined a shower, they wouldn't have another opportunity until their next scheduled shower day.

YOU ARE IN ROOM [redacted]
YOUR SHOWER DAYS ARE
TUESDAY/THURSDAY/SATURDAY
IF YOU REFUSE, YOU NEXT SHOWER
WILL OCCUR ON THE NEXT SET DAY

Image 12: Shower policy sign
Source: Photo by Author

Patient care techs were overworked, and many patients tried to be understanding of the PCTs' constraints. But the hospital's staffing situation sometimes put patients in the position of having to sacrifice physical comfort and bodily self-determination. Some patients were chronically exhausted and didn’t particularly want to be showered, even three days a week. But many other patients were frustrated by the limited shower schedule and by the necessity of agreeing to take a shower whenever it was offered, on your appointed day, whether at 4 p.m. or 9 p.m. and whether it was a convenient time for you or not. In some cases, patients mentioned having showered daily or twice daily at home and feeling distress at being out of their accustomed routine.

As nursing staff explained, any grooming beyond the basics tended to fall by the wayside:

> Just the fact that they feel like they are not themselves anymore. Because we have so much to do. Like we try to, like, help groom the patients or, you know, do their hair, do different things. But a lot of times, we don't have time for that. They don't even get showered every day. So we don't have time to keep people shaved or hair nice or hair clean or facial hair down, or nails looking a certain type of way. So when people are used to a certain type of upkeep, in their outside life, you know, that's something that really bothers them here. And a lot of times, I see patients, when we do take them into the bathroom, they're just looking at their self, like *Who am I*?... We try to help that as best as we can here. Like, trying to keep their clothes clean, make sure they have clean clothes. When it's their shower day, make sure we're brushing their hair, helping them brush their teeth, wash their face, put on deodorant or aftershave, whatever it is. A little perfume. We try to do some things that like help them feel a little better. (staff, inpatient)

For some patients, family members were able to come in, bring necessary products, and help with shaving or hair care, but certainly not all patients had family who would or could spend that kind of time, regularly or at all. With staff and family, patients were concerned about seeming too particular or ungrateful for the care and attention they were receiving. But at the same time, it was frustrating to be unable to perform routine grooming tasks to one's own standards or according to one's own preferences. Patients might have complicated skin or hair care routines at home, for instance, but they often felt compelled to suspend these practices while someone else was assisting with their care.

Patients talked about feeling ashamed of their physical state, concerned or aware that they had body odor or looked visibly unclean. They talked about feeling self-conscious at being unable to maintain their usual standards of self-presentation. Black patients, in particular, expressed concern about not being "put together," about ashy skin and/or hair that hadn't been trimmed or styled. As has been well-documented (e.g., Donahoo 2022; Rosette and Dumas 2007), there are complex racial dynamics at play surrounding Black hair and self-presentation, and many patients were careful about how they might be perceived. Nearly all of the patient care techs were Black women, and many of them talked about understanding how patients felt. As one Black, female PCT explained, looking carefully groomed, "might make them feel better, you know, it might make them approachable, more approachable [to White staff]." She talked about the pressures of respectability politics and how older Black patients, in particular, might feel profound discomfort at not appearing "neat" in a predominantly White public context, especially a medical environment. As she put it, ideally, they would want to be "impeccably dressed," but failing that, they certainly felt the pressure to look "clean" and "presentable." Beyond respectability politics, Black patients could be wary of not being treated on par with other patients, especially if they weren't able to manage their self-presentation.

The structural conditions of the hospital created a situation in which PCTs were both well-situated to empathize with Black patients' racialized discomfort at their diminished ability to manage their self-presentation, but also unable to do much about the situation, due to their own workloads and the complexity of patient and staff scheduling considerations throughout the day. In the course of the daily schedule, staff didn’t have time to wash and comb out patients' hair (let alone condition or put longer hair in protective styles), so staff would generally not wash Black patients’ hair at all. Family members, if they were available, could bring in suitable products and take the time to help patients with hair care, but otherwise, it largely didn’t happen. Black women often wore head scarves or wraps to feel presentable and put together for therapy.

Patients of all races complained of bodily discomfort, of feeling a greasy sheen on their hair or skin that made their flesh crawl. One patient described how she felt when she was especially restricted in her hygiene:

> I couldn't take a shower and wash my hair for like a week and a half because of the abrasions and so my self-image was really low. I felt like crap, and I looked like it. And everyone here was very gracious and kind. But I—I just—I felt icky. I thought I looked icky. (TBI, White, female, inpatient)

Patients might feel disgusted with themselves and self-conscious about inspiring disgust in others, and there could be longer term consequences of neglecting more time-consuming grooming tasks. As one woman explained:

> I was in the ICU for four months. And during that time, I had at least two strokes while I was there. Then when I got transferred out of there to a skilled nursing facility, they tested me for COVID, and I tested positive for COVID. Yeah, so I got COVID in the hospital. And they didn't take care of me in the hospital. They had to cut my hair off. Because they just let it get all matted. And, you know, it was pretty upsetting. I had nice, really pretty long hair. (stroke, White, female, outpatient)

This patient hadn't been in a position to maintain her own hair, and no one prevented it from becoming tangled beyond saving. Her hair was a significant part of what she liked about her own physical appearance, so her cropped hair contributed to her sense that she was living in an unfamiliar body, inferior to the body to which she was accustomed.

Beyond the psychological effects, lack of time for hygiene could even have medical consequences. In at least one case I encountered, a young Black man's head wound was missed entirely (both in the acute hospital and at inpatient rehab), in part because no one washed or carefully examined his hair. The wound remained matted closed with blood and dirt, until his mother found it. The patient explained:

> There was a lot of dirt and a clump of hair that was covering it. And so when that fell away, and the nurse took a look at it, they realized it actually wasn't attached, it was a flap of—yeah ... but the weird thing is not just that they didn't wash my hair. I thought there'd be like, an examination. You know? I had to keep looking. I was really scared. I was like,

> what if I have other wounds? ... and even when the wound was discovered and they were treating it. My mom was the one who kind of noticed that like—so—the wound was revealed, but there was this flap of—this is gross, sorry. There was a flap of skin dividing it, and the skin had hair on it. And inside the wound there were like clumps of hair and dirt or something inside it. So when different nurses—and of course [the nursing staff] cycle. It wasn't the same people all the time. Different nurses would take a look at it and do the cleaning. They'd say stuff like, *Oh, looks like it's scabbing over....* Until one day [my mom] thought like, *Oh, this thing isn't healing. Let me come look.* And she noticed that a lot of what they were describing as scabs were actually clumps of dirt and hair. So she pulled them out. And then that revealed that the flap of skin that was going over the wound wasn't actually attached to anything. And so then that's how we, you know, had the wound doctor come, and she clipped it off, and then now the wound has begun to heal. That's why it's been like, a month. (TBI, Black, male, outpatient)

This patient sustained a brain injury in a fall from a building, so multiple areas of his body had been damaged. When the head wound was discovered, the patient became anxious that if something like a head wound on a brain injury patient could have been missed, there might have been other serious oversights. Especially given that he was being treated for head trauma, he assumed they had examined his head closely, both initially and as time went on. But even after the wound was discovered, multiple nurses mistook dirt and matted hair for scabbing and failed to notice loose skin that had to be detached before healing could begin. The oversight may have occurred for a variety of reasons, but I can't help but imagine that greater attention to this patient's personal care by the staff might have revealed the problem sooner. Even if a wound hadn't been present, no one wants dirt and blood matted into his hair for weeks at a time.

As all this discussion suggests, hygiene in the hospital was, at its best, functional but not enjoyable. Patients generally didn’t have the luxury of engaging in their preferred personal care regimens, and many patients talked about having to surrender vanity or even basic personal standards. Patients had to subdue their sense of themselves as experiencing subjects with idiosyncratic preferences and a desire to pursue creature comforts and take pleasure in small luxuries, as their bodies became part of the hospital workload.

Loss of Bodily Privacy

Many patients talked about having to actively repress their sense of shame and their desire for physical dignity. As medical objects, they had to become accustomed to open discussion (often in front of groups of staff) of their bowel programs, and to staff helping them shower, dress, and use the toilet. Many patients told me they couldn’t afford to feel ashamed about or uncomfortable with bodily exposure because the daily routine and interactional norms of the hospital required patients to surrender their modesty.

For both safety reasons and for therapy assessments, even patients who could perform certain tasks independently often had to be observed while showering and using the toilet. Many staff tried to compromise, when they could, and give patients as much privacy as possible, but patients felt some staff could be intrusive, as this patient described:

> Or like I—I would go number two. And it'd be taking me a while. I would always have constipation because I would hold it for so long every single day. So I—very like, self-conscious about it. And I'd be going and then the nurse would swing her head around and be like, are you done yet? And I'd be like, What the heck? So that would make it harder for me to go because I'm like, Oh my gosh, like the nurse is just like listening. So it was a miserable experience on that end. I could probably tell you a million stories. (stroke, White, male, outpatient)

Patient dignity could be undercut by the exigencies of hospital life, particularly when rushing staff acted automatically, without taking time to learn the needs and routines of particular patients. Several patients who needed help standing or transferring but who were entirely capable of wiping themselves were extremely put off by what they saw as "invasive" staff behavior. One patient felt he was touched "in inappropriate places" (stroke, White, male, outpatient) and another talked about how some staff members would, almost by default, "give [him] a swipe" (TBI, Black, male, outpatient) even when he didn't need and hadn't asked for help wiping himself.

Staff and family encouraged patients to see staff as highly trained professionals who were inured to disgust, who had "seen it all" and were used to providing the sort of assistance patients found highly uncomfortable. To some extent, this "it's their job" professionalization framing helped patients adjust to having their bodies handled by hospital workers. But many patients said they eventually just arrived at a sense of resignation, as this patient said:

> At some point, you just got to give in. And I did. And I just had to have them help me. I had some hard times. You know, having people wiping you, you know, you're like, Oh my god. Putting diapers on you again. Like you're—like I was a baby. You know, and some of the nurses were men. Which was okay, but that was—and at some point, you're just like, okay, okay. Ignore this. Just gotta let them do their thing.... But you lose a little bit of your dignity when you have a stroke. That's what I feel like. Because you got somebody watching you wipe your ass. Why are you watching me do everything? Oh god. I was always such like a private person. (stroke, White, female, outpatient)

As this patient explained, resigning oneself to a loss of dignity could also mean altering the way one saw oneself (e.g., as a once private person who no longer had the luxury of privacy) and allowing one’s boundaries to be transgressed. As another patient suggested, this process often involved a certain amount of depersonalization:

> Like you get to the point where you're like, you know—who cares? Look at me. I'm naked. I don't care ... I think after a while you just let go. You know? It's just body—body parts that need to be clean, you know? (stroke, White, female, outpatient)

To be comfortable with their circumstances, many patients tried to think of themselves as "just body parts that need to be clean." In the process of subduing shame and reconciling themselves to indignity, patients often distanced themselves from their bodies, objectifying themselves as a means of managing discomfort. Patients also talked about a sense of powerlessness. Even as they remembered and profoundly appreciated staff members who treated them with dignity, it was strange to realize that other people had the power to bolster or diminish their sense of personhood by interacting with their body with care or with carelessness.

Many patients saw no alternative but to endure the discomfort for the duration of their stay. But over time, and when possible, some patients tried to re-establish physical boundaries and reclaim privacy and personal dignity. As Connor put it:

> We have so many interruptions. So yeah, it's difficult to have any privacy. But you know, like, when I was in, like, the ICU, I had no privacy. They would just like, do whatever they wanted. And so like, since then, I have started to like, set boundaries. Like now I can shower myself, so why do I need a PCT to like, wash me? That's something that we usually do in private. So I have made it private. I used to urinate like, wherever. And that's weird. But it's what I had to do. But now, I make it a point to go to the bathroom. Even though I don't use the toilet, I still want to do it in there. To create a sense of privacy. So yeah, it's not perfect. But I think I'm making an effort. (stroke, White, male, inpatient)

Emilia also talked about how they tried to, in a sense, reinstate their sense of the strangeness of certain behaviors. It was possible to get used to "urinating wherever" if you had no other choice. But it was also possible to decide that extraordinary circumstances no longer applied, to choose to reclaim your sense of what was and was not "normal" or acceptable behavior for you.

Connor and Emilia lived in the hospital for months, much longer than the average patient, so particularly by the end of their stay, they were feeling the strain of not having a door they could lock, or a time they could feel certain they wouldn't be interrupted. They collaborated with staff to designate a short period of uninterrupted time in their daily schedule. It was in Connor's chart for all the staff to see: for just half an hour each night, they were not to be disturbed. Even so, they found themselves having to enforce this boundary. They put a sign on the door and, despite the awkwardness, ignored knocks and turned people who entered away, until the staff adjusted to the new routine. Connor and Emilia made a concerted effort to maintain these boundaries even though it felt counter-normative, in a hospital setting, to insist on keeping your private space private, if only for a short window each day.

For a while, Connor had to endure the discomfort of living in someone else's workplace and having your body become the site of daily labor. He had to get used to the idea of numerous strangers seeing and handling his naked body, on any given day. But as Connor recovered and became increasingly independent, Connor and Emilia pushed to reverse the normalization of invasion of privacy that had once been necessary. It felt somehow radical to insist on adhering to non-hospital norms of courtesy and privacy, to stipulate that no one should walk in on you while changing or using the toilet. As Emilia explained:

> He doesn't need help being changed beyond what I can help him with. So if we have an interruption, like, when he's going to the bathroom, or when he's getting changed, even though everyone on that floor has probably seen him naked or probably wiped his ass at some point, we both have agreed that that's no longer allowed. So he's going to use the urinal in the bathroom. Or when we're in the bathroom, and I'm helping him to the toilet, we're going to close the door. And if anyone comes in, they're going to come back later. There was one time where he was sitting on the edge of the bed. His pants weren't done yet. I was helping him put on his pants. A nurse came in and I said, no, not right now. Again, this nurse has probably seen it all for [Connor]. And I think the nurse really just wanted to write their name on the board. Like I don't think the nurse really wanted anything. And Connor was like, it's fine, Emilia, and I was like, No, it's not. Because you're not at a point where you're lying in bed and they're wiping your ass, anymore. Like, you're at a point where you can dress yourself. You don't need a nurse to help you. So let's keep it at that point. Let's reestablish that boundary that nobody walks in on you when you're changing. (wife of stroke patient)

Coping with becoming a medical object and a part of the hospital workload heightened patients' sense of alienation from their own bodies. Patients and their loved ones insisted on recognition that patients were present in their bodies, as experiencing subjects, while their bodies were being handled. Some patients began to experience the body as an inconvenience, both to themselves and to others. In many ways, the body as object of care was no longer afforded the opportunity to be a source of comfort and pleasure. At the same time, patients were adjusting to neurological changes that in some cases, estranged them from their bodies (or particular body parts) and caused them to experience the body as uncooperative or unreliable. They were grappling with what it meant to be a mind or a Self, inside a body. The apparent disconnect between the commanding "I" and the unresponsive body contributed to a sense of mind-body alienation. For stroke and TBI patients, the injured brain and the affected bodies could be sources of shame and frustration, and in some cases, sites of resistance as patients reasserted boundaries and insisted on exercising control over their comfort and care.

Emotional Change

Changes in emotional landscape and emotional expression struck at the core of the Self. Patients' sense of their own personalities, to a great extent, hinged on how they felt and their ability to translate those feelings into visible affect, in interaction with other people. Damage to the right and frontal areas of the brain, in particular, caused changes that patients and their loved ones experienced as changes in personality or as the patient not acting or feeling like “themself.”

Some patients still felt "like Me," even in the presence of dramatic shifts in affect and behavior, as in the case of Caroline,[29] a patient whose family was at their wits' end about her post-TBI emotional volatility:

> Interviewer: Do you think your personality has changed at all?
>
> Caroline: I'm still me. I'm me! How am I gonna change? It's been [over forty] years. I'm not changing. (TBI, Black, female, outpatient)

Caroline was irate about her current circumstances, but she expressed that she was fundamentally the same person. In her view, the changes in her life were due to her family's controlling behavior and her consequent inability to get back to her usual routine. To me and to others, she seemed highly emotionally labile, but she felt her sorrow and anger were due not to an internal change but to the change in her life conditions. Caroline's case highlights two epistemic problems: First, patients and outside observers often had different perceptions of whether the patient had changed and to what degree; and second, it could be difficult for patients, staff, and family to determine

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[29] See *Naomi, Caroline, Jada, and Aliana.*

whether the unfamiliar emotions were attributable to neurological change or to some combination of other factors, such as medication side effects, coping with trauma and adversity, or grieving the "well" body and adjusting to disability.

Not Feeling “Me”

Many patients felt a distinct shift in their emotional landscapes, and they connected that change, at least in part, to the injury to their brain. Just as many stroke patients reported that feeling physically "off" was an early symptom, several stroke patients pointed to shifts in emotion that at the time, felt as unaccountable as they were unsettling, but that they later connected with the stroke. One patient reported feeling sudden, intense irritability, for no apparent reason. Another patient had a series of unusual emotional outbursts:

> And then I was doing errands. But I realized I couldn't text. I couldn't type, I couldn't write, like, everything was just disconnected. So I realized I needed to see a doctor. So I found, you know, a primary or an internist. And when I made the phone call to set up an appointment, I just immediately started bawling, like crying. And I'm very controlled. Like I cry twice a year. That's it. So it just came out of the blue. And then I called my sister-in-law to watch the kids and I started bawling again and terrified her. So I was like, okay, something's really not right. (stroke, White, female, inpatient)

It could be comforting to have a clear explanation, to understand emotional changes as stemming from damage to a particular part of the brain associated with emotional regulation. Knowing the emotional change wasn't "Me," but was due to the brain injury could help people alleviate guilt or embarrassment at emotional outbursts. At the same time, the idea that “the brain injury” could alter one's behaviors, perceptions, emotions, etc. could be disquieting, causing patients to wonder if their feelings were valid. Is it a “real” feeling or a symptom? Is it coming from Me or from my brain?

Many patients were more emotionally labile, post-injury. They apologized for crying in interviews with me and in interactions with staff. They felt their emotions were uncommonly accessible, lurking just below the surface and all too easily unleashed. As one patient described it:

> It fluctuates, right? Sometimes I'm okay, I'm fine. And I'm weepy sometimes. I was texting my husband's cousin and I was asking her something, but I misunderstood what she said. I'm like you know, my aphasia's still not great. And she's like, No, I didn't mean it like that! So things like that happen. Frustrations at therapy like, I cry at therapy. You know, that happens…. When I was trying to find other places to get speech therapy, I was so frustrated. I was calling so many different places ... so now my sign of frustration is crying, which—I'm not a crier. So that's been a new situation for me because I never was—never a crier. (stroke, Hispanic, female, outpatient)

Changes in emotion could feel odd, different, "not me," and they could also threaten a patient's sense of themself as someone poised, controlled, and steady. In some cases, patients were surprised at their unusually strong reactions to minor events, but in other cases, the emotions didn't seem connected to any stimulus at all. For instance, some patients experienced a condition known as pseudobulbar affect, caused by both stroke and TBI. Pseudobulbar affect is marked by sudden and uncontrollable bursts of emotion—sobbing or laughing, for example, with no particular trigger. The experience of emotion untethered from situational cause could be deeply unsettling.

Interactional Challenges and Alien Emotions

Pseudobulbar affect provides a good example of the interactional challenges behavioral and emotional changes can present. For instance, it feels rude not to laugh if another person is laughing. But usually when we laugh along with someone, it's clear to both parties exactly what we're laughing *at*. When someone is laughing at nothing (or seems to be responding disproportionately to a minor stimulus), the interaction is thrown off script. Should I also laugh at nothing, or should I let my conversation partner laugh alone? Part of the awkwardness of pseudobulbar affect, for the patient, was knowing they were putting other people in a difficult interactional spot, as one therapist articulated:

> There's one guy right now, he had kind of uncontrolled laughter. But he, you know, it wasn't on purpose. So you kind of feel like, do I laugh along with them? Or do I ignore the laughing? How do you want to best deal with it? So I always ask, you know, is this—is your laughter on purpose right now or no? (staff, inpatient)

This patient came up with a system in collaboration with one of the psychologists. He used one hand signal to let people know when he was laughing "on purpose" and they should feel free to laugh along and another to signal that he was laughing due to the pseudobulbar affect, so they should ignore the laughter and carry on as if nothing was happening.

When it wasn't clear whether emotional expression was "real," it often provoked anxiety in conversational partners. People were thrown off-script and unsure how to proceed, and they struggled to interpret the "meaning" of the emotional display. For instance, when Connor's mother and Emilia were being trained to help him transfer via lift, Connor giggled a few times, prompting everyone involved to try to interpret what was wrong:

PT: *Are you cold?*

Connor: *No.*

Emilia: *What's wrong? Are you nervous? Are you okay with us doing this?*

Emilia and Connor's mother were both a little bit on edge—they were learning how to operate the lift and they wanted to get it right and avoid hurting Connor. They knew he was in a vulnerable position, being hoisted aloft by two people operating an unfamiliar apparatus, so they knew he might feel anxious. And given recent events and Connor's difficulty communicating, they were all highly alert to any sign from him that he wanted to communicate. Under these circumstances, an unintentional giggle touched off a cascade of worried inquiries. Was the giggle a sign of discomfort—was he feeling unsafe? Or was it the pseudobulbar affect?

Uncontrolled emotionality could present interactional challenges, but it also destabilized patients' sense of Self. They experienced emotion they could not claim as their own, emotion that didn't seem to come from anywhere or be provoked by anything. For instance, Emilia described pre-stroke Connor as "never one to really get caught up in emotions, he was always pretty even-keel and neutral. And very rarely got, you know, upset about things." Now, however, he was having trouble with emotional regulation; laughter or tears seemed to "overtake" him. Even as his emotional regulation improved, he was concerned that a negative experience or interaction might once again trigger an uncontrolled response.[30]

Connor's physician recommended a low dose antidepressant. The doctor explained that, on this medication, “the laughing gets less, the crying gets less"; it still happens, but you can “bring it down to neutral easier.” For Connor, medication was a reasonable antidote to extreme laughing and crying jags. But in some ways, medication further muddied the waters of the Self by adding another variable to the mix. Were particular emotions a proportionate response to a difficult situation? A reaction to recent traumas? Were they dampened by pharmaceutical regulation? Heightened by brain injury?

Situational or Neurological?

Of course, patients’ lives didn't stop because they were hospitalized. All of the factors that affected them in their usual lives continued to impinge on them, post-injury. Naomi,[31] for instance, pointed out that in addition to having had a stroke, she was only a few weeks postpartum. Beyond whatever may have been happening hormonally, the stroke had separated her from her newborn. She was also still in the process of grieving the deaths of two close family members. It wasn't clear,

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[30] See *Three Perspectives.*

[31] See *Naomi, Caroline, Jada, and Aliana.*

even to Naomi, how much each of these factors and the neurological injury were contributing to her post-stroke emotional state.

As previously mentioned, Becca, her husband, and their adult disabled son were simultaneously hospitalized for COVID-19. Becca had a stroke, and her husband died. Months later, she was still grappling with her decision to take her husband off the ventilator. Staff discovered a hole in the ventilator tubing, so they knew her husband had been deprived of oxygen. From what Becca was told, and from her horrified impression of how he looked when breathing support was removed, she believed her husband would have been left in a condition he wouldn't have wanted to live in if he had remained on the ventilator and pulled through. But after coming to day rehab, she met post-COVID patients who had been on the brink of death but had recovered. Becca was experiencing doubt and guilt, second-guessing herself. When she made the decision, she felt under pressure from her children, and she "couldn't think right" due to her recent stroke. Becca was more emotional lately, but her changed emotional landscape could have been related to a number of factors. As she recovered from her own stroke, she was still grieving her husband's loss profoundly:

> It's been hard. It's been hard. Because he was my everything. We were—we were in love. But we had made a cabin in the backyard ... and so I go in there all the time. And my daughter bought me a journal that says Letters to My Husband in Heaven. And with his name engraved and the day he died. So I go in there and I write to him. It's beautiful, you know? So one day I was in there, and I heard him in the front calling me. I heard him saying Honey, honey. He was looking for me. So now I go in there every day and write to him and wait for him to say something to me. (stroke, White, female, outpatient)

In cases like Becca's, it was impossible to sift out emotions and trace them back to distinct circumstantial or neurological origins, which could make it difficult for patients to assess how much of what they felt was a situational response to be expected of anyone in their position, and hopefully temporary, and how much was a potentially enduring consequence of brain injury. These questions could be diagnostically relevant too, as this interaction describes:

> The team is discussing Mr. A's case. *There are cognitive changes that go along with right brain stroke, such as impulsivity and anxiety*, the doctor explains, *so that may be a factor*. The resident asks Mr. A's assigned nurse how he's been. She says he's been depressed. Mr. A told her, "A few days ago, I thought I wanted to die." He said, "I don't have a plan, but…" Then, as the nurse puts it, he went on "a bit of a rant."
>
> "As far as nursing care, he's very helpless," she says. *Can you itch right here for me? Don't leave me! I don't want to be alone.*
>
> The resident wonders if Mr. A's mood is a stroke symptom or "adjustment to disability or true depression/anxiety." The doctor says it can be hard to tell, which can make it difficult to establish a treatment plan.

As with Mr. Dawson,[32] it was difficult to attach a treatable diagnosis to the patient's emotional expression and behavior.

In some cases, staff were firmly convinced an emotional shift was caused by several interacting factors, but they chose to lean on the neurological explanation when talking to the patient. Particularly in cases where crying was incompatible with cultural norms or with a patient's gender performance, staff might use a neurological frame to help the patient save face. Many patients seemed to appreciate the opportunity for stigma avoidance, as this patient suggested:

> I—you know, um, you know, we were brought up tough. You know what I mean? Like, not weak. We never cry. And I cried. For the first—it showed me different emotions. Because it does that to your brain. (stroke, White, male, inpatient)

Even if increased emotionality could have any number of viable explanations, it was often easier for patients to frame it as part of what injury "does to your brain."

Some patients experienced the opposite extreme: instead of feeling unbridled emotion, they felt eerily flat or detached. A physician described one such case:

> I had a patient the other day who actually came to me because he was worried that he *wasn't* crying, he wasn't actually having enough emotionality, and he was bothered by that. So,

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[32] See *Depression vs. Despondency.*

> you know, he said, he went to a funeral, and he, in any other circumstance would have cried or felt sad. And he's like, I'm having a problem actually engaging with my emotions. (staff, inpatient/outpatient)

As in the cases of emotional volatility, it could be difficult to discern whether the cause was neurological, psychological, or some combination of factors. As one patient told me:

> Like this whole process, I haven't cried once. I haven't gotten angry. I just think that's weird. Because it like—seriously, it's like, I'm not the same person at all that I was before ... so you would think that I would have some emotion, some feelings about that, but I don't. So that's weird. So we're working on that. (stroke, White, female, outpatient)

She was aware of what she felt she *should* feel, what she expected someone might feel in her position, but she made those observations at a remove. The flatness could feel like disconnection from Self, but equally distressing, it could make patients feel distanced from the people around them, as Zoe described:

> So what happened to me with the stroke was—the biggest thing was that I felt disconnected. Like my—what I was *thinking* felt normal, but I couldn't control my actions, my communication, my emotions. I had muscle control. But there was still a disconnect. (stroke, White, female, inpatient)

Zoe experienced other upsetting symptoms, including a fog she likened to "pregnancy brain." She always prided herself on her parallel parking skills, but she tapped another car. Then, when she went to get her insurance card from her purse, she pulled out her health insurance card instead. She eventually had to have surgery to repair a congenital malformation that caused the initial brain bleed, and when she came out of it, her physical symptoms were far more pronounced than before. It was far from the outcome the surgeon led her to expect. But she reported that she still experienced a tinge of relief; her greatest fear, going into the surgery, was that the "emotional-mental disconnect" would return. She explained:

> I have another, hopefully forty, fifty years to live, and to not feel like myself or to be able to portray who I am, was terrifying to me. So I feel so lucky that I feel connected to who I am. It's not perfect, but it's there. And I feel like Me. But I have had zero control of my

> legs. It's like dead leg, dead arm, you know, like my whole left side of the body is just not functioning ... but it's like, at least I'm here. (stroke, White, female, inpatient)

No one wanted to lose mobility, and as previously described, loss of mobility could have tremendous ramifications for patients' relationships, roles, and identities. But for some patients, feeling an emotional disconnect—either flatness or extreme lability—was even more damaging to their ability to maintain a stable sense of Self. Patients wanted to feel both in control of their emotions and know that their emotions were situationally and interactionally appropriate. Most of all, perhaps, they wanted to experience the emotions they expected to feel, to maintain an emotional landscape in keeping with their familiar, pre-injury Self.

Behavioral Change

Emotional change and behavioral change are highly interrelated. In all likelihood, a patient behaving in an agitated fashion is experiencing some combination of frustration, anger, etc. Someone who is acting crankier lately is likely feeling more irritable. Staff talked about right and frontal brain injuries being implicated in both change in emotional regulation and in certain types of behavioral change (e.g., disinhibition; loss of ability to read and respond to social cues).

Insight

In many cases, patients who displayed marked behavioral changes also lacked insight, which could be something of a mixed blessing. On the one hand, it's hard to work on modifying behavior unless you acknowledge it exists; on the other hand, what you don't know can't hurt you. In particular, patients in early stages post-injury, with more profound lack of insight, could seem entirely unaware they were behaving in ways that might have horrified their pre-injury Self. As a psychologist put it:

> Sometimes not having awareness is easier on the patient, but harder on the family or harder on the staff. When you have a patient that has good awareness of their difficulties, even though it's not their fault, there can sometimes be shame or guilt associated with it. So they have a [behavioral] reaction, and they feel badly about it. (staff, inpatient)

In contrast, patients with limited insight might be annoyed that people were getting on their case or complaining about their behavior, but they were not particularly aware of or concerned about their behavior itself. Depending on the type and severity of injury, patients might or might not regain insight, as recovery progressed. Some patients, such as Alan, regained insight and were able compare notes with family members and accept the flaws in their own memories and perceptions:

> Interviewer: What was that like, when you couldn't communicate?
>
> Patient: I thought I communicated fine. [laugh] I thought I was communicating fine! It was everybody else [who] had the problem, not me.
>
> Interviewer: What was that like though?
>
> Patient: It was terrible, but it was fine with me. [laugh] Everybody else was there, I wasn't. My kids was like, dad—you know, and this was after I started talking a little better. They were like, dad, we didn't understand you for nothing. We just nodded our heads. (stroke, Black, male, outpatient)

At the time, as Alan put it, "everybody else was there, I wasn't." Only in retrospect did he realize he had been speaking nonsensically. He accepted the accounts of observers who, in a sense, had been more present at the time, more accurate in their ability to assess and report.

For patients who went through post-traumatic agitation and post-traumatic amnesia and came out the other side, it was often unsettling and embarrassing to hear, after the fact, how they had acted. They often had no memory of how they behaved, which in itself was discomfiting. But they were also forced to accept that they had acted in a way that wasn't “them;” rather, some kind of brain injury Mr. Hyde had emerged in their absence. Patients often apologized and felt a sense of responsibility for having subjected staff and loved ones to this behavior. Staff talked about patients writing letters, months later, to apologize for how (they were told) they behaved during their inpatient stay. I came across one such apology in the breakroom: a patient sent notes to the therapists and to the nursing staff expressing gratitude that the staff had still helped her, even though she had been "awful." "I am so sorry. I wasn't myself," one note read.

Patients often talked about having been told about their misbehavior by family:

> Well, I was in a car accident I can't remember being in the car accident though. I just remember waking up. Maybe, I don't know, another day or two days later. And then when I woke up, I really didn't know what happened. It was just like blank. And then my mom said I was a little snappy ... I don't remember being snappy. My mom told me. And I had to apologize to people because I didn't know that I was doing that. (TBI, Black, female, outpatient)

Often, in the most acute stages when insight was lacking, behavioral changes were most distressing not to the patient but to the people who knew the patient best (and who felt the patient’s behavior reflected on them).

Family Coping with Behavioral Change

To family, a patient often seemed “like a different person,” in a way that could be frustrating and uncanny and evoked feelings of ambiguous loss (i.e., the patient is alive, but is, in a sense, gone) (Boss 1999). Family reacted to behavioral changes in a variety of ways, including embarrassment and annoyance, although some family insisted patients were behaving "normally," even when staff were fairly certain their behaviors were a symptom of their injury. Staff, of course, tried to reassure embarrassed family members that they were used to this sort of behavior and didn't blame the patient for behavior they understood to be beyond their control. One PCT told a story about a stroke patient who would sundown; when he did, he would become angry and lash out at staff:

> But you know, we do this all the time. So it's like, it's not personal. You don't take it personal. And [his wife] just looked at it as, it's still abuse. Just like, it's abuse. Like he would curse, and he would yell, and he would NOOO! Like, he would call people out of

> their names. But it would not be all the time. It would just be just random sundown moments that he would have. [His wife] would just cry and cry, and I would just go give her a hug. And I don't even think we were able to hug but I was—I gave her a hug because sometimes you just need a hug. (staff, inpatient)

The transition between hospitals—for instance, transferring from acute care to inpatient rehab—could be one of the most chaotic periods of time, especially under COVID-19 restrictions. Many TBI patients were still highly agitated and confused when they transferred to rehab. At the time of my research, patients were allowed to have visitors, within limits, but patients first had to be screened for COVID. So for the first twenty-four hours or so, patients were alone in the new environment without family. Several patients and families told me stories about a rough transition—patients didn't remember where they were or why they were there. They called family members repeatedly, not understanding why they were alone. In some cases, they were convinced they were being unlawfully held or harmed, and they threatened to sue or call 911 or the FBI. As one patient's sister explained:

> He was—he was not happy with the transfer. He thought that—and again, I think this was in his head. He said they—they lied to him about what was going on, why they couldn't get him in there and whatever. And then he didn't like the fact that the beds had netting over them. Because he was trying to get out. He was abusive. He threatened people. Now, I ended up talking to a doctor and then the psychiatrist over there because I was terrified they were going to send him home or something. I thought, I can't do—I wouldn't know how—they were like, no, no, no, it's okay. We're used to dealing with this. It's okay. It's—we understand. (sister of TBI patient)

It could be heartbreaking to see a person you loved behaving so uncharacteristically, and furthermore, some family members felt responsible for shielding staff from the patient’s behavior, although staff tried to convince family they were inured to it. Families felt guilty about the patient's abuse of staff, but they often weren't aware this behavior was common and staff were prepared to deal with it. Some families feared the patient would be ejected from the hospital, and the family would have to find some way to cope with this alarming behavior at home.

In many cases, family found behavioral changes frightening. One wife recounted that her husband had vivid hallucinations of tigers and crocodiles and, perhaps most disturbingly, a little girl under his bed who smelled of decay. He was crying out to God for relief, and all she could do was watch and sob. After the fact, her husband didn't remember what had happened, but she was still haunted by having seen him in such pain and behaving in such an uncanny way.

As disturbing as it was to see a family member obviously hallucinating or delusional, it could be upsetting in a different way when a patient's grasp of reality appeared to be fine, but they were exhibiting more subtle changes, such as deficits in judgment and inhibition. If a patient wasn’t behaving in a way the layperson expected a person with “brain damage” to behave (i.e., not exhibiting signs of cognitive impairment or obviously confused and disoriented), family might be inclined to hold the patient responsible for their rudeness, volatility, impulsiveness, etc. It's harder to distance the behavior from the person when the behavior isn't so outlandishly different from "normal" behavior and is therefore easier to read as intentional and within the patient's control. A patient who was always thoughtful and modest before might now ramble on and on in a self-aggrandizing way. Kind and mild-mannered patients might swear or make inappropriate comments. They might make cutting remarks, saying what shouldn't be said. They might fail to read social cues.

One family member described this sort of behavioral change:

> You wouldn't know there's anything wrong, except he's a little bit slower and slightly unsure on his feet, just a little that I can tell. And his speech patterns are different than they were before ... so it's hard for me to qualify or quantify. He is—he's—he's smart. His vocabulary is excellent. He knows exactly how to express himself. But there's—it's the way he talks is—just—it's different. It's—everything is a little bit louder ... and the psychologist over there did warn us that part of the damage from here is that you don't recognize that, you talk, I talk, you talk, I talk, you talk, I talk. It's just: I talk I talk I talk I talk. [laughs] But he's smart! I hear him talking to his friends. I mean, he's absorbing everything that they tell him here. (sister of TBI patient)

As this statement suggests, these sorts of changes could be harder to put your finger on, less obvious and undeniable than amnesia or disorientation. They often involved breaches of unspoken social rules, such as turn-taking in conversation, as the sister described. Her brother was "smart," and the aspects of him she associated with his intelligence were still there: he was well-spoken; he comprehended information readily. Like her, many people struggled to articulate exactly what was "wrong." They might talk about someone seeming "off" or not themselves.

And of course, it was harder to intuitively connect this subtler behavior with the brain injury. If someone was obviously suffering—hallucinating crocodiles or trying to pull out their g-tube—it was distressing to see, but it was also easier to absolve the patient; that person was clearly seriously impaired. However, it was common for both stroke and TBI patients (especially with right and frontal injuries) to have the sorts of lingering problems that might come across as inconsiderateness or social ineptitude, especially to people who don't know brain injury could cause these sorts of changes.

Blame It on the Brain Injury

In these cases especially, staff tried to use neuroanatomy to distance the patient's Self from the patient's behavior. For instance, staff might explain that a patient had a frontal lobe injury, and that damage to the frontal lobe can cause disinhibition, which can cause someone to say something they wouldn't say otherwise or don't really mean. As one doctor explained:

> I think probably the most common times we're incorporating [discussion of neuroanatomy when talking to patients and families] is when families are trying to understand the impairments. I think especially with patients who have frontal lobe dysfunction, more behavioral impairments, more cognitive impairments, impulsive. When they have frontal lobe dysfunction, sometimes what I'll see is families can get very frustrated with their loved ones. Because they may seem, you know, cognitively with it enough to communicate with you. But they're probably not understanding things. They're not able to make effective decisions because of that…. So sometimes when they are getting upset or impulsive or not

> listening, it's not that they're not wanting to or they're being defiant. But it may have more to do with the area of their brain that was injured, that controls their ability to do that. (staff, inpatient)

Staff also pointed out that there are limits to compassion and empathy. Up to a point, families could tell themselves that patients were exhausted, in pain, had been through trauma. When families reached a breaking point in their ability to excuse misbehavior by pointing to typical extenuating circumstances, it helped to be able to resort to a neuroanatomical explanation.

Staff had a variety of techniques for helping families cope with distressing behavioral changes, and when patients were out of the more acute stages and capable of understanding and accepting what happened, staff used similar framings with them. The overarching theme was that none of what was happening was unexpected, considering the patient's particular injury and stage of recovery.

When patients passed through the fourth stage on the Rancho Scale, their behavior could be particularly upsetting to family. Patients might be disoriented and agitated, making absurd accusations and trying to walk on a broken leg or pull out an IV. Patients might behave in offensive or sexually inappropriate ways. They might be volatile, crying or screaming or berating loved ones. Staff “educated” family, explaining the stage-like progression of TBI recovery, and framing the patient’s disturbing behavior as explicable, expected, and in fact, a sign of progress.

As upsetting as it could be to see a family member exhibit typical Rancho 4 behaviors, staff were able to walk families through the scale and point out how the patient was scoring higher now than they had been before. Rancho 4, unpleasant though it could be for all involved, represented an improvement over previous stages when the patient was less aware and responsive. Agitation was reframed as a good thing insofar as it was a promising sign of progression. Staff also pointed out that although they couldn’t predict how long a patient would be in each stage, the patient would likely continue to progress to stage 5 and so on, eventually. The message was: upsetting as it is to see your family member become frantic or aggressive, this behavior is expected, and this too shall pass.

In the meantime, families had to learn new interactional strategies. For instance, when confronted with someone who wasn't making sense, who seemed delusional or irrational, the initial inclination was often to counterargue, to try to pull the other person back into consensus reality by pointing out where they were wrong. Staff tried to convince family it was counterproductive to argue with a confused or disoriented patient. As one TBI patient's sister remembered it, they told her: "Don't argue with him. Just, you know, take it in. You could correct him if you want, but don't argue with him."

Pushing back too insistently ran the risk of upsetting the patient. And, in many cases, the patient would just forget everything you explained a few minutes later. Family might think they were doing a good thing—confronting delusions or allaying fears—but all they would accomplish was causing temporary distress. Therapists especially tried to model this nonconfrontational behavior to family. Staff also used this sort of "humoring" to get through the workday and avoid behavioral escalation, as this interaction illustrates:

> The patient is in a "wraparound," belted to his wheelchair because he's mobile but highly confused. He's still in post-traumatic amnesia and has no idea why he's here. He can wheel himself around the floor, propelling himself with his feet, and he talks/yells to anyone who will listen about how he's being kept here against his will. He's at the nursing station, talking to one of the more seasoned brain-injury floor PCTs.
>
> Patient: *Whose got the proof of it? I want a video! I want the proof! I want all the proof. Nobody's got it. That's the problem. I'm going to sue them over that. Kept me here nine days. Stole $1000 from me. If they lose their job for that—I don't care. They keep me here ten days and never show me proof of what they say happened at my house? I know exactly what's at my house.*
>
> PCT: *I hear you.*

> Patient: *And they won't even let me go to Walgreens and buy baseball tickets for my kids!*
>
> The PCT keeps her responses short and her tone neutral. By the end, he tells her she gets him, and he knows she has his back.

At the same time, however, families also had to learn not to "humor" in the wrong ways and at the wrong times. For instance, if a patient was aphasic and their verbal communication was incomprehensible, family members' inclination might be to behave as though they could understand, to minimize discomfort for all parties. They may not want to embarrass the patient by calling attention to the nonsensical speech, and they might also feel uncomfortable breaking interactional norms by acknowledging the hitch in communication. A staff member explained how this impulse to smooth the interactional waters could be counterproductive:

> I had this one patient presentation where she just had no awareness, would not stop talking. Would laugh all the time. And she was very nonsensical output. Very much language of confusion, a lot of pure aphasic output where you had no idea what the heck she was talking about. Her family would like, laugh with her, or try to gather something from what she was saying. You know, you absolutely couldn't because she was so neologistic. There was a lot of non-words that you could not gather. But they were just trying, which is totally—so I'll just start from the beginning and say, like, I totally get what you're trying to do, but we've got to just like stop her in tracks, like, stop her immediately when you don't know what she's saying. And like, treat her like an adult. Say, "I don't know what you're saying right now. I'm so sorry. However, these are some things I could do." (staff, inpatient)

When a patient gained enough insight to begin building on that self-awareness, it did them no favors to preserve a comfortable fiction, rather than helping them learn to recognize and adapt to their post-injury changes. Family had to learn to respond constructively to inappropriate behavior. Staff tried to teach them to contextualize changed behavior as a result of the brain injury but also to find ways to set boundaries. As this staff member explained:

> I give them strategies of what you can do, you know? Visually put your hand up. The visual hand sign is enough to say, "Stop. That's inappropriate." And I need to walk out until you get control. You may have to do that every three to four minutes, because the part of the brain where they store memory—you *just* told them. (staff, inpatient)

As this example highlights, staff also tried to normalize frustration. Even knowing that a patient wasn't trying to be difficult or stubborn, it could still be challenging to deal with their behavior, with the tenacity and patience required to respond to it. Staff tried to point out that all families get frustrated with each other from time to time in order to minimize family guilt over their inevitable frustration. Knowing a patient was behaving this way because of the brain injury helped absolve the patient, but it could also make family members feel guilty for getting annoyed at someone they knew didn't mean to act this way.

It helped when families had a precedent to draw on. Some people reported they hadn't been shocked or blindsided by the behavioral change because they had known or cared for another person who went through stroke or TBI. One woman referred to a sister who permanently lacked impulse control following a TBI over thirty years ago. The woman knew traits like impulse control were part of "the higher brain function," so when her brother later sustained a TBI, his behavior was easier to contextualize. As she explained:

> [My sister is] still intelligent and whatever, but she just—she wants it, she wants it now, she has to have it. She'll get—she'll nag you until you give it to her. So we kind of knew some of those things might happen. Just from that experience. And she's—she holds a job. She's smart. She's good hearted. (sister of TBI patient)

This woman had already assimilated the fundamental message staff tried to impart: you could still be You—smart, good hearted—even if certain aspects of your personality had changed. As one staff member put it, "Your husband is still in there, your daughter is still in there. You know, they're still the person you know and love. We just have to learn to manage this a little bit differently" (staff, inpatient). Of course, families and patients struggled, to varying degrees, to accept this "still in there" framing. In some cases, it was easier to accept, if the changed behaviors were exaggerated versions of preexisting traits, as opposed to behaviors that seemed entirely out of character, such as a kind and patient loved one becoming angry and volatile.

Premorbid Personality

It could be ambiguous whether a patient's behavior was new, preexisting, or an exacerbation of a previous tendency. Staff tried to subtly make inquiries with family, if possible, to learn what they could about a patient's "premorbid" personality. This interaction provides an example:

> The next patient is sitting out in the hall. The doctor talks to him about removing his g-tube, at some point before he leaves.
>
> Doctor: *It should be quick, but not very pleasant.*
>
> Patient: *I won't feel it.*
>
> Doctor: *You're a pretty chill guy. When we pull the tube, just relax and make sure you don't tighten up your stomach muscles.*
>
> After they walk away, the doctor comments, *He's so chill. It's nice.*
>
> Nurse Practitioner: *Nice change of pace.*
>
> Doctor: *I was asking his family about his premorbid personality. They said he was chill, but not like this.*
>
> The doctor explains that the patient has frontal lobe damage, right side, so this flattened affect is about what you'd expect.

When trying to elicit this sort of background information from families, staff often had to exercise tact. For instance, staff might want to know if a patient would always monopolize conversation or if their extreme loquaciousness was a sign of disinhibition. As a speech therapist explained, they often tried to approach the question indirectly:

> So you know, what was his humor like before? So is he extroverted? Is he introverted? Tell me about like, how he is socially? And see if they mention anything, before I blatantly say like, "He never stops talking. We need to work on that." (staff, inpatient)

Family could be offended at the implication a patient was behaving rudely (or worse, was a rude person). Family might also minimize the problem, making excuses for what staff observed or claiming the behavior was "normal" for the patient. Certainly, staff had to take natural human variation into account. Traits like ability to concentrate or respond to social cues vary considerably among uninjured people. For patients with limited insight, staff had to rely on a combination of their own observations, family reports, and assumptions based on the patient's personal history. If family were insistent that a particular behavior was the patient's norm and staff had reason to doubt it, they pushed back gently:

> And they go, oh yeah, he's scatterbrained or whatever word they say. But we tend to remind them that a lot of times with a brain injury, the patient may have had these small things before, but the injury will exacerbate that, like multiply it by ten. And we'll say, would you say that his inattention was to this level? You know, it's pretty quiet in here. And he's still having a hard time focusing. Or you and I are the only ones talking, and it's making him pretty upset. Did he do this at family gatherings? Like, would you guys have group conversations, and he would get mad? (staff, inpatient)

In other cases, however, family members had a particularly fine-grained sense of how a patient had changed. One TBI patient's wife described how, although her husband had a pre-TBI ADHD diagnosis and had always been a "busy" person who struggled to sit still, the TBI had worsened his concentration difficulties and hyperactivity. She noted that being cooped up in the hospital was difficult for him and was likely making him antsy, but knowing him as she did, she felt she could recognize a difference. He was more restless than usual, beyond what might be expected as a consequence of cabin fever.

In this patient's case, his TBI was mild, and by the end of his inpatient stay, his cognitive and behavioral changes were already relatively subtle. Some patients, however, might never achieve this level of recovery. Families whose loved ones were more drastically changed had to reckon with the possibility that they might never be entirely the same again; in some cases, they would always be profoundly different. As one doctor explained:

> And sometimes these patients who have such a devastating injury, they never may be—may emerge from post-traumatic amnesia. Which, again, that means they're going to be

> agitated on an ongoing basis. It's very hard to deal with these guys, even when they come to clinic, if they are fifteen, seventeen years after injury. They're inappropriate. They make comments like, *Oh, you look ugly today*, you know? *Look at your—around your eyes, look, oh, my god, you got so old. You're ugly.* Or they would have—make sexually inappropriate, you know, things. (inpatient, staff)

It can be devastating to contemplate the possibility that, for instance, the sweet, supportive partner you married is now (and may always be) insensitive and temperamental. Even if you understand the unkind and inappropriate behavior isn't intentional, isn't entirely (or at all) within their control—isn't "them"—are you prepared to live with this new version of the person you love? What if this person is embarrassing you in public, being aggressive or insulting to people who don't know the context of the brain injury? What if they have a shorter fuse now and they're exploding at your children? How do you reconcile feelings of love and loyalty for someone who seems so unfamiliar to you?

Even if family understand the changed behavior isn't the patient's fault, and even if they hope for improvement, family members can experience something akin to grief when grappling with the "loss" of the person they love or, at the very least, the loss of some elements of who and what their loved one was to them. One patient's spouse talked openly about the grief and fear she experienced when she thought her husband might not recover:

> Brain injuries, progress is measured in months, and years. And that is foreign to anything you've ever dealt with before. And so when somebody tells you that, you think to yourself, oh my god, I'm going to jump off the building. And, you know, I was looking up on the thing on—you know, how to kill yourself, so that I could kill myself. But then I couldn't leave him ... and you know, just abandon him so that I could kill myself. So it was just—it was—it was hopeless for a while. (wife of TBI patient)

Spouses could be mourning not just the changes in their partner but the changes they envisioned for their shared future and for themselves. As one staff member described it, families (spouses in particular) are confronted with a changed person, with no guarantee the qualities they formerly valued would return, and they had to ask themselves, can you love this person, as they are now? Or, failing that, can you continue to care for them out of loyalty to who they were before?

Loved ones often looked for signs of the "old self coming through." As discussed in the previous chapter, patients and their loved ones pointed to signs that a core Self endured. Often, they identified subtle behavioral continuities, such as sense of humor or an impulse to be generous with staff. When patients began to "return," family could involve them in discussions about the changes they had been through, as one wife described:

> It broke my heart. It broke my heart. It really did. Because to know what he was like before, and then to see him very vulnerable, and just—it just really broke my heart. Because you don't like seeing your loved one like that. And you just want to take it away if you can, you know, but you can't ... so I just tried to be very reassuring and not take anything personally, that he would say. Because he did get really mad a few times. And some of it I kind of was—I could laugh some it off because it was so outrageous. Some of the things he would say would be so outrageous, it would make me laugh, but not in front of him because I don't want to hurt his feelings, but inside I'm like, that is hilarious. And then one time I was telling him about it and we both started laughing. It was so out of character for him, and he's like, ooo. But I knew that it was not him, you know? (wife of TBI patient)

It was helpful to be able to laugh in the face of the strangeness of seeing the person with whom you are most familiar become suddenly alien. And it was even more reassuring to finally be able to laugh about it with him when he began to come back to "himself." But not every patient came back to the same extent.

Patients and Self-awareness

The perspective of patients who *remain* in post-traumatic amnesia or in a similar condition is a significant lacuna in my study. Per my IRB approval, I was only able to interview patients who were judged by staff to be capable of giving informed consent. At the inpatient level, in particular, that often meant talking to patients who had relatively favorable recovery outcomes. Many patients I spoke to, both inpatient and outpatient, had come through periods of amnesia, disorientation, and agitation. They generally had next to no memory of this time, and they relied on accounts from family members and staff. But for the most part, these patients came through these states and did not remain agitated in the long-term. They certainly experienced a variety of changes, and they expressed a multitude of concerns about them. But the patients in my study were generally not the ones staff talked about who were volatile or sexually inappropriate or extremely disinhibited, in the long term. The emotional and behavioral changes in my sample tended to be more subtle, along the lines of increased hyperactivity, heightened emotionality or flattened affect, or diminished ability to read social cues.

And of course, these changes often went hand in hand with diminished self-awareness, so patients might not be entirely realistic about how much they had changed, in the perception of those around them. But to the extent that patients in my sample had changed behaviorally, and insofar as they recognized those changes, they were often quite concerned about them. They might feel ashamed of their behavior or guilty about exposing other people to unpleasant conduct.

As they did with family, staff often used neuroanatomical explanations with patients to alleviate some of this sense of responsibility. Staff encouraged patients to, as one speech therapist put it, "blame it on the brain injury." Speech therapists actively worked to help patients recognize and gain control over behavioral symptoms. But at the same time, "blaming it on the brain injury" was a way of managing guilt and deflecting social opprobrium.

Many patients made a distinction between their intentional behavior and behavior "coming from" the brain injury. To be "not myself" was deeply disquieting, and patients fervently hoped to "get back to normal" or "get back to me." But until patients could work their way back to that old Self, if a complete return was ever possible, it could be, in some ways, a comfort to separate the Self from the brain or the brain injury. As one staff member put it:

> That's what I always say: You're having a hard time, you're frustrated, guess what? Blame it on the brain injury. Let's work through it, you know, because we can have kind of a shared goal, a shared enemy almost in that way. (staff, inpatient)

It was a deliberate, self-protective sort of alienation: thinking of the injured part of the brain as an adversary or obstacle preventing you from behaving as you otherwise would. Patients and family absorbed this framing, as this patient and his wife articulated:

> I mean, granted that it's a brain injury, and people act really out of control. And I did. And then—it was my brain that did. If I didn't have a brain injury, I would never do that. I'm not that kind of person. I got respect and love and kindness for people. And if I was in my right state of mind, I would have never done that. (TBI, White, male, inpatient)

> And I don't want him to feel that he's wrong. Because, you know, in the beginning, too, I could see that, you know, he'd be like, did I say the wrong thing? Or did I, you know, do the wrong thing? Not, you know, knowing. And I don't, I didn't want him to feel that way. Because nothing he did was wrong because he didn't know what he was doing. (wife of TBI patient)

Blaming it on the brain injury served an exculpatory purpose and allowed patients and loved ones to be on the same side, rather than at odds over the patient's behavioral changes. If the brain was responsible, the patient, to some extent, avoided identity contamination. The undesirable behaviors were seen as emanating from the brain, not the Self.

Patients with behavioral changes (who had some degree of insight) were often concerned about adhering appropriately to interactional norms. As previously discussed, even patients without behavioral changes were self-conscious about their disabilities causing them to appear rude (e.g., Connor and other patients who had difficulty speaking being concerned about not saying please and thank you; patients with memory deficits taking great pains to remember people’s names). Behavioral changes were all the more challenging because the relevant standards of behavior were often subjective. Patients struggled both with self-awareness of their own behavior and with assessing the relevant social norms.

Nico, a stroke patient, talked about feeling self-conscious now in a way he never had before. Pre-stroke, he was a gregarious person who reveled in making provocative jokes and comments. But staff had told him that “lack of filter” is associated with injury to the particular area of the brain affected by his stroke, so now he struggled to distinguish between behavioral impulses that would have been normal for him, and disinhibition caused by the stroke. Now that he was aware people might view him as disinhibited due to the stroke, he was second-guessing jokes and comments he felt he wouldn't have worried about before. As he explained:

> They were wondering if through the stroke, I lost control of my inhibitions ... and in reality, because they said that, I've put a filter on. I've started controlling my compulsions. And I resisted my impulses. And my inhibitions have never been higher. Because if they knew me before? Yeah, they wouldn't be worried about filters. (stroke, White, male, inpatient)

He was all right with being viewed as brash and irreverent before, when those behaviors were part of him, part of his personality. But he didn't want those same types of actions to be construed as the effects of brain injury, a sign the stroke had changed him. So he put greater than usual effort into self-monitoring.

In many cases, once patients regained a baseline level of insight, they had to systematically relearn self-awareness.[33] The process involved the tutelage of the therapists and interactional feedback from family members who had to learn how to consistently but kindly call attention to behavioral changes. In some cases, patients believed there was nothing different or inappropriate in their behavior, but as they received negative feedback from others and began to notice tensions in their relationships, they could regain the ability to self-assess.

Regrettably, this section focused on family more than patients. In many cases, behavioral change was accompanied by lack of insight, so patients might not acknowledge change or agree that their behavior was a problem. Meanwhile, family members grappled with the disconcerting

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[33] See *Speech: Pragmatics.*

difference, a loved one who seemed to have been replaced by an imposter. Staff helped family contextualize what was happening and cope with behaviors as best they could. When patients regained insight, they often learned about their agitated behavior secondhand. These tales of misbehavior were unsettling (and often embarrassing) for patients; patients felt ashamed by, but also distant from, this reported version of themselves, the Mr. Hyde that temporarily supplanted them.

As patients progressed in recovery, they worked to gain awareness of lingering changes. Often, as discussed in Chapter Four (Shifting Relationships), patients were most acutely aware of their behavior when they could see its impact on the people around them (e.g., loved ones recoiling from bursts of anger) or noticed its negative impact on their own lives (e.g., distractibility causing them to leave jobs partially finished). In many cases, however, patients talked about behavioral change as a bizarre phase they passed through, a period of absence during which they had no control and recorded few memories.

Mental Change

As alienating as it could be for patients to feel their bodies were handled like objects or to experience a body part as foreign or frustratingly uncooperative, it was perhaps all the more unsettling for patients to feel damage to the brain had caused mental change, such as disruption to their ability to perceive and understand reality and to present (and experience) themselves as reliable, rational subjects. People with minimal (or no) mental changes, such as Connor, were relatively rare among stroke and TBI patients. In those cases, despite profound physical and even emotional changes, it seemed easier for patients and their families to separate the changes from the Self. As Emilia, Connor's wife, put it "From the very beginning, his family—we all knew that

Connor was still Connor." From the start, it was evident that Connor was "in there," his mind and core Self embedded within the altered body. In many other cases, however, patients dealt with changes in mental characteristics—such as memory, perception, judgment, and cognition—and in the process, came to experience the Self as unreliable.

Memory Disruption and Lack of Insight

Many patients experienced disruptions in their personal histories and sense of time, including forms of amnesia. Post-injury patients were often confused and disoriented. In this state, they could forget facts that seemed like essential self-knowledge, as this patient's wife explained:

> Watching him go through—and he remembers none of this—the waking up, the not knowing who he was. Then, you know, a few days later knowing me, and then you know, didn't know our children, didn't know he had children, and all these little things (wife of TBI patient)

In my interview with this patient, he talked about his children a great deal; it would be an understatement to say they were important to him, central to his life and how he saw himself, as a father and family man. But in the midst of post-traumatic amnesia, he had forgotten they even existed.

Patients coming out of post-traumatic amnesia often had to be convinced of the reality of recent events. Many patients only “knew” an accident had occurred because someone they trusted showed them photos of their damaged vehicle or pictures of them unconscious in a hospital bed. In one case, a patient had been riding motorcycles with his friends, and his accident was captured on a GoPro camera. He had the eerie experience of watching a video of himself being injured, knowing he would probably never regain his own firsthand memories of the accident or the days that followed.

In the grip of post-traumatic amnesia (PTA), however, patients often rejected others' accounts of what happened, even if they themselves had no accurate memory of events, as this interaction illustrates:

> The doctor and nurse practitioner find the next patient in the hall. He's still in PTA, but he's physically mobile, so he wheels himself around the ward.
>
> Nurse practitioner: *Do you know why you're here?*
>
> Patient: *My wife told me to be here.*
>
> Nurse practitioner: *So, you're here for rehab. You were walking your dogs and fell and hit your head.*
>
> Patient [skeptically]: *Hmmm.*
>
> Floor nurse: *It's true! Why would we make it up?*

Patients in PTA were often disgruntled about being in the hospital; this patient seemed complacent in this interaction, but he often wheeled the halls asking everyone he met to direct him to the nearest exit. Often patients were angry and frightened to find themselves in an unfamiliar place for unknown reasons. This patient knew he was somewhere unfamiliar, but he wasn't clear on why, other than that his wife said he had to be there. Like many patients, he also confabulated, filling the gaps in his memory with whatever felt plausible.

As in this example, staff tried to gently orient patients by reiterating a simple, factual account, whenever they interacted with the amnestic patient. In some cases, doctors showed patients medical imaging to lend authority to their version of events. As one doctor explained, "If they're constantly fighting me that there was no nothing, they just broke their leg, and it was—everything is fine up there ... [I can show them] okay, well, this is where you bruised your brain." As with photos or videos of an accident-damaged vehicle, it was harder to deny this kind of concrete proof.

Patients who were completely “lacking in insight” often appeared not only unaware of their condition but entirely untethered from consensus reality. In some cases, patients later remembered these periods of confusion from a more lucid perspective. Scott, a stroke patient, had vague memories of how his grasp on reality shifted over time and across settings:

> And they put me into a medical-induced coma. Which was wild. I tripped like crazy. Thought I was working on a tropical cruise ship. Which I wasn't. And I hallucinated that I had—or I had imagined that I had developed these friendships with all these people on a cruise ship that never existed. And then I got to the [rehab] hospital, and I was convinced that the cruise ship was parked in the lake. And that it was a hospital Disney cruise ship or something ... and I was just convinced of certain things that—convinced that my children were in danger, and that I had gotten a threatening text. And so we were in the hospital. And soon as my family left the room, I like shot up. And I was just hunting through my phone to try to find the email or text to confirm that was happening. And of course, I was terrified and trying to address that immediately, but only to find out that that too was imagined and fake.... Soon after that, I was talking to my wife and my parents and they helped kind of piece together my memories because I could not remember anything that had happened. (stroke, White, male, inpatient/outpatient)

Scott remembered trying to make sense of his situation and cobbling together a distorted version of reality, but many patients had only fragmentary memories of these periods of delusion, if any memories at all. Family members were the primary historians, for themselves and patients. Seeing patients in this state of unreality could be unsettling, and as previously discussed, family members often wanted to try to anchor their loved ones back in a shared version of reality.

Loved ones also worried that patients, in their confusion, might do irreparable damage to their personal and professional relationships. In many cases, families temporarily confiscated patients' laptops and phones because, left to their own devices, patients were prone to making incoherent calls or sending unprofessional emails. Patients could also put their own physical safety at risk if they forgot about mobility and balance changes or were unable to recognize that they needed help.

This lack of awareness could be dangerous and could set back healing. One patient described a period of time in which she couldn't retain awareness of her physical condition:

> And the other thing is, I was so thirsty. I'll never forget that. All I wanted was ice and ice water. Like I was waving people in from the hallway to try to find me some water. And they'll be like, I can't give you water. Because they didn't want me to get pneumonia. And it turns out I had a tracheotomy and I had a feeding tube. I don't know. And I was also on a ventilator. All kinds of—all kinds of bad stuff. (stroke, White, female, outpatient)

Another patient shattered his leg and sustained a TBI in a workplace accident. At the acute hospital, he was kept on an orthopedic ward, not a neurology ward. His rehab doctor speculated that on the orthopedic ward, they were less attuned to how closely TBI patients have to be watched and perhaps not equipped to provide the level of supervision this patient required. Because he was agitated, disoriented, and lacked insight into his condition, he further damaged his healing leg because he couldn't remember to keep weight off it, as his wife described:

> And that was in fact, the reason he had to go back and have that second surgery. He did that to himself. But he didn't know, you know, he was to put no weight on it ... so he was walking on that leg when he wasn't supposed to, you know—because he didn't know he wasn't supposed to. His brain was not getting it ... I mean, I would see him stomp his foot because he was so mad. He had a cooling blanket, and he would break that. He broke it, banging his leg against that bed because he didn't understand his surroundings. (wife of TBI patient)

A few patients were later able to remember and recount what it was like to go through the process of learning to doubt their own memories and having to trust outside evidence over their own internal sense of reality. Finn,[34] for instance, had been in a motorcycle accident, and he recounted his initial confusion and disbelief and his dawning recognition that his version of events deviated from the truth:

> And I went to [inpatient rehab]. This is my first cognition that anything was going on. Immediately, I rejected—they said, you've been in a bad accident with your motorcycle. And I was like, There's no way. I know why that was. I had had a dream. Because somebody had said to me, it's motorcycle related. Somebody said that, and it stored in my subconscious.... So that's when I had like a dream where I saw my motorcycle in the garage,

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[34] See *Finn's Rocky Day Rehab Transition.*

> and I was convinced that it was in the garage. And that my—there was no damage to my motorcycle and that. So I said, unless I got a new motorcycle or a different motorcycle, I'm pretty sure my motorcycle is in good shape. And it's sound, and there was no accident. So I convinced myself there was no accident. At all. And I didn't know what was happening to me. I assumed the worst nefarious thing. That some bullshit was going on, and that I was on the receiving end of it. Then my brother-in-law, as I was awake, and I was able to understand, he said, no, this really did happen to you. And so it was him telling me it, that I started to say, to myself, what about this dream, this experience I had with handling the handlebars of my motorcycle and seeing it in the garage, and that it was okay? I said that must be false. It has to be false. If what he's telling me is true, then, this is something that I engineered in my brain over this event. So that's when I said, I'm tricking myself here. If he's telling me that this really did happen. And he went through all the details of it. And I was in a position to where I couldn't say no, that didn't happen that way. He went with the police, he got the accident report all that stuff. The idea that the other driver was given a ticket, all that stuff ... so that I had to then accept that I put some veil over what had really happened to me, and I was inventing things in my brain. And that I was acting as if those things were reality. That's what woke me up, to where, I now have to be very careful. And I have to begin to figure out, how do I methodically determine what is true input and what's not? (TBI, White, male, outpatient)

Finn's experience was fairly common; he had been confused and agitated when he arrived at inpatient rehab, and he thought he was being lied to and kept against his will for nefarious purposes. It took time and objective evidence, delivered by someone he knew and trusted, to convince him to accept a new version of events. The realization shook him. It introduced the possibility that he could "trick himself," that his brain could cause him to believe falsehoods that felt true. He knew he had to find a way to "methodically determine what is true input and what's not" because it had been made clear that he couldn't count on his ability to discriminate fact from fiction.

Many patients, TBI patients in particular, lost weeks to months of time. By the time they were capable of consenting to be interviewed, they generally knew the outline of what happened to them, but their memory consisted of fragments or flashes at best. They reconstructed their own histories from medical accounts and family narratives. This interaction demonstrates how patients and staff talked about the absence of key memories:

> G says he has no memories of the time around the injury.
>
> “You will not remember those—it will not come back,” the doctor says. The doctor says, during that time, “you’re awake and alert, but your brain isn’t laying down new memories,” which can be confusing for some patients and family. He explains that nerve cells in the brain, when they get shaken up or disrupted, won’t remember.
>
> G’s wife says she wants to understand what happened in the accident, so it’s frustrating that G will never get those memories back. He was alone on the dirt-bike track at the time of the incident, so if his memories will never return, they'll never really know what happened.
>
> “In the meantime, let’s look forward," the doctor said.

G later repeated the doctor's framing in our interview, saying his "brain wasn't essentially laying down new memories" (TBI, White, male, inpatient) in the aftermath of the injury. This concept helped him wrap his head around the idea that the brain could be experiencing but somehow not recording. It was bizarre for patients to hear accounts (and see photos) of themselves during periods of time they couldn't remember. Patients reported having seen photos of themselves with their eyes open, apparently aware, at stages of their recovery they could no longer recall. Family members told them stories about how they interacted, carried on conversations, and recognized their loved ones during these memory blanks.

It was odd for families to realize a patient had no shared recollection of these interactions, but it was perhaps stranger for patients to think about who they were during this lost window. It was bizarre to think about who they had been while they were, as one man put it, "walking this earth with a clouded brain" (TBI, White, male, inpatient). They couldn't remember being that person, so who had that person been? Who had been "at the wheel" for that period of time? It was helpful to be able to think of it as a recording error: they had been there, experiencing, but their memory apparatus wasn’t running, wasn’t “laying down new memories.” Patients also talked about the uncanniness of having "lost" chunks of their lives. As one man explained:

> I don't remember the hit. I don't remember going down. I'm just assuming as soon as I fell over, I hit my head. [The other driver] could have killed me and I wouldn't have known it … it was like three months was taken out of me. And then it's like, Wake Up! Now survive today's world! I'll get over it. Through time. But it's just a lot to take in. (TBI, White, male, inpatient)

Part of their life experience was permanently cut off from the continuity of their personal history. Another patient said, "I felt like there was a piece of me missing" (TBI, White, male, outpatient). In cases where patients were also aware they had been delusional or confabulating, it could feel like the missing memory had been, at least temporarily, replaced with a fiction. As this patient also explained, in the place of the “missing” span of time, he "had conjured up for myself an impossible memory."

Patients were often aware the missing piece was a traumatic event that changed their lives for the foreseeable future. Some patients framed the loss of traumatic memory as a mercy. But it was also odd to have such a crucial period of your life accessible only through secondhand accounts. Many patients had horrific stories to tell—a car running over their left side or nearly bleeding out in someone's arms. But though the stories were their own, they had no direct access to them, as this patient described:

> You have to take the front of this door off with the overhead crane. And it weighs—if I was to guess the weight, I'd say it weighs about 10,000 pounds … it's bigger than this room. And it's about five inches thick, and that thing's steel … and [my coworker] was moving the door out. The pins gave out. All I heard was a boom. So when I turned around, the door was falling towards me. So I started running backward. And then I turned around and that's when it got my—I turned around to see it and it went right here. And then I stepped back. And that's when it busted my leg in half. And then it snapped me back. And that's when I hit my head on the iron beam. That's all I know. I don't remember—I don't even remember being there that day. And I think it's because of my head injury that I don't remember that because usually I remember everything at the job, you know. So that's what happened. And I don't remember any of it. But that's—the guy that was there—one of the guys that was there, told me that's what happened. (TBI, White, male, inpatient)

It was hard to sort false memory from true, your own memories from eyewitness testimony. For instance, this patient said, “all I heard was the boom.” Did he retain a sense memory of hearing "the boom," even though his recollection of the accident and the days surrounding it had been wiped out? Or was he just imagining how it would have been, based on what he had been told?

In some cases, family members described weeks of complicated and painful medical procedures in the aftermath of injury. Patients and family alike were often glad patients "slept" through these periods and retained no memory of emergency surgeries, gruesome wounds, or how close they had come to dying. Staff, patients, and family all suggested that family members, in some ways, carried more trauma than patients because they had intact memories of the patient on the verge of death or lying unresponsive or agitated and distraught, in the grip of post-traumatic amnesia. As one staff member put it, family "didn't have the luxury of checking out." Patients often felt guilt at having subjected loved ones to difficult experiences they themselves couldn’t remember. In some ways, it felt like shared trauma because the patient's body and brain bore the scars, but the family carried the memories.

While many patients lost segments of their past, some also experienced ongoing impairment to short-term and working memory. Of course, due to the nature of the problem, patients weren't always aware it was happening. As one patient's wife explained:

> We talk every day on the phone. So a lot of it is me repeating myself. You know, things we just talked about the day before. So there's a lot of that. He's very excited to tell me things that, you know, he's already told me, but he doesn't know it. (wife of TBI patient)

But as insight returned, patients often found memory lapses acutely frustrating and socially embarrassing. Patients worried about how they came across in social interactions—whether forgetting names made them look careless or impolite and whether repeating themselves in conversation made them look impaired or unintelligent. It’s a peculiar and vulnerable condition to know your memory of every interaction is suspect or that you don’t remember people who remember you. Patients struggled with the knowledge that other people had access to information about them and their history that had slipped their own minds.

Altered Perception

Patients also learned they couldn't necessarily rely on their own perceptions. In the process of rehab, patients had to accept and adapt to these perceptual gaps. As previously discussed, stroke patients particularly might experience hemineglect; in the bodily change section, I discussed the experience of recognizing (or failing to recognize) inattention to a part of one's own body. But hemineglect often extended beyond the body itself. Therapists set tasks intended to call attention to what the patient was disattending. For instance, patients with hemineglect were often asked to circle all instances of “the” in a paragraph. The patient generally missed quite a few along the "neglected" side of the page. The speech therapist would then point out which ones they missed and ask them to go back and try again with a different word, using a new strategy. They might, for instance, draw a bright line down the neglected side of the page, to draw the patient’s attention.

Patients had the odd experience of becoming aware of gaps in awareness. It sounds like a paradox: to be aware of that of which you are unaware. But patients were often tasked with exactly that—they had to bear in mind that their brain was systematically missing things and remember to compensate. Understandably, patients found the experience surreal, as this woman described:

> It still freaks me out a little bit. It amazes me. Like, I was in a session a couple of weeks ago. We had to be in there about ten minutes, sitting around a table, and we all had to say stuff about what we did over the weekend. And then somebody came in, like maybe [the psychologist] to pull out somebody for something. I didn't even know [the other patient] was [there]. I said, how long have you been sitting there? I was like, where the hell did you come from? And apparently, he was there the whole time. And we all spoke, and he spoke. (stroke, White, female, outpatient)

This woman's cat was also taking advantage of the situation:

> If I'm eating breakfast in the morning or something, I have a cat that knows to come on my left side. So he jumps on the table, he comes on the left, and he steals my food. So I look—I know to look, in the morning when I'm—anytime I'm eating, I have to look and make sure he doesn't—because I won't know. Even if I'm watching for him. (stroke, White, female, outpatient)

As this woman described, the problem wasn't strictly visual. When the person sitting to her left was pointed out, she could see he was there. But left to its own devices, her brain would gloss over him, fail to notice him, or forget about him, even if he was speaking. Similarly, even though she knew to watch out for the perfidious cat, she sometimes had her food stolen from her plate. Her brain didn't register objects on her left, and even though she was aware of the issue, sometimes she would forget to remember.

Many patients experienced spatial disorientation, of some kind of another. As previously discussed, patients in post-traumatic amnesia were often confused about where they were. Patients also misperceived the spatial positioning of their own bodies; for instance, feeling like an ankle was badly twisted but looking down to see their foot sitting flat on the floor. Other patients, particularly elderly patients with vision problems, experienced hospital delirium in some form or another, becoming confused and agitated by the unfamiliar, institutional space they could only hazily perceive.

Patients and their loved ones also talked about distortions in perception of time. Staff and family often took the brunt of patients' confusion and annoyance when patients felt they had been waiting for help or working on a task for much longer than they had been, in reality. The neurological problem was often compounded by pain and boredom. For instance, many patients were supposed to sit up in a chair for periods of time to prevent deconditioning. It was also inconvenient (if not impossible) for nursing staff to put patients back to bed during short breaks between therapy sessions. Not only did staff want to avoid spending several minutes transferring the patient into bed, only to have to get them up again, but they also wanted to ensure the patient was ready when their next therapist arrived to avoid a disruptive delay. This issue was a frequent point of contention between staff and patients, and it was exacerbated by patients' perceptions of the passage of time. Patients might have memory and/or perceptual problems, and those cognitive distortions, coupled with how slow time seems to trickle by when you're uncomfortable and bored, meant that patients often believed they had been left sitting for intolerably long periods.

This sort of confusion could also foster resentment toward caregivers. Family members told stories about having explained to a patient why they had to leave and how long they would be gone, only to come back and find that their family member had forgotten their explanation and thought they had been missing for hours or days. In some cases, patients themselves talked about how their experience of time was altered, as Finn did here:

> You're gonna have these various kinds of things following a traumatic brain injury that play with time. That you are going to have to get used to. That time may be different for you. The duration and the elongation of time may need to be adjusted from what you previously had thought.... Oh, time right now seems like it's going very well. I mean, we—I'm able to stay abreast of it. I know, early morning from late night. We had a time change, just recently. I was very up on that ... but I know that going forward, there may be adjustments ... that the chemistry of my brain with its injury is going to maybe play tricks on me with time and that I'm ready for that. (TBI, White, male, outpatient)

Finn highlighted several common themes—the sense of temporal displacement and the struggle to be “up on” what’s going on. He also explained that being out of one's habitual environment and routine exacerbated the feeling that time was out of whack. Patients lost many of the usual markers by which they measured time's passage over the course of the day, week, or season. While inpatient, other people set their schedule, told them when to get up, and came to collect them for appointments. Time moved strangely and the customary guideposts had been removed. Finn felt like he was now "abreast of" things like the end of daylight savings time, but he was also aware that, due to his brain injury and the changes that followed, he couldn't always rely on his own perceptions of time.

The Untrustworthy Mind

As patients begin to recover, the return of insight could be unsettling and painful. Like Finn, some patients were wary that their brain might be playing tricks. Some patients became concerned about what they didn't know they didn't know. As they became aware that their memories or perceptions had been (and might still be) altered, they began to view the Self as potentially unreliable.

As awareness of the scope of their problems increased, patients could experience frustration and/or a dip in mood. They could also feel a sort of existential terror, a fear that they had lost the ability to distinguish real from unreal. As a patient's wife recalled:

> He said, I've been hallucinating; it's so bizarre. He goes, I've been seeing people in my room.... He was like, Betsy, she was here with the kids. And I was trying to get her to talk to me. And she kept looking at me. And she wouldn't talk to me, and I thought she was mad at me. And I'd shut my eyes. He goes, and then, like a little bit later, I'd realize Betsy wasn't here. I'm just—I think I'm making this up. I think I'm hallucinating. He knew it ... and then he would talk like, Hey, Jeff, you got to square that off. You've got to do that. Or everything's gonna be a mess. This job isn't going to be right, Jeff. Jeff! And then I'd say, Honey, Jeff's not in the room. Look, it's a rain day. Construction's not happening today. Jeff's not here. And then he'd say, Oh, okay. And a little bit later, he'd go, Jeff, Jeff, fix that! You know, so I could bring him out of it. But then he would go back in it. (wife of TBI patient)

As another patient framed it:

> Your brain is the thing in your world that tells you what's wrong. So when that is interrupted, you have no way of understanding what's working for you and what's not working for you ... because it's injured, it's not going to be able to tell you what's wrong. And [the staff is] here to help with that. [They'll] tell you what's wrong. And then [they'll] give you avenues to work on that. (TBI, White, male, outpatient)

In the process of recovery, patients confronted the idea that they could no longer trust their own perceptions, even insofar as determining what was or wasn't wrong with their own bodies and minds. Patients had to trust and rely on external perspectives. In many cases, patients' judgment had been impaired, along with their alterations in perception, so they had to accept the substitution of others' judgment for their own faulty judgment.

Impaired Judgment

Staff had to tread carefully in pointing out judgment deficits. Patients could learn to identify holes in their reasoning and gaps in their judgment, but it was difficult to point out these flaws in a way that wouldn't be construed as insulting. Speech therapists dealt with reasoning and judgment, setting patients logic puzzles and running through hypothetical scenarios. For instance, a patient with severely impaired balance (as well as judgment) might be asked “What would you do if you were home alone and the doorbell rang?”[35] The therapist would then provide feedback on the response, pointing out, for instance, that a patient with mobility problems should perhaps call for someone else to answer the door, rather than trying to jump up themselves and risking a fall. Through these exercises, patients were forced to review (and encouraged to come to terms with) the evidence that their judgment was no longer reliable.

Patients' ability (or inability) to judge risk was, for obvious reasons, a frequent topic of discussion in the inpatient setting. The following scene illustrates how staff confronted judgment problems:

> On morning rounds, the doctor reports that Mr. Y took another fall. The resident says he's not surprised. "Yeah, but it shouldn’t happen,” the doctor says. The biggest worry, he explains, is when Mr. Y goes home and isn't under staff supervision. The doctor says these falls happen because people are used to being independent. They may try to get up out of habit. They may also think they can do more than they actually can.

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[35] See *Speech: Pragmatics.*

> The resident says they'll have to talk to Mr. Y about being more aware.
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> When they bring the fall up, Mr. Y says the fall was "more my fault." He says he's fallen three times this week and that these socks don't grip. Mr. Y says he was lucky he fell on his "behind," but that he did hit his head a little. The resident asks, "Why do you think you keep falling?"
>
> Mr. Y concedes that, the first time he fell, he was dizzy. But the second time, he says, it was because of the socks. But "it was my fault," he says. "The ladies" told him not to try to stand by himself, and he did anyway.
>
> The doctor says, "So Mr. Y, our biggest concern is what it will be like when you go home … with the stroke, your judgment is probably off. Just a little." He says, *You seem like a really bright guy, so you probably recognize your judgment may be off.*
>
> Mr. Y says he wishes he were strapped into his chair, so he wouldn't be tempted to stand.
>
> When we leave, the resident suggests they find a PCT to buckle Mr. Y's wheelchair belt. The doctor tries to find Mr. Y's nurse, but the nearest nurse says she isn't assigned to Mr. Y. The doctor says, "Well, his seatbelt's not buckled, and he's already fallen twice."

In this case, Mr. Y was fairly cooperative. He didn't push back at the suggestion that his judgment was impaired, and he agreed that it was in his interest to have his movement restricted, since he wasn't certain he'd be able to stick to the safety rules. But the doctor was also careful to rhetorically separate Mr. Y's impaired judgment from Mr. Y himself. Staff generally framed lack of judgment as a problem emanating from the injured brain. Staff often took pains to emphasize that the patient's intelligence was not being called into question and that pointing out a defect in reasoning wasn't equivalent to impugning a patient's intellect.

In many ways, rehab encouraged patients to make finer distinctions between different mental skills and characteristics. Patients might learn to recognize that memory, concentration, reading comprehension, etc. could all be intact, despite deficits in other mental skills. Scott described one lingering area of concern:

> I think the biggest cognitive problem I would have was like, my parents would come over periodically, and they'd be like, you know, they'd want to eat dinner with us. They would pick up dinner. They would ask me like, what should we get? And in my mind, like, I want

> something that everyone's gonna like. My dad's really picky ... but my wife likes to eat very healthy. And I do too now. So that was making that decision so much harder. So I would have panic attacks because I knew they'd be on their way over and I'd have a limited window of time to figure out dinner for everyone, something everyone's gonna like. I was panicking, constantly. (stroke, White, male, inpatient/outpatient)

Unlike many patients at his stage of recovery, Scott had returned to his job. He was able to work as a computer programmer, and in many regards, his cognition was intact. But he found himself melting down when asked to make decisions that required him to bear in mind and reconcile multiple competing preferences, under time pressure. Scott sought out more speech therapy exercises that targeted deductive reasoning and critical thinking, in part, because he recognized these areas as distinct from other areas of mental performance. He knew he was still an intelligent person, but he learned to differentiate the specific ways in which his mental functioning had changed.

Cognitive Change

Many patients saw cognitive change as especially discrediting. It was painful to have one's reason called into question, to be seen as cognitively impaired or diminished. In some cases, patients found themselves struggling to perform tasks they would have found trivial before, the cognitive version of going to take a step, assuming your body would be there for you as it always had been, and feeling your legs give out. As a stroke patient put it:

> I couldn't read. I couldn't like—like everything is like—shaking like and—and then trying to write something or type something was just incredibly painful. And like memory was just like—the short-term memory, just like gone ... I kind of joke, but it's almost like you fried your brain out like from doing too much. (stroke, White, male, outpatient)

This sort of sudden, profound change was instantly noticeable, and immediately alarming. But in other cases, patients only became aware of cognitive change when confronted with structured tasks in therapy. As a TBI patient's husband recounted:

> [She] thought at the beginning—like she thought that everything was fine with her. And my daughter and myself we noticed that no, there is something with her brain. She talks differently. Like a child, if you wish. Like repeating stuff and get stuck in some objects, some ideas, and repeat them several times a day. So we definitely noticed that something is not right. But she kind of—she thought that everything was fine. And then [the therapist], for the first time she saw her, she gave some stupid tests, like drawing this clock and put numbers and put hands to show ten after ten, or something like that.... She eventually did it, but it was so painfully slow. And with the hands, she even started mixing it up. And then eventually she did it, but it was painful to watch. And then she understood that yes, something is not right ... because—it's one thing to notice that something is not right, versus another thing completely when you just see that, you know, such a simple task took her five minutes or so. (husband of TBI patient)

The fact that the task seemed so trivial heightened the patient's alarm. There was no way to excuse or explain her performance; under any normal circumstance, she should have been able to draw a clock face signifying a specific time. Some patients found speech therapy especially unpleasant, for just this reason;[36] it called attention to cognitive changes that weren't apparent under other circumstances. A patient might feel more or less “normal" when sitting, chatting, and reminiscing with visitors. But when given a spatial logic task or a working memory challenge, the patient could become painfully aware that a “stupid test,” something they would never have doubted their ability to do, was now intensely difficult.

As with calling attention to diminished judgment, staff had to be careful in how they presented these sorts of cognitive changes to patients. As a speech therapist put it:

> I think one of the hardest things for patients to accept is like a cognitive diagnosis. And I'll get things like, "I'm not stupid." And I'll always say, oh, I don't believe that you're stupid. My very first cog patient that I ever had in my entire life is now a NASA scientist. That man is infinitely smarter than I probably could ever imagine. Sometimes I always say like, I worked with people who are way smarter than me. (staff, outpatient)

Therapists took care to distinguish between intelligence as a global concept and specific cognitive skills as applied to particular tasks. Even so, patients' attempts to save face often got in the way of the therapeutic program. A TBI patient's wife noted that he attempted to redirect

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[36] See *Speech: Cognition.*

conversation, changing the subject or pivoting to trying to teach the speech therapist something he knew well when confronted with a failure that highlighted his cognitive change. Speech therapist after speech therapist told me something along the lines of, "I'd be a billionaire, if I had $1 for every time a patient had a reason why they couldn't potentially do something" (staff, outpatient). Many patients reacted to evidence of change by trying to explain it away.

Patients might point to a situational explanation—they hadn't gotten much sleep last night or they were distracted by construction noise outside. They might also try to invalidate the task, claiming it wasn't something they cared about or would normally bother to do (e.g., I don't have a problem with my memory; I just don't care about remembering that). A common patient tactic was claiming they would never have been able to perform the task in the first place. This TBI patient exemplifies that view:

> I didn't care for school too much. That's why I was an ironworker. So, my academics ain't all that great.... Speech [therapy] is all right. They're just trying to make you use your brain a little bit more, which is fine. [laughs] Haven't used it in a long time. I mean I can build you a building. I know my job. I can read the prints and stuff like that. But, you know, you give me a three-page letter, I probably got to read it three, four times to understand it. Try to understand it. Comprehension never was good with me. I gotta physically see it to do it. (TBI, White, male, outpatient)

This patient downplayed his formal intelligence and highlighted other aptitudes. He was self-deprecating, but also clear that he had certain areas of cognitive strength; they just didn't happen to lie in areas covered in speech therapy. Therapists were cognizant that patients varied widely in "pre-morbid ability," but patients often used the "I was never good at this" excuse to a degree that stretched the limits of plausibility. In these cases, therapists had to point out that even if you weren't "good at math" before, you were probably able to perform simple operations like tallying up a bill.

Many tasks in therapy tried to mimic "real world" activities (e.g., making a schedule or splitting a check), but often, patients had no real benchmark for how well they would have performed in a certain capacity before. As this patient's wife described:

> There was one time the therapist was in the room doing speech therapy with him. And she said, I want you to do some rhyming words. So the word is cat. And he said, kitten. And she said, No, *rhymes with* cat. And he said, kitten, lion, tiger. And she goes, that's the category. Those are all in the same category. We're talking about rhyming. So she goes cat, bat. And he goes, Oh, mat, fat, sat. And she goes, yes. But then she said, rhyme with tick. And then he just looked at her ... and then he said [to me], Was that easy for you? And I said, Well, you know, there was just a lot involved with it. I said, you'll get it. But I thought, Yeah, of course. It was extremely easy for me. It would be easy for your granddaughter. But, you know, you don't say that. (wife of TBI patient)

In these cases, it might not be immediately obvious to patients that a task should have been "extremely easy" and was presumed to have been easy for the patient pre-injury. As in this example, patients often turned to the people around them—family, therapists, even me when I was observing—to ask for this sort of validation. Would this be hard for you, too? Is this objectively difficult or is my difficulty with this task evidence of cognitive change?

Many patients also reported feeling generally “foggy” or “slow," and this sense of hampered cognition was strongly associated with complaints of not feeling "like myself." For many patients, symptoms like diminished cognitive endurance or concentration lingered for the long term. Many patients were acutely aware of a decline in mental acuity, loss of their ability to multi-task as they once had, or a sense that their reasoning faculties were impaired. Even patients who were on the upper end of the cognitive recovery spectrum noticed and were frustrated by these sorts of changes, as this TBI patient expressed:

> The only thing is—I think, I mean, well, I know that I need to take more frequent brain breaks. The only thing I've noticed is that if I'm concentrating on something really hard for several minutes, I get more tired, my brain gets tired, more than it would have. I mean, typically, you know, I've been working at home for the last two years. So yeah, I would sit there, and I'd be working on something, and I'd get so ingrained in it, you know, I'd be like, oh, I need to get up in ten minutes to get something to drink. And three hours would go by

> in the blink of an eye. And I'm like, Oh, I meant to get up three hours ago, you know? And I just—right now, I don't think I have that stamina. (TBI, White, female, inpatient)

As discussed in the identity section, patients whose role performance or identity were closely tied to elite mental ability were especially vulnerable to hyper-monitoring differences in cognition, but regardless of degree of identification with cognitive skill, patients noted and were frustrated by increased brain fog.

For some patients, the problem was more subtle: they felt the same as always, but they knew their brain had been damaged, so they were aware there were likely differences they didn't notice. One TBI patient talked about having been shown images of his brain—the bleeding and swelling, but also indicators of recovery. Objectively, he knew he had sustained brain damage, but he felt cognitively much the same:

> I seemed, and I think I feel, perfectly normal. You know, like, I wasn't acting erratic or anything. But it was like, a little terrifying for me, because she said that we don't know how it will manifest like, we don't know what—so I was just dreading like—maybe—I thought I didn't want to go home and—doing something that's completely, you know, that I didn't encounter. (TBI, Black, male, outpatient)

This particular patient was reading *Siddhartha* in the hospital, and neuropsych testing revealed only minor changes in areas such as working memory. But he had a fine-grained sense of his own mental acuity, and because he knew his brain was—he had seen the damage in black and white — he was concerned that hidden signs of cognitive change remained to be discovered. As previously discussed, many patients did, in fact, find that changes were thrown into relief once they were outside of the hospital environment, so his fears weren't unfounded. But in his case, it was more a matter of waiting for the other shoe to drop because he knew to expect a certain, impossible-to-predict amount of cognitive change.

Gary, another TBI patient, presented a similar dilemma. As he put it:

> In the back of my head, on the bottom, up on the top, and in the front, because my brain—[the accident] busted my skull, and it smashed my brain and pushed my brain forward, and my brain pressed against my forehead.... But they keep saying that I got four areas of my brain that was damaged. But I don't feel any different. I don't forget anything. You know? I'm not any smarter than I was before the accident. But I don't think I'm any dumber either. (TBI, White, male, inpatient)

Even though he accepted the evidence of brain injury, the medical record was difficult to reconcile with his subjective experience. In his case, other people noticed changes, of which he was unaware. As his wife explained:

> At first, he was still more fixated on the leg, what he could visually see was wrong with him. So he wasn't comprehending. He still, now even, says things to me ... he doesn't feel pain in his brain. You know, he doesn't hear voices, he says, and he doesn't see weird things. And he goes, and I don't feel like there's anything wrong there. Because he doesn't, feel it or see it, like he does his leg. So he has to kind of be reminded. (wife of TBI patient)

His brain injury wasn't visible and wasn't causing him physical pain and discomfort like his injured leg. He wasn't experiencing the types of symptoms he associated with "brain damage," like hallucinations. He had been through post-traumatic amnesia, agitation, and disorientation, but he couldn't really remember that period of time; he understood it had happened, but it was in the past, a past he didn't even remember experiencing. He also pointed to evidence such as his robust long-term memory, his ability to accurately recall details of events from years before, as signs that his mental faculties were intact. Gary's wife reported that he was still very much struggling with short term memory, but again, it was a difficult problem for him to recognize. While other people noticed that he repeated himself and failed to retain information from one conversation to the next, by definition, it wasn't an obvious issue to him because he didn't remember having forgotten.

Ultimately, he had to take his cognitive changes more or less on faith. He respected the staff, and he reconciled himself to the fact that they wouldn't keep him in the hospital unless he needed to be there. He was aware there were gaps in his awareness—cognitive changes that were evident to others, if not to him.

For many patients, it was upsetting to become aware of their incomplete awareness, and it could be all the more uncomfortable to realize that other people might notice (potentially embarrassing) things, of which they themselves were unaware. Are you speaking in a loud and uninhibited manner? Are you noticeably cognitively impaired? Would you know if you were? Patients talked about watching other people watching them for signs of change. They knew that difference was expected of them, and they were conscious of being monitored for changes. As a TBI patient said:

> I know [my family has] been scared. When I had a—a concussion or whatnot. So like, they're asking questions and stuff like that. I can tell that they were trying to discover how my brain was at the time ... it kind of worried me. Because I thought they were, you know, thinking about my condition, or what my thoughts were. And I didn't feel any different at the time. So it kind of worried me that they were thinking about what's going on in my head. (TBI, White, male, inpatient)

Many patients were aware of heightened scrutiny, and it made them self-conscious. Staff cited examples of patients who, in their awareness that people were on the lookout for cognitive changes, perhaps overcorrected. They might babble awkwardly, speaking quickly and rushing to fill silences, seemingly trying to demonstrate their undimmed intelligence. Patients were both vigilant for signs of change in themselves and aware that others might be monitoring them for changes as well.

Distinguishing Neurological Change from Other Mechanisms

Patients weren't wrong in feeling they were being carefully observed and assessed. Even for staff, it could be hard to discern how much of what they were seeing stemmed from brain injury and how much was caused by myriad other complicating factors. From a diagnostic perspective, several issues could make a case more confusing. When patients had aphasia, for instance, it could be difficult to assess cognitive change. Staff could err in either direction. As a doctor explained, if a patient was only able to respond to yes or no questions, staff members might underestimate their degree of awareness, mistaking a communication problem for a cognition or awareness problem. On the other hand, confusion could sometimes masquerade as aphasia, when in fact, the problem was not language impairment but an inability to string a coherent thought together.

Any number of medical issues could cause changes in mental status, unrelated (or indirectly related) to the original neurological injury. It's worth quoting the below exchange at length because it highlights the diagnostic complexities at play and how vigilant staff had to be:

> Attending physician: *If someone has acute mental status changes on a rehab unit—let's say they're somnolent, there are cognitive differences—what do you think? What do you do?*
>
> The medical student says you should see if there have been any medication changes recently. The patient might be reacting to a new medication. You should also look at the labs—check for signs of infectious processes; check for liver function. You should see if there's an environmental cause—start thinking about hospital-induced delirium.
>
> *Anything else you want to add?* the attending asks the resident.
>
> The resident says to check for intracranial problems, like a new bleed. She says to check on how well the patient has been sleeping.
>
> Attending: *Sleeplessness—that's a biggy. The first thing most people do is they freak out, which is not the thing to do. So this is why we're talking about what to do now. You have to be methodical. You give the patient an exam. You check for fever. You look for wounds. Yes, you actually physically examine the patient! In the old days, when we didn't have a CT in the building, we had to really think about whether the patient needed a CT scan because you'd have to drag the patient over to [the acute hospital]. Here, we just do it, to be on the safe side.*
>
> The resident adds that you should check blood glucose, too.
>
> Attending: *Yes. Immediately get blood sugars.*
>
> The medical student suggests you could get a complete blood count to check for anemia or a high white blood cell count, indicative of infection.
>
> Attending: *Patients don't read our textbooks. They don't know they're supposed to present with black tarry stools and emesis when they have a stomach ulcer. The symptoms may just be lethargy and the therapist saying the patient's not doing well today.*
>
> Medical student: *Low sodium?*

Attending: *Yes. A rapid drop could do it.*

Medical student: *Dehydration?*

Attending: *That's a common problem here.*

The resident suggests a transient ischemic attack could cause mental status change.

Attending: *Usually not an acute change, but okay. You got most of the possible options, except for one really important one. You should review the medications list. Polypharmacy is an issue with a lot of patients in this setting, and certain drugs and drug interactions can cause toxicity. You should get blood levels on admission. Always, if the patient is on a drug that can cause toxicity. You should get a urinalysis, obviously. You could also get a chest X-ray. The symptoms of pneumonia aren't always what doctors expect. Patients don't know they're supposed to present with a cough, like in the textbooks.*

When staff noticed cognitive symptoms, especially a change in the "wrong" direction, they had to explore a lot of possible explanations. Was it a symptom of the original brain injury or an emergent neurological issue, like a new bleed? Was it an interaction of the underlying neurological condition and a new stimulus, like fatigue from intensive therapy or an environmental change? Or was it any number of complicating medical factors?

When patients experienced "fogginess" or mental fatigue, they also struggled to identify its origins. They asked themselves, how much of what I'm experiencing is new? How much is a reaction to my situation? How much is transient, and how much is permanent? How much of what I feel is Me and how much is the brain injury? Patients struggled to construct a stable sense of Self, as their memory, perception, cognition, and judgment were called into question. It could be unclear to staff, families, and patients alike how much of what they observed was preexisting (like concentration difficulty caused by premorbid ADHD), how much was a reaction to present circumstances, and how much emanated from the injured brain.

In a way that was somewhat analogous to how patients felt about immobile limbs, patients talked about the uncooperative, unreliable brain. The brain would not oblige when presented with challenging tasks; it deserted the patient in their time of need. In some ways, this framing of the obstructive brain assisted patients in separating their Selves from the identity threat represented by cognitive change. Breakdown in cognitive processes could feel very close to a breakdown of the Self, as this patient suggested:

> My train of thought functioned, but like, everything else was just like, this gooey mess that I couldn't really, like piece together that well, in order to portray who I was, or like, what I was thinking. So it's like, I felt like I lost myself. But I was there. If that makes any sense. (stroke, White, female, inpatient)

When patients couldn't think clearly and/or struggled to present cogent thoughts to the world, it could feel equivalent to the disintegration of both one's internal image of Self and the Self one presented to others.

Patients were fighting a battle on many fronts. In many cases, they struggled to recognize changes that were evident to others, which could be both embarrassing and discomfiting. They worried about how changes—especially in behavior, cognition, and emotion—affected their ability to present themselves to others in a manner that suited their sense of who they were and how they wanted to be perceived. In some cases, they were told stories about themselves and their behavior, but they had no memory of that time period or that version of themselves. Patients also experienced self-alienation: their bodies might feel unresponsive or foreign; their emotions might feel untethered from events and out of their control; and their minds might feel clouded and unreliable. In many ways, the injured brain or the uncooperative body felt distinct from the Self. If patients could think of the changes they observed (and others reported) as emanating from the injured brain, they could alleviate guilt at their behavior and insulate the Self from stigma. "Blaming it on the brain injury" could, in some cases, preserve patients' sense of themselves as intelligent or kind or even-keeled people, despite changes in cognition, behavior, and emotion.

Connor's Story

Connor's stroke caused locked-in syndrome, temporarily depriving him of the ability to communicate with the outside world. For that reason, it seems fitting to relay his story, as he told it, in his own words. The following is an extended excerpt from my interview with Connor:

Emilia and I got married, and the next day I was dizzy. And I had double vision. Then the next day, I had tingling in my arm. And I was dizzy. The next day I went hiking with my sister because I promised her I would. And we went out for brunch. And I had trouble holding my coffee. That night we ordered pizza, and I had trouble signing for it. And we went to urgent care … [The clinician at urgent care] told me he wasn't worried. He told me, wait a night. We will see where it goes. If I'm not better in a few days, he said I should see a neurologist. He shrugged at me. He told me he doesn't think it's a stroke.

That night, I went to bed, and I had a stroke. I remember laying there, and when it was happening, I reached for my phone to call 911. I couldn't get it. So I—next thing I know, I can't move.

Interviewer: What did it feel like when it was happening?

Like my body was spasming, and I had no control. I wanted to call somebody. I wanted to yell out for help. But I couldn't talk. I couldn't reach my phone. I thought if I can just dial 911, even if I can't talk, they will come. But the night before, I asked my friend to check on me the next day because I knew something wasn't right.

Interviewer: And Emilia had just left on vacation? You were supposed to join her a couple days later?

Yeah. So I asked my friend to check on me. So the next day, I was lying in bed waiting and I heard my phone ring many times. It probably was my friend and Emilia and my parents. My friend knows that I always answer. So when I didn't, she was worried. So she came to my house and checked on me, and found me. And right away called 911. I don't know how long I lay there. I tried to hold my urine as long as I could, but I ended up wetting myself. All I could do was watch and listen.

So when the ambulance came, they actually thought I was on drugs. They thought I overdosed. My friend told them I would never. They didn't believe her. Then they actually asked her if she wanted to have them take me in the ambulance or have me drive with her. I couldn't go in a car. I don't know what they were thinking. So I was in the ambulance. They still thought I was overdosing, so they gave me Narcan. And I was aware, the whole time. But I couldn't do anything.

Interviewer: Does Narcan do anything, if you don't have opioids in your system?

No. It didn't affect me. But they tried. Then I got to the hospital. And they ran a lot of tests. They didn't know what was going on. I remember them cutting off my clothes. And they were very confused. And the room was very bright. They put all the monitors on me. They put a catheter in me. They intubated me.

Interviewer: And you have full memories of all of this?

Yeah. And I could breathe the whole time, but they thought I couldn't. So I had tubes all over. And my jaw was so clenched that it was biting my tongue. And they were worried I would bite off my tongue. They couldn't unclench it. They tried a lot of times, and they put gauze in my mouth to help. I remember when I finally let go my tongue was like a big wad. It was like a ball.

And every time I wanted to ask for help there was nothing I could do. I just had to wait for someone to notice. So one time I was laying [slumped to the side] for a long time. Someone even came and talked to me and gave me breathing treatment … and I couldn't ask them to bring me up.

Until we found a way for me to communicate, I was helpless. They call it locked-in, and it is very accurate. I feel trapped. I am helpless. Every time somebody left the room, I didn't know if they would come back and keep me alive. I didn't know if I was going to be alive or dead. But I had no say.

Interviewer: So you thought they might just decide to, you know, not keep you alive?

Yeah. I know they were having those conversations. The doctors said I would never breathe on my own.

Interviewer: But you could breathe the whole time?

Yeah. I knew I didn't need the trach. So I knew that it would come out one day. I knew… the doctor said I would never have any movement. He said I would be a paraplegic. I heard him tell Emilia.

Interviewer: So he told Emilia that while you were in the room?

Yeah. He said he's always an optimistic person, but even he had to accept that I would be paraplegic. My family knew right away that I was in there. They could see it in my eyes. Even when my eyes were—they were going different directions. But they knew. The doctors took about three days before they admitted that I was locked-in. I don't think they had ever seen anyone with locked-in.

…

Interviewer: And then, what was it like when you saw Emilia for the first time?

I actually thought—I thought she should leave me. I didn't want her to have a life of just looking after me. I didn't want to be a burden. I wanted her to have a full life.

Interviewer: Did you tell her that?

Yeah.

Interviewer: What did she say?

No. [laughing]

…

Interviewer: So you said they finally figured out a way you could communicate. What was that process like?

Well, at first it was one blink for yes, two blinks for no. But I didn't really have control of my eyelids, so they thought I was saying no a lot.

…

I knew I wanted to be alive. When I was lying in bed alone, there were times when everything went black, and I thought, if I let it stay that way, I will die. But I held on. And I stayed awake. And I knew someone would find me. So I waited. And I decided then, if I have the opportunity to die right now and I am choosing to live, then I will always choose to live. And I wanted to tell people that, but I couldn't.

Interviewer: So what happened when the doctors thought you were saying you didn't want to live?

My parents convinced them that I wouldn't say that. That I wanted to be alive. They knew.

…

At night, I felt really alone … Emilia couldn't sleep with me until maybe the ninth week … so I was alone. And at night, I had no control. So sometimes I [slumped over], and they couldn't fix it. They didn't know.

Interviewer: So what did you do to occupy your mind or to keep from being bored?

I stayed focused on the present. I try not to think about past or future. I didn't know how hard it would be to recover. I didn't know how much work. I thought I had to wait and, because my mind is totally fine, I thought my body would get there. I didn't know that I would have to work so hard. But now I know, and I am willing.

…

Interviewer: Did they explain to you what had caused the stroke to happen?

They have said that it was spontaneous. Nobody knows. I have accepted that. I think I wondered why, but now—it happened. I have to deal with it. So I will … they thought I might not live. They thought I would never breathe. They thought I wouldn't move. They don't know me. I will make sure I am better.

Three Perspectives

In neurorehabilitation, PCTs' work could be physically and emotionally demanding.[37] It was often stressful and exhausting, especially as the COVID-related staffing crisis progressed, and they were forced to operate short-staffed. The skill and finesse required to do the PCTs' job with this patient population was underappreciated. Nearly all the PCTs were Black women, as compared to the almost universally White, female therapy staff, and many of the PCTs felt underrecognized

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[37] I plan to write more about the patient care techs in future work.

and, at times, disrespected by patients and families who, in some cases, treated them like "the help." The patient and his wife in this story were not those people. They were, for the most part, beloved by the hospital staff. But in presenting all aspects of this story, it's important to understand the pressures on PCTs in this institutional context, as well as the perspective of the patient.

When I interviewed Izzy, a PCT, she mentioned a recent tense interaction with a patient:

> I had a patient not too long ago, and I hate to say it, but I'm banned from his room. Only because I walked in his room after my lunch and asked his wife, "Did he urinate?" And he got so mad that I didn't ask *him*. His blood pressure shot up, as well as his heart rate. And I didn't see the big deal. Just because I asked your wife, "Did you urinate?" [laugh] But he got so mad at that. Because he said, "You got something to ask, you ask me." So. I was banned from his room.

To Izzy, it seemed like a small slipup and a disproportionate response. As it happened, however, I had interviewed the patient and his wife a few days before I spoke to Izzy, and they both independently told me their versions of the same story.

It's also important to know that the patient in question is Connor, the locked-in patient. As previously described, he had recently been through a harrowing experience in which medical professionals failed to recognize that although he couldn't move, he was entirely aware inside his body. All of which casts the interaction with Izzy in a different light. As Connor told it:

> I have had one interaction that I think went poorly. And it probably stems from the fact that this individual—she didn't—she did not talk to *me*. And I feel like, I'm a person. I can respond. Even when I could not talk, everyone talked to *me*. And that's how it should be. But this individual did not. And that upset me. Because it made me feel like she did not see me for who I was. (stroke, White, male, inpatient)

Emilia, Connor's wife, presented even more background that brought out additional elements of the situation. When Connor was in long-term acute care (LTAC), before coming to inpatient rehab, he had a series of similar interactions. Emilia remembered a particular incident with a physician who came into Connor's room and addressed Emilia and Connor's father, talking *about* Connor, but ignoring Connor entirely. Emilia described herself as "not a confrontational person," but she found it heart-wrenching to watch this doctor disregard Connor. Emilia spoke up, as she explained:

> I didn't say it directly like this. I was probably more scared and afraid when I told him this…. I said, "It breaks my heart to have you talk *about* Connor instead of *to* Connor." I told him, "We are not your patient. Connor is your patient. We're here to advocate and we're here to interpret and we're here to help translate. But Connor is your patient. And he heard everything that you said, he understood everything you said."

The doctor was flustered and backpedaled and awkwardly told a story about something similar that happened to him, when his wife gave birth, but thereafter, he addressed Connor directly. Unfortunately, this interaction wasn't an isolated incident. During his time at the LTAC, staff members habitually came into Connor's room and "treated him as if he was just a thing," an object in their workspace. Emilia reported:

> I actually started staying overnight with him the last week we were in the LTAC because he was not getting the attention or help that he needed overnight. And like, people would come in and have conversations in the middle of the night and not know that he was aware and awake. And he would hear everything, and it was just rude.

Given this context, one can see why the interaction with Izzy was a charged moment for Connor. He had finally regained the ability to speak, and after a long period of dehumanizing treatment, he was ready to assert his right to be treated with respect.

Emilia also explained that in previous interactions with Izzy, they had found her "pretty abrasive" and noted that she "didn't take the time to acknowledge Connor too much," so when she came into his room that day, their relationship didn't have the strongest foundation. When she went to take his pulse, she held the pulse oximeter over his paralyzed hand, waiting for him to hold his finger out. She had worked with him before, so it felt insensitive or thoughtless that she didn't remember he couldn't lift that hand.

Then she started directing questions to Emilia, ignoring Connor. How many calories did he have today? How much did he urinate? Emilia told Izzy she could speak directly to Connor, but she talked to Emilia anyway. Izzy may have been harried, and she may have been trying to get the information as quickly as possible from the person who could relay it most efficiently, but Connor was, understandably, at a breaking point.

So he asked Izzy to speak to *him*, not Emilia.

Emilia explained one final element of the situation. Connor's stroke caused problems with emotional regulation. Especially in the early days, post-stroke, "he would have these massive mood swings between like, really, really, really intense laughter. And then, later, super intense crying spells." Connor's emotional regulation had improved considerably since then, but he was still concerned about losing his composure. He feared being "overtaken" by emotion. Emilia had no such fear. She felt Connor was able to navigate tense situations calmly, and in his interaction with Izzy, she recalled Connor telling Izzy, in a quite reasonable manner, that he was *in* his body and should be spoken to as such.

But as it happened, Izzy was taking Connor's vitals at that moment, so his agitation registered on the machine. Emilia recalled:

> And I could see like his skin became flushed, and then his vitals skyrocketed. His blood pressure was through the roof … I think his heart rate was 160.

He had what amounted to a trauma response. And Izzy told him to "calm down," which made the situation worse.

Emilia suggested they hold off on taking vitals for now and take a break, and as Emilia remembered it:

> [Izzy] kind of stormed out and we could hear her down in the hallway. A minute later, like, probably not even a minute later, three nurses came in. They were like, "Connor! What's wrong? Are you okay? What's happening?"

To Izzy, it seemed like Connor suddenly flipped out, but given the context, it's easy to see how their exchange triggered his response. And as Emilia explained, Connor was also nervous. He was afraid of losing control of his emotions, but he was also anxious about speaking up. As Emilia said:

> Connor's not one to rock the boat. He's not one to put up a fuss. He's not one to disagree, in this type of situation, because he wants everyone on his side. He doesn't want to make any enemies. He doesn't want to be a curmudgeon, you know. He wants to get along with everyone here. Because he knows how valuable everyone is to his recovery.

Connor was invested in being a good patient, likeable and easy going, and he also didn’t want to lash out at someone who was doing her job. In that moment, however, and given all of Connor’s recent experiences, he was moved to use his newly recovered voice to assert his personhood.

I Volunteer for an Experiment

Image 13: Leg prepared for neuroscience experiment
Source: Photo by Author

While conducting my field research, I volunteered to participate in a few neuroscience trials, at the inpatient facility. On one occasion, I had several electrodes affixed to my leg to monitor the muscles firing in my ankle and shin. The researcher instructed me to respond to a sound or light by pushing down on the plate in front of me, in a specific way. But, for the life of me, I could not figure out how to engage the correct muscles in the precise way the researcher wanted. Again and again, he told me to push “like I was pushing a gas pedal.” But again and again, I wasn’t doing it hard enough or soon enough or in exactly the right way. My repeated failures were recorded by the electrodes and displayed on the screen at the front of the room. I tried to get the researcher to describe what he wanted, in a different way. Which muscles should I engage? Could I try a few motions until the electrodes registered what he wanted, and then he could tell me to replicate what I had just done? But he just repeated "like pushing a gas pedal." The mutual frustration built between us. I was annoyed at him, but I felt guilty about the annoyance. I had asked so many people to participate in my own research over the past months.

I don't think of myself as particularly athletic, but I was a dancer for much of my life, so (perhaps falsely) I imagine I have above average awareness of and control of my body, but here I was repeatedly failing at something that was clearly supposed to be so simple as to require almost no explanation. None of the previous subjects had this problem. I knew that because the researcher very helpfully told me so. "It's like pushing a gas pedal. You do know how to drive, right?" It felt like this man was edging closer and closer to calling me an idiot, outright. I heard myself overexplaining the mechanics of how I drive—that I never have my entire foot flat against the gas pedal but rather use the ball of my foot and slide it up and down, rather than applying direct pressure. But in the process of minutely dissecting the mechanics of an action I normally do without much conscious awareness, I was beginning to doubt myself. More than that, I was beginning to question whether I *did* know how to drive. Maybe I was doing it wrong? Hopefully not *dangerously* wrong, but maybe idiosyncratically?

Meanwhile, the researcher and I had an audience, a prospective PhD student observing the study. I had told him I was here doing my own PhD research. Now it looked like I couldn't follow simple instructions. And possibly also couldn't drive. An uncharitable part of me hoped the prospective student was on my side, that he understood the real problem here was that the researcher couldn’t come up with a better (or even just an alternative) way to describe what exactly he wanted me to do.

Eventually I managed to produce some good-enough data, and we moved on to the second stage of the experiment. He would be testing my sensation at a few points on my foot and ankle to determine my minimal perceptible stimulus. After the debacle of the first part, I wanted to do well. I knew this wasn’t the sort of thing you *could* do well or poorly, but by now I felt like I had an indefinable something to prove. I was also acutely aware of the possibility that due to the way the experiment was set up, I might incorrectly claim to feel something when no stimulus had been delivered. I would be unaware I was reporting a phantom sensation, but both the researcher and the observer would know that not only was I too clumsy or obtuse to follow simple physical instructions, I was also an inaccurate perceiver and reporter of my own sensations.

We made it to the final section. On the third round of stimulation, with the electrode applied in a new location, I felt burning. This part required the electrode to fire continuously, repeatedly tensing a muscle near my knee. The longer it went on, the more it felt like the electrode was burning a hole in my skin. I knew it couldn’t be, but when I looked down, I almost expected to see my skin reddening and smoking. I told the researcher about the pain. I tried to mention it almost casually. By this point, I was concerned about causing further delay and inconvenience or being perceived as difficult. He told me there was no way I could be feeling what I was feeling; the electrical stimulation couldn’t be causing any physical damage, and it shouldn’t be painful. What did I want to do? Stop now? Ruin the experiment because of pain I shouldn’t even be feeling?

It wasn’t unbearable. And now that I was reassured it couldn’t be causing any real damage, I knew I could easily deal with it for another thirty seconds or so. I told him to go ahead and restart the stimulation. The odd, burning pain resumed, but my most pressing concern was what to do with my face. On the one hand, I wanted to seem stoic, the opposite of the hysteric I feared I appeared to be. On the other hand, he had essentially told me the pain I was feeling wasn't real. If I showed no outward indication of the pain, this time around, was I validating his assumption that … what *was* he assuming? That I had an exceptionally low pain threshold? That I was malingering or imagining things?

Of the three research studies in which I participated, this was the most unpleasant. Even though one of the others involved what the recruitment email described as "electrical stimulation of the cervico-medullary junction … an intense experience, that people tolerate to varying degrees." Of the three, however, the gas pedal experiment was also the most illuminating. I spent months observing patients in therapy sessions who were having "e-stim" applied to coax hemi-paretic muscles to contract. I listened to therapists trying to break down deceptively simple actions into their component parts. I watched patients experience the frustrations and humiliations of repeatedly trying and failing to perform tasks they had taken for granted. They never had to think about the biomechanics of walking, before now. They never had to plead with their hand to release its grip on a spoon. Thought and action had been indistinguishable.

My short, voluntary experience, as an able-bodied person taking part in an experiment, is not remotely equivalent to the experience of a stroke or TBI patient in rehab. But at the time, it felt like a glimpse into what it might be like to be given instructions that feel impossible to execute, or to think about a routinized action until it began to feel alien, or to feel put on the spot and like your basic competence has been called into question.

Shane and the Brain Diagram Misunderstanding

I saw the brain diagram many times, in many contexts. Patient educators, therapists, and nurses pulled it out to explain to patients and families where an injury occurred and what functions were associated with that area. It was a common educational tool, and it was included in a lot of the informational packets that were left with patients and families, for their future reference. On one side of the sheet, it showed the left hemisphere of the brain, and on the other side, it showed the right. Each side had the functional areas mapped out and labeled—memory, balance, speech, etc.

When I interviewed Shane, a White man in his fifties, husband of stroke patient Serena, he told me he'd been "studying" this diagram every day, but he was confused because the problems on the page didn't seem to correspond to his wife's symptoms. His stepdaughter was shown brain imaging when Serena was in the acute hospital, but at the time, Shane was in the hospital too, with COVID, so he missed the initial explanation.

He pulled out his phone to show me the diagram, and it was immediately clear what the problem was. Shane had taken a photo of only one side of paper. The following exchange illustrates how misunderstandings can arise. It's easy to see how staff might believe they conveyed a certain piece of information, while patient and family remained in the dark.

Shane knew Serena had a left-sided stroke, so he was looking at the functions labeled on the left side of the diagram. I tried to explain to Shane what was wrong—that he was looking at an image of the entire left hemisphere, so the left side of the photo was not the "left brain" but the frontal half of the left brain.

Interviewer: So I think this whole—this is all the left side. Because the way it's divided—

Shane: No, this is the right side.

> Interviewer: Um, no. So the way it's divided is, if you sawed your head in half this way. This is my left hemisphere. And this is my right. And so there's another side of this paper that they gave you. And that shows what's going on on the right. See, this says—
>
> Shane: This is the left side?
>
> Interviewer: Yeah. This whole thing here is the left side.

Shane started looking at the functions listed, puzzling over why most of them didn't apply to Serena.

> Shane: So something is the memory. That's what's throwing her off a little bit, too. They said something about that … not the spelling so much. She's pretty good on that. I mean she can do those puzzles like nothing.
>
> Interviewer: But it depends on what *part* of the left side was affected. Because you can have an injury in the left at the very front, and maybe that makes it—like it says there, inhibitions are on the left front. So someone could be swearing and not be able to stop themselves.
>
> Shane: Right. Well, no, she don't swear. I mean when she swears, she'll let you know about it.
>
> Interviewer: Well, right. And maybe it wasn't the front left of her brain that had the problem, it was some other part of the left side of her brain…. These are the different lobes. So you've got—this is the frontal lobe here, and you've got a left front and a right front … the parietal lobe goes across the back like this, and you've got a left parietal, right parietal.
>
> Shane: But there's nothing wrong with that.
>
> Interviewer: Well, so I don't know where her—I don't know where her stroke was on the left side ... so that may be a good question to ask them because this whole side of the page here, this is all left brain.
>
> Shane: Right? Where did the stroke happen?
>
> Interviewer: Yeah! Any of these things could have been affected. You just have to ask them "and so what part of the left brain?"
>
> Shane: What part of the left brain? What caused it?
>
> Interviewer: Yeah. Because, for instance, sometimes people who have a left-brain stroke, they have trouble speaking because—
>
> Shane: But she [doesn't have trouble speaking]!

Shane started trying to guess the part of her brain that had been affected by matching her symptoms to the labels on the drawing.

> Shane: I mean, she didn't have no problem speaking. At first, she kind of slurred her words a little bit. But, I mean, memory, she hasn't lost her memory. I mean, balance. Yeah, she's—she's losing her balance for sure. I'm thinking it's right in here.
>
> Interviewer: Could be in that area. You don't know. So I think you just have to ask … and you could even bring in that picture.

Shane was talkative. I repeatedly tried to explain that I wasn’t any kind of expert and couldn’t help him puzzle out the location. I referred him to various staff members who could give him the information he needed, but he was undeterred.

> Shane: Is it the back? Because according to this—memory? Eh, little loss of memory. But balance? Yeah! She's off of balance. So would it be in the blue here? Think about it.

He eventually circled back to the idea that Serena wasn’t moving her left arm because her brain “wasn’t telling her to do that.”

> Interviewer: Right. And so the signals go in both directions. So basically, when I put my hand on the table, I'm getting—
>
> Shane: Your brain's telling you to do it.
>
> Interviewer: Well, right, But—so my nerves in my fingers are—
>
> Shane: Your brain's telling you to do that.
>
> Interviewer: —sending signals up to my brain.
>
> Shane: It's all the brain!

I gave him the contact information for a patient educator and encouraged him to reach out to her or ask Serena’s medical or therapy teams. He had questions on a number of fronts.

> Shane: They're going to give her something to move her hand, or something. Some kind of medication.
>
> Interviewer: Yeah, I don't know. I'm not sure what that would be.

Shane: To shrink the brain, I guess it's called.

Interviewer: So if she had a bleed in her brain, they probably want that blood to reabsorb. But, yeah, I don't know. I think you would just have to ask questions.

Like many patients and family members, Shane was very inquisitive. He took photos of all the papers Serena and he were presented to make sure they had a copy. He pored over the brain diagram. But there were gaps in Serena’s and his understanding of her medical situation—what exactly happened, why it happened, what the implications would be, and how the team was treating her. They just didn’t know how to go about answering their questions.

Chapter Seven: Understanding and Finding Meaning

In this chapter I will discuss how patients understand what happened to them, both as a biomedical event and as part of their personal narrative. I will explore some of the primary metaphors patients and staff use to describe patients' injuries and discuss what purpose these metaphors serve in helping patients comprehend and find meaning in their experiences. Finally, I will touch upon how patients frame and answer "why" questions that help them understand and give meaning to their traumas.

Understanding the Biomedical Event

Memories of Initial Diagnosis

A few patients had straightforward, unclouded memories of having been diagnosed, as this patient described when asked whether he had any unanswered questions about his stroke:

> No, they are very—they explain everything here. Even at [the acute hospital] they sat me down and explained everything. Where it happened … it was in my cerebellum. (stroke, White, male, inpatient)

Crucially, a cerebellar stroke generally affects balance and coordination, so this patient had no significant mental symptoms. Even in the acute hospital, he had been able to understand and retain a clinical explanation.

In some cases, patients had a clear memory, but they recalled being told inconsistent or misleading information:

> And then they said I did not sustain a concussion because I was—I remember the impact, like on both sides of my body. And I remember hitting the ground with my head because it was so painful. And when the accident first happened, right away the EMTs asked me what hurt and I said, "My head hurts." And I guess it was just swelling immediately across my hairline from left to right…. But they said I didn't have a concussion, which I thought was—I was really surprised by that. They left me in like the bright lights, you know, overnight in the ER. They weren't monitoring me. Because I was kind of dozing because I was so tired. So I was like, "Well, this is kind of weird. If I have a concussion, they would be monitoring me more closely." But they didn't. And it wasn't until I came to [inpatient rehab], where they were like, "Yeah, you did sustain a concussion." (TBI, White, female, inpatient)

Technically, this patient wasn’t diagnosed with a concussion but with a TBI, albeit a relatively mild one. It was still serious enough to require inpatient rehab. In her memory though, the acute hospital staff said her brain was uninjured, and it wasn’t until she arrived at inpatient rehab (on a brain floor) that anyone clarified her diagnosis for her.

A lot of patients had foggy memories of how and when they first learned what happened to them, as another stroke patient recounted:

> It's a little bit hazy because I was on the narcotics. But um, I was in the ICU. And then the head neurologist comes in … and he starts like explaining it a little bit. And I'm like, I think I'm like—I understood what he was saying. But also like, not really, like, totally understanding what he was saying. Like, when someone says you had a stroke, it's not like completely processed. Like, you hear the words, “You had a stroke.” But not everything was like, retained in your brain. But yeah. It's not like a solid memory though. (stroke, White, male, inpatient)

The patient’s father recalled his son’s confusion, at that stage:

> He was kind of in and out of understanding what was going on because of the narcotics and that. And I think I talked to him a little bit about it, but I don't think he remembered. And then one day, I was in the hall talking to someone, you know, and I said, “My son had a stroke,” and I walked in and he said, “I had a stroke?”… He kept initially perseverating about the jet skis. And we think that he thought he crashed on the jet ski, initially. But now he clearly remembers the whole thing. (father of stroke patient)

The patient was riding a jet ski when he had his stroke, but he wasn’t in an accident. He had a brain hemorrhage caused by an arteriovenous malformation. Between the stroke and the narcotics, however, his memories were jumbled at first. And he wasn’t really capable of taking in and retaining the information when he was first diagnosed, perhaps in part out of shock. His father highlighted another common issue: patients often remembered hearing about their injury for the first time from family or through some other incidental contact, like the overheard hallway conversation. However, that wasn’t necessarily the first time it had been explained to them; it may just have been the first time they held onto the memory.

Many patients had no memory at all of a doctor providing a diagnosis, explaining what happened to their brain, or describing the areas that were affected, at least not until they arrived at inpatient rehab. Some patients were aware they may have been told but simply didn't remember. As previously described, a significant proportion of patients had indistinct or entirely missing memories of their acute hospitalization.

More telling perhaps was the fact that many family members reported no one had delivered a clear diagnosis. As a patient's partner described:

> So they didn't [explain his diagnosis] really. They kind of glossed over a lot of things, and I didn't really get explanations on things. It was incredibly difficult. All they kept telling us was, "He had a brain injury" … So technically, they've never told me what brain injury he has. They never said he had a concussion or any of the stuff that came along with that, so we never really got anything official that said, "Here's what happened." (wife of TBI patient)

Patients and family alike commonly reported having unanswered questions about the clinical picture.

In many cases, patients recalled having received most of their information from therapists, nursing staff, or family rather than in a formal interaction with a physician. As one patient explained:

> When I got here … [my doctor] gave me a little bit of info. But later it was my nurse who started telling me about everything.… [The doctor] is a busy man. And since I came from another facility [he] probably thought that I knew. (stroke, White, male, inpatient)

Often, nurses were a key source of information because they tended to be the most accessible medical staff, but as described in Chapter Two (Managing Expectations) nurses generally didn't feel it was appropriate to deliver diagnostic information beyond the most basic details. They often tried to refer patients and family back to the doctors. But as one patient explained, nurses often ended up being more informative than the doctors anyway:

> [At the] first hospital, not so much, just honestly, like—actually a nurse told me, and not even a doctor. So that tells you something there. And she was like, "I can't say much, but I am—" She's like, "I feel so bad. I'm sorry!" And she was apologetic, but yeah, we got nothing from the doctor, unfortunately. But I'd say at [the acute hospital], like you had a team … so you have a lot of people coming in that way. You have people that are residents. You have your primary doctors. And everyone had little different pieces to kind of cover. (stroke, White, female, outpatient)

A combination of insufficient communication on the part of staff and family/patients misunderstanding (or patients being unable to remember) meant that patients were often uninformed, even fairly late in the process. Several patients I spoke to were unclear on the details of what happened to them, even as far along as the day rehab stage, as these examples suggest:

> Well, I don't know if I had a brain injury. I just had some—I don't know. When I was in the—I can't remember … and then I had some—I don't know what they call it. Ablasions [sic] or something like that? And I don't know if it's—I guess it's maybe like a stroke or something or—family of a stroke. I don't know. So it's talking goofy. I remember talking goofy. [The nurse] said I started talking goofy. She says, "Well how many arms were you born with?" "Four." "How many legs were you born with?" "Four." I remember that. And then she says, "Hold on. I gotta get somebody." And they took me down and did a scan or something whatever, and they said he has some—I don't know what they call it—maybe mini strokes or something. (TBI, White, male, outpatient)

> I went to the neuro doctor on Monday … and it was unclear because when I first had [the stroke] they told me it was a brain bleed. And I thought that was kind of weird because then they started pushing blood thinners, Plavix and aspirin. And I'm like, why would you give me blood thinners, if I have a brain bleed? ... So when I went to the neuro doctor, he said "No." He said, "I don't know why they told you that." He said, "You had a blood clot" … The whole time, I was thinking I had a brain bleed and it ended up being an ischemic stroke. (stroke, Hispanic, male, outpatient)

As the second patient's quote suggests, he worked in a health care profession, and he was relatively medically literate: he knew the difference between a hemorrhagic and ischemic stroke, and he knew enough to be surprised when he thought they were giving him blood thinners for a bleed. He also didn't have significant cognitive symptoms, so while it's possible the confusion was on his part (due to medication, trauma, or simple misunderstanding), it's also possible he was given incorrect information.

Patients varied in their degree of interest in learning more about their neuroanatomy or what exactly had happened in the course of the stroke or TBI. Some patients were squeamish about hearing potentially upsetting details, were uninterested in the medical nitty-gritty, or preferred to focus on prognosis and what they could hope for moving forward, as this exchange illustrates:

> Interviewer: So have they shown you images at all?
>
> Patient: Yeah.
>
> Interviewer: What was that like to see?
>
> Patient: It doesn't matter. I don't care. It is what it is. It happened. And now I live with it. (stroke, White, male, inpatient)

This patient was highly motivated to recover; his mindset was deliberately future-oriented. Other patients were focused on whether a particular unpleasant symptom was going to improve, as this patient explained:

> And the only questions I would have is, "How long is it going to last? The pain?" So it's not like I care about the origins anymore. I care more about, you know, when's it gonna end? (TBI, Hispanic, male, inpatient)

People with an unresolved problem (e.g., aneurysm that had not yet been fixed) or whose condition had an unknown cause wanted more information about why it happened, in large part because they were worried it might happen again if the underlying cause wasn't found. As this patient articulated:

> It confuses me because I was a healthy person, except with my diabetes. And all of a sudden, I fall and all this happens. Or in the beginning, when I got dizzy when I was getting my iron infusion, and they took a scan. And then they found all these aneurysms. Where'd they come from? You know what I mean? So have I gotten those questions answered? No. And that was one of the questions I forgot to ask [my doctor] today. Where did these aneurisms all come from? You know, what did I do, that they all created to be here? (stroke, White, female, inpatient)

Even patients who weren't interested in learning more about how and where exactly their brain had been damaged were very invested in learning more about what they could do to increase their chances of recovery and prevent further damage from occurring (e.g., stroke patients learned that having had one stroke increased their risk of having another, so they wanted to learn more about stroke prevention). As I'll discuss in a later section, many patients also wanted to know if they had done anything wrong, anything that might have contributed to their present troubles.

However, some patients were very interested in hearing the precise details of what happened to them. When it was made available to them, these patients appreciated the opportunity to view brain imaging or hear about which functions were associated with the particular areas that were affected. Some patients spent time on Google and YouTube learning whatever they could about neuroanatomy and neuroplasticity.

Patients who were interested in brain anatomy often took comfort in being able to link their symptoms to a concrete cause. To know that what they were experiencing was "expected" validated their experience and diminished the unsettling sense of dealing with the unknown. As a therapist explained, through discussing neuroanatomy staff tried to convey that, "You're not alone in this. It's nothing we've never worked with before" (staff, inpatient). Within this framing, staff acknowledged that the symptoms might be strange and frightening to the patients, but the staff had seen it many times before and were prepared to deal with it. As the following excerpt suggests, staff were able to explain frightening events as expected symptoms of injuries to a specific area of the brain.

> Dr. P explains to the patient and his significant other why the patient was hallucinating.
>
> Dr. P: *The place where he had the bleed, a lot of blood was on his brain. And it's in the place where he realizes what he sees. It's not the meds [causing the hallucinations]. As long as he knows it's not real and he isn't terrified, we don't want to give him anything that could slow down recovery.*

In a few sentences, the doctor explained that unnerving hallucinations were due to injury to the part of the brain where the patient "realizes what he sees." It was alarming to lose one's ability to distinguish real from unreal, but the biomedical explanation suggested that the problem was localized and treatable. It wasn't that the patient was *losing his mind*; it was just that the part of the brain that performed the specific function of discerning reality was swamped with blood, thus experiencing technical difficulties. The doctor also justified his treatment plan: First, the hallucinations were an expected symptom of the patient's injury, not a medication side effect; and second, as long as the patient could tolerate the hallucinations, the doctor preferred not to prescribe an anti-hallucinogenic because that sort of drug might impede neuro-recovery.

Especially with cognitive and behavioral change, being able to attach symptoms to a clear underlying physical cause helped patients medicalize their experience and re-define what was happening to them as a medical process rather than a change in who they were as people. As a therapist explained, it helped to hear "there's a name for what you're going through" (staff, inpatient). The patient was experiencing a clinical event—precedented and treatable.

Metaphors and Narratives

Whether or not a patient was interested in the particulars of what had happened to them or in neuroanatomy, most patients used one or more of a handful of explanatory frameworks offered by the staff. The frameworks served a variety of purposes, such as underscoring staff advice or destigmatizing changes that threatened identity.

The Brain Battery

To begin with a fairly straightforward metaphor, staff used the brain battery metaphor to explain what patients were experiencing and to teach them how to husband their energies. As a patient educator explained:

> So again, we all have a brain battery. When we are fatigued and tired, you're going to realize that you're not going to be able to process information as well because your brain battery's down to 5 percent. So when I'm face to face with someone, I can draw them a picture and say, “Before, you had 100 percent. Today, you're at 35 percent.” And that just simply means that you're starting your day off with 35 percent charge. So what happens if you go to bed at night, and you forget to plug your phone in and you wake up and you're like, “I got to get to work!”? And you look, and you're like, “Oh, no, I only have 25 percent!” Is your phone going to last throughout the day? Well, the more you use it, guess what? It's going to go down to zero. And you're eventually going to have to charge it. That's exactly how the brain battery is. (staff, inpatient)

The brain battery helped patients understand their cognitive fatigue and framed it as a problem partially within their control. Due to injury, patients were starting at a deficit, but by making sure they rested and optimized sleep to recharge their brain battery, they could maximize what they had. Staff also taught them that exertion and overstimulation could drain their brain battery faster, so they could take measures like dimming the lights in their room or turning off ambient noise like the TV or radio.

The Brain is a Muscle

Perhaps unsurprisingly, this metaphor was used to explain the importance of exerting oneself in therapy and to underscore the message that therapy was an ongoing process that required commitment and would produce incremental results. Patients often referred to therapy in workout terms:

> And then from a cognitive standpoint, it's just been recalling or strengthening a lot of my memory muscles or making sure that they're not gone. (TBI, White, male, inpatient)
>
> So the lady I've seen—the therapist, she gave me those assignments I do to get my brain stronger. (stroke, Black, female, inpatient)

Staff used this metaphor to explain that after a heavy day of “exercise,” the brain would need to recover, like the body after the gym. Another crucial use of this metaphor was to explain the importance of repetition. Patients were often confused or annoyed when asked to perform the same tasks over and over. Therapists used the brain as muscle analogy to explain that patients were doing “reps,” as they would in a workout.

Tailored Metaphors

Staff often used ingeniously personalized metaphors to convey a message in terms a particular patient would understand or identify with, as the nurse in this example did:

> So then [the stroke patient] tells me he's not gonna quit smoking. I'm like, “Okay.” I'm like, “Listen, hey, I'm not even talking about the cancer aspect of smoking.” Like, let's just—who cares? You're not even worried about that. Back burner. I said, “You're an electrician, right?” … So I said, “Okay. What would you rather work on—new construction or old construction?” He goes, “New construction.” And I'm like, “Okay. Because when you're working on old construction, and you go touch those wires, all the plastic cracks away, right? And it's just a mess. Because now you got to pull new wires. But now you're pulling new wires, and you're cracking the old wires, and it's just this—ugh, it's aggravating.” And he's like, “Yeah. How do you know that?”… And I said, “That's what smoking does to your arteries and veins. So you keep smoking, and all your veins are going to crack, just like in that old building.” I said, “And then you're going to have more clots, and you're going to throw another clot and you're going to have a stroke. That's one of the millions of reasons that smoking is bad for you.” He came back in with a patch. (staff, outpatient)

She knew he wouldn’t respond to health shaming or cancer scare tactics, so she put an image in his head that was powerful and easy for him to visualize

The Disordered Files

This metaphor was commonly used for patients with aphasia and or memory and cognitive symptoms. As a speech therapist explained:

> Sometimes I tell patients, it's essentially like your brain and all the knowledge that you've acquired over the years is still there, but it's as though someone came to your file cabinet and tipped over all your files. So all the information's still there, but you just can't get to it in the efficient organized way that you used to be able to get to it. Because it's now in disarray. (staff, outpatient)

Staff might refer to a disarrayed filing cabinet or a ransacked library, but the message was the same: Everything you had before is still there; it's just harder to retrieve. In this metaphor, therapy was a process of reorganizing, learning new retrieval strategies, and learning to work around the disorder. This metaphor was used to destigmatize cognitive changes by highlighting that nothing had been "lost." When patients said they were once intelligent but now felt stupid, staff could explain that their intelligence and body of knowledge—the files/library—were still there.

Under Construction

Patients often talked about the Self as a work in progress in the sense that they felt they weren't back to "normal" or back to "me" yet but were working toward that end goal. Work in progress could also be a way of forestalling feared change. If a patient didn't want to contemplate identifying as disabled or giving up prized identity characteristics such as "breadwinner" or "caregiver," they could instead identify as a "work in progress," in transit between states of being, on their way back to their desired Self. This framing was bolstered by one of the common explanatory metaphors used by staff—road construction and/or rewiring.

Doctors, therapists, patient educators, and nurses explained neural pathways and neuroplasticity by describing the injured brain as being under construction. The established neurological connections were "pathways and roads that the brain takes every day" (staff, inpatient), but due to the injury, some of these roads were blocked. The flow of traffic had to be rerouted to get around the part that was under construction.

This metaphor was useful in numerous ways. First, it explained why therapy had to be challenging and patients had to push themselves as much as possible. As a therapist said:

> If it's [a task] that's simple for you, it's not kind of pushing you to that next level. It's not making a new neural pathway necessarily. (staff, outpatient)

Patients were forging new connections, carving new paths, building fresh roads. Of course, it would be more challenging than traveling via existing infrastructure. This analogy also explained why changes might linger:

> And now your brain has to either find or build a detour to get to all that knowledge that you've acquired over the years, right? And we all know detours aren't the most efficient way to get to things. (staff, outpatient)

The patient could "build" a new way to get from point A to point B, but they might have to accept that they would get there more slowly than they had before. Staff also used the road analogy when patients were frustrated at staff-imposed restrictions (e.g., on driving or returning to work):

> We are building things, and you're doing it, and that road is still being built, even if you don't feel it yet. So even though you can't drive on that road, it's still being built. (staff, outpatient)

In this way, staff reassured patients that their work in therapy was paying off but justified temporary restrictions on the basis that the metaphorical road was not yet ready for traffic—it had to be smoothed, the lines painted on, etc. Staff also pointed out that construction projects were undertaken by an extensive team, so patients, family, and staff all had to work together to achieve results. Perhaps the most important use of this metaphor, however, was to illustrate that, as a therapist explained,

> so we can't necessarily fix that part of your brain that was affected by the stroke. But your brain is super able to make changes around that injured part. So it's like a detour, right? We can create new pathways for motor recovery and motor return to kind of make up for that spot of your brain that was injured from the stroke. (staff, inpatient)

Patients wouldn't get the damaged parts back, but they could find alternative routes. A variant of the roadworks analogy was "rewiring" —connections that had been disrupted could be replaced. But in many ways, patients found the road construction analogy most identifiable and intuitive, and it helped them understand how damage might be lasting, even as the changes it caused could be surmountable through hard work and perseverance.

Waking/Emergence/Return

Waking, emergence, or return was a useful metaphor for patients who had periods of unconsciousness, amnesia, heavy brain fog, or disorientation. It helped family understand what to expect as a patient began to regain awareness and once again exhibit traits and behaviors that recognizably belonged to that person. As a patient’s wife explained:

> They didn't know if he was going to make it or not. And they said time would tell, as far as his prognosis. And he was unconscious for about five days or so. And then he started slowly waking up. And he recognized me, and he recognized our neighbor who was there every day with me. And after that, he started kind of waking up more and more. He doesn't remember anything about being in the hospital at all. (wife of TBI patient)

In this metaphor, the person was always there, fully intact but asleep. They just had to shake off the fog of sleep, and they would be back with their loved ones. Patients also used the awakening metaphor to describe how it felt to be in a liminal state of consciousness—not yet fully alert or aware. It made sense for them to liken the unusual experience to more familiar forms of altered consciousness, like drunkenness or sleep. As one patient described:

> [I was] aware of everything, talking, but not aware of it. Feeling like—like, if you just wake up. Are you with it yet? Someone just woke up. First time you open your eyes. And someone says, “Hey there, Virginia, can you go to the store? I need some milk and this and that. Then after, come back here. I need you to pick up my dry cleaning. What appointments do you have today? A three [o’clock]? A five? ... and you're still feeling groggy. “Yeah. Give me a second. Give me a second.” Yeah, that's the feeling. I assume when people say they've tripped acid, that's what they're talking about. They're like [groans]. (stroke, White, male, inpatient)

The idea of needing some time to shake off post-sleep grogginess also helped patients and family understand how someone might be there and not there—not asleep but not yet fully conscious. According to staff, the idea that patients “woke up” from a coma fully and instantly, like in the movies, was one of the most common and problematic misconceptions people brought into the rehab process. In the movies, people were out one minute, and the next minute, they opened their eyes and were able to converse, recognize people, etc.

As family described, the return to consciousness was incremental and fluctuating. The patient might show signs of alertness or recognition that suggested they were "returning," interspersed with periods of fogginess or unresponsiveness.

> It's not like in the movies where they wake up and they're like, "Oh, hi, Mom! Where am I? How long have I been out?" It was gradual and it was slow over time. At first, he would wake up, he would look at you. He might nod his head. He might give you a thumbs up. And I mean, you know, just slight, a very small flicker movement of the thumb. But that was in response to you talking to him. Now, early on, when he was in the coma, they would come in and they would do a sternum rub,[38] and sometimes he would open his eyes, and he would look. But then he would go right back out. And then, I would say five weeks, six weeks [later], he just slowly came out of it [and] was a little bit more aware. Would say yes/no. Then it was, he would talk to us, he would say very short sentences. (mother of TBI patient)

The progression wasn't strictly linear. As another family member described: "It was really weird. Because it would be like a 180. One day, he would be very with it and would know what was going on. And then the next day, just be like a totally different person" (wife of TBI patient). Staff tried to prepare families for a slow process, full of stops and starts, ebb and flow, and they tried to explain that the end result might not be what family expected, as a therapist explained:

> Or if somebody, let's say, was in a minimally conscious state and they emerge, their family assumes, "Oh, they're gonna keep progressing like that, and then they'll be back to them." And that's really especially true for like memory, where people think, "Okay, like, my loved one was in post-traumatic amnesia. They've emerged. So now their memory should be perfect, right?" [But] it's a hierarchy, right? Your memory was crap. And then it improved. But we still have—you know, just because you can form new memories doesn't mean that skill's perfect. (staff, inpatient)

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[38] Sternal rub was a form of "noxious stimulus" applied by rubbing the knuckles against the breastbone. When patients were still minimally conscious, staff used various forms of noxious stimuli—including pain/discomfort—to try to evoke a reaction.

Staff also described how these fluctuations could affect a patient's insight and therapy participation. One day, a therapist and patient might have a highly productive session, in which the patient accepted what had happened and even acknowledged their own physical and mental changes, but then the next session, there would be no "carry over," as the staff called it. The patient would be back to confusion and denial.

The "spark" was another consistent feature of this metaphor. The precise terms varied, but family consistently talked about a light in the darkness an indication that the patient was beginning to regain some core element of personhood or awareness that had been dulled or absent. Family used phrasing like "you could just see that his spark was coming back" (wife of TBI patient), "I was seeing little flashes of her personality" (daughter of stroke patient), or "there was a glimmer that he started to become aware of what had happened to him" (wife of TBI patient). In contrast to this light or glimmer were the moments of darkness or apparent void:

> And there's times where I think he knows who I am, and I think he sees me. And I'll ask him to give me a kiss, and he'll do it immediately. And then there's other days where he looks at me and—empty. And those are the hard days. [tearful] (partner of TBI patient)

As the patient returned, emerged, or awoke, they were metaphorically coming out of this darkness. The "sparks" were glimpses of some sort of core Self—a mind or personality or even a soul—still submerged in darkness but unextinguished. Family spoke as though some kernel of the Self was present all along but obscured:

> But other than that, it's still my best friend. Still, you know, my [Gary]. Each day, there's a little more of him that comes back ... [Gary's] still—it's still [Gary] in there. It's just not all of [Gary] yet. (wife of TBI patient)

The staff used the waking/emergence/return metaphor to prepare families (and eventually patients) for the reality that there was no "light switch," as some staff and family put it. Consciousness wasn't an on/off proposition. Waking/emergence/return would be a gradual process of ebb and flow. But unlike the disordered files or the road construction, staff didn’t teach patients and families this metaphor. Patients and family seemed to reach for it spontaneously, both to articulate what it felt like to be in a liminally conscious state (e.g., like being drunk or groggy) or to explain that they recognized a fundamental and recognizable core Self that was once again becoming visible.

Why Did This Happen to Me?

I’ve already discussed patients’ attempts to understand the biomedical causes of their current symptoms and to use metaphors to describe and interpret unfamiliar experiences and states of consciousness. But patients also looked for more existential answers to the “why?” question.

Blaming the Patient

Staff often talked about stroke risk factors, as this example illustrates:

> The doctor says the next patient had a very, very large stroke. He says the man had a history of cocaine and alcohol abuse, which may have contributed. He also has diabetes and high blood pressure. “Lots of risk factors.”

When staff talked to stroke patients about risk factors, they intended to help patients understand what happened and (hopefully) encourage them to make changes that would prevent additional strokes. But hearing that smoking, diabetes, diet, and exercise, etc. could contribute to stroke (especially without an understanding of statistical risk) could cause patients to feel a sense of guilt and responsibility. Family also frequently addressed risk factors with patients. As a patient’s husband said, “I told her, ‘I don't want to see you die over a stupid vape. You know, if you can save twenty years on your life, don't worry about the vape. Just be normal’” (husband of stroke patient).

Even if staff and family didn't explicitly blame patients or even remonstrate with them about making changes in the future, they often pointed to patients' decisions as explanatory factors, as this patient's partner did:

> I think [the stroke happened] because he had stopped taking his medicine…. I did notice that his eating habits was kinda off. And I used to say stuff about that myself. I used to say something about that because a lot of things he eat a certain kind of way, I don't eat that kind of way. So I think that pretty much played a part, the eating and the medication…. And he kinda, I will say, live a stressful life. And we don't tend to think it's stressful until something happens. Because we go on day by day, day by day, day by day. So he had a lot—he has a lot going on. So I think they kind of played a part in it all. (partner of stroke patient)

Patients spoke in similar terms—for instance, mentioning a smoking habit that "probably had something to do with my stroke" (stroke, Black, male, inpatient). The patient whose girlfriend thought his stroke had to do with eating habits, stress, and medication noncompliance cited the same three factors, when talking about potential causes of his stroke. Another patient reported that he was always responsible for taking clients out and showing them a good time: "That's what got me into this trouble. Drinking. I have vascular disease. And I never knew I had vascular disease. Until I had the stroke," he said.

Often, patients pointed out extenuating circumstances. For instance, one man explained that he had stopped taking his blood pressure medication because it caused frequent urination, and as a contractor who traveled between sites, there was often no convenient bathroom available. But even though patients often had explanations for their choices, many of them felt a sense of responsibility and guilt. Many of them wondered, as one man put it, "whether I brought it on myself" (stroke, White, male, inpatient).

However, many other patients had a somewhat mixed interpretation (e.g., pointing out that their health behaviors may have been contributing factors but weren't necessarily causal) or using phrases like "it's part of life" or "my body's just having issues" (stroke, Black, male, inpatient).

As one patient put it: “It’s nobody’s fault. Not at all” (stroke, White, female, inpatient). In her case, staff had a differing interpretation: she was unvaccinated and had a post-COVID stroke, so they felt what happened to her might have been avoided.

TBI patients had a similarly complicated relationship to guilt and assessing risk. In a few cases, patients explicitly blamed themselves:

> Oo, I be so mad at myself … because I'm not the type to put myself in these type of losing situations. Like, ahhhhh. Before I hit the first guy, I was finna fight a group of ‘em. And me fighting a group of ‘em by myself? I probably wouldn't. I don't know why. I don't even know what happened. (TBI, Black, male, outpatient)

This patient knew he was injured in a fight, but he didn’t remember what happened exactly or what preceded the altercation. But he felt getting into a losing fight was out of character for him, and he blamed himself for his TBI.

Another patient was hit by a car in a crosswalk. “I was really beating myself up [about the accident],” she said. She couldn’t remember if she had checked for traffic before crossing the street, and she was “very harsh on [herself]” in the aftermath of the accident (TBI, White, female, inpatient). Several male patients were injured in motorcycle or dirt-bike accidents. Most of them framed the accident as someone else’s fault or as a fluke or one-time error. One patient described how he was always “a very responsible person on a motorcycle” (TBI, Hispanic, male, inpatient). He “always” wore proper protective gear, but “just this one time” he was riding in shorts and without a helmet.

Another man explained:

> I don't hold any guilt … I didn't do anything to me. But I got put in that situation. I've been on bikes ever since I was eighteen. And I'm almost sixty. I’ve never wrecked a bike. I’ve never ran into anybody.... [The driver I collided with] just blew a stop sign and ran me over. So everybody blames the bike. I blame piss poor driving. Because everyone goes, “Oh, I told you that bike would kill you” … What about the piss poor driver that ran me over? I just—I don't know. I got a lot of anger. (TBI, White, male, inpatient)

Directing anger outward seemed to help in managing feelings of guilt, but not feeling personally responsible didn’t necessarily insulate patients from feeling guilt for other reasons, such as having caused their loved ones to suffer the trauma of nearly losing them and/or requiring family to make sacrifices to fulfill their care needs. Hayden was injured in a dirt-bike accident that caused a series of brain stem strokes that led to locked-in syndrome. As his wife reported:

> I've seen [Hayden] cry twice, in knowing him. And one was when we put our dog down, and the other was when a friend had passed away. [Hayden] was a tough guy. [Now, Hayden] cries every day. [tearful] He apologizes profusely, even more times a day. And I hate that he feels he needs to do that. He's mad at himself, even knowing full well that this was nothing he could have prevented. There's nothing he could have done. This could have happened taking the bike down to the barn, that same day. there's nothing—this malfunction on the bike was inevitable at some point. He beats himself up so much. He—he's very, very sad because of [our son]. He says [our son] doesn't deserve this struggle. (wife of stroke patient)

Hayden told me that he sometimes sat and ruminated about what he might have done differently. He was an experienced rider, and the bike had a mechanical fault, but not feeling entirely responsible for the accident itself didn’t necessarily shield him from self-recrimination.

Looking for an External Cause

In addition to patients who blamed another party for causing an accident, some stroke patients focused on errors that might have been made, signs that were missed, or actions medical providers failed to take to mitigate damage. In some cases, they seemed to have credible reason to believe there were errors at the acute care level, but in other cases patients seemed to be essentially grasping at straws in an attempt to find a reason why. One man contracted Bell’s Palsy shortly after a balance test, and despite his medical team’s protestations that one event had nothing to do with the other, he thought there might be a connection. Two other patients had a similar reaction: in both cases, they were blindsided by their stroke; they were physically active people who saw themselves as healthy. One patient fixated on the possibility that an angiogram she had nine days prior caused the stroke. As she explained,

> But everybody says, if that would have been the case, it would've happened right away. So I don't know. But that was what was through my mind. Because I've never, ever had anything like this before. So it's concerning. But you know, if you can't prove anything or anything, [you've] got to accept the fact. (stroke, White, female, inpatient)

This patient was in her seventies, and age itself was considered a risk factor, but it was hard for her to believe that she was the sort of person who had a stroke. The other patient presented a paradox: on the one hand, she insisted, "I'm very pro-vaccine. So this has nothing to do with that. This has nothing to do with that. And I'm—I'm not saying that it was the reason that this happened. Clearly, I had an [arteriovenous malformation], and it was there" (stroke, White, female, inpatient). But she kept coming back to the fact that the AVM ruptured nine days after she received the COVID vaccine. She was casting about for an explanation. She was someone who had "lived [her] whole life with zero issues at all," so the stroke felt unaccountable. She didn't want to be perceived as an "anti-vaxxer," but she couldn't get past the idea that the vaccine might have been "part of the spark to like trigger this whole thing" to the pointed that she chose not to receive the second dose prior to her surgery to deal with the AVM.

A Sense of Injustice

Many patients—both stroke and TBI—felt a sense of cosmic injustice. This shouldn't have happened to them. They didn't "deserve" this. They "did everything right." For stroke patients, this sense of unfairness usually hinged on a perception of having lived a healthy lifestyle, as one patient explained:

> Because my thing was, "Okay, what did I do for this to happen?" I had started eating different, eating better. Walking. I wasn't really going to the gym. But I was doing a lot of walking every day, like three or four miles a day, sometimes five miles a day. So I'd walk

> like at work on my lunch break. I would try to do at least two miles at work and then do the rest when I get off work. It didn't matter if there was snow…. And you know, I started losing weight, started to change my diet. I mean, I wasn't the best at eating healthy. But so, this is all the things that I'm thinking about. Like where did I go wrong? Or did I wait too late to start being serious about my health? So all these things are going through my head. I'm just trying to see like, where did I mess up at? (stroke, Black, female, outpatient)

Like this patient, many people expressed mixed feelings. On the one hand, they wondered if maybe their choices contributed to what happened, but at the same time, they felt they had generally done everything right, to the best of their abilities.

Several patients felt betrayed by God, feeling unfairly punished or insufficiently rewarded. As Caroline said,

> [distraught] I believe in God. and I love God. I wonder, "What the fuck are you doing?" Like, I haven't been this bad. Why? Why are you doing me like this? I try my hardest. I love God. Why don't he love me? Like, what am I? I love him. Why doesn't he love me? (TBI, Black, female, outpatient)

Other patients were comforted, to some extent, by the thought that God must have a plan, even if it seemed like what happened to them was unequivocally negative. Many patients expressed a willingness to surrender to God's will, as this patient explained: "So I just—it's just gonna, I'm just gonna play it day by day. And what the outcome is, is what God has planned. It's all I can do," (TBI, White, male, inpatient). In other cases, patients and family believed God had some greater purpose for allowing the stroke or TBI to happen and could be relied upon to shepherd them through whatever obstacles lay before them.

For some people, the idea that their suffering was part of a grand design gave them a sense of meaning, as Hayden articulated:

> I'm still searching for answers, so I think He plays a big role in that … don't know if there is [a greater reason for the accident]. But, you know, if it was to protect my son or my family, then I could justify it. But it would be satisfying to know that this isn't all there is. There's a bigger picture of something it may be a part of. That would be more satisfying than—than nothing. So. I want to believe there was a reason for this. (stroke, White, male, inpatient)

Hayden had been riding with his son shortly before his own dirt-bike accident. If he could believe that somehow his accident might have been in some way a sacrifice to protect his son, it was easier for him to bear, especially given his guilt over the way his injury drastically altered his family's lives. If there was a greater purpose, then maybe it was Hayden who made a sacrifice on behalf of his family, not his family who were forced to sacrifice for him. Other people wanted to believe God would provide, that there had to be a reward in store for their belief or a karmic repayment for their goodness. As Luke said,

> I took care of my mom and dad until they passed. Diabetes. It was not easy. My mom used to cry because I gotta like, wash her up. That was bad for her. I'd say, "Mom, that's okay." She didn't want her son to see her like that. But I'm not having my mom sit in dirt, pee, and stuff…. One of her sisters told me, "[Luke], your grace is gonna come back to you" … [tearful] Jesus is helping me. Paying me back by letting me still live. Because I cared for her. (stroke, Black, male, inpatient)

Luke's quote presents another common theme: the idea that God saved the patient from death or more serious injury. Despite their injuries, some patients felt lucky, blessed, or even chosen. They expressed gratitude and, in some cases, a sense of renewed purpose because they believed God must have spared them for a reason.

Scott, for instance, might well have been angry about his circumstances. He was a young father who had a stroke caused by an arteriovenous malformation. But he reported feeling blessed that the bleed happened in "no man's land," as he put it—an area of his brain that "doesn't specifically control like, super important things" (stroke, White, male, inpatient). Naomi was grateful her stroke affected her non-dominant side. Several TBI patients felt they had a brush with death and were spared. As one man put it, "And I was blessed. So I was handed the golden ticket for some reason. And I'm lucky every day that someone chose me and said, 'Let's get you back to [your wife] and back to your kids'" (TBI, White, male, inpatient).

Another patient who was injured in a workplace accident explained:

> One of the guys that was there told me what happened. One second later, or one step more forward, I wouldn't be lying in his bed. I'd be lying in a casket in the ground because it would have smashed me. So God was looking out for me that day. That's all I can say. That's all I can think … I'm gonna start getting more involved in God. Because I think it's his—he's the reason why I'm here above ground today. (TBI, White, male, inpatient)

As this patient suggested, a few of the people who believed God spared them were not strongly religious before the accident. In his case, he saw his survival as the proof he needed that God existed and cared about him.

An Obstacle to Recovery

Many patients struggled to find a satisfying explanation for what happened. Even if they understood the proximal cause—the biomedical explanation—they often searched for a distal cause. Either they looked for someone or something to blame, or they questioned whether a higher power had a plan, or they felt an abstract sense of cosmic injustice. Often, however, patients came to believe that contemplating "why?" was unproductive. As Naomi's husband put it, "I say, 'Those type of questions you'll never get the answer to. You'll torment yourself by asking those type of questions.'" As a patient explained:

> I was devastated [after my stroke]. And then they had a psychologist come in. And I was very emotional after the stroke. Like, I wanted to cry all the time. So she suggested that I put my head on my pillow and just cry. It was the best thing I did. I cried for like twenty minutes. And I got it out of me. And then I stopped, "Why me? Why did I have this? Why did God do this to me?" And then I just focused on getting better. (stroke, White, male, inpatient)

As discussed in Chapter One (Goals Over Time, Goals in Conflict), many patients adopted a deliberately blinkered approach—they tried to set aside anxieties about the future in favor of focusing on recovery. Similarly, some patients did their best to avoid ruminating about a past they could not change.

What Does It Mean?

Mixed or Neutral Interpretation

Most patients saw their brain injury as a turning point—a decisive moment in their personal narrative. But there were a broad range of interpretations of what exactly it meant. Some patients told themselves things could have been worse. They didn't necessarily see stroke or TBI as an opportunity for self-improvement or a boon from God, but many patients were aware they had been relatively fortunate and that, if they were not more cautious in the future, they could be less lucky next time. As one patient explained:

> So even though I have to go through all of this and whatnot, in my mind I know it could have been a lot worse. So for me it's like, you know, it's easier to accept it. I accept this happened. But I accept that it could have been a lot worse too. So be grateful that it was just this and not worse. (stroke, Hispanic, male, outpatient)

His life had changed, and not for the better, but he acknowledged that it wasn't a worst-case scenario.

Many of the elderly patients were open about the belief that their best days were behind them, and they had very few goals or hopes for the future beyond minimizing dependence and discomfort in the time they had left. They adopted a fatalistic attitude. As Inez put it:

> And it's just the way it's gonna be. It's not anybody's fault. It's the way life goes … I wish [the stroke] hadn't happened. But it's happened, and you can't go back. I like myself the way I was before.… But this is the way I'm going to leave this world, I think … I would like to say, "Oh, sure, I'll be the old [Inez]." But I won't be. And I can't do anything about it. (stroke, White, female, inpatient)

The very oldest patients had this attitude in common. Unlike patients a decade or two younger, they didn't hold out much hope for a complete recovery. They wanted to be comfortable and independent to the fullest extent they could and for as long as they could, but they acknowledged the end would come sooner or later. Injury wasn't a rock bottom before a triumphant resurgence, but it also wasn’t a tragic event that ruined their lives. It was just a fact of life; the natural endpoint of the human condition.

Negative Interpretation

Some patients saw themselves and their lives as forever changed for the worse. They felt they would never be the way they were before, and the lives they expected or hoped for felt permanently out of reach. One patient explained that he considered suicide when he thought he might not recover to a level he found acceptable. And although he ultimately had what many would consider an excellent recovery, he worried that his life and his marriage were forever changed. In describing his wife, he said: “We were soulmates. We were—there wouldn't be anything that one of us wanted to do that the other one didn't want to do … I don't know if we're ever going to get back to that magical existence.” He said that whether his life would continue to be worth living depended on his wife. “If I got to the point where it was just perfectly clear that she was so despondent over our life, then there would have to be- in my mind, for me, there would have to be some way to take that burden away from her” (TBI, White, male, outpatient). He said he would probably consider suicide over divorce.

Another patient articulated her complex emotions, a year out from her stroke:

> I guess I'm alive, so I should be happy about that. But it's like, it's [physically] painful every day. [laugh] I am happy that—my daughter got engaged. So there. I get to see that … but I'm not gonna be able to fully enjoy it. Instead of just enjoying the fact that she's getting married, and she's having a nice big wedding, all I can think about is what I'm not going to be able to do at the wedding, at the reception You know? It's all I can focus on. Which is wrong. Wrong, wrong, wrong. I can't go there. Because when you go there, it just brings you down. It's hard not to go there …I get tired of hearing myself complain, but I don't know what else to do.… And this morning, getting up was—getting up is brutal … and then I'm like, “Ugh, what am I getting up for?” Well, at least I gotta come [to day rehab]. I got something to do. But like on a Saturday, they're try to wake me up at like 9 or 10 o'clock. I'm like, “For what? What am I going to do? What are you waking me up for? I'm

> just gonna sit up in pain. What am I gonna do? Just sit around and look at you?" (stroke, White, female, inpatient)

She was still experiencing chronic pain and mobility issues, and she was having a hard time reminding herself that it was worth it to wake up in the morning. At the same time, she felt guilty for complaining and guilty for failing to appreciate the things she was supposed to find joy in, such as her daughter's wedding.

Positive Interpretation

Many patients framed the turning point as a positive—a second chance or an opportunity to begin anew. As Connor described:

> Well, when I had my stroke, I believe I had the opportunity to die. And I chose not to. Since then, I believe if I cannot have a positive outlook and see the humorous side in things, then I should have died. If I cannot enjoy life, then why do I have it? So I would say, since my stroke, I am more positive. (stroke, White, male, inpatient)

His wife Emilia reported that Connor had "really struggled with finding his path in life" before his stroke. He was intelligent and capable, and he found himself getting bored and restless in his previous jobs. They both hoped he might find meaning and purpose in whatever he decided to do going forward. When I asked Connor what he thought his life would look like in a year, he said:

> I have no idea. And I am happy about that. Before my stroke, if you asked me that same question, I would have said "I have no idea. And that is scary." But now, I have no idea, and I am happy about that. (stroke, White, male, inpatient)

As he saw it, he had chosen to live, and he was now choosing to view his future not as frightening and uncertain but as a blank slate, with limitless promise.

Other patients saw stroke or TBI as a wake-up call—a chance to pull themselves back from a dangerous path or become a better version of themselves. For some people, it was as simple as adopting a healthier lifestyle to prevent future health complications. As Alan said,

> I'm not gonna do, you know, stupid stuff. I'll try not to. I constantly do stupid stuff, but I'm trying to do better. Like, I'm trying to eat better and changing some things in my diet, stuff like that. Because it's like people where I—even around here, like they had two or three strokes. Like man, I don't want to go through this again. Once is enough for me! (stroke, Black, male, outpatient)

Another patient had been an alcoholic prior to his TBI. He saw his accident as a chance to begin again. His formerly estranged wife was also hopeful, but she was more measured in her optimism. As she saw it, a near-death experience might feel "life-changing," but it didn't necessarily alter the underlying issues that contributed to their problems before. As she explained:

> I'm worried when he comes home—because he's going to be back in that environment where he was before—we're going to fall back into old habits and old routines. And are you going to get stressed out in two months from now by something and decide you need to start drinking again? Or are you going to start spiraling down into a dark place? Because we're still exactly where he was living when all that was happening. So there's concerns, right? Because I hope that the light he has now continues to come home and stay. But I don't know. (wife of TBI patient)

At the moment, her husband was highly motivated, working hard to achieve recovery. But she feared that this experience wouldn't be a shortcut to lasting meaning. She was able to support the family on her salary, but she hoped he would find an occupation, if only to give him a sense of structure and purpose once he was finished with rehab.

Like many patients, Mariah saw her accident (and the fact that she survived) as a God-given second chance:

> Who I was before? Party girl. Wild. I was one foot in and one foot out. I had one foot in school, work. I had all that lined up. But I also had a foot in partying, using drugs, selling drugs. You know, with a man who hit me. From all that—moving too fast—to now. Having this time to sit down and actually take a look at my life and who I am and what I'd like and my goals and my worth and the fact that God gave me a second chance to prove myself … I know the future Me is gonna be great. Living. Worry free. Good job. Happy. Everything that I have worked hard for. And truly, truly what I deserve. (TBI, Black, female, outpatient)

Mariah had—and would likely continue to have—serious ongoing post-injury changes. She described feeling self-conscious about her appearance, and she certainly hoped to regain mobility and improve her ability to speak. But at the same time, she saw the disruption of her life as a positive. "I don't want to be who I was before this," she said. As opposed to hanging on to a previous version of herself, she wanted to escape who she was before and build back better.

Some patients said their stroke or TBI had shown them what was truly important or revealed who really cared about them, prompting them to reexamine their commitments. They talked about reprioritizing family, deprioritizing work and material gain, and renewing a relationship with God or embarking on psychological or spiritual self-examination. Several felt they had been, as Scott put it, "probably very kind of inward, self-focused. You know, probably more focused on my job and my pride. Pride in my work and stuff" (stroke, White, male, inpatient). Having seen the work the therapists did and the ways they helped patients in their time of greatest need, he hoped to find outlets for serving others.

Other patients felt they had gotten caught up in their desire to provide for their families and/or pursue career success and financial enrichment. As one patient put it,

> So I'm not going to do that no more. I'm just going to be a normal guy, a great guy, and a great dad, and a great husband. And a great grandpa … I'm gonna make a better life, and a smarter life, and a more loving life. For me and my family. (TBI, White, male, inpatient)

Some patients were inspired to stop putting off cherished plans for an uncertain future. As one man explained, his accident showed him "you're not guaranteed tomorrow" (TBI, White, male, inpatient). Nico, a stroke patient, described the stroke as "literally the best thing that's ever happened to me, aside from my [children] being born" (stroke, White, male, inpatient). In his life before the stroke, he felt he lived entirely for others—to provide for his children and make them happy or to assist his clients and contribute to the family business. If he had been asked, "What makes *you* happy?" he felt he would have had no answer, aside from taking pleasure in the happiness of those he cared for. He was also in a rut—working long hours and cycling through the same routines. As he explained,

> When I'm driving and I see an overpass with semis on it, I think, “If that thing fell right now, I’d be smushed out of existence. Not the biggest problem in the world.” It's not suicidal, but it's not—and it's also not having a fear of death. It's just not caring. [It’s what happens] when you stop caring about yourself to the extent that you can't answer the question, “What do you like to do?” (stroke, White, male, inpatient)

He'd been planning to buy a ranch, but that was a plan for the distant future, when his children were in college. After his stroke, he pulled the trigger and bought the property. He wasn’t exactly sure how the logistics would work with his shared custody arrangement, but he no longer wanted to put off happiness and enjoyment for some indefinite point in the future. “There is no [stroke-related] deficit that has negatively impacted my life compared to the benefits I've gotten,” he said.

Patients sought answers in a variety of ways and from numerous sources. As mentioned, patients for whom the root cause of their injury was still present (e.g., patients who had yet to undergo treatment to permanently fix the arteriovenous malformation or aneurysm that caused their stroke) were uneasy at the idea that they had some kind of hostile presence still lurking in their brains or a “ticking time bomb” that could begin to bleed again at any time. Patients whose stroke had no identified cause were also unsettled by the uncertainty and spooked by the possibility that whatever had been left unresolved could linger undetected, reassert itself in the future, and cause problems down the road. Other patients focused on learning more about the neurological particulars of their brain injury because being able to link unsettling symptoms to damage to specific areas of the brain made their problems feel more concrete and less threatening to their sense of Self.

Other patients sought answers from other sources. They questioned why—for better or for worse—their lives had arrived at this juncture. Finn's post-injury self-exploration encapsulated many commonly expressed themes. In a session with Dr. Rose, he said,

> *The accident was bad, but that doesn't mean everything in the aftermath has to be. I think of it as an opportunity. Out with the old, and in with the new. And I have faith. I think God has a hand in it. I didn't die on the side of the road that night. I see his hand in that. I think it's because there's something more left for me to do.*

Like many patients who were involved in an accident, he had to grapple with his sense of culpability. As did many of the dirt-bike and motorcycle accident patients, he had complicated feelings surrounding the accident. He didn't feel it was his fault; he blamed the other driver. But he also said he wasn't wearing a helmet that night, although he usually did. Ultimately, he decided to give up riding, but not because he felt guilty for having assumed the risk to begin with. He acknowledged that biking was part of his identity—as he explained, *People identified me that way. I was a biker. Two wheels is the modern equivalent of riding a horse.* Biking and what it represented were a significant part of how he saw himself and wanted to be seen. But following his accident, he said he needed to have *some level of humility* and not *tempt fate anymore*. He appreciated the years of enjoyment it had given him, but he said it wouldn't be part of his "reboot."

As he saw it, he had spent his whole life pursuing money and status. He had also been "the crazy one," although he clarified that he meant "fun crazy." Before his injury, he wasn't looking to live a peaceful life. But now, he felt he had lost "that driving thing," whatever it was "in [his] gut" that motivated him to prioritize seeking accolades and social position. And he was grateful to have lost that part of himself. "In [the] latest permutation of who [Finn] is," he wanted to "emulate Jesus" and prioritize generosity and focus on friends and family. He embarked on this new project of giving to others by agreeing to sit for an interview with me, although he said he wasn't usually one for engaging with institutions like universities or the government.

While many patients felt like a great deal had been taken from them and hoped to return to their pre-injury lives and Selves to the fullest possible extent, some patients framed the rupture as a positive—they weren't hoping to maintain continuity between the past and the present, at least not entirely. As Finn explained, he wanted to "feel peace in my heart, in my soul, in my mind, and in my brain." The disruption to his brain helped him achieve what he came to see as a positive new direction for his mind, heart, and soul.

Mr. Dawson Goes LOA

Mr. Dawson, a Black man in his sixties, was one of the first patients I got to know. When I met him, I hadn't conducted any interviews yet, and I was nervous. I didn't know how patients would respond. Would the questions seem intrusive or obtuse? Would the interview be overly taxing? I had no idea how receptive people would be, to me or my questions.

Before I interviewed him, I stopped in to visit Mr. Dawson a few times. I sat and chatted with his sister and him. They told me about their large family—stair-step siblings, all close in age, one born right after the other. Mr. Dawson told me stories about spending summers in the South with his grandparents. He went down there every year, until he was old enough to say he didn't want to go. He was a city person by then. He missed his grandparents, but he didn't want to spend his summers in the rural South.

Mr. Dawson's sister worried about him. After his last stroke, it seemed like he withdrew. He didn't come around as much to family events, even though they tried to draw him out. He'd always been traditionally macho, not the type to express his distress or reach out for emotional support. Mr. Dawson was feeling vulnerable, in many new and unsettling ways.

Before my interview with him, he had a heart-to-heart with one of his brothers. He hadn't wanted his brother to see him "like this," in the hospital, brought low. But when they talked, they both opened up, as Mr. Dawson explained:

> Me and him is like—you showing some kind of weakness, when men come to visit each other in the hospital. And we talked about that today. And I said, I want you to come see me all the time, man. Cause that's a rule that we gonna change.

They were emotional in front of each other, in an unprecedented way:

> And I told my nurse, "Don't tell my brother I was crying." But when I found out it was him knocking at the door, I started crying. You know? That was—that was a big moment for me … I couldn't hold it, with my brother. He cried too.… He said, "No, man." He told me, "I'm not as strong as you think I am." I think he's seen that I wasn't—so I think we've made a little headway. He's seen that—that was the first time he ever saw me crying … I seen him cry before. He cried at my mother's funeral. I didn't let nobody see me cry.

A few times during our interview, he told me he didn't want to talk about a subject anymore. It was difficult for him to discuss his future plans. He didn't like to think about moving to skilled nursing. I was acutely aware I was asking him to speak about intimate topics, with a virtual stranger. And he'd just been telling me how uncomfortable he was with emotional displays.

At the end of the interview, I asked if there was anything else I should know, anything important we hadn't covered. He said, "I just don't—there's other things, but—I don't know. I don't feel safe telling you about them."

I felt immediately chagrinned. I had pushed him too far, made him feel unsafe, failed to build rapport. I stopped the recording and thanked him. I told him how much he had helped me.

"You helped me too," he said. He said he'd told me things he hadn't told anyone.

I felt a little better then. Obviously, there were limits to how much anyone would tell a stranger. He didn't seem upset with me. I hoped, in my first-time interviewer bumbling, I hadn't pushed too far.

I sat with him for a while, until he was ready to get back into bed. As we waited for a PCT to assist him, he said he had to become more patient, since the stroke—another thing that changed.

You're only one who calls me "Mr. Dawson," he said. *You can call me William.*

I was erring on the side of overly deferential. It felt disrespectful to call an older person by his first name, without invitation.

"Come back, okay? I like talking to you," he said before I left.

I told him I would. Not to interview him, but just to chat.

But the next day, when I came back to see him, his room was empty, and the bed was stripped.

In speech that morning, the therapist noted a "mental status change." He was LOA—leave of absence—sent over to the acute hospital to figure out what was wrong. What did that mean? Was it something easily treatable, like a UTI? Or did he have another stroke?

I didn't know what to do. My grandfather had just died, and I was leaving that evening to go home for the funeral. I knew I would likely never see Mr. Dawson again. He was scheduled to discharge, and he would be gone by the time I got back. I would never know if he was all right, and he would never know I genuinely meant to come back to see him.

I had his sister's contact information from having interviewed her, but contacting her to ask what happened to him seemed like an ethical violation. So I didn't do anything except feel horrible. I wasn't able to keep my promise to visit him again. I didn't want him to think our interaction was strictly transactional on my part, that as soon as I had gotten my interview, I felt no further obligation to him.

That's part of this research too: trying to respect people's boundaries, trying to figure out what my own boundaries should be, caring about people I would never see again, and hoping they understood my gratitude.

Conclusion

Chapter One: Goals over Time, Goals in Conflict

Contrary to my initial expectations, inpatients were not (yet) focused on considerations like loss of professional roles or changes in significant relationships. Inpatients cited very tangible, short-term goals (like toileting independently; managing pain; eating solid foods) and the vague, overarching desire to get "back to normal." As I termed it, the inpatient Self was a "self in suspense." Patients at this stage bracketed the question of how and to what extent their lives (and their Selves) would change. They wanted to focus first on achieving as much recovery (and getting as close to their version of "normal") as possible, before coming to grips with how enduring changes might impact their social roles and identities.

Building on symbolic interactionist theories, I found that the "Self in suspense" was shaped by patients' interactions with their social environments and with interlocutors such as staff and family. The environment of the hospital was highly controlled and structured, insulating many patients from the stressors of their day to day lives, and staff and family encouraged patients to focus on the present and avoid thinking about future possibilities that could demoralize them and hinder their recovery.

At the outpatient level, patients left the carefully organized routine of the hospital and all its supports and amenities and became more aware of the challenges their stroke or TBI imposed. As it became more difficult to maintain a "Self in suspense" in the face of the demands and exigencies of daily life, staff encouraged patients to begin to prepare for and accept what they framed as "a new normal." In some cases, patients lacked "insight" into their own changes as inpatients, and over time they regained the ability to recognize the changes in their bodies and minds. This emerging awareness, coupled with post-hospital life and attempts by staff to encourage patients to accept and adapt to their lingering changes, contributed to bringing patients out of "suspense" and toward a re-constructed sense of Self and identity.

Chapter Two: Managing Expectations

I identified several factors that contributed to patients having unrealistic expectations for recovery, including misleading outside sources of information (such as Google research conducted by patient or family; or success stories highlighted in hospital advertising), miscommunication between patients, staff, and family, and a pervasive lack of familiarity with the process and aims of neurorehabilitation among patients and families.

In managing these expectations, I found that staff had one paramount goal: preserving patient motivation. Staff had to balance this goal with the need to prepare patients and family for what they could expect in the future and the ethical imperative to be honest and transparent and involve patients in their own care to the greatest extent possible. As they endeavored to keep patients and families informed while still preserving hope and motivation, staff used a variety of framing strategies, including what I termed "for now" and "yet," to encourage patients to prepare for the likelihood of ongoing disability while retaining hope for a more complete recovery. In this way, staff bolstered the "Self in suspense" by encouraging patients to think of adaptive strategies as potentially temporary. Although staff acknowledged that patients would eventually have to accept their "new normal," they wanted to ensure patients' progress was not hampered by the dejection that could come from confronting realities for which patients were not yet prepared.

Chapter Three: The Transition Home

This section built on the existing body of literature on social stratification and health outcomes. Specifically, I found that patients at South rehab (who were demographically less affluent people of color) were at a disadvantage as their recovery progressed because they, their social networks, and their communities lacked access to resources that were more readily available to the (predominantly White, higher-SES) North rehab population. In particular, South rehab patients struggled to access adequate, reliable transportation and in-home assistance. On the whole, they had fewer resources at their disposal to ease their transition home, support their ongoing rehabilitation, and help them (and their families) build workable strategies to accommodate their disabilities.

Chapter Four: Shifting Relationships

Patients confronted fundamental changes to their social roles and important relationships. In many cases, patients found they could no longer conform to their ideal models of role performance. For instance, patients might go through a period of identity crisis as they found they could no longer teach their children how to drive or perform thoughtful gestures for their partners. In the most successful cases, patients were able to envision new ways to fulfill the same relational roles (such as continuing to be a thoughtful and supportive partner by listening attentively, instead of performing service tasks such as giving their partner a massage or preparing a favorite meal).

Overall, I found that patients and their loved ones had to renegotiate the boundaries of their relationships. In particular, patients and their caregivers tried to establish rhetorical and interactional space between caregiving and intimacy. They underwent a process of learning to care and be cared for, in a way that was acceptable and sustainable for both parties. This dynamic necessarily evolved over time as rehabilitation continued and patients' needs changed. Partners initially had to learn how to be depended upon more than ever; but they also had to learn to cede control back to the patient as time went on and the patient recovered and/or gained adaptive strategies. In a parallel process, patients developed interactional and framing techniques that allowed them to adjust to diminished privacy and curtailed independence.

Chapter Five: Re-constructing Identity

Building on Erving Goffman's work on stigma, I looked at how patients formed or rejected disability identity, in interaction with other patients, the institutional environment of rehab, and cultural models of disability. In keeping with Goffman, I found that patients often strove to distance themselves from identity contamination, particularly by association with stigmatized others such as highly visibly impaired patients. However, I also found that patients preserved a desired sense of Self by framing themselves as (and trying to enact the role of) the "model patient," as I termed it. At the same time, patients sought to associate themselves with recovery narratives, repudiating and distancing themselves from the specter of incomplete recovery.

One of my primary findings was that patients' identities were often bound up with their ability to engage in paid labor and their sense of themselves as "providers," as literature on American culture's valorization of economic productivity might have predicted. Patients varied in their degree of identification with a particular profession. For some people, the job itself wasn't central to their identity: it was most important to be gainfully employed and to work under desirable conditions. But for other patients, it was important not just to be financially independent or a provider; it was important to retain their specific professional identity and the sense of meaning associated with a vocational "calling."

There was, however, a significant subset of patients who regarded their stroke or TBI as an opportunity to shift their priorities away from career-building or maximizing earning potential. The narrative disruption of injury and recovery gave them space to reconceptualize themselves, for instance as someone who puts family before work.

Traits and characteristics such as athleticism or intelligence were also central to patients' identities. In some cases, patients valued themselves (and felt valued by other people) for their ability to be “exceptional” in some respect. But crucially, even if patients did not think of themselves as brilliant or athletic, they wanted to avoid the stigma associated with being thought “stupid” or “weak.”

Finally, I found that patients and families highlighted relational and emotional traits (such as generosity, patience, kindness, or thoughtfulness) when asked to identify aspects of the patient that were unchanged by stroke or TBI. Patients and family bolstered their sense of an enduring Self by emphasizing that these sorts of attributes were both most important and least subject to change.

Chapter Six: Brain, Body, and Mind

Once again, building on the work of symbolic interactionists, I found that patients’ sense of Self was constructed in a complex and continuous interaction of their own perceptions and experiences, their sociocultural environment, and their exchanges with others (including staff, family, and other patients). For instance, patients experienced a variety of new physical sensations, many of which were unfamiliar in ways that were disconcerting but often difficult to pinpoint and contributed to the feeling I termed the “not right” body. At the same time, being interacted with as a medical object heightened patients’ sense of alienation from their bodies.

Overall, patients’ phenomenological experiences and interactions with others fostered a sense of alienation from the Self. Patients’ bodily experiences were characterized by what I termed “loss of automaticity,” “the uncooperative body,” and “the body as unreliable witness.” At the same time, patients experienced a sense of alienation from their minds and emotions and confusion around what was “Self” and “not Self,” emerging internally or resulting from external stimuli. They struggled to come to terms with perceptions, experiences, and sensations that framed the Self as in flux and unreliable.

Ultimately, I found that staff encouraged patients to use what I called the “blame it on the brain injury” frame to distance the Self from unsettling changes in the body and mind. Patients and significant others learned to regard unusual (for the patient) behavior, emotion, and cognition as symptoms emanating from the brain. They were encouraged to conceive of the brain as an organ that could malfunction and (hopefully) recover, distinct from the enduring Self.

Chapter Seven: Understanding and Finding Meaning

In thinking about how patients coped with the tremendous and abrupt narrative rupture caused by stroke or TBI, I identified several principal metaphors patients used to “repair” their self-narratives. These metaphors were central to neurorehabilitation culture, and staff not only used them to frame their own understandings of patients’ circumstances and experiences but also encouraged patients to assimilate these metaphors into their own narrative construction of Self.

Some of these metaphors served a disciplinary purpose, helping staff to “correct” patient behavior and induce cooperation with therapeutic regimens. For instance, “the brain as a battery” and “the brain as a muscle” promoted desired behaviors, such as self-monitoring for fatigue and participating energetically in repetitious therapies. However, other metaphors helped patients preserve their sense of the continuity of their lives and their Selves. “The brain under construction,” “the brain as a disordered filing system,” and “emergence” were all useful tools for patients attempting to frame themselves and their significant identity characteristics as still present but merely temporarily obstructed. Patients, staff, and loved ones spoke of a “spark” or “glimmer” of the essential person that had at times been obscured but was preserved and (ultimately) reemerged.

Finally, patients exhibited two primary narrative modes of making meaning from their experience. When asking themselves “why” the stroke or TBI happened to them and what it meant for their futures, they leaned on biomedical and spiritual explanations. The biomedical model was often associated with conceptions of risk (either risk-taking behaviors or health risk factors) and encouraged patients to either try to distance themselves from blame or vow to change their habits going forward. The spiritual model led many patients to see themselves as somehow elect, chosen by divine providence to continue to live or fortuitously turned away from a dangerous path. For many patients, either the biomedical or the spiritual model helped them integrate the stroke or TBI into their personal narratives and gave them a sense of meaning and purpose.

Overarching Themes

To be diagnosed is to be offered an explanatory framework for a set of experiences. That's not all diagnosis is, of course, but it is, at least in part, an epistemological tool. If you are, for instance, diagnosed with Autism Spectrum Disorder, you gain a way of organizing and making sense of your experience, a lens through which you can understand what you feel, how you think, how you interact with the world, and how other people respond to you. You also gain a potential identity and a way of contextualizing challenges you may face: you are neuro-atypical; you are disadvantaged and disabled by a social world structured to accommodate the characteristics and preferences of neuro-typicals.

In most cases, stroke and TBI patients were not looking for a new way of understanding themselves, for a redefinition or a new social identity. Diagnostic labeling could be helpful in understanding their symptoms—why this leg wouldn't respond or why they were finding it hard to match words with images. But in the early stages of rehabilitation, diagnosis was conceived of as an obstacle to overcome rather than an ongoing part of one's life and oneself that had to be integrated into one's identity.

Patients' recovery goals and priorities shifted as they progressed through rehab, beginning with vague (uninformed by experience) goals like "getting back to normal." In early stages, patients focused on immediate and pressing concerns (e.g., getting out of the hospital) and/or on possibly unrealistic long-term goals like walking again or “getting back to 100 percent.” As a staff member explained,

> A lot of patients, they're really living in the future ... the time when they'll be able to walk, quote unquote normally. Or they're living in the past, like thinking about what ifs and whether they could have done something to prevent their stroke. (staff, inpatient)

As patients progressed through rehabilitation and as they left the hospital and reentered their social contexts, they increasingly grappled with questions like: Is this Me for now or forever? Is this what I’ll be like, just until I recover? Or is this the “new normal?”

For the most part, patients in inpatient rehab hadn’t yet begun to take on a disability identity. The suddenness and unexpectedness of the disabling event and the ethos of recovery contributed to patients feeling like a “work in progress." They bracketed the question of what this injury would mean for their future or their identity, and they adopted a wait and see approach.

To some extent, we all experience a Self in flux, a difficulty in discerning what is fundamentally Me and what is situationally determined. The Self is constituted in constant exchange between self, others, and environment. We use social insignia, accolades and credentials, group memberships, social relationships, etc. to construct a stable sense of Self, to anchor our identities and provide points of reference. We may identify as a mother, an Asian woman, a journalist, a person who went to a particular college, etc. These identities are subject to change over time, but they contribute to a more or less stable sense of Self. I may know that I’m not in shape to run a marathon tomorrow, but if I’ve trained for and run marathons in the past, I can still think of myself as having run a marathon, as the “type of person who” runs marathons. But particular identities can also become more or less salient over time and across contexts.

With stroke and TBI, these anchoring roles and characteristics can be called into question. Take, for example, a man whose concept of fatherhood involves being a provider, being able to get down on the floor and play with his kids, being able to drive his children to soccer practice, being able to divide household responsibilities with his partner, being able to someday teach his children about the hobbies he loves. What does it mean to "be a father" if some or all of that will no longer be possible or not in the way he had planned?

Stroke and TBI patients also confronted alienation from the body and mind. They often faced the epistemological and ontological challenge of figuring out where a particular phenomenon was "coming from": How can I know what part of this emotion or this behavior is "me" and how much is the brain injury, or the new medications I'm on, or a reaction to the situation in which I find myself? To the extent that they could, patients and family highlighted personality continuities—such as sense of humor or love of family—and characterized discontinuities as temporary phenomena.

Patients might have lost their memories leading up to and following the traumatic event. They might not immediately (or not ever) have the "insight" to recognize their own symptoms. They might have to take a lot on faith: accept a loved one's or medical professional's account of what brought them here; accept someone else's definition of what is and is not a problem for them. Patients had to learn to live with the Self as unreliable—to acknowledge that they were not always able to trust their own perceptions, memories, or judgments.

Patients were taught to connect these unsettling symptoms to the injured brain. People with physical, mental, emotional, and behavioral changes, due to brain injury, drew conceptual and rhetorical distinctions between the concrete functions of their brains and their concepts of mind and Self. To preserve the apparent continuity of the Self, they attributed threatening changes to injured areas of the brain.

"Blame it on the brain injury" was a useful self-protective strategy, particularly when a person was behaving in ways that were contrary to their sense (or a loved one's sense) of who they fundamentally *were*, as a person. If a loving partner was suddenly irritable and lashing out, if a highly verbal extrovert was struggling to communicate and engage in "appropriate" social interaction, if an engineer who valued his cognitive abilities above all else was struggling with basic cognitive tasks, it could be comforting to conceptually separate the Self from "the brain injury."

This distinction gave the patient, family, and staff an external "It" to battle as they worked toward recovery or, at later stages of rehab, toward adaptation to long-term change. In coming to terms with the idea that injury to an organ could create sweeping changes in the body and mind, patients contemplated the distinctions between brain, mind, body, and Self. In a therapy session, a patient and psychologist had the following exchange:

> Patient: *People tell me I'm an intelligent, kind person*.
>
> Psychologist: *Do you not think that about yourself?*
>
> Patient: *I don't know anymore. I think there are some times I've displayed those qualities. But I don't know if they're me. If they're my value.*

As this patient progressed through the process of rehabilitation, he came to the conclusion that: *I've got a brain, a mind, and a soul, and they're all separate. And I also have to honor their container.*

Like many patients, brain injury compelled him to think about what the various aspects of himself meant to him and to others. What did he value most in himself? What did others value? What did he *want* to be valued for? Brain injury and rehabilitation reshaped his personal narrative:

he saw it as a turning point—a rupture in the continuity of his Self and his story. He was in the process of deciding what was most essentially Him, which parts he wanted to carry forward and which parts he wanted to leave behind.

Appendix: Methods

In designing my project, I wanted to analyze complex, subjective experience, so I opted for a small-scale, qualitative approach, informed by grounded theory techniques (Charmaz 2006). I chose stroke and TBI patients particularly because I wanted to capture both cognitive and physical change (as opposed to, for instance, spinal cord patients whose changes are, in most cases, physical), and I choose to focus on patients who were expected to recover, to some extent or another. The facilities also treated neuro-oncology and neurodegenerative disorder patients, but for them, rehabilitation focused mainly on staving off and adapting to decline. While neuro-oncology and neurodegenerative patients are fascinating populations in their own right and for their own reasons, focusing on both expected recovery and expected decline would have been too broad an analytical scope.

As described in the introduction, I conducted my research at three primary sites: the inpatient neurorehabilitation wards at a rehabilitation hospital and two affiliated outpatient day rehabs. I chose the two day rehab sites because they were among the largest of the day rehab facilities, and they served contrasting populations. One was located in an affluent suburb and catered to a population that skewed White and higher SES, and the other was located in a less affluent suburb that drew from a predominantly Black and Hispanic and lower SES population.

I collected observational data, interview data, and limited survey data, in the form of a basic demographic questionnaire administered to patients. I included patients, family, and staff in the study, but the patients were the focal participants, with staff and family providing contextual data

Staff acted as key informants, explaining the ins and outs of neurorehabilitation. It was also important to take a triangulation approach to data collection because, in many cases, patients were not able to provide the full story. For instance, when I interviewed patients with significant memory gaps, family and staff were helpful in filling in blanks. In some cases, patients lacked insight, so staff and family provided a useful counterpoint to patients' accounts.

In-depth interviews more fully captured patients' subjective experiences, beliefs, and understandings than more standardized data collection methods might have. Observational data provided valuable context for data derived from patient interviews and elucidated the interactions between patients, significant others, and medical and rehabilitative personnel and infrastructure.

After transcribing interviews and fieldnotes, I began a process of qualitative coding. I proceeded through an iterative series of coding cycles, identifying codes and categories as they emerged in the course of the analysis. I began with a round of open coding, and then used a focus coding strategy (Saldaña 2012) to cluster similar codes and develop significant categories. Throughout this process, I paid attention to how demographic characteristics shaped individual experience.

Interviews

I conducted semi-structured interviews with patients, patients' significant others (partners and family), and staff. I used two types of instruments: a standardized demographic questionnaire and interview guides (tailored to each of my three subject groups: patients, family, and staff). Interviews ranged in duration from thirty-five minutes to three hours. Staff interviews generally lasted approximately one hour because many staff members chose to speak to me on their lunch break. In many cases, I broke up patient interviews over more than one session so as not to fatigue patients.

In general, I interviewed inpatients on the weekends. Many patients were exhausted at the end of the therapy day. They generally had six full days of therapy scheduled per week, so many of them preferred to be interviewed on their day off. Day rehab patients were interviewed on their lunch break or at the end of their sessions for the day. I interviewed patients and family in person, at the inpatient or day rehab facilities, and I interviewed the majority of staff in person, although some staff members opted for a remote interview via Zoom on a day off. In a way, the pandemic made remote interviewing easier because of the sudden ubiquity of video conferencing.

After conducting interviews with patients, I administered a standard demographic questionnaire. Patients who were capable of doing so filled out a paper questionnaire, but for patients who were unable, for whatever reason (e.g., lack of fine motor control), I verbally administered the questionnaire. I collected demographic information on the patients for the purposes of sampling and analysis. I did not collect demographic data for staff or family.

My interview guides were informed by my pilot research. They were adapted and refined over the course of the study as it became clear which probes were effective and in what order, and as interesting questions emerged. In a handful of cases, I conducted follow-up interviews: I interviewed one physician twice (once in her capacity as an inpatient attending, and once to discuss her outpatient clinic); I re-interviewed one locked-in syndrome patient and his wife because their stay at the inpatient facility was inordinately long, and a great deal had changed for them in the time between our first interview and the patient’s discharge; and I re-interviewed one stroke patient and his wife when I encountered him again at day rehab, after having interviewed him as an inpatient).

In all cases (with one exception)[39] subjects were interviewed privately, for both ethical and methodological reasons: to protect confidentiality and to ensure interviewees could speak freely.

Ethnography

One day I was following a medical team on rounds, and I mentioned having recently visited with one of their patients. "After we round, do you just go hang out with patients?" the resident asked, sounding somewhat bemused. I did, in fact, spend a fair amount of time "hanging out" with patients and their families, in their rooms, between and after therapies. In many cases, it was the most effective way of building rapport and gaining rich insight into the patients' circumstances, as situations evolved throughout the hospital stay. If, for instance, I had simply interviewed Luke and Sarah and then moved on, I would have missed much of the conflict surrounding Luke's discharge planning.

I also shadowed rounds with medical teams (composed of various combinations of attendings, residents, medical students, fellows, nurse practitioners, and physician's assistants). I followed both stroke and TBI teams, as routinely as possible, over a period of several months. I also shadowed nurses and PCTs, across all shifts, including the 3–11 p.m. and the overnight shift.

Shadowing the nursing staff provided an entirely different perspective because they spent more cumulative time with patients than the doctors did, and they saw patients at all hours of the day, as opposed to primarily during morning rounds. Across five months, I also observed sessions with therapists in all disciplines (PTs, OT, and SLPs), at inpatient, day rehab, and long-term outpatient. I was also able to sit in on a few day rehab vocational sessions. At day rehab, I

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[39] One TBI patient (White, male, inpatient) preferred to be interviewed with his partner in the room.

shadowed therapists, nurses, and a psychologist. The psychologist's sessions provided invaluable insight into what patients were coping with at that stage of the process.

I recorded fieldnotes by hand. Handwriting notes was less obtrusive than typing, and in many cases, I was taking notes on the move (e.g., when shadowing rounds or observing PT or OT sessions), so it was impossible to carry a laptop. Patients and staff were generally comfortable with notetaking, across all settings. One virtue of my site was that I had access to "backstage" spaces (Goffman 1959), so after observations, I could sit in the staff areas and go back over my notes, away from the patients. As soon as possible after recording handwritten notes, I reviewed what I had written, filled in any gaps, and rewrote any oddly abbreviated or semi-legible words, to avoid later confusion.

With subjects' permission, I audio recorded interviews. I used an AI transcription service (Otter.ai), but in many cases, the transcripts were very poor quality, and I had to spend a great deal of time cleaning them prior to data analysis. My subject population included many patients who had difficulty speaking loudly and/or clearly, so the AI often struggled.

Sampling Framework

In the course of my pilot research, I found evidence that the following factors interacted with my central topics of interest in important ways: type and extent of injury, gender, and socioeconomic status. My sampling strategy was designed to capture variation along those lines, with the goal of capturing the dimensions that had most bearing on the research question, *not* achieving a statistically representative sample. The plan was to go in with sampling targets and continue recruiting until I achieved saturation. I used self-reported level of education and profession as rough indicators of SES.

I planned to conduct interviews with twenty-four patients, twenty to thirty significant others, and eight to ten staff members. My original sampling targets were as follows:

Table 1: Original Sampling Targets

	Low SES (as indicated by educational attainment and occupational status)		**High SES**	
	Male	**Female**	**Male**	**Female**
Traumatic Brain Injury	3	3	3	3
Stroke	3	3	3	3

Source: Author

In the field, my sampling strategy changed, in several respects. First, I ended up interviewing many more staff members than expected because I became aware of the wide variety of patient-facing roles in both inpatient and outpatient settings. I interviewed *and* shadowed attending physicians, nurses, PCTs, PTs, OTs, SLPs, vocational therapists, and psychologists. I also interviewed at least one social worker, patient educator, chaplain, bioethicist, interpreter, physician's assistant, nurse practitioner, and therapy manager.

Second, the day rehab sites became more important than I initially anticipated. I always planned to spend time at the day rehab sites to gain perspective on where patients go after inpatient rehab and how their recoveries progress and their perspectives change, but once I was in the field, it quickly became clear that day rehab was an equally important part of the picture. As I spoke to patients and staff, I repeatedly heard that patients don't focus on concerns like changes to relationships and professional identities until day rehab. In order to capture much of what I was interested in learning, I had to speak to patients across at a broader range of timepoints—both inpatients (most of whom where in the initial weeks and months following their stroke or TBI) and outpatients (who ranged from months to around a year post-injury).

Ultimately, I decided to double my initial patient sample target, to include an equivalent outpatient sample. I chose not to interview a sample of outpatient family members equal to my inpatient family sample because outpatients, on the whole, had a greater degree of insight and were better historians, so it wasn't as essential to hear a parallel family account.

I interviewed a handful of long-term outpatient staff and shadowed several outpatient therapy sessions to get a sense of what that stage entailed, but I didn't target long-term outpatients for interviews. The long-term perspective will be a fruitful area for future study, but in this research, I focused on the inpatient and outpatient day rehab phases. My final sample was as follows:

Table 2: Across All Sites

Patients	50
Family	26
Staff	63
TOTAL	139

Source: Author

Table 3: Broken Down by Site

	Inpatient	**Outpatient**		
		North Day Rehab	**South Day Rehab**	**Long-term Outpatient**
Patients	27	14	8	1
Family	24	1	0	1
Staff	46	2	6	4

Source: Author

NOTE: I also interviewed four staff members at two other day rehab facilities and one "float" therapist who worked at numerous day rehab sites, as required.

Table 4: Inpatients

		Male	**Female**
Stroke	**Low SES**	4	3
	High SES	6	3
TBI	**Low SES**	4	1
	High SES	3	3

Source: Author

Table 5: Outpatients

		Male	**Female**
Stroke	**Low SES**	3	4
	High SES	3	3
TBI	**Low SES**	3	4
	High SES	3	0

Source: Author

Table 6: Racial/Ethnic Composition of Sample

	Inpatient		Outpatient	
	Stroke	TBI	Stroke	TBI
Black/African-American	4	0	3	6
White	12	9	6	4
Hispanic	0	2	3	0
Other (Middle Eastern)	0	0	1	0

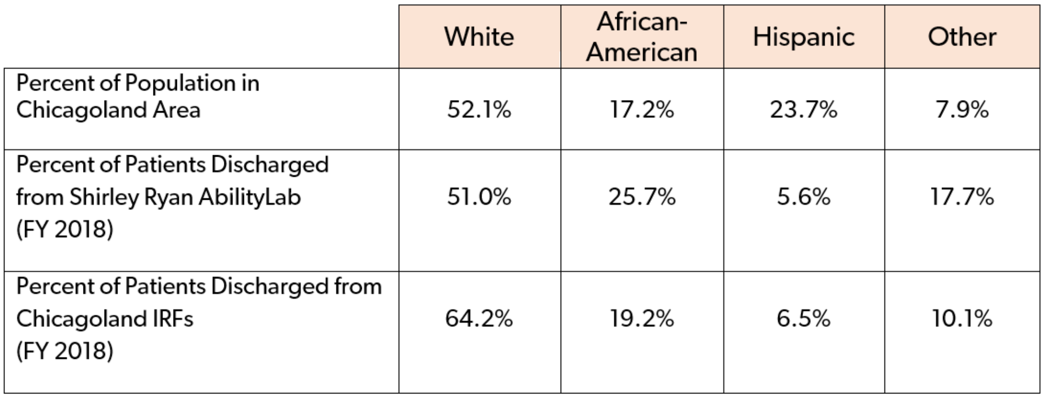
Source: Author

I deliberately oversampled stroke inpatients because two of my stroke interviewees were locked-in syndrome patients. They provided a fascinating perspective, but it was an unusual diagnosis, and in many ways, they weren't "classic" stroke patients. Both spent a great deal longer at inpatient rehab than the average patient; one of the LIS patients was back at inpatient rehab for his second stay. They were also outliers in that they had profound physical changes but were not cognitively affected.

In several cases, I interviewed an "extra" patient simply because I encountered a patient whose perspective filled a gap or added an interesting dimension. In one case, I did so on the basis of a misunderstanding. On rounds, one of the attendings mentioned that a patient was a truck driver, so it was crucially important for him to regain the ability to drive. I wanted to capture the viewpoint of an inpatient whose livelihood depended on driving, but as I interviewed the patient, I learned his doctor had the wrong impression. The man was actually an owner of a trucking company. Like most people, he hoped to get back to driving in the future, but he was very financially secure, and his career in no way depended on his ability to drive.

The facility drew patients from throughout the Chicagoland area, from neighboring states, and beyond (Shirley Ryan AbilityLab 2019). African-Americans were slightly overrepresented in the patient population at the inpatient facility in comparison to other Chicagoland inpatient rehabilitation facilities (IRFs), and Hispanics were somewhat underrepresented, in comparison to other Chicagoland IRFs. Interestingly, Hispanics are vastly underrepresented at all Chicagoland IRFs, in comparison to their proportion of the total Chicagoland population.

Table 7: Race and ethnicity percentage of patients discharged from Shirley Ryan AbilityLab and from Chicagoland IRFs



	White	African-American	Hispanic	Other
Percent of Population in Chicagoland Area	52.1%	17.2%	23.7%	7.9%
Percent of Patients Discharged from Shirley Ryan AbilityLab (FY 2018)	51.0%	25.7%	5.6%	17.7%
Percent of Patients Discharged from Chicagoland IRFs (FY 2018)	64.2%	19.2%	6.5%	10.1%

Source: Shirley Ryan AbilityLab, 2019

Due to the demographics of the population from which I drew, my sample predominantly included White and Black patients. I didn’t deliberately exclude Asians and Pacific Islanders, of course, but I didn’t encounter any patients from those racial and ethnic groups who were appropriate for my study. I also had a far more difficult time recruiting female TBI patients because women are underrepresented in the TBI population, so in the end, I fell short of my female TBI targets. Women are less exposed to TBI risk factors (nearly all of my male patients had been in industrial accidents or motorcycle/dirtbike accidents, while all of my female TBI patients had either fallen or been in a car accident, either as a pedestrian, driver, or passenger). However, one attending also cited research suggesting a neuroprotective effect of progesterone (e.g., Espinoza and Wright 2011).

My sample captured a broad range of ages—the youngest patient I interviewed was eighteen and the oldest were in their nineties. While stroke patients tended to skew older, I had stroke patients across all age groups. TBI patients also ran the gamut, with clusters at both ends, as a TBI attending pointed out:

> We know brain injury patients, it tends to be a bit of a bimodal distribution, where you see a lot of young patients who've been in injuries and then also older patients who may be

> experiencing falls and other forms of trauma. I will also say, because of the aging population, we're also seeing patients who are living longer and actually being more active later in life. So it's actually not uncommon for me to sometimes see a sixty year old snowboarding injury, or something to that effect, where I think, you know, maybe ten, fifteen years ago, you wouldn't see as much of injury in that population related to trauma (staff, inpatient)

On the whole the older patients I encountered had falls (with the exception of a few who were highly active and injured themselves in accidents while traveling or exercising), and the younger patients were in motor vehicle accidents, although I interviewed one patient who fell from a building, one who was assaulted, and two who were shot in the head. Several patients had been involved in workplace accidents; they were in their forties to sixties.

Recruitment

I began by reaching out to staff members (both in person and via email) explaining my project and asking to schedule an interview. In most cases, I first interviewed a staff member and then explained the ethnographic component of my research and arranged to shadow them, if possible. I recruited patients in the course of shadowing staff.

Prior to accompanying a medical team on rounds, I asked the physicians which of their patients were capable of giving informed consent. I approached those patients to introduce myself, explain my project, and obtain consent, before rounds. During rounds, I stayed outside the rooms of patients who had declined to participate or who were not deemed capable of informed consent.

If a patient agreed to participate in the ethnographic component, I followed up to request and arrange an interview. I consulted staff to ensure that I didn’t approach patients who were not fully capable of understanding the aims of my study. I obtained written consent from all interview participants and verbal consent from all observation participants.

I followed similar procedures at the day rehab sites, but rather than following physicians on rounds, I recruited patients through the therapists. Each morning, I asked the therapists I planned to shadow which patients on their caseload would be capable of consenting. Far more outpatients were consentable, so day rehab recruitment was easier.

I used a network sampling strategy to sample patients' family members, aiming to interview at least one family member connected to each focal participant. When I explained the interview process to patients, I asked them to nominate a significant other I could approach for an interview. I explained that the person could be a family member, partner, or friend, as long as they were involved in the patient's care and post-discharge planning. No patient nominated a friend, so all "family" participants were partners or family members (including patients' parents, children, grandchildren, and in one case, a niece).

In a few cases, I failed to interview an inpatients' significant other. The inpatients themselves were a captive audience: if they were willing, I was invariably able to find a time they were available by staying late, arriving early, or coming in on the weekends. Family members, however, could be harder to pin down. A few family members agreed to an interview and then never responded to repeated attempts to arrange a time. I hit my sampling target anyway because I included a few family members of patients I was unable to interview (two aphasia patients and one disorders of consciousness patient).

While I ultimately filled my female stroke patient sampling quota, it took a lot longer and I had to be more tenacious in searching for appropriate female stroke patients. My sample was small, so my difficulty may have been entirely due to chance: maybe the wards just happened to be light on consentable female stroke patients during my study. But when I asked the staff why I might be having trouble recruiting female stroke patients, one theory emerged.

They reported that prior to menopause, women have fewer strokes than men, and post-menopausal women have strokes at roughly the same rate. You tend to see older female stroke patients because women, on average, live longer and have strokes later. So it was possible that, among the female stroke patients I encountered, a disproportionate number had more severe strokes, so might have been more likely to have cognitive or communication problems that precluded participation.

Gaps and Selection Bias

My sample was biased toward patients with fewer communication deficits, and this bias was, to some extent, unavoidable. Nonverbal patients and/or patients who were unable to understand and engage with interview questions were excluded from the sample. However, I did my best to accommodate patients who were able to communicate verbally but who found it difficult or taxing, by breaking interviews up into smaller chunks of time, when appropriate. I tried to be cognizant of patients' physical, cognitive, and attentional stamina.

At the outpatient level, I was able to interview and observe patients who had once been unable to communicate but who had since recovered. I was able to observe speech sessions with aphasia patients who were capable of understanding and giving consent but who were unable to participate in an interview. I also interviewed a few family members of inpatients with severe aphasia. So while nonverbal and severely aphasic inpatients were absent from my sample as interviewees, I was able to glimpse their perspectives from other angles (by observing therapy sessions, speaking to family members, and eliciting retrospective accounts from outpatients who had recovered enough to be interviewed).

Similarly, my sample excluded the most severely cognitively affected patients who were not judged capable of giving informed consent. Interviews with staff members and observations on the inpatient wards provided some basic information about the most severely impaired patients, but these more severely injured patients' own beliefs and experiences were inaccessible to me at the inpatient level. I did, however, interview many outpatients who at the time of their inpatient stay would not have been consentable but who had recovered sufficiently, by the outpatient stage, to give consent.

Due to the structure of my study, I also missed the perspective of patients who discharged to skilled nursing or went home but received home health services rather than attending day rehab. Some of the patients I interviewed had stints in skilled nursing facilities or long-term acute facilities at some point prior to coming to day rehab, but on the whole, I followed the patient trajectory from inpatient rehab to day rehab and therefore lost the perspective of patients who went on to skilled nursing.

There were also selection effects operating with respect to the demographic groups that ended up at the inpatient and outpatient facilities. The organization itself reported that their patient population was roughly representative of the racial demographics of all Chicagoland inpatient rehabilitation facilities (IRFs). However, for reasons unknown to me, Hispanic patients are underrepresented at Chicagoland IRFs on the whole (Shirley Ryan AbilityLab 2019).

I was not able to procure data on the SES demographics of the inpatient population, but it is possible that lower SES patients were underrepresented. Low-SES patients may be less likely to survive TBI or stroke. Low-SES patients may end up being given treatment at a later stage or past the point at which treatment would have been significantly ameliorative of damage. However, the inpatient facility accepted Medicaid, Medicaid qualified, and Worker's Comp patients, and patients remained on the ward until they reach established metrics for discharge. Numerous factors linked to race and SES affected patients’ ability to access day rehab (as discussed in Chapter 3: The Transition Home), which may have systematically skewed the day rehab population. My sample was too small to be racially representative, but I tried to capture a roughly proportionate number of Black and White patients, and I conducted my analysis with intersectionality theory frameworks and relevant literature in mind.

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