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To all my Teachers

…it will be the silence, where I am, I don’t know, I’ll never know, in the silence you don’t know, you must go on, I can’t go on, I’ll go on.

— Samuel Beckett, *The Unnamable*

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ABSTRACT

Hospice and Palliative Medicine is a relatively new medical specialty that treats patients who are suffering from uncontrolled symptoms or for whom the goals of medical care are ambiguous. These role sets frequently overlap for the chronically and terminally ill, patients whose care is not well managed by the logic of medical intervention that emphasizes both the maximization of longevity and the curing of illnesses. Considering this unique role and patient population, how do these kinds of physicians establish criteria for success, and how do they make this intelligible to their colleagues in other specialties to promote the work of HPM. And how do they do this when they are working at the discretion of skeptical and guarded colleagues? The internal structure of professional bodies has been treated as generic and unproblematic for understanding the inter-relations between different professional groups. With the growing functional differentiation within professions, understanding intra-professional collaboration and competition is needed. The sociology of Professions has been marked by an emphasis on how different kinds of professionals dominate their areas of work to the exclusion of all competitors. This "turf model" emphasizes competition at the expense of collaboration, and the ready-at-hand theoretical alternatives to the turf model have traded pure competition for pure collaboration. These extreme theoretical alternatives are both motivated by a shared theoretical progenitor, ecology. In this dissertation, I emphasize an ecological model of the professions by observing the different lines of influence that draw different professional bodies together and push them apart. To do this I advance a further theoretical innovation, ontology as a social theoretical device for understanding the small worlds individuals occupy. Functional differences cause cognitive, linguistic and practical differences between social groups that undermine their ability to successfully collaborate. Using the case study of Hospice and Palliative Medicine, I advance our understanding of the professions and organizations and elaborate on how the work of these clinicians is completed despite the professional circumstances that promote failure at the expense of success.

CHAPTER 1

DEATH AND THE PROBLEM OF COLLABORATION IN MEDICINE

> ”Though thou shouldest be going to live three thousand years, and as many times ten thousand years, still remember that no man loses any other life than this which he now lives, nor lives any other than this which he now loses. The longest and shortest are thus brought to the same. For the present is the same to all, though that which is past is not the same; and so that which is lost appears to be a mere moment...”
>
> (Marcus Aurelius 2.14 — *Meditations*)

> “I don’t think I’ve attempted enough, and I don’t think anybody does. I think it’s an age of terrible specialisation. I think everybody has many more capacities than they have the gall to try out. And I regret how little adventuring I’ve done, not how much.”
>
> (Orson Welles)

Ernest Becker in *The Denial of Death* (1975), describes human beings’ unique awareness of mortality: “Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever.” The terror that this awareness causes requires mechanisms for coping, one of the primary being the unequivocal denial of this certainty. Rather than, as Camus instructed (Camus [1942] 1991), maintaining a defiant individuality in the face of death, Becker argues that individuals seek “immortality projects” that undermine their own personal concerns with finitude, such as the accumulation of wealth and status. He further argues that civilization and culture are meta-narratives in which individual immortality is achieved. Medicine has contributed significantly to these immortality projects by reducing morbidity and delaying death. Throughout medicine’s history, several advances have elongated human life and created effective means of saving individuals from acute moments of danger. Despite these advances, death remains inevitable, and the architecture of medical practice continues to provide curative and life-prolonging treatments up to and following life’s terminus.

Despite being guided by the principle to “do no harm”, clinicians harm the dying. Death is met by medical professionals as yet another *medical* problem, and treatments are deployed to reverse illness, despite being futile. This consequential and reliable failure produces pain in the dying and harms decedents who witness the suffering of the terminally ill. The problem is largely derived from medicine's efficacy: having created so many effective interventions for the care of the ill, the system of medical treatment has continually marched forward to the brink of human finitude and camps on the border territory, unable to relax its posture of treatment and action, that so reliably aids the curably ill.

Hospice and Palliative Medicine (HPM), the medical subspecialty that now specializes in the care of the incurably and terminally ill, has a unique set of characteristics that make it distinct within the tapestry of modern medical specialties: one of several dozen medical specialties that work in hospitals to provide care to acutely ill patients, it is the only one that specializes in the care of those that are dying. Treating the dying, these clinicians cannot save their patients from death. Further, they have committed themselves to a domain of practical specialization that is shared by nearly every other kind of clinician, and they encourage their colleagues to share in what little exclusive expertise they have carved out for themselves in medicine. This is a particularly exotic quality of HPM as new specialties in medicine establish themselves by creating novel or unique domains of practice, contributing to the growing complexity of the division of medical labor. The number and variety of medical specialties involved in the care of patients in the hospital leads to several practical problems in the work of providing care to patients.

As the specialization of clinicians' expertise narrows, there are fewer shared bases of knowledge to which they can orient themselves to and fewer means of establishing shared practices with their colleagues in other areas of medicine. Collaborating with colleagues is particularly important in such a refined division of labor, where the jurisdiction to perform particular kinds of interventions is controlled by different kinds of clinicians, and non-specialists defer to their colleagues. This also leads to the proliferation of the evaluative criteria used to judge good practice, as well as the work styles different kinds of clinicians use to complete their work.

In this dissertation, I will explore how functional differentiation, particularly growing specialization in medicine, impedes the ability of different clinicians to successfully collaborate on the care of their patients. Functional differentiation is by definition a feature of the division of labor and delineates types of professions from one another. Growing *internal* differentiation, or specialization, in the tasks completed by professionals of the same kind, leads to several problems of coordination: the practical specialization in a specific area of a profession begets distinctions in the attitudes, vocabularies, and systems of evaluations professionals adopt to structure and complete their work. The surgeon sees the patient as a material system that can be physically manipulated, while the internist, not afforded the same physical intervention into the patient's body, sees a constellation of reported symptoms and continuous data points marking vital signs. Success for the surgeon is a living patient and a 30-day window in which no post-operative complications arise, while for the internist success is a reduction in reported symptoms and improving test results. When the work of professionals is marshaled in organizations, that assemble the interactions of expert workers into distinct and interdependent teams, these practical differences in work are coterminous with social differences: greater interaction between specialists and relatively fewer interactions with colleagues in other areas extends differences in how work is completed to how it is talked about.

These different ways of doing, understanding, talking about, and evaluating work are instigated by growing internal differentiation through specialization in the professions and represent what I refer to as "divergent ontologies". These ontologies are substantially different cognitive schemas for organizing how work is executed and the culture that surrounds it within the specific community of fellow workers individuals work in. Despite possessing different ways of understanding what is the work of the profession and how it ought best be practiced, professionals in highly collaborative areas such as medicine must bridge their differences in how they think, talk about, and evaluate their work to find means for successfully integrating these diverging ontologies through shared practices. In exploring how these diverging ontologies are bridged with shared practices I closely examine the work of HPM clinicians in hospitals. In doing this, I hope to offer revisions for some of the most influential theoretical schemas sociologists use for making sense of the work and structure of professions.

1.1 The Ecology of Professions and Organizations

Sociologists have long understood professions, such as medicine and law, as structured by contestation, wherein different putative and extant professions compete over areas of work. These competitions for jurisdiction are ultimately resolved by workplace and state-level settlements: some professions become subordinated to others (i.e. nursing relative to medicine), or they share jurisdiction (i.e. accounting and law when it comes to tax law), both through the mandate of law and professional agreement (Abbott 1988). This model of the mutual constitution and domination in the professions relies upon an implicit turf model: professions narrowly define an area of practice and carefully guard that turf against incursion, seeking to penetrate the territory of related but independent professions. Though this model for understanding the professions has been incredibly successful, organizing a great deal of social scientific research on work and occupations, key cracks in this paradigm of research have begun to show. Eyal (2013), following in the actor-network tradition, emphasizes the need for sociologists to emphasize the networks of different stakeholders who are mobilized to constitute different areas of scientific and professional work, while Menchik (2021) describes a broader set of actors who play a role in the "professional project" constituent of the profession, beyond the core cadre of autonomous and guarded professionals.

Though this turf model is itself ecological, its emphasis on competition fails to account for the full variety of relationships that occur between and within professions. In this dissertation, I seek to provide a more substantively ecological description by emphasizing not only how competition contributes to the structure and behavior of professions but also the role of collaborative relationships in determining the structure and content of different professional bodies. In this work, collaboration is more than pure and simple symbiosis, such as in a division of labor where professions occupy narrow, well-defined niches and mutually contribute to each other's work, but also the ways that different areas, directly and indirectly, influence one another through their behavior. The ecological niches within organizations that different kinds of professionals occupy will be distinguished in a variety of ways in this work. This more thoroughly ecological treatment of professional behavior is better able to account for a theoretical tension within the established and long-running tradition used for understanding the professions.

1.2 Functional Difference and Organizational Dependence

The origins of the study of the professions placed differentiation and specialization at the center of the sociological definition. Parsons (1939) identified professionalization as the result of differentiation based on identity and organization and the specialization in knowledge and practice, following in the functionalist tradition that sees the division of labor as unproblematically organizing society through organic solidarity (Durkheim [1893] 2008). This theoretical lineage substantively informs the turf model as presented in Abbott (1988) and Freidson (1988), some of the most consequential texts in the study of the professions. However the emphasis on competition in the turf model fails to address a fundamental paradox within the professions; growing specialization, consequent of the growing complexity of society, requires that individual professional groups continually specialize and differentiate into narrower and narrower task areas, while at the same time their interdependence on one another grows. This interdependence and difference is in continuous tension as success in any one professional endeavor requires close collaborations with other professional workers who share less and less of the cognitive and practical schema used to complete work (Moorhead 2010).

A key finding of this dissertation is that functional differences and interdependence between different groups within organizations in the professions lead to diverging linguistic and cognitive repertoires professionals use to navigate consequential decisions. These differences are the result of the domain specialization that marks the greater ability of professionals to engage with more and more sophisticated technologies and techniques used in the successful execution of their work (Laumann and Heinz 1977). This leads to "cognitive narrowness" causing individual professionals to attend to features of their work that fall squarely within their domain of specialization, and to pay comparatively less attention to parts of their work that fall outside their specialization but which remain within their professional purview.

However, greater specialization leads to a relatively weaker connection to the central professional knowledge that defines the profession a specialist is engaged in (Stichweh 1997). This ultimately leads to a "professional paradox" (Moorhead 2010), wherein specialist workers have fewer and fewer connections to one another as they more narrowly focus on certain parts of the professional project. The paradox is caused by the epistemic infrastructure required for specialization, organizational difference leads to social differences with the consequence that even in how individuals speak and think they are separated (Carlile 2004; Collins 1998).

The case of medicine is a professional domain wherein these different tensions take on particular import: for one, the decisions that are made within the medical domain are matters of life and death, and short of preserving an individual's life, the decisions that are made by doctors and nurses directly influence patient's well-being, the second most important thing in a person's life besides their continued survival. What's more, with the growing emphasis on the role of patients in influencing what happens in their care (Kelley 1995), and the continued importance of the patient-clinician relationship (Timmermans 2020), having a better understanding of how expert workers relate their expertise to lay clients and colleagues becomes more and more important.

1.3 The Sociology of Death and Dying

Fortunately, my research follows several notable studies of the care of the dying in hospitals and the work of palliative care in particular (Abramson 2017; Christakis 2001; Heimer and Staffen 1998; Shapiro 2019; Timmermans 1999). Most significant for my work is Roi Livne's recent book *Values at the End of Life: The Logic of Palliative Care* (2019). Rather than being a detriment to the novelty or timeliness of my analyses, I am encouraged by the similarities between my own and Livne's findings. Our two approaches to palliative care diverge in substantive and critical ways that will have important implications for how we understand what the case of HPM has to say about our sociological theories in general.

Critically Livne overemphasizes the degree to which clinicians in HPM are oriented to their "professional project" (Menchik 2021) as a revolution in healthcare, and the degree to which related but functionally distinct areas of medicine support it. Certainly, I agree that HPM has its roots in a paradigm of medical treatment that is discordant with the dominant medical culture of medicine, but HPM clinicians are not so motivated by seeking particular ends for patients as Livne describes. As my analyses into the emergence of this area of medicine reveal, and will be reviewed shortly in Chapter 4, two competing ideas of what palliative care is and what the subspecialty ultimately would be, confronted one another throughout the formalization of HPM. One side won out in this competition with some relatively minor but influential compromises, and this vision for the future of the subspecialty was of a medical discipline oriented to the unique problems of the care of the dying and integrating specialized care of the chronically and terminally ill into the dominant culture of medicine. Its aim was not to radically transform medicine as Livne implies but to establish a curiously overlooked dimension of patients', well-being, as an important resource in the domain of medical decision-making.

A focus on patient well-being, rather than the well-defined clinical metrics used to evaluate the conduct of clinicians or the efficacy of treatment, does have a paradigm-shifting influence on how clinicians engage their patients in decision-making. Despite this, significant resistance against the professional project of HPM remains from patients and clinicians alike, and far more than Livne describes in his work. This resistance to how HPM functions is not due to economic incentives or the hegemony of cultural ideas held by clinicians and reinforced by the attitudes of patients, but can be attributed to how clinicians intervene in the care of their patients and the epistemic resources that have developed to support the worthwhile endeavor of reducing mortality and compressing morbidity to the final years and months of life.

This difference in my own and Livne's emphasis is revealing to the more fundamental theoretical and methodological differences that separate our engagement with this area and the insights we can contribute to the sociological canon: where Livne emphasizes a "new economy of dying" that motivates clinicians and patients to elect to enact limits on care that extends life by mustering professional, moral and financial incentives, I find a medical specialty that is bridging different areas of medical practice by orienting clinicians to an obvious but underappreciated area of patient care. In bridging different areas through social interaction HPM is a niche constructor, creating its own ecology of work, and influencing the work practices of neighboring and related areas.

Crucial similarities in Livne's and my findings are illustrative of the practices that HPM is currently oriented to: Livne notes that HPM clinicians "tame" the preferences and ideas patients have for their care, and the goals they seek to achieve by engaging the medical system. I also find that HPM clinicians help to construct an achievable goal from the unordered preferences patients state, but I too find that HPM clinicians are doing this *for their colleagues* as well, who might possess ideas about patient care that become unachievable. Further, I find, as Livne does, that HPM clinicians rely upon the formulation of "values" in their practice, and that these are constructed through interactions with HPM clinicians (Livne 2019:22).

Importantly, Livne and I differ in our use of values as a construct for the sociological explanation of observed empirical phenomena. Where Livne treats values as being preserved through two logics of economization (one a prudent relationship to abundance and the second the allocation of scarce resources to mutually exclusive and finite ends), my use of values treads much closer to how they are used within the field of medicine to talk about who patients are and the practices clinicians use. Values, rather than being the cognitive resources that individuals use to make decisions, are constructed from the idiosyncratic and disordered preferences individuals have and serve as a medium by which incommensurable attributes of individuals and situations can be rendered into comparable pictures. This sense of value does have its origins in the social economy of Marx ([1867] 1981) but deviates from its standard use in economic sociology and Livne in particular. In this view, preferences cause values rather than values causing preferences.

Lastly, though both Livne and I are investigating decision-making in hospital settings, my emphasis remains on the professional and organizational influences that determine what decisions can be made and which ones ultimately are made, while Livne emphasizes the role of a social movement in changing the underlying logic of medical care in hospitals at the end of life. Of far more importance in my analyses is how HPM clinicians can successfully collaborate with their colleagues in other areas of medicine, who have fundamentally different ideas about what ought to be done, not because of normative differences that exist because of a political commitment to reform, but due to their functional differences inside of an organization. These functional differences then have further higher-order influences on both their evaluative criteria for professional conduct and how they think and talk about what gets done during the work of treating patients.

1.4 The Structure of this Dissertation

To explore how the profession of medicine has dealt with the continued problem of death and inter-specialty collaboration I have conducted ethnographic observations and interviews with physicians and nurses around the country, collected the profiles of physicians from online databases, and gathered a great deal of ephemera regarding the history of one specialty of medicine and the structure of many others. As this data is going to be used throughout this dissertation I immediately introduce it in the following section, Chapter 2. In this chapter, I further outline the unique perspective I bring to bear on the issue of transparency and openness in qualitative social science, and the problem of missing data in particular in qualitative interviewing studies.

In Chapter 3, I examine the recent history of Hospice and Palliative Medicine and the social movement that led to its accreditation as an official subspecialty in medicine. This chapter shows that a number of diverging imperatives led to the formation of this subspecialty and that compromises between two competing groups continue to influence the practice of HPM. I further analyze the digital trace of the emergence of this area of medicine in the academic medical literature. Chapter 4 continues these analyses but focuses upon the contemporary practice of HPM and contextualizes the later chapters by providing a high-level analysis of the structure of specialization within which HPM is embedded and the training sequences clinicians complete before entering it.

Chapters 5, 6, and 7 are the main empirical chapters of this dissertation and rely upon the interview and ethnographic data to make a few claims about the specific work of HPM, the disposition to treatment in medicine generally, and the unique position of HPM in the networks of collaboration that form in the care of the chronically and terminally ill. In Chapter 5, I explore how HPM clinicians create evaluative criteria for their practices. This task is not a straightforward one, as the patient population they treat is not amenable to the dominant form of success clinicians in other areas of medicine strive for: patients cured or saved from imminent death and returned to a normal state of life. Treating patients who almost certainly will die in the near term means that HPM clinicians are often failing by the criteria commonly used in medicine to judge whether clinicians have done a good job or not. I find that HPM clinicians establish successful practice by orienting themselves and their colleagues to shared and achievable goals of medical care. In Chapter 6, I more closely examine this process focusing on how HPM clinicians create plans of care and relate to their colleagues and patients to constitute values from the idiosyncratic utterances of patients and form them into a coherent set of values that accord with the values held by clinicians.

Lastly, Chapter 7, aims to make a broader contribution to the sociology of professions and organizations by articulating how the case of HPM, the specific behavior of these clinicians relative to their colleagues in other areas of medicine, warrants sociologists amending their established theories for how professionals establish their domains of expertise and practice. Rather than carefully guarding and viciously defending their "turf", HPM clinicians have established a domain of practice between different areas of medicine that further bridges the practices of different clinicians. This can be most obviously seen in the repeated claims of my respondents that they do "what any doctor could do", which I identify as a kind of universal competence that is shared by all professionals in medicine. Such claims by my respondents are not easily explained by the ready-to-hand theories in the sociology of work and occupations, professions, or organizations.

CHAPTER 2

DATA AND METHODS

I started preliminary research for this dissertation in February 2020 with informal pilot observations with a palliative care service in a large teaching hospital. At that time in the hospital, there were only small rumors about a new flu in China. No more than a month later, that field site and the prospect of conducting in-person interviews, let alone observations of one of the region's largest hospitals swamped with patients, was definitively closed. I lamented the fact that I was not going to be able to complete my dissertation with a hospital ethnography in the style of Bosk's *Forgive and Remember* (1979) that had been of such note to me in my first year of graduate school. I completed data collection using remote interviews conducted with physicians and nurses from across the country. I continue to be impressed with the generosity of my respondents nearly all of whom were working in major medical centers across the country, who took time from their demanding work schedules to answer my questions. As the emergency of the pandemic tapered off, I managed to gain access to a field site and begin conducting observations two years after I originally intended.

In completing this dissertation, I have endeavored to attempt to overcome the opacity of qualitative research and attempt to "show my receipts", to give as full an accounting as possible for how I went from data to findings and insights. Attempting to improve on established methods is a very tall order, particularly considering that the attempt has no doubt been tried before. In this chapter, I review my recruitment strategy, interviewing technique, the instrument used, and the specific process used for analyzing completed interviews. I close this chapter with a discussion of the theory of interviewing, the logic of data imputation in qualitative research, as well as strategies for accounting for how we, as qualitative sociologists, arrive at our insights.

2.1 Data Overview

The data for this dissertation, except for portions of Chapters 3 and 4, were gathered through ethnographic observations, and remote and in-person interviews. Interviews were gathered from physicians and nurses working primarily in the inpatient setting on Hospice and Palliative Medicine services using a non-probability sample.[1] In recruiting respondents, I first collected lists of university-affiliated academic teaching hospitals with palliative care services, then collected the names of the faculty members and affiliated nurses with those programs. Second, I used the affiliated university's publicly available directory to cross reference collected names with email addresses and then sent direct appeals to the putative palliative care clinicians. Some individuals who were contacted did not qualify for the study, working primarily in a research function and having no clinical experience, and a larger proportion of direct appeals were never answered (response rate = .08). Further recruitment was conducted through snowball sampling from directly solicited respondents. Between February 2021 and May 2023, I interviewed 79 physicians and nurses working in HPM, Oncology, Cardiology, Emergency Medicine, and Surgery. Respondents are drawn from 46 different hospitals across 19 different states.

I primarily interviewed clinicians from HPM ($N = 67$, 86%) and clinicians from specialties HPM commonly collaborates with including five Cardiologists, four Oncologists, one Emergency Medicine physician and one Surgeon. One respondent was interviewed twice, and most respondents were attending physicians ($N = 71, 91\%$). Three respondents were Advanced Practice Nurses, two were Registered Nurses, one was a resident, and one was a fellow. All but three interviews were conducted remotely via Zoom.

Additional background information about respondents, including where and when they received their medical degree, whether they practice allopathic or osteopathic medicine, and residency and fellowships they completed, was collected from publicly available databases and public-facing profiles associated with their faculty and clinical appointments. Table 2.1 displays descriptive statistics for interviews and respondent characteristics. An inductive process was adopted for these interviews where an initial round of interviewing on general features of the work of HPM clinicians and analysis helped to sharpen the analytical focus on an emerging theme: the common problems

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[1] I refer to physicians and nurses collectively as "clinicians". If I specifically say "physician", this is because I am describing a feature of the medical field or the work of medical professionals that is unique to doctors or exclusively performed by them.

Table 2.1: Descriptive statistics for respondents and interviews.

	N	Mean	Std. Dev.	Min	Max
Interview Len. (Mins.)	78	45	11	24	68
Female (0/1)	78	0.56	0.5	0	1
MD (0/1)	73	0.95	0.23	0	1
Med. School Year	71	2001	11	1976	2018
Residency Year	69	2005	10	1980	2021
Fellowship Year	56	2009	8.8	1981	2022

respondents face in their clinical practice and the ways they resolve these problems. Once this focus emerged, a standardized interview guide was adopted and used for remaining interviews ($N = 42$).[2] Analysis of completed interviews was conducted in a similarly inductive way, with reading and successive re-readings and memo writing on analytically salient themes helping to further focus and refine sociological insights.

Rather than adopting pseudonyms for respondents when reporting quotes and anecdotes from the interview data, respondents are labeled with an anonymized code, using the following scheme: a prefix identifies the respondent's specialty (PAL for HPM, HO for Oncology, EM for Emergency Medicine, GS for General Surgery, and CD for Cardiology). A further prefix identifies the respondent's clinical role (PH for physician, N for nurses), and then a modifier for physicians identifying their "rank" after a slash (A for Attending, F for Fellow, R for Resident, RN for nurses and APN for advance practice nurses). There is then a three-digit suffix that identifies the order in which the interview took place. PAL-PH/A-002 was the second palliative physician to be interviewed, and they are an Attending, while PAL-PH/F-031 was the 31st palliative physician to be interviewed, and they are a Fellow.

The use of artificially constructed pseudonyms in the reporting of qualitative data inadvertently frames readers' interpretations and highlights attributes of individuals that do not directly represent their true social characteristics such as their cultural background, race, or country of origin (Heaton 2022); the use of codes is intended to avoid this possibility though I do indicate the gender and

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[2] For reference the standard interview guide can be found in Appendix A.

region of the country respondents work in to provide context.[3] Quoted material with "double quotation" marks indicates verbatim quotes, while material between single 'single quotation' marks is paraphrased. This convention was adopted from Livne (2019) and Jerolmack (2013).

2.2 Interviewing

Initially, I was skeptical about the prospects of conducting interviews remotely with respondents. Robert Weiss in *Learning From Strangers* (1995), an excellent book on the interviewing method, stresses that phone interviews generate comparatively lower quality data than in-person interviews as the lack of face-to-face contact reduces the engagement of the respondent and undermines the ability of the interviewer to quickly establish rapport and the appropriate frame for the conversation. Certainly, there were downsides to conducting interviews via Zoom: several respondents answered my questions from their cars as they ordered coffee at Starbucks, some answered my questions as they walked into work, and others arrived 45 minutes late, haggard from children stuck at home during the pandemic. Despite these drawbacks, there are some definitive upsides to remote interviews: for one, as Figure 2.1 shows, one advantage is that conducting interviews remotely allows one to gather data from subjects across the US very quickly. Without the constraints of traveling to respondents, or having them travel to you, multiple interviews can be conducted in a single day. Further, audio recordings of remote meetings are easily made with excellent sound quality and if respondents have their cameras on, very little is lost in the way of expressions that indicate salient emotional responses to questions.[4]

The first round of interviewing was largely exploratory and focused on what HPM clinicians

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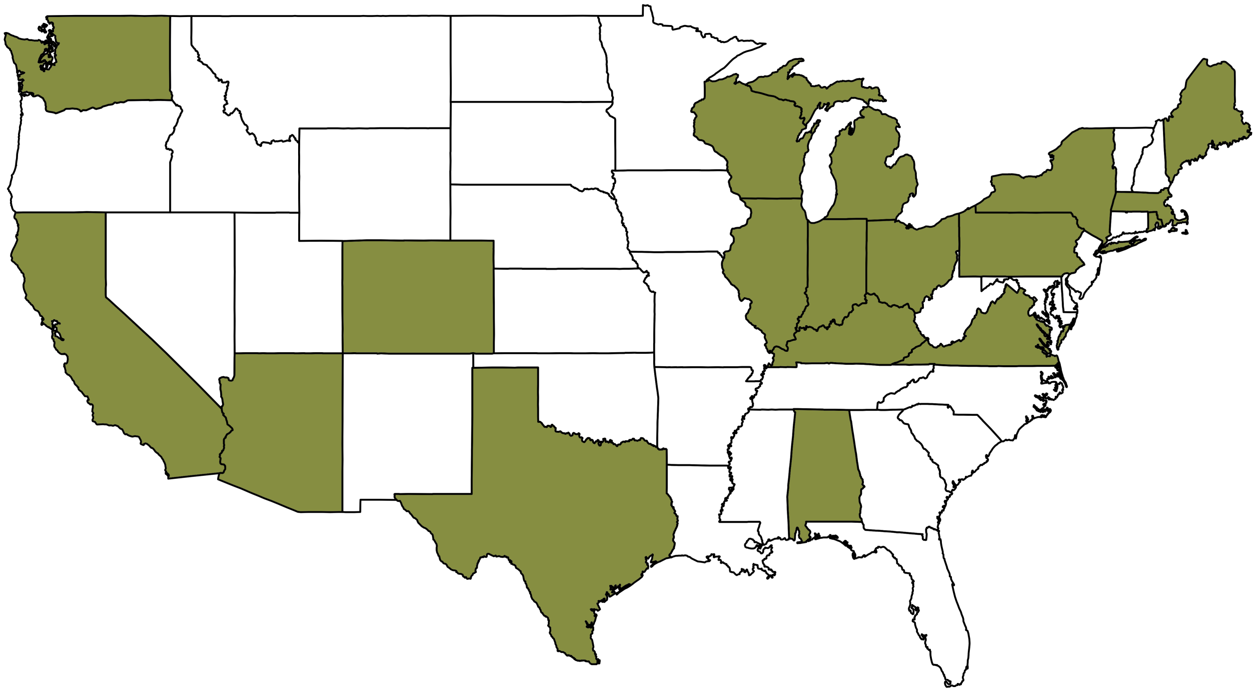
[3] Gender and the region in which respondents work does not directly influence the analyses in this dissertation, but these attributes are salient in much of the social scientific literature on medicine and work and I include them as they can be of interest to the reader.

[4] Physicians are particularly guarded about their time and if given the option, will opt for the shortest length for a meeting possible. My invitations to participate in my study indicated that interviews would last between "30 and 45 minutes". Conducting my research I discovered a helpful tool for maximizing the amount of time I could get from respondents: in the back and forth of scheduling, if a respondent gave three times in which they were available such as "between 3 and 4 PM Tuesday, anytime Friday, or between Noon and 5 PM Friday" I would choose the one hour Tuesday slot, knowing that this would very likely preclude the respondent from scheduling any other obligation at that time and guaranteeing an hour of their time.

Figure 2.1: States from which respondents are drawn.



do in their day-to-day work, and gaining a command over the complex idiom of medicine. In these interviews, I pursued lines of questioning that would help to elaborate upon how HPM is distinguished from other areas of medicine including the distinct patient population they treat, as well as the unique techniques and treatments they use. Very quickly, I identified what about this case is sociologically interesting; how these clinicians understand good practice given the fact they are so often working with patients who ultimately die of their illness. Treating the terminally ill is made further difficult, as these early respondents themselves emphasized because they are often consulted "late", as the patient is imminently dying and many consequential medical decisions have already been made that influence their well-being and disposition at death.

2.3 Length of Career by Training Cohorts

Considering the history and current practice of HPM that will be outlined in Chapters 3 and 4, the experiences of younger and older clinicians in this area can be consequentially different. Many older physicians in the field entered before its official certification as a medical specialty and so did not pass through the standardized curriculum now required to practice HPM. Further, as a nascent subspecialty with an ambiguous reputation they have a particular understanding of their relationship to other specialties compared to their younger colleagues, who completed their medical school education and residency training with HPM well-established in the medical mainstream. To help account for the influence that the length of respondents career can have on their experiences practicing HPM, I have plotted, in Figure 2.2, the number of respondents by five-year training cohorts based on three different indicators for career length: the year in which the respondent received their MD, the year they completed residency, and the year in which they completed their fellowship, if they completed one in any field of medicine.

As can be seen in the top panel of Figure 2.2, there is a fair representation of respondents across all training cohorts by medical school graduation year going back to the 1980s which is further echoed in the middle panel, which plots the year in which the respondent completed residency. The bottom panel does indicate that respondents who completed a fellowship are more likely to have done so in the last 15 years, possibly due to the recent certification of HPM and the creation of a definitive fellowship path. 28 respondents from HPM have entered the field through the official certification process since 2008.

As will be further explored in Chapter 4, there are a variety of paths HPM clinicians follow to enter this area of medicine. Respondents are drawn from a number of different medical backgrounds and these differences in training and practice are likely to leave traces in their current dispositions to patient interactions and ability to collaborate with members of other specialties. Table 2.2 shows the counts of HPM respondents by the primary board from which they completed their first specialty training. I define a physician's primary board as the area of medicine in which they completed their residency unless they have completed fellowship training, in which case the first fellowship they completed is considered their primary board.

The above overview shows the geographic, age, and training heterogeneity for respondents in my sample. They indicate that respondents are drawn from a number of geographic contexts and have been working for a varied number of years in medicine and HPM in particular. These

Figure 2.2: Five-year training cohorts by med school, residency and fellowship year.

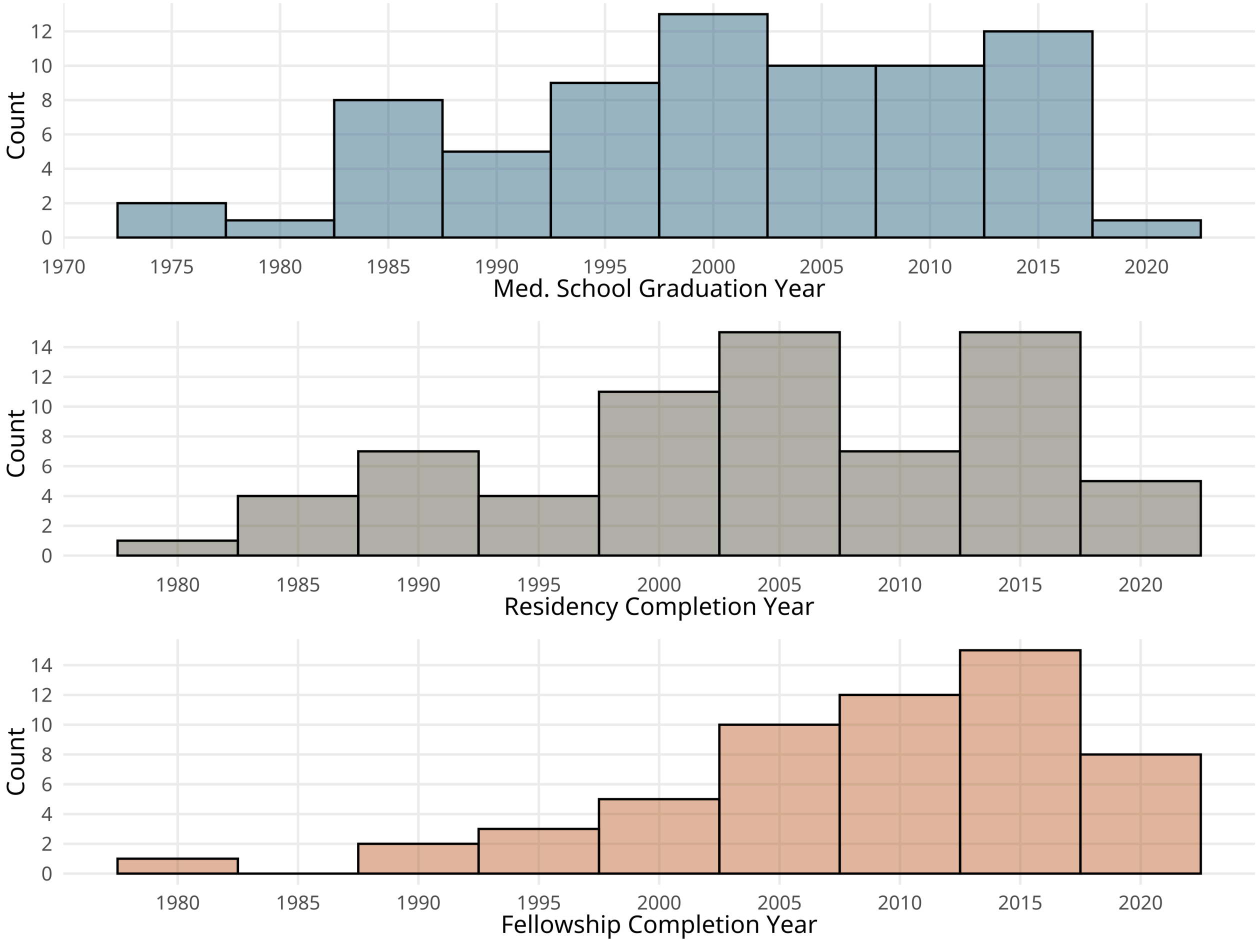


Table 2.2: Counts of HPM respondents by primary board.

Primary Board	N	%
Internal Medicine	29	43
Family Medicine	14	21
NA	5	7
Geriatric Medicine	3	4
Oncology	3	4
Psychiatry	3	4
Emergency Medicine	2	3
Neurology	2	3
Pediatrics	2	3
Anesthesiology	1	1
Gynecology	1	1
Pediatric Hematology/Oncology	1	1
Surgery	1	1

analyses provide important context for the insights I generate in this dissertation. Fortunately, I have had further opportunities to pursue data collection that afforded greater context for the interview material.

2.4 Ethnographic Observations

Between June 2022 and September 2023, I conducted in-person ethnographic observations with the palliative care service of a large Midwestern, university-affiliated teaching hospital. The IRB process for this research was very long, in part because it was reviewed and approved by the University of Chicago's Biological Sciences Division, which was unfamiliar with social scientific methods that use ethnography. I first contacted and gained initial access to this field site in January 2020 to conduct pilot observations before receiving IRB approval. When the University of Chicago's restrictions on in-person research were lifted and the research was approved by the IRB, I contacted the section chief of the hospital's section of Hospice and Palliative Medicine and requested the opportunity to pursue observations with their staff. After gaining the support of the section chief, I met with the majority of the HPM clinical staff and outlined the nature and purpose of my research, and what participation would look like for them. Verbal consent to participate in this study was gained from the focal research participants (HPM staff) as well as clinicians they might encounter whose interactions I would observe.

During my fieldwork, I completed approximately 150 hours of observations with physicians and nurses over approximately 40 days with 8 different clinicians. These observations were conducted primarily every week as a part of the research plan outlined to the clinical staff. On a normal day of observations, I participated in the HPM service's interdisciplinary meeting, where current fellows, rotating residents, and medical students, supervised by the attending on service, share their experiences working with patients. The meeting is both pedagogical when individuals share didactics on an area they are expert in, and cathartic. Meeting participants shared information on cases they were troubled by, or required assistance in navigating, as well as commenting on the work of their colleagues in other services. Meetings closed with a short memorial to patients who had been treated by HPM and who had recently died. After this morning meeting, I would follow one of the service's clinical staff for the day as they met with their patients during morning rounds. This would include visiting the patients' rooms and observing the HPM clinician as they interacted with the patient and any family members who might be present.

Great pains were taken to ensure that the privacy and autonomy of patients were protected in the course of this research. Patients are not considered research participants as per the research agreement with the IRB and so patients were not consented to participate. To observe the interactions of clinicians with their patients, I did receive HIPAA releases from patients that were signed by them or to which they gave verbal assent if they were physically unable to sign a form. When in a patient's room I did not take any notes and instead waited till the interaction was over and I was out of the room to jot down my observations. No identifiable information was collected on patients such as a precise age, name, or the name of the clinician with whom they were interacting.

The ethnographic data is used in this dissertation to supplement the interview data allowing first-hand experience of the work dynamics I heard interview respondents describe. Rather than mapping the talk outside the environment to action in the environment, I use these observations as an opportunity to contextualize interview findings and determine the legitimacy of different interpretations (Lamont and Swidler 2014; Pugh 2013). Observations afforded further evidence of the features of the work of HPM I commonly identified in my interviews.

2.5 Why Not Hospice?

The focus of this dissertation is the practice of clinicians working in the inpatient setting, and particularly how HPM clinicians work on the care of the chronically and terminally ill, interdigitating with their colleagues in other more traditional areas of medicine. This site presents particular barriers to analysis due to the privacy protections of patients and the busy work schedules of respondents. An early option in pursuing a dissertation that investigates the social constitution of the dying process in medical contexts was to pursue an investigation of hospice. Even after developing the interest in medical decision-making for terminally ill patients, a not infrequent suggestion was to pursue this line of questioning with hospice workers and patients rather than individuals working and being treated in the inpatient setting.

The key distinction between the treatment of the terminally ill in hospitals and those in hospices, or those patients being treated by experts in HPM and hospice workers, is that individuals pursuing hospice care have already made most of the consequential decisions they will make in their medical care. Pursuing hospice, rather than the care of a clinician in Hospice and Palliative Medicine in the hospital, is a decision to forgo a host of medical therapies. I focus on the inpatient setting rather than the outpatient setting or hospices because the inpatient setting is where patients and their clinicians have the most intense activity around determining what is wrong, what is appropriate to do about it, and all the collaboration and compromise that goes into deciding what *will* be done.

2.6 Selection Effects

In making comparisons to other kinds of specialists about whether they consider the death of a patient a failure, the kinds of clinicians who are asking for HPM's help may be systematically different from those clinicians who aren't asking for their help. This may lead to a selection effect influencing my findings about the different dispositions of clinicians in their evaluations of medical practice. The issue is separate from the kinds of patients that HPM sees, which are naturally distinct, because they are severely ill or dying, while most patients seeking care are not. The kinds of clinicians who are not asking for HPM to be involved in their cases, and so are not being captured by this research, may very well perceive the deaths of their patients as natural parts of their work and do not shirk the responsibility of their care, which my respondents emphasized they observe in some of their colleagues. Such clinicians might have a relationship with their patients similar to HPM, regardless of their specific specialization.

The influence of such a selection effect is likely tempered by the fact that, in the care of patients who are terminally ill, many kinds of clinicians are involved in their care and any single clinician can request HPM be consulted on a case. That means the kinds of clinicians that are going to ask for HPM's help might be unique, but the kinds of clinicians that HPM is working with are not.

Further, families can request that HPM be involved and though these requests could be ignored by the primary clinicians treating them, from my experience in my field site, it is a legitimate avenue by which HPM gets new consultations.

To account for this possible selection effect, the insights in this research should be confined to the understanding of a group of clinicians *contra* their colleagues in other areas that they are commonly working with. As my direct observation of other clinicians' behavior is restricted to a few instances, it is important to understand the comparative attitudes of different kinds of clinicians to the problems of death and collaboration in medicine as indicative but preliminary. HPM clinicians see their colleagues as neglecting an important area of their work, and this seems to result from the fact that this is how they perceive their colleagues' behavior.

2.7 Showing Your Receipts

In the opening to his book, *Talk at the Brink* (2012), David Gibson notes:

> Most qualitative sociology, once written up, comes with an implicit injunction: trust me. That is because while years of ethnography and/or interviewing regularly generate mountains of transcripts and notes (or, these days, their digital counterparts), what ends up in books and articles is, by necessity, tremendously distilled, and rarely if ever are readers given access to the raw data; consequently, they have no choice but to trust that the author's distillation is a faithful one.

There is no silver bullet to the problem of transparency in qualitative research as the process of doing any kind of research, writing it up, and communicating it to readers is meant to save the audience the time of having to do the very research themselves. A map is only useful because it is not a 1:1 simulacrum of the terrain it represents, but there are better and worse maps. Inclined to ecumenism, Gibson further notes a similar situation exists in quantitative research, but quantitative researchers are in an advantaged position relative to their qualitative peers to reveal the process by which they conducted their data collection and completed their analyses (Christensen, Freese, and Miguel 2019; Healy 2020). In this section, I will outline the means that I have adopted to help overcome some of these barriers to transparency that are ubiquitous in qualitative research, a method that I call “showing your receipts”

Showing your receipts means providing an accounting of how researchers went from their data to their insights. Naturally, there is all sorts of ephemera, both material and conceptual, that is generated in the process of conducting empirical research, and some of it is going to describe how a finding was made, but won’t be easily communicated or distributed. Some showing of receipts might reveal information researchers agreed to keep confidential, such as the identity of a respondent. In Gibson’s case, the solution was to use data that was already available to everyone and to restrict his analyses to that data, with minimal reliance upon background information that would take a great deal of time to hunt down.[5]

Qualitative research, though its process and data are substantively different from its quantitative counterparts, is amenable to the very process of transparency and reproducibility, what has come to be described as open science (Open Science Collaboration 2015). To address the issue of increasing the openness of qualitative research I will address the issue of missing data in qualitative research, how we should theorize missing data, and treat it as a problem in qualitative analyses. I will demonstrate how I have addressed this problem in my work and provide a framework for others to use to describe and address the problems themselves. Most of my comments will relate to interview studies but can be extended to ethnographic projects that deal with field notes and inductive coding.

The sacrosanct distinction between quantitative and qualitative research will impede the endeavor of promoting a more transparent data collection and analysis process in qualitative sociology, and the accusation that this effort is the inappropriate application of a quantitative paradigm to qualitative work is surely forthcoming. Good data and good data *management* speak for them-

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[5] This effort seems to have been in vain for Gibson. *Talk at the Brink* uses conversation analysis to examine the decision-making process of the Executive Committee during the Cuban Missile Crisis, and relies upon audio recordings of that body’s meetings. In the book, to allow the reader direct access to the data and to help make the analyses more transparent, Gibson provides a URL to a publicly available archive of the recordings and encourages the reader to examine them when reading specific sections of the book. Unfortunately, that archive no longer seems to have the recordings. I attempted to access the recordings through another source but 15 minutes of Googling did not reveal where the audio tapes might be accessed. The issue of the fragility of material stored on the internet is discussed in Abbott (2014).

selves, and it remains a critical precept of science whether one is in Physics or Sociology, and the distinctions drawn within scientific disciplines are not necessary nor inevitable. One of the key findings of this dissertation work is that professionals must have shared means of evaluating valued aspects of their work. Having shared criteria of evaluation for things like success and failure in clinical practice, and good and bad methodology in science are going to be key to justifying the continued existence of the profession as an independent area of human activity.

2.7.1 Metaphysics and Ontology of the Interview

Accounting for the insights generated from empirical data begins with understanding where that data comes from, thinking through both the process by which the data was generated (Martin 2017), and where it is distributed in the space of possible values it can take (Martin 2018). Qualitative sociologists have to do the former and have paid comparatively less attention to the latter. Particularly in the case of interviewing, researchers have to think about the instrument they use to get the respondent to say the things that they say (this usually means looking at the specific questions that were asked) but also the context in which those questions are asked (virtual vs. in-person vs. phone interviews, coffee shop vs. office vs. hospital room) and the interactions which are not captured by the process of audio recording and transcription but that can reliably influence what is said. Most importantly, qualitative sociologists have to think about what the practical activity of the interview entails; the respondent is given discrete tasks of recall and/or accounting that have their own distinct ontologies.[6] In the former, recall, the respondent is questioned about an event or experience that they participated in or observed. In the latter, the respondent is asked to provide an *explanation* of their own or other people's behavior. These are distinct cognitive processes and lead to different kinds of data.

Distinguishing these two processes is important for accounting for how data is generated and the forking search path that researchers meander down to get to their insights but these tasks are embedded in a much more recondite space that we should offer a description of. When I talk about

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[6] See Weiss (1995) for the classic account of this in Sociology and Martin (2017) for a recent discussion.

asking questions, particularly in the context of interviews, I mean this in two senses: there are those questions that we *ask our respondents* which are structured by the interpersonal dynamics of talk, and then there are those social scientific questions that we *ask of our data*. Ultimately what I want to do is account for the way that sociologists go from the process of asking questions of our respondents to asking questions of our data and then arriving at conclusions that we communicate to our colleagues and general audiences.

2.7.2 Missing Data and the Interview

One place in which qualitative sociologists should pay greater attention in terms of advancing the transparency of their data collection and analysis is the presence of missing data. To specifically address the issue of missing data in qualitative research I want to contrast two ways of conducting interviews: survey analysis and open-ended interviewing. The process of data generation in survey analysis is at bottom an interview, but an interview of a particular type, one that allows for the specification of missing data. Survey interviews follow a highly articulated instrument, and so missing data and non-response are clearly defined: "Refusal", the respondent refuses to answer a question, or the question was never fielded to the respondent and so is "Missing" (assigned the value -99 or NA). Why a question wasn't fielded to a respondent could be due to a variety of reasons, such as the respondent quitting the interview halfway through or the interviewer running out of time, or failing to ask a "sensitive" question due to the respondent's earlier behavior and to maintain rapport. The dominant paradigm for collecting and analyzing qualitative data doesn't allow for such precise specification of missing data and the problem is inherent in the Grounded Theory method that is now ubiquitous in qualitative projects.

Jack Katz in a recent review of Mario Small and Jennifer Calarco's new book *Qualitative Literacy*, lamented the under-specification of method in qualitative open-ended in-depth interviewing, and in particular the ubiquitous allusion to Charmaz's Grounded Theory in nearly every qualitative article (Charmaz 2006).[7] This method consists "of systematic, yet flexible guidelines for collecting

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[7] See Katz (2022) for the book review and Small and Calarco (2022) for the book.

and analyzing qualitative data to construct theories 'grounded' in the data themselves" and eschews "formulaic rules" [Charmaz (2006); p. 2]. In the Grounded Theory method, theory construction is coterminous with data collection and analysis, where the researcher toggles back and forth between the two activities. "Theoretical sampling" [Charmaz (2006); p. 104] is what drives the researcher's focus in their data collection: early data collection, followed by analysis of that data, and an iterative process of returning to the data and analysis, create categories that then inform more data collection and further analysis. Charmaz's work has been highly influential in qualitative sociology with more than 7000 citations to *Constructing Grounded Theory* (Charmaz 2006) among many other highly cited articles on the subject. Though there have been recent developments in qualitative methods and theory, notably Tavory and Timmerman's *abductive analysis* (2014), it remains a problem that qualitative sociologists have few firm theoretical alternatives to explain how they go from data to insight than Charmaz's framework.[8]

Grounded Theory when adopted as the primary means for organizing analysis and theory development presents sociologists with certain deep methodological problems. Reviewing the process by which it occurs will help demonstrate this: (1) a sociologist endeavors to do social scientific research, (2) they bring their social scientific acumen to bear on an area of social life that they find interesting enough to sustain their attention. (3) They read background literature on that area and its history, and approach possible key informants that will help them get access to a field site/more respondents. (4) The sociologist does pilot interviews/observations with an instrument they developed based on their background reading and early informal conversations with members of the area of social life they want to study. (5) The sociologist does more pilot interviews/observations because they haven't fully developed their core questions. (6) They discover a puzzle, write a standard instrument/core theoretical question, and continue to do the rest of their data collection and analyses.

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[8] Jerolmack (2021) is a recent example that attempts to show its receipts in that it uses a de-anonymized field site with respondents that appear by name. See Duneier and Carter (2001) for a classic example of ways of showing your receipts. And as noted above Gibson (2008b, 2008a, 2011) provides a reasonable alternative and one is unlikely to find Charmaz in his bibliography.

This form of data collection and analysis is deeply scientific as it encourages researchers to hew as closely to their data as possible and develop questions from their direct engagement with their area of interest. But it also means that missing data are inherent in the method, as one toggles between data collection and analysis and changes later stages of data collection based on information derived from the original sample. For example, it becomes quite difficult, using the Grounded Theory method, for a sociologist to understand the frequency with which a particular response to a question occurs in their interviews. If a sociologist is interested in knowing if people got high the first time they smoked marijuana (Becker 1953), but only asked it of half of their respondents because they didn't realize it was a phenomenon until halfway through the interviews. Only the second half of the respondents were given the opportunity to answer the question, so the researcher can adopt the survey analysis paradigm of treating the response as a binary nominal variable with a third response category for Refusal, but no estimate can be derived from the first half of the respondents. Maybe the question was only adopted because (saying 60 interviews were conducted in total in the project) interviewee 22 mentioned that they didn't get high the first ten times they smoked marijuana, but they kept doing it for other reasons. It seems that interviewee 22 has given an answer to the question that will ultimately be asked of the other respondents but their answer is ontologically different than if they had been directly asked the question.

Grounded theory is good because it encourages sociologists to closely adhere to the information contained in the data and indicates moments when the researcher should innovate upon the theories being used to make sense of the social world. But this process generates a problem, particularly in the case of open-ended interviews, which follow an inductive or otherwise less articulated and specified instrument, or closely related instruments are used in the course of interviews: it becomes much harder to say whether relevant information is missing due to non-response or some other reason, primarily because the question just wasn't asked.

2.7.3 Luck is the Residue of Design

The problem of missing data is inherent in the dominant mode of data collection and analysis in qualitative research, but researchers have a few ways of handling the problem. I review them here to motivate my contribution:

Ignore it

The primary mode for handling missing data in qualitative research is to ignore the problem altogether and treat all interviews as comparable, and to perform a kind of naive and taken for granted form of qualitative data imputation. When cases are considered sufficiently similar, one assumes that the observed relationships in later interviews probably hold for the earlier interviews. Ignoring the problem is not a very good way of resolving the fundamental issue primarily because it is sloppy and treats data as equivalent that was generated through different processes. Let me address this in terms of my own interviews: one of the things that I became interested in during my interviews was the different parts of their work that HPM clinicians find frustrating and how they deal with them. You can see that I started to ask about this by the 24th interview but compare the following two interchanges:

> Timothy Elder 22:47
> And so in the course of this kind of work, what would you say kind of regularly frustrates you or you think gets in the way of achieving what you might see as your principal goal in the course of your work?
>
> Respondent 23:07
> Another good question. I would say it’s more the system factors that are there. You know, it’s, that you have a pretty clear path for getting people out, but, for example, getting people out of the hospital, we have rules that are in place that ‘no you have a three day stay’, for example, before you can do that. And it’s like, ’well, they’re ready to go, what are we keeping them here for?

> Timothy Elder 33:22
> Can you maybe name a kind of influence, or an undue influence that might undermine patient autonomy? I don't mean, like a person.
>
> Respondent 33:36
> Yeah. I mean, it's all about money, man. I'm sorry to tell you.

Though they are not prompted with the same direct question, both PAL-PH/A-024 (the respondent in the first interview excerpt) and PAL-PH/A-025 (the second respondent) are speaking to fundamentally similar topics within the interview. PAL-PH/A-024 is frustrated by arbitrary rules, while PAL-PH/A-025 explains the unequivocal role that economic incentives play in structuring patient-physician interactions. Though PAL-PH/A-025 might be nonchalant in how they say this, it was clear from the context of the interview that they found it deeply frustrating. Both speak to a similar theme but these answers were not generated in similar ways. One was produced after the respondent was given the task of giving an account of what they find frustrating in work, the second was in response to accounting for a specific task within their work separate from what they find frustrating. The valence and intensity of these frustrations are different and in part that is revealed by how they arise in the interview context. Ignoring that fact will undermine the quality of analyses.

Pairwise and Listwise Deletion

In quantitative social research, there are established and accepted means of handling missing data using either listwise or pairwise deletion (See Table 2.3 for some data to use as an example): in the former, cases are excluded if there is *any* missing data in that case. If one wanted to predict the probability that someone voted for Trump in the last election, with listwise deletion cases 003, 004, and 005 are excluded in the analysis because they have missing data in any of the columns. In the pairwise deletion, all cases are included despite missing data as long as the dependent variable is included in the case. So with pairwise deletion, only case 003 is excluded.

Table 2.3: Example data with missing values.

ID	Age	Race	Gender	Occupation	Trump.Biden
001	25	Black	Female	Writer	Biden
002	55	Hispanic/Latinx	Male	Data Entry	Trump
003	18	White	Female	Student	NA
004	66	White	Female	Professor	Trump
005	34	Asian	Male	Nurse	Biden

This operation can be conducted in quantitative analyses where missing data is precisely specified (those -99s and NAs in the above table) and statistical tests can be performed to determine to what degree the data is missing at random and different thresholds determine the strategies that can be used for determining what to do with that missing data.

In qualitative research, the same is not true and there are conflicting incentives that produce a troubling tension: sociologists want to maximize their N because that lends credibility to their analyses and allows individual researchers to make claims about the larger population from which they are sampling. The logic and standards for making such claims are tortured in qualitative projects, and I do not review them here, but grant the assumption that a large N is something we use as a means of evaluating research and that individual researchers are motivated to maximize their N because it does lend them credibility.[9]

Pairwise deletion is a means of handling missing data where cases are retained regardless of whether or not they include missing data, but are excluded from any single analysis when there is missing data in the case relevant to the questions in that analysis. With Grounded Theory, all the cases in the dataset can't be compared because the same instrument was not used with every single respondent, so instead sociologists perform a naive pairwise deletion: every interview counts toward the total N but cases are excluded when doing specific analyses or articulating specific

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[9] Lucas (2014) argues that due to the ubiquity of non-probability sampling in interview studies the ability of researchers to make claims about the larger population from which they are sampling is negligible, and provides some convincing evidence: researchers can obtain fairly precise estimates of population parameters from non-probability samples, but correlations between variables are much more vulnerable to sampling bias. Much of social research hinges not on only estimating means but on obtaining the relationships between characteristics in a population. This is particularly true in interview studies such as mine, where the interest is to understand how a feature of individuals (their occupation in my case), impacts another characteristic (their work style).

findings. This leads to differences in the total reported N and the *effective* N in any given analysis.

Listwise deletion is likely an impossible strategy in qualitative research because it would be overly aggressive. There are many reasons why something might be missing from an interview, and, in the Grounded Theory method, nearly by definition there will be missing data early on when compared to interviews conducted later in the analysis. What's more, qualitative sociologists are not allowed to collect sufficient background data on a respondent or the context in which the interview was conducted to allow for the kind of analyses to specify what data is missing at what frequency.[10]

Both of these strategies seem ill-equipped to help with the problem of missing data in qualitative analyses because they either (1) create misleading signals as to the amount of data being used (with Pairwise Deletion) or (2) they are overly aggressive and destroy too much data.

2.7.4 Formal Sociology

I have outlined the problem of missing data in qualitative analyses for two reasons: missing data is a problem for making claims about the questions pertinent to our analyses, and we don't have good ways of specifying where the missing data is in our dataset and why it is there. One way of avoiding the problem of missing data is to adopt a standard template for interviews or ethnographic notes from the start, but the dominant method in qualitative sociology inherently generates missing data. What's more, this is probably a problem worth having, as a standardized approach would be inflexible to learning new things about the social world and developing pertinent, but initially unpredictable, insights.

To better account for where missing data is, and how it is missing (is it missing because a question wasn't asked of respondents or because the data is being asked a question it wasn't designed to answer), I will argue that sociologists should adopt a formal sociological approach (Simmel 1964). In doing this, we can describe with greater specificity how we arrive at insight and make the logic

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[10] Lamont (1992) is an example where such data collection was conducted and afforded greater specification of missingness.

of our analyses available for scrutiny. Such scrutiny helps motivate social researchers to do better research, to save face when their article is finally published and they can answer their critics in straightforward and explicit ways. The problem as to *why* the missing data appears where it appears is a matter of further speculation that requires both individual reflection and deeper methodological engagement than I have space for here.

Coarse Coding

Sociologists ultimately must be able to estimate the amount of data they have, and the specific way that data was generated. That is, we want to be able to have all the receipts and give a specific accounting of our findings by articulating what was asked to whom and how and what they said. This doesn't mean we try to undermine the richness of the answers that respondents give in open-ended interviewing, but that we can properly contextualize that rich data back into the process by which it came to be. To help elucidate this paradigm I return to my dataset, interviews with physicians and nurses working in Hospice and Palliative Medicine and allied fields about how they work together and how they relate to their colleagues and patients.

For my own data collection, I can break it up into three different periods: (1) initial interviewing with a general interview schedule. I began my interviews getting a sense of what these clinicians actually do, what an average day looks like, and learning the vernacular in which they spoke about their work. Medicine has its own esoteric language for talking about patients and illness and what were the important things they were orienting themselves to, such as what a nasal cannula was, what intubation means for a patient's quality of life, etc.. (2) After a period of initial interviewing (approximately 10 interviews) I settled on exploring a few of the salient features of the case that my advisors and I identified as sociologically important including what frustrates these clinicians in their day to day work, how they define success for themselves and identifying the colleagues they have a hard time collaborating with (approximately 25 interviews). The interview guide at this point was narrower but not definitive. (3) I had a standard interview guide that was applied to all respondents and explored the same themes (approximately 40 interviews). This means that roughly only half of my data is directly comparable, though they may still contain missing data.

There is an ontological asymmetry between a question that is asked and one that isn't and the answers or informative comments that are given for it. When a question is asked of a respondent, the respondent can either answer or not answer. But when a specific question is not asked of a respondent, it isn't the case that the respondent can either give an answer or not give one, though it *is* the case that it is a binary of whether or not some informative comment about that question was made in the interview. The respondent wasn't given the task of that question, and so they aren't not doing something by not answering. There are an infinite number of questions that the respondent is not answering in the interview, just as there are an infinite number of questions that are not being asked of the respondent. Coarse coding is meant to capture the consequential distinctions in how respondents manage to provide data that are relevant to the questions that sociologists ask. Further, coarse coding is meant to encourage qualitative researchers to preserve the context in which informative data are embedded, rather than treating data at a more atomistic level.

The basic schema for categorizing answers to questions that were and were not asked of respondents is outlined in Figure 2.3 where response categories are determined by a binary coding: in the top left of the figure, we categorize whether a question was asked of the respondent. If the question was asked of the respondent (value "1" in the binary coding), then we proceed to the top right of the figure and determine whether the respondent answered the question. If the respondent was not asked a question, they may still have rendered an opinion that relates to the content of that question, and so we proceed to the bottom right of the figure and determine whether the respondent made an informative comment about, or incidentally answered the question that was not posed to them.[11]

This schema is important for comparing interviews that use different but continuous interview guides. For example, I am interested in how clinicians in different specialties collaborate, as well as who is easy to collaborate with, and what are the biggest sources of frustration in their work. My

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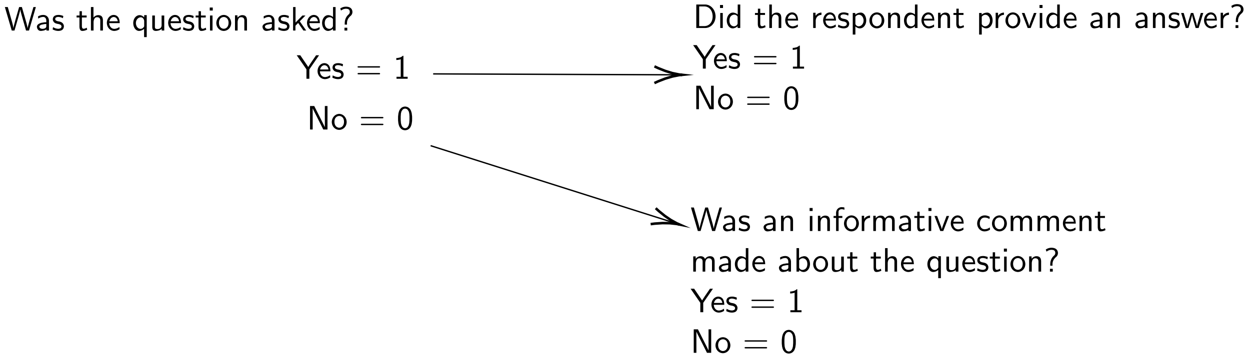
[11] One could consider that this schema is missing a relevant category: it could be the case that a respondent was asked a question and gave an answer to the question, but that answer failed to be informative. This could be the case if the respondent was obfuscatory or confused about the content of the question.

Figure 2.3: The relationship between questions asked and the informative comments respondents can make.



early interviews indicate these to be important areas for my research, but they were only asked of every respondent directly after a standard guide was adopted. To account for this I have developed the following *coarse* coding scheme (see Table 2.4 below). I call it a coarse coding scheme because it diverges from the common form of atomistic coding often adopted in qualitative sociology, and applies higher-order categories to large chunks of text. This way, when analyzing and compiling interview excerpts, the full context of a question and answer can be quickly analyzed. I'll address what this looks like in my own analyses.

I adopt the standard grounded theory method of reading and re-reading interview material. Initial readings and memo writing about analytically salient features of the case lead to different general categories that relate to the arguments I make. There are two generic kinds of coarse codes, nominal ones (does this interview contain an example of X, and if so where?) and categorical ones (given some number of choices, which one does the respondent endorse, and where?). For instance, in Chapter 7 I argue that niche construction, a theoretical paradigm from ecology when applied to the professions and medicine in particular, can help sociologists account for the full range of relationships of collaboration and competition that I observe in my dataset. I do this in part by recounting a variety of, based on the established literature, inexplicable behaviors on the part of the clinicians I interview. These include a few categories that I have identified as "Bridging" and "Reconciling". Each of these coarse codes is of the nominal type, where an interview can either have or not have an example of a respondent speaking to that category. Each category or coarse

Table 2.4: Classification of prompts and answers in an open-ended interview analysis.

	Asked		
	1	0	
Answered	0 (A)	1 (Y)	Informative
	1 (B)	0 (Z)	

code represents a question: does this respondent express an example of an interaction that can be defined as “Bridging” and “Reconciling”?

Sometimes respondents are asked about a specific choice they can make in their work. An example in my interviews is whether or not a clinician is willing to provide a patient with a direct recommendation about what therapy they should adopt. This is a question that I could have or not have asked of a respondent, and to which they could have or not have answered. But those individuals who were not asked the question can still make an informative comment either way. To account for this I use the following coding scheme:

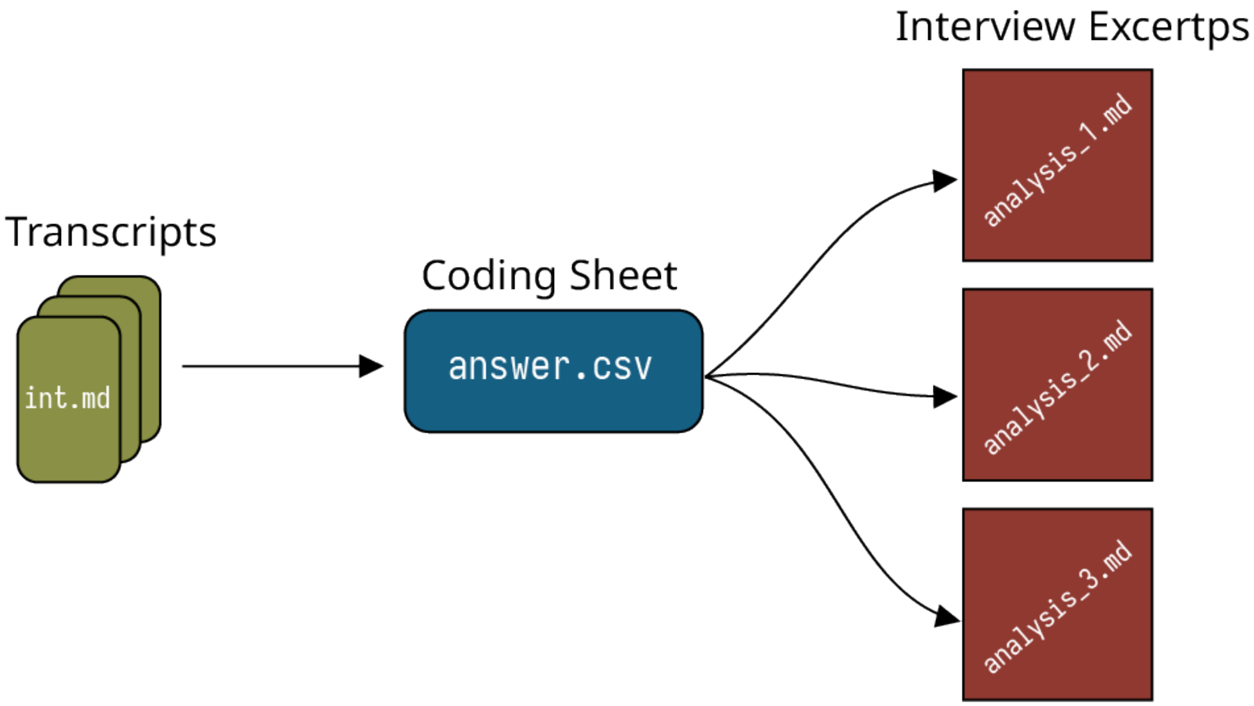
Rather than a classic 2x2 table where four distinct categories naturally follow from the relationship of the two dimensions, this coding system has two higher-order categories and two lower-order categories. In A, a question was asked and no answer was given so there is missing data. In B, a question was asked and the respondent gave an answer and there is data to analyze. Y and Z apply when the question was not posed to the respondent but they made a comment which indicates an answer to the question (Y) or they didn’t give any information about the question (Z). Category A is refusal and Z is missing.

When reading and analyzing interviews I then can insert these coarse codes into a tabular coding document where each row is a respondent, and each column a question. Table 2.5 shows an example of how this coding document looks (there are many more columns in the table that appear in the example). The columns in the example table show a few concepts relevant to my analyses: “SOURCEFRUSTRATE” relates to where respondents mention what the sources of frustration are in their work, while “HARDCOLLAB” and “EASYCOLLAB” relate to who respondents identify as being difficult and easy, respectively, to collaborate in their work. The “RECOMMEND” column indicates whether respondents describe whether they feel comfortable making an explicit

Table 2.5: Coarse coding document with time stamps.

ID	HARDCOLLAB	EASYCOLLAB	RECOMMEND	SOURCEFRUSTRATE
PAL-PH/A-042	B-Surgery (19:46)	B-Family Medicine/Internal Medicine (22:46)	0	Y-Colleagues (1:58)
PAL-PH/A-019	Z	Z	Z	Z
PAL-PH/A-026	Z	Z	Y (6:53)	Z
PAL-PH/A-041	B-GI (40:33)	Z	0	0
PAL-PH/A-023	B-Orthopedics/Trauma_Surgery (21:14)	B-Oncology (25:45)	Z	Z
PAL-PH/A-050	NA	NA	NA	NA
PAL-PH/A-020	Z	Z	Z	Z
PAL-PH/A-013	Z	Z	A1	Z
PAL-PH/A-011	Z	Z	A1	Z
PAL-PH/A-021	Z	Z	Z	Z
PAL-PH/A-016	NA	NA	NA	NA
PAL-PH/A-024	Z	Z	Z	B-System (23:07)
PAL-PH/A-049	B-Intensivists (31:29; 33:01; 33:22; 35:24; 35:33)	B-Emergency/Trauma Surgeons (27:50; 29:05; 29:13)	Y-(14:17)	B-Maximization (4:10)
PAL-PH/A-045	B-CT_Surgeons/Critical Care (27:24; 29:59; 31:53; 31:57)	B-oncologist (26:37)	0	Y-Visitation (07:54)
PAL-PH/A-025	Z	Z	Y (27:13)	Y-System (33:36)
PAL-PH/A-022	Z	Z	Z	Z
PAL-PH/A-027	Y-Cardiologists (42:43; 44:01; 44:03; 44:07)	Z	Y (21:04);A (50:25)	Y-Colleagues (33:28; 50:25)
PAL-PH/A-044	B-GI_Onc (30:05)	B-Genitourinary oncology (30:05)	0	Y-Patients (4:38)
PAL-PH/A-043	0	0	Y-(23:12; 25:30)	Y-Maximization (08:23)
PAL-PH/A-010	Y-Cardiology (30:00)	Z	A1	Z

Figure 2.4: From transcripts to compiled interview excerpts by category of analysis.



recommendation to their patients regarding what decision they should make about their care.

Clearly, from Table 2.5 there are lots of missing values in the data set. To help facilitate further analyses of the codes, I then compile interview excerpts into individual documents, where each document contains all the interview excerpts related to that code. Each speaking turn has a time stamp and so these are used to extract the speaking turn in which the informative comment was made. These are then compiled into individual documents for typesetting and further analysis. The process is visualized in Figure 2.4, where, using a short `python` script, plaintext markdown files store the interview transcripts (green rounded rectangles), and a CSV file (blue rounded rectangle) with the codes and time stamps of interview excerpts is then used to create individual markdown files (red squares) that contain all the relevant interview material related to that analysis.

2.7.5 Toward a Formal Qualitative Sociology

Quantitative scholars are more conveniently situated when it comes to showing their receipts in the process of asking questions of their data. They can share curated datasets, as well as the code they used to generate tables and figures. They can literally show their readers what they did to get the answers they got. They are disadvantaged when it comes to accounting for the process by which that data was generated. They oftentimes do not collect the data: they don't field the survey, nor do they build the sensors or determine the organizational structures that produce administrative data they then analyze.

Qualitative sociologists are advantaged in that they are integral to the processes of data generation, collection, and analysis. Every step of the way the qualitative sociologist can attenuate their data collection, or deepen it and critically reflect on their process. The hallmark of a good ethnographer or a good interviewer is the ability to turn themselves into a sensor of the social world, collecting data in both prosaic and decisive moments. This deep involvement with the data generation process comes with a troubling disadvantage in the tools afforded us for accounting for how we ask questions of the data that we generate.

In thinking deeply about how to show our receipts, I have lingered on a particular problem for a particular kind of sociologist: missing data in open-ended interviews due to the use of a non-standard interview guide. What's more, I have proposed that we do a better job of analyzing where our data is to allow us to see where we are missing information and how that data is missing. Quantitative sociology is not more scientific because it has numbers, theorems, or proofs in which it can communicate its process and insights. I do think such formalisms are the *lingua franca* of science, and an integral part of connecting theory and evidence but it is simply easier to translate quantitative work using that scientific vernacular. No one mode of data collection or analysis has ownership of this scientific language and I think that qualitative sociologists should make an effort to communicate their work with the formalisms that quantitative sociologists can so easily take advantage of.

The sociologist Stanley Lieberson wrote a compelling essay encouraging social scientists to interrogate the criteria by which they evaluate their research and to avoid adopting ill-conceived paradigms from the physical sciences (Lieberson and Lynn 2002). Physics envy has been leveled at the social sciences because of the success of that science in generating so much helpful material for creating more profoundly decisive technology and making sense of fundamental processes in the universe. But, physics is scrutinizing ontologically different entities from the social sciences, fundamental laws that apply across time and space, and that are amenable to unequivocal experimental methods and precise prediction.

The social scientific endeavor is better compared to methods found in biological sciences, particularly in the study of evolution. Darwin's data collection was long and arduous and not predictive, open to revision and dis-confirmation in an iterative process of theory creation through closely analyzing large swaths of observational data. Induction rather than deduction is the name of our game. But induction must be conducted with a great deal of care. Translating our process into the formalism of science, representing their relationships, and accounting for their being using a vernacular shared by quantitative scholars I think will go a long way in helping to more tightly couple qualitative data and analysis to insight and theory.

CHAPTER 3

A PROXIMATE HISTORY OF PALLIATIVE CARE

In the past 100 years, medicine has seen a seemingly inevitable and rapid technological advancement in the face of acute illness and death, and the coalition of science and medicine has come to define the most pristine example of the contemporary scientific enterprise. Medical research can develop a vaccine in less than 18 months of detecting a novel coronavirus, as well as transplant organs from different species into humans, among other seemingly miraculous interventions in the lives of individuals laid low by the vagaries of aging and disease. Speaking solely of the American experience, from its beginning as a formal institution in the 19th century to its height of power as an independent profession in the middle of the 20th, medicine has radically changed human life and experienced great shifts in its structure and practice.

With all of its architecture for innovation and research conducted at the population level, medicine is still oriented to decisive interventions in the individual lives of human beings. The primary locus of healthcare delivery remains the relationship between patients and the clinicians who care for them (Timmermans 2020). With the technological and epistemic advancements in medicine, so too has it become sophisticated in its internal structure, so much so that the term “doctor” captures a highly heterogeneous population of professional workers. Despite all its advancements in technology, technique, and organization, to the end of preserving human life, death remains the singular antagonist, and ultimate victor, in the medical drama.

At a time when death was a more domestic phenomenon, doctors would arrive at the bedside of the sick to announce the imminence and inevitability of death, or death visited through accident or trauma and such announcements were unwarranted, death being obvious and irrevocable (Hertzler 1938). With the rise of scientific medicine, immunology, innovations in public health and the development of life-sustaining technologies and procedures such as closed-chest cardiopulmonary resuscitation, ventilators, organ transplantation, defibrillators, chemotherapy and radiation therapy, illnesses and injuries that formerly guaranteed death became matters of extreme but routine medical intervention (Lewis 2007; Timmermans 1999).

These advances have contributed to the cultural standing of medicine as a profession, the generous remuneration of doctors for their services, and the sustained dominance and expansion of the purview of medicine over all matters related to human health. But, with the extension of life-sustaining therapies so too comes the discovery of new border territories between medicine's ability to intervene and the inevitable end of life. Life-sustaining therapies, procedures, and technologies come at a cost to medical payers, and are often uncomfortable; when a life-sustaining therapy promises that it will simply save the patient from death to return them to the dying state, with all its pain and discomfort, serious questions arise whether such an intervention is worthwhile.

The advances in medicine and the enduring discomfort and inevitability of death, as well as the inability of medicine to expand the clinical concern to issues faced by the dying, would eventually instigate the development of the subspecialty of Hospice and Palliative Medicine, an area that offers a fundamentally different paradigm of intervention. Where other areas of medicine are oriented toward sustaining life in the face of any and all malignancy, HPM seeks to address two distinct domains; pain and symptom management and goals of care. These domains are distinct from the life-sustaining imperative of medicine in general, but not mutually exclusive. Where an oncologist sees malignancies to be shrunk, excised, and killed, HPM specialists attempt to approach human illness from the subjectivity of those enduring it. In particular, they seek to address the experience of illness and keep it free of unnecessary suffering, as well as offer patients the alternative of forgoing further treatment. Many if not most of their patients will die from their illness in the near term, and they have little authority over the management of these patients' care.

This chapter seeks to achieve three objectives: (1) Provide an overview of the changes in medicine that created the need for sustained expertise in the care of the terminally ill. (2) Examine the specific organizations and their activities that originated the specialty of Hospice and Palliative Medicine. (3) Understand the emergence and influence of this area of medicine in academic literature.

The research in this chapter is based upon interviews with key informants who were party to the ongoing efforts to consolidate HPM into an official subspecialty of medicine. Further analyses were conducted through a literature review of the expansive works on HPM conducted throughout the 80s, 90s, and 2000s. Finally, I also conduct analyses of the emerging academic literature on HPM throughout this period using large-scale bibliometric data.

3.1 The Care of the Dying Through Time

Growing concern for the well-being of the terminally ill and the reliable ways in which medicine fails to maintain their well-being was sparked by the work of Elizabeth Kübler-Ross in her book *On Death and Dying* ([1969] 1978) which investigated the attitudes and experiences of the terminally ill. It is in this work that the 5 stages of grief are outlined, which Kübler-Ross developed while counseling the terminally ill at the University of Chicago. The influence of *On Death and Dying* was profound; though death has been a ubiquitous feature of human life, a critical feature of the fiction we read and watch, the taken for granted attitude, Kübler-Ross argues, has been to shun and avoid its personal relevance at all costs. This is noted in the work of philosophers and anthropologists, particularly Becker (1975) in *The Denial of Death* and Elias (1985) in *The Loneliness of the Dying*.[1]

Much of this history came to be documented by noted American Broadcaster Bill Moyers in *On Our Own Terms*, a PBS documentary series that examined the lives of the terminally ill and a novel area of medicine, palliative care, that was designed to help them. The documentary powerfully demonstrated the plight of the severely ill as they approached death and the issues they faced in the contemporary medical system, including requesting physician-assisted suicide, navigating the management of pain while trying to remain home, and the financial burden illness places on families. At the time, palliative care was practiced in few places and its content was largely at the

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[1] The “denial of death hypothesis” as it has been referred to in the social scientific studies of death and dying, refers to the belief that western societies are unique for their attitude toward death. This attitude is to deny its existence for us personally or collectively and that the management of the anxiety of death is a central organizing principle of culture (Greenberg, Pyszczynski, and Solomon 1986). Many social scientists have noted that this hypothesis is inherently unfalsifiable (Kellehear 1984; Zimmermann and Rodin 2004); the primary problem being that the hypothesis requires that social scientists be entirely skeptical of respondents’ self-report that they are not in denial of their mortality (Martin 2011).

discretion of the few physicians who sought to develop it.

3.2 The Early History of Palliative Care

Hospice first served to address these gaps in the care of the terminally ill. Hospices (derived from the Latin *hospitum*, meaning hospitality or place of rest and protection for the ill and weary) were first formed during the Crusades by religious orders such as the Knights Hospitaller to care for the dying. Throughout the Middle Ages and early modern period, religious orders maintained hospices in Europe mainly serving the destitute. The Irish Religious Sisters of Charity started the Our Lady's Hospice in Dublin in 1879 and the St. Joseph's Hospice in London where Cicely Saunders, the most influential modern advocate of hospices, began her career.

In the histories written about hospices and palliative care, the influence of Cicely Saunders cannot be understated. She was a nurse and a social worker who would eventually obtain a medical degree in 1957. She developed a long-standing interest in palliative care, including "total pain" (physical, psychological, spiritual, existential), the use of opioids for physical pain in the ill, and the care for other stakeholders such as family. After establishing what is considered the first modern hospice, St. Christopher's in London in 1967, Saunders introduced the main tenets for specialized care of dying patients to the US during a lecture at Yale University in 1963 emphasizing the "holistic care of these patients as well as the potential for successful, aggressive symptom control in their last days of life" (Lutz 2011).[2]

A variety of social and cultural changes in the US precipitated a growing interest in the needs of the chronically, terminally ill, and the imminently dying. To better establish the history of the development of palliative care in hospices and later the subspecialty of Hospice and Palliative Medicine, I have interviewed several key stakeholders in this early social movement. I present these interviews as a historical narrative, reviewing the specific organizational innovations that were key to the development of this area. In doing this I will describe how two dueling movements

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[2] I have not been able to find a copy of this lecture and am not confident a complete transcription of it exists.

converged and diverged, collaborated, and competed with one another over several decades. These two groups can be described as a counter-cultural "Hospice Movement" and a more mainstream academically oriented "Palliative Medicine" movement. I will describe the leaders of the Hospice Movement ("hospice leaders") and the academics in the Palliative Medicine movement ("palliative leaders"). In recounting this history, I seek to avoid portraying one group as antagonists to a group of protagonists in a historical drama, nor to portray the creation of this area of medicine as an inevitable product of fundamental cultural forces in medicine or society. Though I try to avoid doing this, I fear that I may pay preferential treatment to one group over the other and this is in part illustrative of the cognitive relationship of the key informants to this process. I have attempted to present an impartial accounting of the past, but as one of the primary mechanisms for analyzing the past is the accounts of individuals, it is inevitably tied to *their subjectivity* and membership in a social group. I present the accounts of these key informants but do not treat them as sacrosanct and have endeavored to, where possible, independently confirm names, dates, and events.

The early history of HPM in the US was marked by a deep tension between the counter-cultural impulses of the Hospice movement and the academically affiliated doctors who sought to establish palliative care as a specialty in medicine. The hospice movement first began in the US in hospitals, with several inpatient hospices being established around the time Cicely Saunders delivered her influential lecture at Yale. One key stakeholder in this development (PAL-PH/A-060) noted that three hospices were established around 1974 in New York, New Haven, Connecticut, and Montreal, Canada. Contemporaneous to the establishment of hospices in the Western Hemisphere, a surgical oncologist at the Royal Victoria Hospital of McGill University in Montreal created the term palliative care (Loscalzo 2008). Due to the ancient origins of hospices and the term's association with the care of the destitute throughout the 19th century, it was an unappealing prospect for individuals to seek care in them. The distinction between palliative care and hospice is important to keep in mind: "Palliative care" is a *type of medical practice* that focuses upon the reduction of suffering, while hospice is a particular *organizational form* of that care that focuses upon the terminally ill. Hospice and Palliative Medicine is a specific medical subspecialty that was formed to advance and organize the practice of palliative care both in hospices and in hospitals broadly.

The early inpatient hospices were undermined by the inclusion of a Hospice Benefit by Medicare which allowed the federal government to pay for the care of the terminally ill: the medicare Hospice Benefit allows for hospice care to be paid by federal insurance if (1) a physician certifies that a patient has a terminal diagnosis with a prognosis of six months or less, and (2) the patient agrees to forgo therapy directed at curing their illness or increasing their longevity. If a patient survives past the six months of coverage, they can then be re-certified with a prognosis of six months or less and continue hospice care. The Medicare Hospice Benefit allowed for a modest *per diem* payment for hospice patients to cover their medical expenses and severely limited the kinds of palliative treatments patients can receive. This *per diem* model of coverage has also led to a kind of "risk pooling" in hospice care: different patients will require different levels of care during their stay, some simply require a place to die, while others require intensive management and application of pain medicines, or other expensive medical equipment to properly attend to. These different levels of care entail different costs, so there is an incentive to construct an appropriate pool of hospice patients with many cost-efficient patients and fewer cost-intensive patients.

The most important part of the Medicare Hospice Benefit for the development of Hospice and Palliative Medicine is its dual influences: providing a benefit for hospice coverage meant there was an expansion of hospice care in the United States, but its emphasis on home health care meant that inpatient hospices were abruptly cut short. The bill does cover "short-term inpatient care […] in an inpatient facility […] but such respite care may be provided only on an intermittent, non-routine, and occasional basis and may not be provided consecutively over longer than five days" (Stark 1982), while it specifically defines a "hospice program" as an agency that "provides for such care and services in individuals' homes, on an outpatient basis, and a short-term inpatient basis, directly or under arrangements made by the agency or organization". Inpatient care was severely limited by the Medicare Hospice Benefit and essentially cut off inpatient hospices from federal funding. PAL-PH/A-060 noted that "while the benefit is best known for like, saying hospice is the last six months of life, and the palliative goals of care, the way they really kind of stacked the deck [is by] mandating that only 5% of funds be used for inpatient care. That pretty much killed a nascent inpatient hospice movement."

One important player in the hospice movement, which also contributed to its academic development was critically exempted from the federal government's outpatient mandate for hospice care. The US Department of Veterans Affairs was an early adopter of hospice and continued to provide inpatient hospice care to veterans:

> Jim Hallenbeck was one of those VA pioneers that kind of wrote some of those first palliative care standards in the VA, and was instrumental along with several other people to kind of get the VA going on the palliative care path. And the powerful thing about a big healthcare system, like the VA is, once you sort of put it out there, then it gets kind of disseminated, it gets sort of diffused throughout the system. It takes time, not all the VA's do it well, but there are many outstanding hospices and palliative care programs out there now. [...] So the VA has deep roots in hospice and palliative care. (PAL-PH/A-059)

The Veterans Affairs-administered hospitals continue to provide generous remuneration for hospice and palliative care to this day and were also an early sponsor of Geriatrics and aided the development of this specialty through the 1980s. The VA's focus on both geriatrics and palliative care was in part the result of the population of elderly veterans whose care the agency was charged with (Hallenbeck 2009).[3] The VA established one of the first fellowships in palliative care in the late 1990s.

Palliative care was largely excluded from academic medicine with most physicians working in outpatient hospices. Physician leaders working in this outpatient setting who sought greater influence in the academic medical system were "getting frustrated because it was pretty obvious that the hospice movement, while hospice was expanding, it was not affecting in any way shape or form, dying or chronic, seriously ill patients that were in the hospital system" (PAL-PH/A-060). Hospice leaders sought to establish care for the terminally ill as a "totally separate entity" from "the standard healthcare system", following the paradigm established by Cecily Saunders in

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[3] The limitations on who qualifies for hospice care continue into the present though there are two populations of individuals who qualify for the highest acuity of palliative care while being able to continue seeking curative treatment: veterans and children.

the UK. PAL-PH/A-060 notes that through the 80s and 90s physician leaders emerged that were questioning this paradigm for the organization of hospice care in the US and 'based on the Willie Sutton principle'[4] asked, "Where are the chronically ill and dying people? They're all in hospitals. Somehow we have to go there."

Growing tension between early hospice leaders and palliative medicine physicians widened the cleavage between the two informal professional groups: hospice leaders, those individuals who founded early hospice organizations and sought to keep them separate from mainstream healthcare, and palliative medicine physicians who sought to integrate palliative care into the mainstream in-patient settings of healthcare delivery. The tensions were long-standing due to the clashes of two different cultural dispositions. PAL-PH/A-061, an influential and early palliative care physician leader in the US, describes hospice as a "counter-cultural movement in the early days" largely organized and staffed by nurses and non-academic physicians (PAL-PH/A-061). Hospice leaders were ambivalent about including academic physicians in the movement, with PAL-PH/A-061 describing that "there was not a desire to bring those controlling evidence-based doctors into the field". Many hospice leaders followed in hospices long tradition of religious affiliation and espoused a "fundamentalist religious perspective" in the care of the dying. PAL-PH/A-062 described that hospice leaders "thought of themselves as sort of the misfits because they were doctors working in hospices. They all felt like they were sort of outside the mainstream".

The divide extended to elements of practice beyond the integration of hospices or palliative care into the medical mainstream. Disagreements about the appropriate use of medical therapies were a critical gulf between the two groups: one of the early motivations of the hospice movement was to undermine the medicalization of the dying process (Abel 1986; Syme and Bruce 2009). PAL-PH/A-061 describes a particular disagreement about end-of-life delirium that was a matter of controversy between the two groups, a disagreement that is indicative of their broader orthogonal

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[4] Willie Sutton was an American bank robber with a very prolific career. He is noted for the apocryphal answer to the question of why he robbed banks saying "Because that's where the money is". The quote has had a long life and has come to define a particular heuristic in medicine known as Sutton's Law (Altman 1970; Rytand 1980) where, when diagnosing patients, one should begin with the diagnostic procedures that are most likely to render a clear diagnosis, and which focus on the most obvious causes.

dispositions to practice:

> patients at the end of life get very delirious and confused [...] it's a very scary thing. And the position among a lot of the people in hospice at that point was, don't treat it, this is a natural part of the dying process. And that this has healing and therapeutic value for patients. You can't argue that it's a natural part of the dying process but to be scared out of your mind and feeling like you're being attacked by monsters is a terrifying thing and if you could treat it you should treat it. [...] [Hospice leaders didn't] want to use those kinds of treatments and were not recognizing delirium as a disease or disorder of the brain.

The counter-cultural elements of the hospice movement largely resisted the changes palliative medicine physicians sought to implement including the advancement of the field toward an accredited and certified specialty in medicine. This move toward mainstreaming was first begun via several name changes that occurred across several organizations that were first established to promote hospice in the US: the Hospice Nurses Association changed its name in 1988 to the Hospice and Palliative Nurses Association, the National Hospice Organization changed its name in 2000 to the National Hospice and Palliative Care Organization and the Academy of Hospice Physicians changed its name 1998 to the American Academy of Hospice and Palliative Medicine. The last of these was particularly contentious.

At a meeting of the Academy of Hospice Physicians in Snowbird, Utah in 1996 attended by some leaders from both the hospice and academic physician wings, including Balfour Mount, PAL-PH/A-060 describes that "there was a group of old-time hospice docs who didn't want any change. They didn't want anything to do, frankly, with health care systems or hospitals" (PAL-PH/A-060). During the meeting the organization attempted to change its name to the American Academy of Palliative Medicine, but due to the emotional appeal of the organization's founder, Josefina Magno, the decision was made to compromise, retaining the hospice moniker, and called the organization the American Academy of Hospice and Palliative Medicine. The compromise was meant to ensure that the organization remained intact:

> I and others advocated strongly, the last thing we need is to be splintering into a

> bunch of smaller groups, to have the hospice physicians and then the hospital palliative medicine physicians. And there'll be a different association from the outpatient palliative medicine. And do you mean ambulatory outpatient in the clinic, or do you mean making home visits? There are all these little splinter groups and I argued well, and others that from trying to have an influence in American medicine, the last thing you wanna do is to break up into a bunch of small groups. Look what happened to the surgeons for god's sake [...] You need to be able to manage your differences, but speak with one voice and have enough members so that you carry weight and that point of view carried.
>
> So we have this weird name for the specialty association, which got transferred to the specialty because why open up those wounds? Let's not fight about the stuff that won't matter that much, let's focus on what we really wanna achieve here. And, um, at least that's as far as it's come. Now, what will happen in the future, there are still those pressures of people's hospital-based practice, people feel like they're on a different planet from the home visit hospice docs. And for them to all be in the same professional association or to have the same certification exam is a little odd. But you see it in cardiology, you know, the electrophysiologists are very different than the heart failure docs, which are very different from the, from the valve replacing people. They all exist in cardiology. (PAL-PH/A-062)

Further changes in the late 1990s precipitated the movement toward specialization and accreditation of Hospice and Palliative Medicine. The *Oxford Textbook of Palliative Medicine* was first published in 1993 with further editions in 1998, 2004, and 2011, lending credibility to the academic *bona fides* of the area of medicine. The Project on Death in America (PDIA), funded by George Soros's Open Society Foundation, established a "Faculty Scholars Program" that provided "scholars with two to three years of support for 60 percent of their time on activities to improve professional practice and education related to end-of-life and bereavement issues" (Open Society Institute 1998). From 1994 to 1997 the program funded 38 faculty across the US and Canada. PAL-PH/A-061, who was Director of the Faculty Scholars Program at PDIA notes that it was this program that galvanized change in the movement of academic Hospice and Palliative Medicine, with scholars who "were interested in a little bit more of a rigorous organization that also wasn't just about hospice in the home but was also trying to get it into hospitals and nursing homes and other healthcare institutions".

Several academic studies began supporting palliative medicine physician's call for a medical specialty within medicine. In the 1980s a push in medicine to establish enhanced care for the chronically and terminally ill through mechanisms to ensure cooperative decision-making and communication between physicians, patients, and their caregivers was implemented. After the passage of the Patient Self-Determination Act (Sander 1990), which mandated "that a patient's right to self-determination in health care decisions be communicated and protected. Through advance directives–the living will and the durable power of attorney–the right to accept or reject medical or surgical treatment is available to adults while competent so that if such adults become incompetent to make decisions, they would more easily continue to control decisions affecting their health care" (Kelley 1995). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (commonly referred to as the "SUPPORT Study") (Connors 1995) sponsored by the Robert Wood Johnson Foundation and led by Joanne Lynne was meant to establish the effectiveness of the interventions mandated by the Patient Self Determination Act in the care of patients with life-threatening illnesses. Despite its aim and generous funding, the SUPPORT Study failed to find convincing evidence that advanced directives and other initiatives were helping and "that increased efforts to improve communication about patients' preferences for end-of-life care to physicians did not have a significant impact on the care that is provided in hospitals" (Oddi and Cassidy 1998).

The findings of the SUPPORT Study coupled with the well-publicized medical misdeeds of Jack Kevorkian, who promoted euthanasia and aided terminally ill patients in committing suicide, further demonstrated the desperation of the dying in the medical system[5]:

> I think that a lot of the movement towards developing a field came from his [Kevorkian's] misdeeds. I think there's truth that he was a factor. And then the other thing that was in the early nineties, the SUPPORT study was published [...] there had been this big

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[5] The recognition that systematic efforts to change the US medical system to be more attuned to the needs of patients persists today. One respondent in describing the "hubris of medicine" said that "despite lots of effort, and trying and trying to change the culture of medicine, in this way, it has been a colossal failure. And I think that there's some growing recognition about that, especially in the palliative care literature, like a great example is the use of advanced directives. There's just been, you know, decades and billions of dollars worth of research and like trying to get more people to do advanced directives and trying to get the health care system to use advanced directives. And they don't change anything, they probably don't do anything. The other big one is like trying to get oncologist to change how they talk with their patients about what's going on with their cancer, especially when it's incurable. And again, despite decades of research and thousands of studies and all these different tools and things to try to change it, it hasn't really budged the needle very much at all. Yeah, which is good for me, keeps me employed, but it sort of reflects that like the issue that we're trying to address with this are just such bigger issues that probably extend just outside of medicine, and probably are reflecting of like culture and just like more universal human issues, like you know, death anxiety and stuff like that" (PAL-PH/A-036).

> hope that there would be a single magic bullet that would solve end-of-life problems in the United States. And that SUPPORT was gonna like, show the way, and it was a total bust, like a 30 million dollar bust. (PAL-PH/A-061)

The Robert Wood Johnson Foundation not only funded the SUPPORT Study but provided the organization and initial funding for the Center to Advance Palliative Care (established in 1999) with Diane Meyer, a geriatrician at Mount Sinai in New York City as its head (PAL-PH/A-005), which served to organize the academic palliative medicine physicians. It was at a meeting of the CAPC group in March 2005 where the decision to pursue accreditation was made.[6] PAL-PH/A-060 describes that:

> It was the most amazing meeting because basically, we had two questions before us: should palliative care and palliative medicine become a medical subspecialty, thumbs up or thumbs down? And incredibly, should we let the Academy of Hospice and Palliative Medicine run the show? That was really presumptuous because the current and four prior presidents of the Academy were there." A concern for the integrity of the initial social movement and its unique perspective on the care for the dying continued: "So many of the leaders at that time, even at very high levels, were seeing palliative care as a relatively revolutionary workforce within medicine and if we went for formal subspecialty status under ACGME that would somehow weaken us.
> (PAL-PH/A-060)

ACGME, the Accreditation Council for Graduate Medical Education is the organization charged with accrediting all graduate medical training programs for physicians in the United States and would determine whether the movement would achieve official recognition.

3.2.1 Path to Accreditation

The organization of medicine in the United States is complicated, and the process by which novel areas of medicine become certified as an accredited specialty is even more Byzantine and obtuse. An essential distinction that must be drawn is between three organizations: (1) certifying agencies, (2) professional organizations, and (3) training organizations. The ACGME is the certifying agency

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[6] Many notable physicians in the field were members of the meeting including Christine Cassel, Diane Meyer, Timothy Quill, Robert Arnold, Joanne Lynne, Susan Block, James Hallenbeck, David Weissmann, Charles van Gunten and Jim Tulsky.

that is charged with ensuring that training programs are meeting essential standards of physician education while the American Board of Medical Specialties is the training organization charged with evaluating specialist areas. The American Medical Association is the professional organization that represents the interests of physicians. Despite their distinct mandates, each is interdependent and to become a medical specialty, an area of medicine must coordinate its activity to appeal to all three. This process is fraught with epistemic, practical, organizational, and political challenges.

PAL-PH/A-062, who led palliative medicine's efforts at accreditation noted that between these three organizations, "there are areas where there is alignment, and areas where there is conflict". American medicine is distinct for its level of specialization, and in the late 90s and early 2000s growing concern regarding the numbers of primary care physicians in the US led to talk of a "moratorium on new specialties' due to"a sense that this is getting out of control".[7]

To overcome this hurdle the nascent specialty had to establish that there was evidence of a need for the new specialty, that physicians were already practicing in the area, and that there were educational and clinical standards for practice. The first of these was in part established by the growing recognition that reforms in medicine were not effectively addressing the distress of the chronically and terminally ill (Lynn et al. 2000). To further emphasize the need for specialized palliative care, PAL-PH/A-062 noted the ubiquity of the need for palliative medicine's paradigm of treatment in medicine generally:

> You can find [palliative care] in every aspect of medicine. You can find it in [pediatrics]. You can find it in family medicine, all the subspecialties of internal medicine, anesthesiology, psychiatry. So it has these applications broadly among the way American medicine is divided up.

To secure the second requirement for a new specialty, PAL-PH/A-062 led an effort to establish a parallel set of organizations to those already present in medicine: "the best way to go forward was to set ourselves up as if we were already a specialty [...] we set up our own certification exam. We promoted our own standards for fellowship training, and we tried to make sure everything looked

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[7] See Christakis (1994) for more information about the contemporaneous concerns about the number of primary clinicians and the draw to specialist care.

exactly the same as the recognized ones." The American Board of Hospice and Palliative Medicine (ABHPM) was established in 1995 to organize the certification of new specialists, though certification was not officially recognized by mainstream medicine. Between 1995 and 1998, ABHPM certified 623 physicians coming from a variety of different areas including 4% from anesthesiology, 23% from family practice, 55% from internal medicine, 1% from pediatrics, 2% from radiation oncology, and 2% from surgery (Gunten et al. 2000).

By 2000, palliative medicine had established the three essential features for a new specialty with standards and curricula, a well-developed workforce, and a demonstrated need for the specialty. A final hurdle was to find an established medical specialty board that would sponsor the new specialty to be evaluated for membership in the American Board of Medical Specialties. A few candidates were approached and due to the large proportion of HPM physicians coming from Family Medicine and Internal Medicine, the boards of these specialties were considered appropriate sponsors.

PAL-PH/A-062 described that the "American Board of Family Medicine would not support new subspecialties because they viewed that as an erosion of family medicine so we went after Internal Medicine". PAL-PH/A-062, located in Chicago, leveraged the city's convenient geographic location and the fact that multiple healthcare agencies, including the AMA and ACGME, were headquartered in the city to lobby for membership and sponsorship. "It's either a quick walk or a short cab ride to anybody's office […] So I never called anybody. I made an appointment and I ran over and saw them in their office. Well it turns out it's really hard to say no to somebody who's sitting in your office." Through extensive politicking PAL-PH/A-062 was able to secure the support of the American Board of Internal Medicine (ABIM) to sponsor HPM for candidacy at the American Board of Medical Specialties.

The American Board of Medical Specialties is a conglomerate of all the specialty boards of American medicine, and the internal politics of that organization complicated the process of attaining certification for HPM:

> [ABIM is] enormous. It has enormous power at the American Board of Medical Specialties. Surgery, in contrast, split up into a bunch of little independent boards [...] what I learned was [the surgeons] felt like internal medicine was a bully. They were

> tired of the American Board of Internal Medicine bullying them around and telling them what to do.

Despite this, the HPM leadership wanted to keep HPM specialization open to a broad swath of medical specialties including Surgery. The surgical specialties and the American Board of Family Medicine both were unwilling to sponsor HPM but expressed interest in offering co-sponsorship if a sponsor could be found. Ultimately nine boards of medicine would cosponsor HPM for membership in ABMS. With sponsorship, HPM was certified as an official sub-specialty by ABMS in 2006 and the first physicians were certified in 2007.

The emergence of HPM was a product of a social movement within medicine, with two opposing visions of how it should be practiced: one was counter-cultural and sought to remain independent of the traditional and established institutions in medicine. The other sought to integrate this area into mainstream medicine as one more specialty within the sophisticated division of labor. Modern medicine is a domain in which the scientific values of objectivity and empiricism are prized and so it is little surprise that the vision of HPM which conformed to these values won out. It is further clear from this history that the creation of a scientific basis for the practice of HPM was a strategy for finding support among the wider community of clinicians and scientists in medicine. The efforts of the SUPPORT Study, which sought to establish the efficacy of clinical procedures short of palliative care in the treatment of the dying, revealed the need for more robust interventions. The Project on Death in America's Scholars Program created a pathway for academic clinicians to produce research that established HPM as a legitimate area of study, and the *bona fides* to enter high-status medical institutions. Clinical scholars producing academic research that supported the claims of palliative care's efficacy were instrumental to the endeavor of establishing the specialty. I want to next focus more closely on the emergence of this area of clinical practice from the scientific literature produced about it.

3.3 The Emergence of Palliative Care in Academic Literature

To better understand the emergence of this area of medicine I conducted bibliographic analyses of the emerging literature on palliative care using Open Alex, a fully open catalog of the global research system that includes data on academic publications, authors, institutions, research funders, and journals (Priem, Piwowar, and Orr 2022). Open Alex covers 243 million scholarly works with a total of 1.9 billion citations and provides access completely free. Using Open Alex I collected all scholarly publications assigned the concept "Palliative care".[8]

To help contextualize the analyses of the Palliative Care literature I also returned articles related to Pain Medicine and Geriatrics. These areas share several features with HPM, most importantly the fact that they are relatively new areas, emerging approximately at the same time as HPM. Further, they deal with fairly ubiquitous problems of human health; acute discomfort and old age.

This returns 63586 works in Palliative Care, 24381 in Pain Medicine, and 15111 in Geriatrics. Further descriptive statistics indicate several important features of this literature including the "Publication Year" for all articles as well as the "Age" of articles (Age = 2023 − Publication Year), the "Entropy" of the articles in the literature (to be discussed below), and the "Number of Citations" and "Number of Grandkids" for the articles in the respective literature. The "Number of Grandkids" measure captures the number of articles that cite those articles citing the focal set of articles in the respective literature.[9]

Figure 3.1 displays the number of new publications (top panel) and citations (bottom panel) with the concept "Palliative care" over time. For comparison, I also plot the number of new publications in Pain Medicine and Geriatrics, related and similarly new areas of medical practice. Past studies of the rise of new scientific and medical fields have shown a ubiquitous "S-curve", or logistic growth

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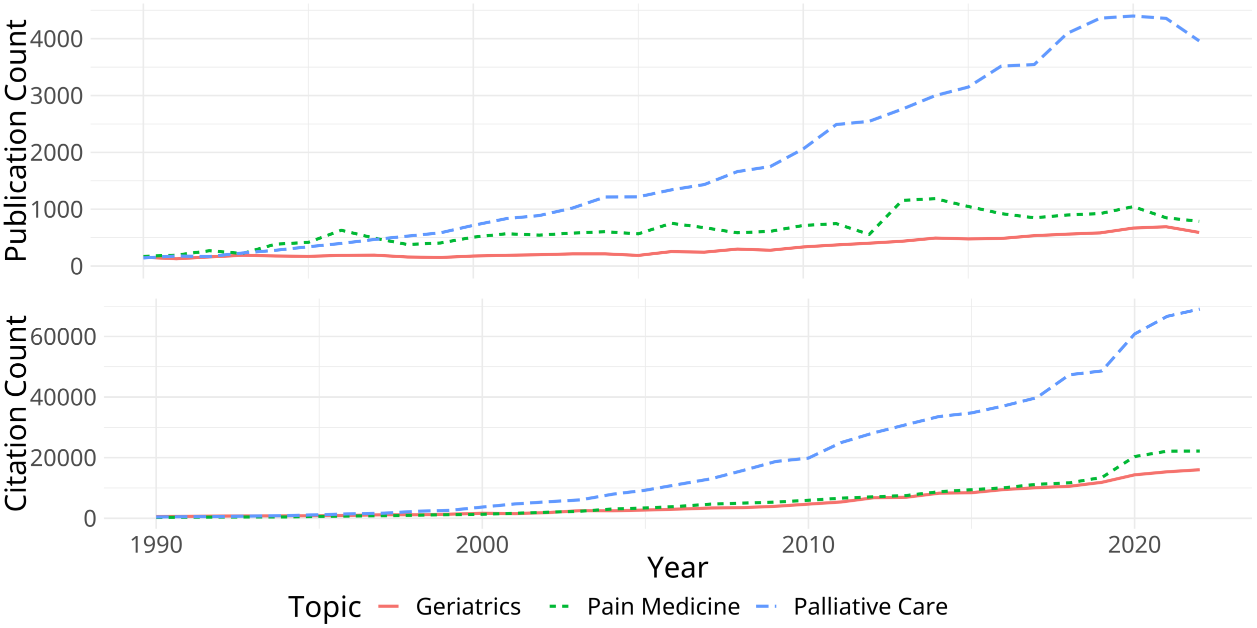
[8] Open Alex uses a machine learning algorithm to assign concepts to scholarly entities where concepts are the abstract ideas works are about. Each assigned concept for a scholarly work is also assigned a "score" which indicates the classifier's relative confidence in the concept assignment between 0 and 1. For my analyses, I took a relatively liberal stance and excluded works where the classifier confidence was <= .60

[9] The "Number of Grandkids" measure is calculated using the following scheme: every article A is cited by N articles and every citing article has C citations. C_i denotes the number of citations for the i^{th} article citing the focal article A. So the number of Grandkids for any article A can be measured by $\sum_{i=1}^{N} C_i$.

Table 3.1: Summary statistics for literature in Palliative Care, Geriatric Medicine and Pain Medicine.

Variable	N	Mean	Sd	Median	Min	Max
Topic: Geriatrics						
Publication Year	15111	2001	20	2008	1914	2024
Age	15111	23	20	16	0	110
Entropy	7300	2.6	2	2.3	0	11
No. of Citations	15111	12	97	0	0	8873
No. of ”Grandkids”	7300	780	5371	52	0	273251
Topic: Pain Medicine						
Publication Year	24381	2006	14	2010	1893	2023
Age	24381	18	14	14	1	131
Entropy	13104	2.4	1.8	2.3	0	11
No. of Citations	24381	8.9	71	1	0	8290
No. of ”Grandkids”	13104	421	3893	50	0	383112
Topic: Palliative Care						
Publication Year	63586	2013	8.4	2015	1860	2024
Age	63586	11	8.4	9	0	164
Entropy	34284	2.8	1.9	2.8	0	10
No. of Citations	63586	11	46	1	0	5709
No. of ”Grandkids”	34284	476	2044	52	0	146274

Figure 3.1: Counts of new Palliative, Geriatrics and Pain Medicine publications over time



in publications, authors, and citations (Bettencourt et al. 2008). The S-curves indicate rapid growth and then stabilization in an area, where a steady state is achieved and academic or scientific areas maintain a healthy amount of reproduction in terms of new contributors and publications. Between the end of the 1990s to 2010, the number of palliative care publications doubled, before doubling again in the 2010s. The number of publications reached its apogee in 2020 before a small dip in the number of new publications. As I will review in the next chapter, HPM is relatively common in US hospitals, but the publication data does not indicate a clear steady state for the scientific literature produced about HPM.

The geographical diffusion of institutions producing the literature on palliative care can be observed in the US over time in Figure 3.2. In the 1980s, the field developed at healthcare-related and educational institutions on the East Coast while in the 1990s a wider swath of educational institutions began producing literature on the subject. Particularly energetic contributors grew south along the eastern seaboard and in Chicago as well as the Bay Area and Southern California. The 2000s and 2010s saw similar developments till the whole of the country was blanketed by palliative care-producing institutions.

The rapid growth and spread of literature on palliative care can be partly attributed to the influence of a single study published in the *New England Journal of Medicine* in 2010. I next examine the influence of this study in more detail.

3.3.1 Temel Study

The "Temel Study" (Temel et al. 2010), named for its lead author, investigated the role of palliative care in the treatment of patients newly diagnosed with metastatic non-small cell lung cancer. Contrary to the taken for granted relationship between Palliative Care and Oncology, where the former was only helpful to the latter when patients unsuccessfully pursued aggressive therapy and were approaching the end of life, the study found that early referral to palliative care increased patients' longevity. The further puzzling finding of the study was that this increased longevity was achieved even though patients who received the treatment of an early referral to palliative care did not receive as aggressive therapy as patients in the control group. The study's finding that palliative care has a moderating impact on aggressive therapy while also increasing longevity led to both speculation as to why the relationship existed and arguments that palliative care should have a more robust role in the treatment of cancer patients regardless of their prognosis.[10]

After the release of the Temel Study, palliative care has changed significantly and the study's influence is frequently cited by palliative care clinicians as being a watershed moment for the discipline. One of my respondents described the study's influence on their practice:

> ”We did not work very well with the Oncology Group...That was actually before the Temel study came out. I'm oldish now. So I think that kind of revolutionized the way that oncologists think about [palliative care]. And there are younger oncologists now that have been trained in the space of palliative care." (PAL-PH/A-053)

The findings from the Temel study that early referral to palliative care led to increased longevity

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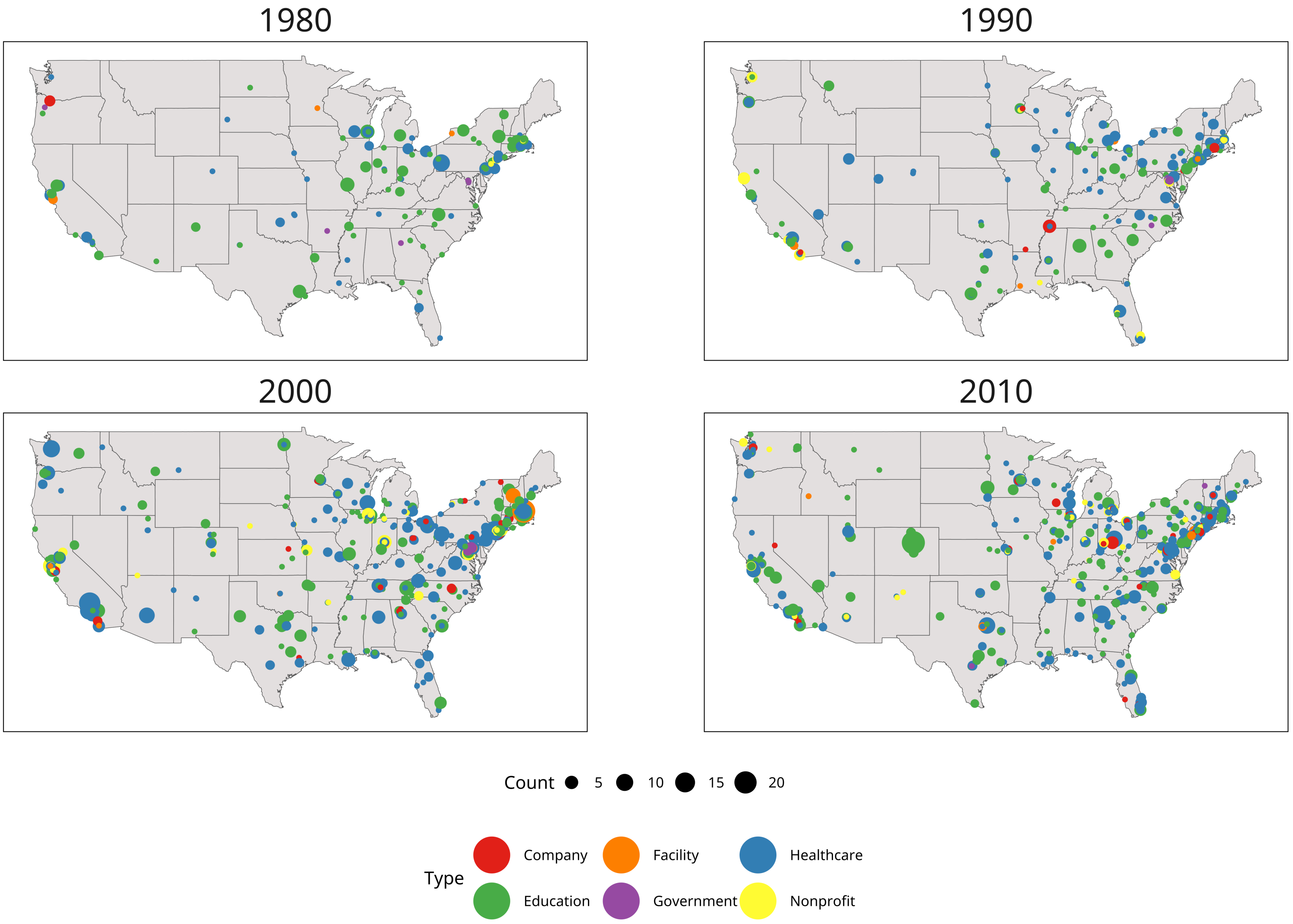
[10] Curiously, the primary finding of the Temel Study was suggested fully 150 years earlier in the *British Medical Journal* in an article entitled "Palliative Treatment in Cancer" (Hunt 1860). In this article, the author suggests that in the treatment of "cases of true scirrhus in the breast in which there is a hard and moveable tumor, not yet advanced to the stage of ulceration", the breast should be supported by "a capacious corset, which will then become a comfortable support, instead of acting, as a tormenting *vise*". In applying this treatment, which is primarily directed at comfort, the author has "often succeeded in relieving the patient of all pain for months together, and also in preserving the isolation of the tumor, and in many cases diminishing its size."

Figure 3.2: National diffusion of palliative literature.



in patients compared to those that received no such referral without receiving the same acuity of treatment is difficult to reconcile with the role of palliative care in most hospital settings. Hospice and Palliative Medicine, the medical specialty in which palliative care clinicians practice, began as an area of medicine focused on treating patients at the end of life, those that by definition had received unsuccessful therapies, where success is defined as remission or cure illness. This is a curious finding and poses some puzzling implications for HPM: one of the primary warrants of HPM is to address the well-being of patients and particularly to address their well-being at the end of life but the organizational justification that the Temel study creates for HPM is to aid in the curative paradigm that was identified by early palliative care entrepreneurs as producing a great deal of pain and suffering for the same patients.

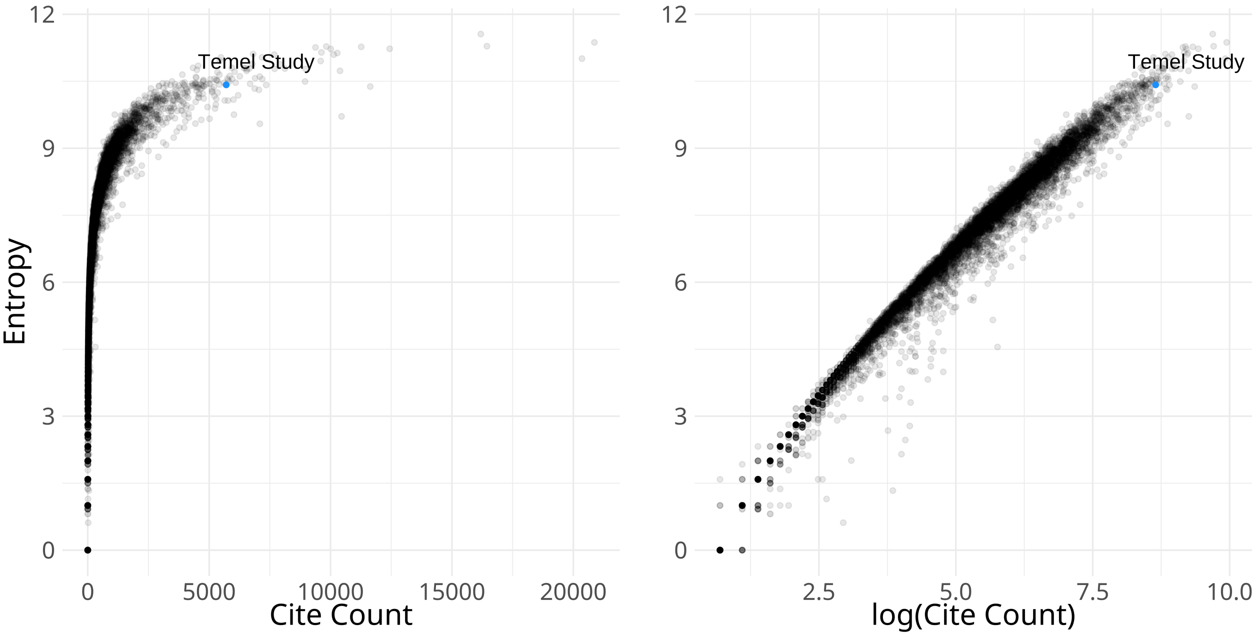
The Temel study broadened the concern of a wide swath of medicine to a fundamental concern that HPM had long been concerned with: the care for the ill must include a concern for their well-being rather than solely treating their underlying illness. The Temel Study is the highest cited article in palliative care, and poses a significant question: considering that the Temel Study focuses upon a fundamental and universal need in medical care, are other areas of medicine turning their focus to this area?

If the Temel Study is serving to integrate different areas of medicine we would expect to see its citations spanning a wide area in the space of journals in medicine. To better understand this we can use some insights from information theory. Entropy as defined by Shannon (1948) is the uncertainty or randomness in a message or information source and is mathematically defined as:

$$H(x) = -\sum p(x) * \log p(x) \tag{3.1}$$

where $H(x)$ is the entropy of an information source, and $p(x)$ is the probability of occurrence of each possible message. When used in the context of citations we define $p(x)$ as the probability of a journal containing a publication that cites the Temel Study where probability is derived from citation counts with:

Figure 3.3: Entropy by Citation Count for all articles in the *New England Journal of Medicine*.



$$p(x_i) = \frac{j_i}{\sum j} \tag{3.2}$$

where j_i is the count of publications in journal i citing the Temel Study and j is the vector of all citation counts by all journals. Entropy varies between $(0, \infty)$, and $H(x)$ is minimum when $p(x) = 1$ for a single outcome, which means there is no uncertainty, and the entropy is 0. $H(x)$ is maximum when all possible outcomes are equally likely, i.e., $p(x)$ is uniform across all outcomes. In this case, $H(x)$ is maximized and approaches infinity as the number of possible journals increases. The entropy score of any given article indicates how widely influential an article is by being broadly cited across many different areas.

To understand the relative influence of the Temel study I have calculated entropy scores for all the articles in the *New England Journal of Medicine* between 2000 and 2023. Figure 3.3 displays the entropy scores of all articles by the number of times they are cited. The left panel shows raw citation counts on the x-axis and the right panel shows the log of the citation count, to adjust for sizable outliers. All articles are indicated by black points and the Temel Study is highlighted in blue.

The number of citations an article receives is highly correlated with entropy ($\rho = 0.55$), and most of the palliative care articles fall within the expected amount of variation. Were palliative care articles to be more likely than other articles published in the *New England Journal of Medicine* to span greater space in the literature they would fall higher into the upper left quadrant of the plot, having a higher entropy relative to their number of citations. Though the Temel Study is one of the most highly cited articles in the *New England Journal of Medicine* with a high entropy score, it does not have an entropy that is higher than what we would expect given the number of citations it has. It is a highly influential, likely the most influential article about palliative care, but a relatively unremarkable article in terms of bibliometrics.

Focusing upon the Temel solely affords a relatively small window into the comparative influence of different literatures in medicine. To get a better window into the influence of palliative care relative to different areas of medicine I have calculated several metrics of the performance of articles in different areas. The "entropy score" as expressed in Equation (3.2), the number of citations per article per year for all articles, the number of "grandchildren" per article (the sum of the citations received by all the articles that cite the focal article), and the entropy score over time for all articles.

3.4 Summary and Conclusion

Past work has argued that four interrelated dynamics are key to new areas of science and medicine establishing themselves (Frickel and Gross 2005). New areas are likely to successfully establish themselves when:

1. High-status intellectual actors harbor complaints against what they understand to be the central intellectual tendencies of the day.
2. Structural conditions provide access to key resources: employment, prestige, and organizational resources.
3. Greater access to various micromobilization contexts, the more likely it is to succeed.
4. Movement participants frame the movement ideas in ways that resonate with the concerns of those who inhabit an intellectual field or fields.

Each of these can be seen in the above history I review: early leaders in the HPM movement were themselves high-status academic clinicians, who successfully leveraged their positions to gain access to organizational resources to establish faculty positions that enhanced the academic *cache* of this new area. Further, certain key individuals used their connections to help convince stakeholders in the consequential organizations to support the establishment of HPM. Finally, they framed this new area of medicine as addressing the problems experienced in the lives of patients that were unmet with sufficient interventions in medicine.

In different moments, palliative care leadership advocates for hospitals to adopt it on the basis that it is a cost-saving specialty (Sheridan et al. 2021), in other moments that it can help extend longevity as in the case with the Temel Study, and in others, it is advocated for as a kind of universal troubleshooter. At bottom, my respondents often talk about Palliative Care in terms of changing the relationship of physicians with their patients, relaxing the normative order of medicine, and redressing grievances about overtreatment. They often do this by arguing that the well-being of patients and families should be forefront in clinical decision-making regardless of the objective standards and evidence-based practices now ubiquitous in medicine (Timmermans and Berg 2010).

CHAPTER 4

THE CONTEMPORARY PRACTICE OF HOSPICE AND PALLIATIVE MEDICINE

As reviewed in the last chapter, HPM is a relatively new subspecialty in medicine and has experienced a great deal of change since its inception in the 1970s and its accreditation as an official subspecialty in 2006. In this chapter, I will provide a broad structural overview of the current status of HPM: where it is practiced in hospitals, the process of specialization and inter-specialization, and the sequences of training that clinicians have followed. Along the way, I will further provide insights into the overall structure of specialization and subspecialization in medicine to contextualize the organization of HPM.

Specialization and subspecialization are important phenomena in contemporary professions (Stichweh 1997). Specialization determines the tasks professionals are oriented to as well as the mode by which they understand their overall engagement with the profession. In a highly collaborative profession such as medicine, functional differentiation leads to heterogeneity in the cognitive and linguistic resources clinicians use in their work. This chapter also seeks to advance two theories of the work of professions: ecology and ontology. An ecological focus in studying the professions requires carefully contextualizing the environment in which professionals work, including the demographic composition of the population of interest as well as the life histories of professional entities. These ecological differences implicate ontological distinctions between different areas of professions. Important differences in practice arise from differences in the “ages” of professions and individuals that compose them, as well as the reliable interconnections that occur between different areas that arise from shared training sequences. What’s more, the underlying structure of a professional area influences the degree to which novel specialties can arise and persist. Using HPM as a case study and the various “environments” of medicine it is now embedded in, I seek to advance a deeply ecological engagement with the sociology of professions.

To this end I will complete several different analyses in this chapter; first, I examine the hospitals that host HPM services in the US and in particular their location and characteristics. I then outline the structure of specialization in medicine within which HPM has emerged and now operates, emphasizing the generic life histories clinicians of all types have to follow and the particular sequences that HPM clinicians follow to arrive at their area of practice. This analysis naturally invites a comparison to other areas of medicine and I analyze several that share important characteristics with HPM including Pain Medicine, Geriatrics, and Sleep Medicine. The first two areas are natural comparisons with HPM as they share both domains of practice (pain management) and patient population (older adults). Sleep Medicine is used as a comparison case as it is also a relatively new area of medicine that has been sponsored by multiple different areas within medicine. In reviewing these life histories I also analyze the demographic composition of different areas of medicine based on gender and age, reviewing this for some of the largest specialties in medicine. The data for this chapter is compiled from several secondary sources including `doximity.com`, the Department of Homeland Security, and the American Board of Medical Specialties's *Board Certification Report*.

4.1 The Location of Hospice and Palliative Medicine Services in the US

The primary theoretical principle in this dissertation is to return to a more fully ecological understanding of the professions and expert labor. One of the first steps to such an understanding in the case of HPM is to provide an overview of where it is practiced. In particular, the number and variety of hospitals that host HPM services. To estimate the number of HPM services in the United States I draw from the Center to Advance Palliative Care (CAPC) through their website `getpalliativecare.org`. CAPC is a national organization "dedicated to increasing the availability of quality, equitable health care for people living with serious illness".[1]. I scraped data collected by CAPC through their Palliative Care Quality Collaborative dataset, meant to collect quality information about palliative care providers and services around the country. Free membership to CAPC

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[1] Sourced from their website at `https://www.capc.org/about/capc/`

allows HPM services to be listed on the `getpalliativecare.org` site which can help them connect with patients seeking palliative care. I combined this dataset, scraped from the above URL, with publicly available data from the Department of Homeland Security on the complete number of hospitals in the United States and Outlying Territories.[2]

Using this data, I estimate that only 28% of all inpatient hospitals in the United States have an HPM service. Curiously, my estimate of the prevalence of HPM services in American hospitals is far lower than that regularly produced by CAPC. I have attempted to better understand the source of the discrepancy, but requests I made to CAPC for data sharing were denied. From the data available to me and by my estimates, these services are not distributed equally across US states as can be seen in Figure 4.1. This figure shows the percentage of hospitals in states in the continental US (including the District of Columbia) that host an HPM service. Note in this figure the high concentration of HPM services in the North East, North West, and Ohio and their relative absence from the mountain states (notably Wyoming) and certain states in the South (notably Alabama).[3] Unfortunately, I can only speculate as to why I observe this specific concentration and absence of HPM from hospitals in certain states.

To better understand the different ecologies where HPM services are located, I use linear probability models to estimate the probability of a hospital hosting an HPM service given different characteristics, including the number of beds the hospital has (its size), the type of hospital facility (General Acute Care, Critical Access Hospitals, Military Hospitals), its owner (Public, Private, or Not for Profit) and whether it has a Trauma Center, indicating the general acuity of care that hospital can provide. These attributes index features of hospitals that are likely to influence certain barriers that hospitals have to overcome to establish an HPM service.

A primary rationale for HPM has been to moderate treatment in the face of incurable illness and death. Though HPM is now marketed by major national professional organizations as a medical

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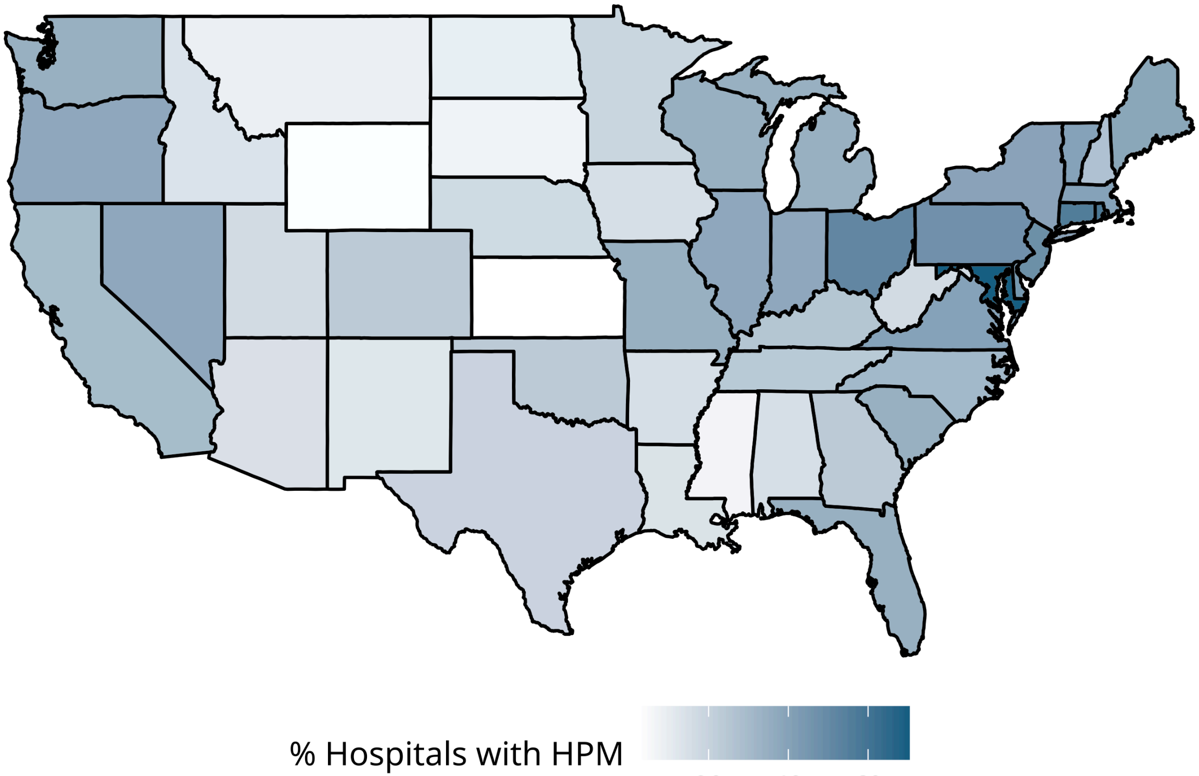
[2] See the DHS website on Homeland Infrastructure Foundation-Level Data at `https://hifld-geoplatform.opendata.arcgis.com/`

[3] Percent of hospitals with an HPM service instead of HPM services per capita in the state are plotted as the interest here is in determining how common HPM services are across the US, rather than the relative concentrations of palliative care. Table 8.2 in Appendix B shows raw counts and other information related to Figure 4.1.

Figure 4.1: Percent of hospitals with an HPM service by state.



Data Source: Department of Homeland Security, Homeland Infrastructure Foundation-Level Data and getpalliativecare.org. Collected in 2023.

specialty that is primarily concerned with controlling symptoms, a perception persists that HPM clinicians are "death doctors" and will prematurely convince patients to moderate or quit curative therapies.[4] Apprehension on the part of medical staff may prevent hospitals from adopting HPM.

Though patient care is a primary concern of medical staff, hospitals require remuneration to continue operating, and in a fee-for-service model of medical care, palliative care has little to offer hospital administrators who are concerned with the bottom line. HPM clinician's interventions are relatively inexpensive, and because they advocate for moderation in the face of medical futility, can further moderate spending on expensive medical therapies. In part, this has led some advocates to promote HPM to hospitals as a "cost-saving specialty" (Morrison 2008; Sheridan et al. 2021; Starks et al. 2013). Further, despite the modest costs of the medical therapies HPM clinicians prescribe, there is still a non-negligible cost associated with hosting staff in HPM, who are not directly addressing the underlying illnesses patients present with.

Table 4.1 displays results from linear probability models estimating the probability of a hospital hosting an HPM service. The hospital "Type" reference category is "General Acute Care". "Critical Access" hospitals provide care to undeserved populations primarily in rural settings, and "Military" hospitals are those administered by one of the branches of the US Armed Services. The "Owner" reference category is "Proprietary", meaning the hospital is administered by a profit-generating corporation. "Government" hospitals include those administered by the local, state and federal governments. The reference category for the "Trauma Level" is "None" meaning the hospital does not have a certified trauma center capable of specialized medical services and resources to patients suffering from traumatic injuries.

Four models are specified and I introduce explanatory variables in sets, beginning with the size of hospitals (in hundreds of beds), before introducing the type of hospital, the owner of the hospital, and whether the hospital hosts a trauma center.[5] The size of hospitals remains significant through

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[4] This reputation was particularly powerful in the late 90s and early 2000s. One respondent reported that "at the time at University of Chicago, the chair of medicine was an oncologist, Harvey Gollum who was dead set against palliative care and said 'there will be palliative care at the University of Chicago over my dead body' (PAL-PH/A-050).

[5] In employing standard Ordinary Least Squares (OLS) models to estimate binary outcomes, it is crucial to acknowledge inherent limitations of the Linear Probability Model (LPM). Primarily, LPM can yield predicted probabil-

Table 4.1: Linear Probability Model predicting whether hospitals have an HPM service.

	HPM Service Present			
	1	2	3	4
No. of Beds (100s)	.108***	.096***	.092***	.086***
	(.003)	(.003)	(.003)	(.003)
Type - Critical Access (0/1)		$-.145^{***}$	$-.144^{***}$	$-.120^{***}$
		(.014)	(.015)	(.015)
Type - Military (0/1)		$-.191^{***}$	$-.125^{***}$	$-.106^{**}$
		(.035)	(.037)	(.036)
Owner - Government (0/1)			.023	.024
			(.018)	(.018)
Owner - Non-Profit (0/1)			.147***	.140***
			(.013)	(.013)
Trauma Level 1 (0/1)				$-.023$
				(.014)
Trauma Level 2 (0/1)				.204***
				(.023)
Trauma Level 3 (0/1)				.110***
				(.019)
Constant	.110***	.168***	.087***	.075***
	(.007)	(.009)	(.012)	(.013)
Observations	5,024	5,024	5,024	5,024
R^2	.231	.249	.271	.288
Adjusted R^2	.231	.249	.270	.286
Notes:	*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$ General Acute Care = Type Reference Category For Profit = Owner Reference Category			

all four models, indicating with every additional 100 beds the probability of hosting an HPM service increases by approximately 10%. This effect is tempered with the inclusion of further explanatory variables: both Critical Access and Military hospitals are approximately 10% less likely to host HPM services when compared to General Acute care hospitals and Non-Profit hospitals are 14% more likely to host an HPM service compared to For Profit hospitals. Lastly, When compared to hospitals that host no trauma center, those that host either a Level 2 trauma center or Level 3 trauma center are 20% and 11%, respectively, to host an HPM service. These results indicate that larger hospitals that provide care to critically injured patients are more likely to host an HPM service.

4.2 Inter-Specialization in Medicine

Medicine is a heterogeneous professional area internally differentiated by a large number of rigidly defined sub-professional groups, or specialties. This structure of specialization is important for understanding how the complicated task of treating acutely ill patients is performed. The complex division of labor in medicine has developed as a result of both political and practical organizational influences. The development of new sub-areas of medicine helps to secure the work imperatives of the super-ordinate areas they are embedded within. Beyond the base politicking that generates diversity in medical specialties and subspecialties, there are organizational and epistemic influences on the growth in the diversity of medical sub-areas. A strong scientific and technological imperative in medicine has led to the development of esoteric mechanisms for treating acute illness that require lengthy periods of training to perform. A result of this is an intensive but narrowly defined expertise among subspecialists. This phenomenon is not unique to medicine but can be observed across a number of both professional and scientific areas (Elder and Kozlowski 2023; Laumann and Heinz 1977; Moorhead 2010). For example, within the social sciences the growth in both topical and theoretical literature, as well as the methodological sophistication of different

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ities that are not bounded between 0 and 1. Such predictions are not probabilistically valid, as they cannot represent true probabilities of occurrence. As illustrated in Figure 8.3 in Appendix B, I examine this by plotting the predicted probabilities from the LPM. My diagnostic checks reveal that a relatively small proportion, no more than 12%, of these predictions lie outside the theoretical bounds of 0 and 1, suggesting a moderate incidence of this issue in my models.

areas, requires greater specialization of social scientists *within* their own area to make recognizable scholarly contributions.

Genuine interdisciplinary and inter-specialty collaboration is mediated by the degree to which scholars, scientists, and medical professionals have a working knowledge of neighboring areas of their discipline. Precisely estimating the degree and nature of inter-specialty engagement will help understand the degree to which such collaborations also occur. These analyses then can be used to understand the medical field at two levels of analysis: (1) structural/organizational level: estimating the degree to which areas of medicine are related by shared specialization or transitions between areas indicates an underlying relationship either in knowledge or practice of different areas. (2) Individual level: the analysis of co-specialization or transitions between different areas provides information about the professional life histories of clinicians in medicine which can address questions of interest to medical professionals and scholars of the professions alike (Abbott and Hrycak 1990; Christakis 1994).

This section uses data collected from the American Board of Medical Specialties' *Board Certification Report* (American Board of Medical Specialties 2018, 2019, 2020, 2021, 2022), which compiles information on the current specialties and sub-specialties of allopathic medicine as well information on their constitution and history. My analyses of inter-specialization and transitions between different areas of medicine completed in this section provide a small window into a larger and more consequential area of study; the analyses here are retrospective and static, dealing with the training and certification that clinicians have completed in medicine and HPM in particular. They indicate the degree to which transitions between different areas occur, but provide little indication as to the differences in practice, if any, such inter-specialization or transitions cause. Further study is warranted, in both medicine and other professional areas where collaboration is both necessary to the successful execution of tasks, and prevalent.[6]

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[6] Important studies of inter and intra-professional collaboration have been conducted in medicine (Oh 2014; Schrepel et al. 2022), industrial design (Carlile 2002, 2004), as well within science (Collins 1998), but their qualitative methodology limit the scope of the implications of these studies, and the quantitative science of science scholarship, though immense, is largely superficial. Areas that warrant further exploration to understand the collaborations that occur between different kinds of experts on shared tasks are the architectural/building professions as well as the military

In addressing the structure of specialization in medicine it is first helpful to approach the broadest division. Modern medicine is composed of two distinct paradigms, Allopathic Medicine ("Medical Doctors", or MDs) and Osteopathic Medicine ("Doctors of Osteopathic Medicine", or DOs). Allopathic and Osteopathic medicine are primarily distinguished by their history and philosophy of practice, though the reality of contemporary medical practice has led to a nearly complete convergence in their function: osteopathic medicine originated as a competing professional entity to allopathic medicine, what was referred to as "regular medicine" in the 19th century. The medical methods used to treat even common illnesses were brutal, and in many instances caused greater harm than good (Bloom 2002; Conrad and Schneider 1992). Osteopathic medicine emphasizes the holistic treatment of patients, including the manipulation of the musculoskeletal system. In 1969, the two distinct medical professions merged and now besides the distinction between osteopathic and allopathic schools of medicine, DO and MD physicians complete the same training in their residency and later subspecialization in subsequent fellowships. DO physicians are outnumbered by their colleagues in allopathic medicine.[7]

After graduating from medical school in either allopathic or osteopathic medicine, physicians need to complete an accredited residency program to become fully qualified clinicians capable of independent practice. Physicians can choose between 19 different primary boards to initially specialize in during their residency training. These include: Anesthesiology, Dermatology, Emergency Medicine, Family Medicine, General Surgery, Internal Medicine, Neurology, Neurosurgery, Obstetrics/Gynecology, Ophthalmology, Orthopedic Surgery, Otolaryngology, Pathology, Pediatrics, Physical Medicine, Plastic Surgery, Psychiatry, Radiology, Urology. The length of residency training varies by primary board, ranging from 3 years in Family and Internal Medicine and 6-7 years in Plastic Surgery and Neurosurgery.[8] After residency, physicians can pursue further specialty

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and policing. The first of these areas I hope to explore in follow-up work.

[7] There are still some parallel and overlapping professional and pedagogical institutions that complicate the structure of medicine. The American Osteopathic Association oversees the certification of specialty boards and physicians in them for osteopathic physicians, though DOs can still pursue training in ACGME and ABMS-certified programs.

[8] For reference, I have included Table 8.1 in Appendix B which displays the residency length for all primary boards in medicine.

and subspecialty training in a fellowship, though their choice of residency training constrains or expands their fellowship training options.

Figure 4.2 shows the current structure of specialization in the largest certifying body for allopathic medicine, the American Board of Medical Specialties. As of 2021, 25 primary boards sponsor a total of 92 subspecialties. The figure can be viewed as a set of mutually exclusive paths individuals can take through specialty training in medicine. The center blue node should be interpreted as a physicians' origin medical school, from this they can then pursue residency training in one of the green intermediate nodes, and further subspecialization can be pursued in one of the peripheral red nodes. With this in mind, it is apparent the degree to which residency training can facilitate further specialization: different residency areas are more or less heterogeneous, with Internal Medicine and Pediatrics hosting the greatest number and variety of subspecialties, and Orthopedic Surgery and Urology hosting the fewest. Physicians specializing in Internal Medicine, the largest area of medicine, have the greatest variety of future career paths to choose from, and these sub-areas are in part unified by their organization under Internal Medicine. Physicians who initially specialized in a relatively narrow field like Neurosurgery will have a truncated and highly specialized engagement with medicine.

HPM is unique within this structure of specialization: because of the heterogenous coalition of organizations that supported the accreditation of HPM a number of different paths were created for physicians to specialize in this area. Physicians can complete initial specialization in 10 different areas before advancing to a fellowship in HPM. These include Anesthesiology, Emergency Medicine, Family Medicine, Internal Medicine, Pediatrics, Surgery, Obstetrics and Gynecology, Radiology, Psychiatry and Neurology, and Radiology. This is a relatively unique feature of HPM shared by only a few other subspecialties.[9] This means a physician who wants to eventually spe-

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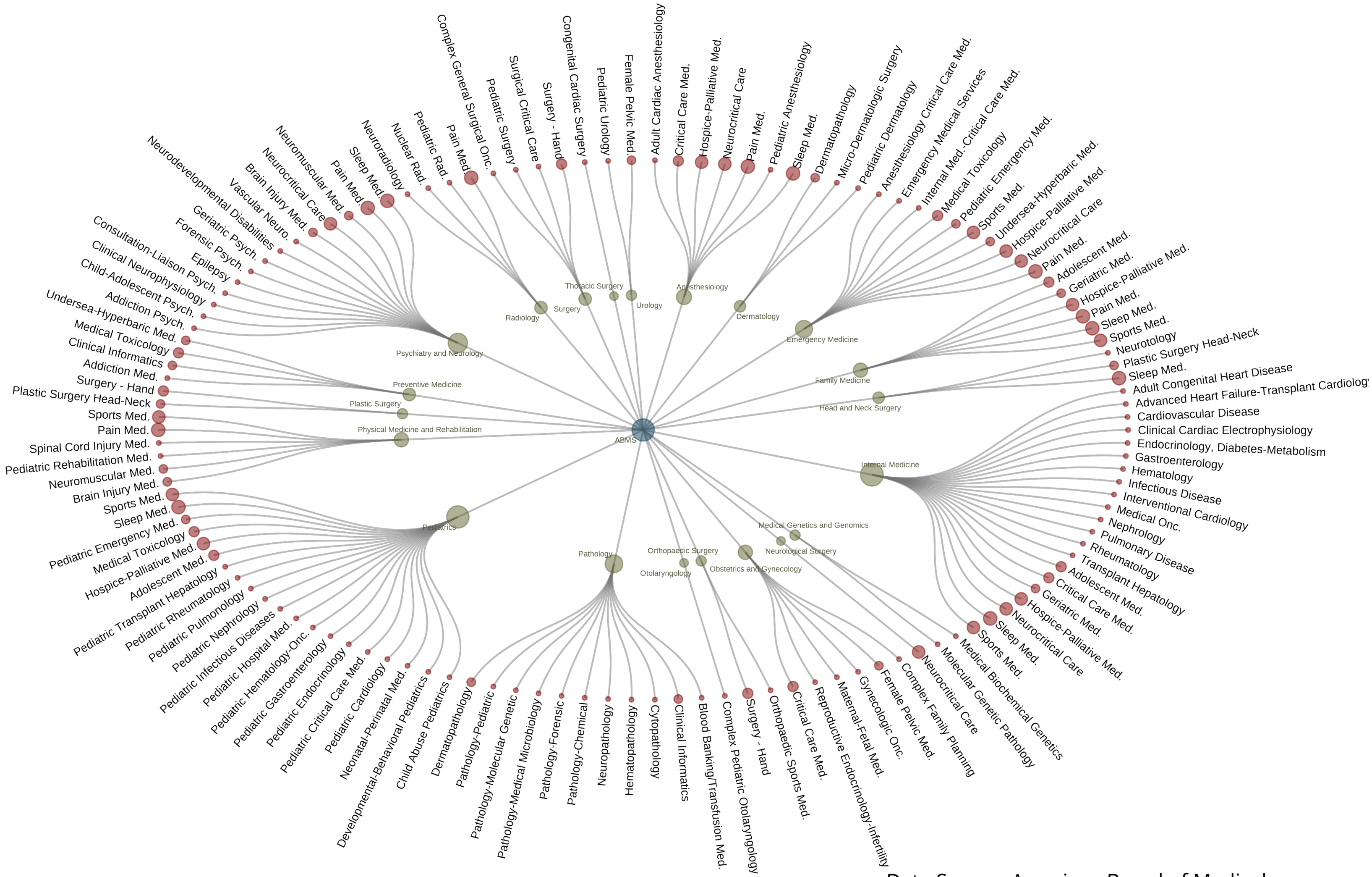
[9] The cosponsoring structure of HPM is changing in likely inconsequential ways. From 2008 to 2020, 10 different primary boards cosponsored HPM including Surgery, Obstetrics and Gynecology, Radiology, Psychiatry and Neurology, and Radiology. In 2020, these cosponsors dropped their sponsorship of HPM and became "qualifying boards" meaning "Diplomates entering HPM from qualifying boards (ABOG, ABPMR, ABPN, APR, ABS) will become diplomates of ABIM (the HPM administrative board) for HPM and follow ABIM guidelines for MOC in HPM. These diplomates may choose to continue their primary certification, but they are not required to do so" [personal communication with ABMS representative]. Though a substantive change in the organization of medicine it will have

Figure 4.2: Specialties and Subspecialties in the American Board of Medical Specialties.



Data Source: American Board of Medical Specialties "Board Certification Report" 2019-2020 cialize in HPM must complete a residency program in one of ten different cosponsoring boards of certification. For comparison, a physician who wants to eventually specialize in Critical Care Medicine can choose between only three initial areas of specialization, Internal Medicine, Obstetrics, and Gynecology, Anesthesiology, while a physician who eventually wants to specialize in Nephrology can only initially specialize in Internal Medicine.

Subspecialties that host clinicians from different primary boards are “cosponsored” by these boards. 20 total subspecialties have multiple cosponsoring primary boards and HPM is unique in the number of primary boards that cosponsors the subspecialty. The median number of cosponsoring boards for all subspecialties is 2 with Pain Medicine and Sleep Medicine having the second most cosponsoring boards at 6 each. Figure 4.3 shows the 19 primary boards and the 20 subspecialties they jointly cosponsor. The size of the nodes in this figure represents the number of sponsored sub-specialties, for red-colored primary boards, or the number of co-sponsors, for blue-colored sub-specialties. HPM is the center large blue node in the figure and has a similar co-sponsorship structure with other new areas of medicine such as Sleep Medicine and Pain Medicine.

This cosponsoring structure is important for several reasons: professions establish themselves by controlling particular “jurisdictions”, domains of expertise that allow them to both constitute the idiosyncratic symptoms patients present into a diagnosis and the authority to recommend the appropriate therapy (Abbott 1988). The system of mutual competition and definition, resolved by the specific workplace resolution of competition for tasks, constitutes the overall structure of the profession. Cosponsorship of different areas by superordinate specialty areas is a means of resolving competitions over new areas of practice by establishing mutual authority, as well as representing genuine epistemic connections between related but organizationally distinct areas. Specialty areas that share cosponsored subspecialty areas are more highly related to one another, and likely to have a greater amount of collaboration within the workplace due to these connections, either because there are shared frames of reference from training or due to organizational similarities inherited

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little impact on the actual paths that physicians can take going into palliative medicine. My dataset includes physicians from these former cosponsors.

from the superordinate area of medicine from which they originate.

To be sure, the cosponsoring structure is a result of politics (Zetka 2011), but important practical and epistemic influences are overlooked when exclusively emphasizing the competition of specialties over material or professional resources. As outlined in the previous chapter, the cosponsoring primary boards of medicine established cosponsorship over HPM to avoid denying their patients the opportunity to receive expert treatment from this new area. HPM's diversity and number of cosponsors indicate a general agreement that this area of medicine represents a novel and substantial change in the practice of medicine, oriented to a domain that had been previously underappreciated within the medical field.

A closer examination of the network plotted in Figure 4.3 helps to indicate these different dynamics. The highest number of cosponsors for subspecialties is HPM (10 cosponsors), followed by Sleep Medicine (6 cosponsors), Pain Medicine (6 cosponsors), and Neurocritical Care (5 cosponsors), and the median number of cosponsors for sub-specialties is 2.5. In the case of Neurocritical Care, the cosponsors are likely due to shared patient populations and techniques used in their practice as the cosponsors have overlapping domains of expertise: Neurological surgery shares an anatomical system, Anesthesiology a domain of similar treatments (anesthesia in surgery), and Emergency Medicine a patient population (acutely ill patients). Pain Medicine's cosponsors are similar to HPM and this is likely due to the ubiquity of pain as a symptom of disease and the treatment paradigms used to address chronic pain, including its psychosomatic and neurological components (Psychiatry and Neurology), and physical therapy (Physical Medicine and Rehabilitation).

4.3 Specialization in HPM

Table 4.2 shows the breakdown of HPM specialists by their primary board between 2008 and 2019. Though there are 10 cosponsoring boards from which HPM clinicians can initially specialize, the majority of HPM physicians are drawn from Internal Medicine. In the first eleven years HPM was recognized 8662 physicians were certified in the subspecialty and of that total 62% had their

Figure 4.3: Primary Boards and their cosponsored subspecialties.

Data Source: American Board of Medical Specialties
"Board Certification Report" 2019-2020

Table 4.2: Specialists in HPM by primary board of certification between 2008 and 2021.

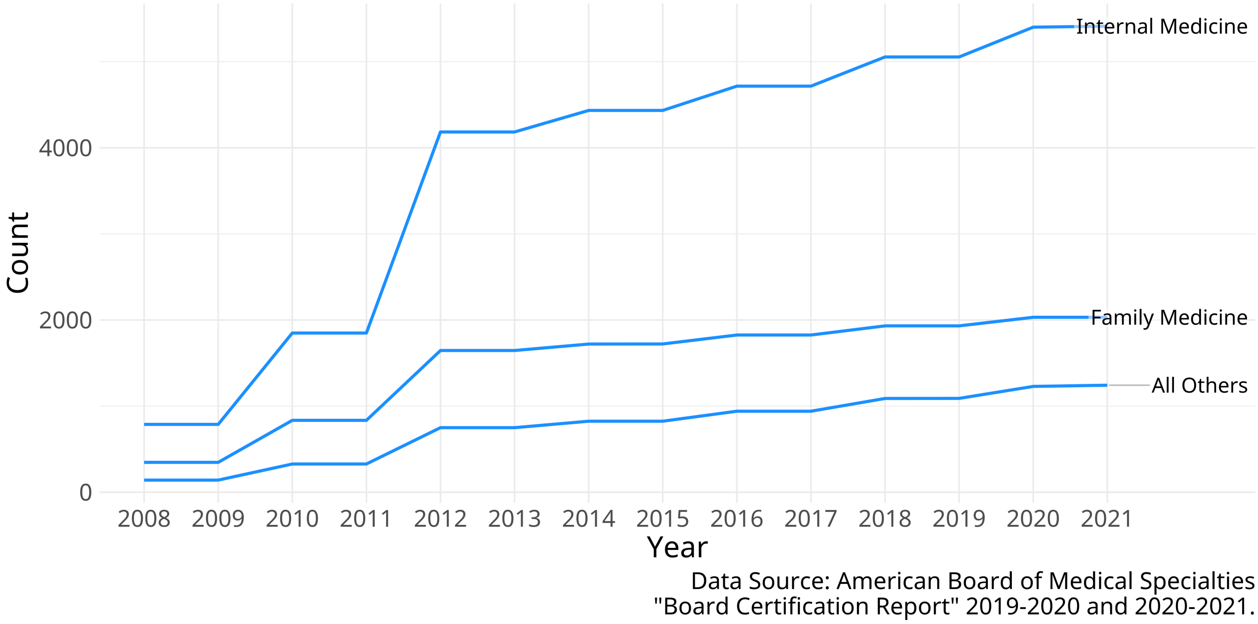
Primary Board	Total	%
Internal Medicine	5401	0.62
Family Medicine	2032	0.23
Pediatrics	410	0.05
Emergency Medicine	207	0.02
Psychiatry and Neurology	160	0.02
Anesthesiology	146	0.02
Surgery	87	0.01
Obstetrics and Gynecology	80	0.01
Radiology	70	0.01
Physical Medicine and Rehabilitation	69	0.01

primary board in Internal Medicine, followed by Family Medicine with 23% of all HPM physicians, and then Pediatrics with about 5% of the HPM physicians. The seven remaining cosponsors collectively contributed only 10% of newly certified physicians.

For three years following the official certification of HPM, new subspecialists in HPM could pursue certification through a "grandfathering" process, where practicing physicians could sit for the board certification exam without completing a mandatory year-long fellowship. This offered mid-career physicians an opportunity to make a lateral transition from their current area of practice to HPM, bringing with them their varied and substantial expertise in other areas of medicine. At the end of this grandfathering period, certification in HPM required the completion of a year-long fellowship in an ACGME-accredited program. This requirement largely closed this path as mid-career physicians who wanted to enter HPM would have to take a substantial step back in their career, essentially returning to being a student with a loss of status and income, to pursue fellowship training.

This grandfathering period can be observed in Figure 4.4 which shows the number of new certified clinicians in HPM by year and their primary board of certification. In the first three years of the recognition, some 3000 physicians joined HPM from other areas of practice within Internal Medicine. Though less substantial, large gains were also made from Family Medicine. Despite the cosponsoring structure outlined above, very few physicians from the other cosponsoring boards

Figure 4.4: Cumulative sum of new HPM certified physicians by primary board.



Data Source: American Board of Medical Specialties
"Board Certification Report" 2019-2020 and 2020-2021.

have taken advantage of the opportunity to join HPM.[10]

The HPM workforce is not solely composed of individuals who have entered the subspecialty since 2006, as a substantial number of practicing HPM physicians entered the field before the subspecialty was officially accredited. In the period before official accreditation, HPM physicians could take any number of different paths to the specialty and in the following section, I examine some of these different paths that physicians followed to arrive at HPM.

4.3.1 Sequences to Hospice and Palliative Medicine

The above analyses show that HPM is a field marked by inter-specialization: the subspecialty is embedded in diverse areas of medicine and draws clinicians from different areas who are capable of following different paths to the subspecialty. There is a further caveat that up until the official certification of the subspecialty in 2006, clinicians practicing in this area did not follow a well-defined sequence of training.

In this section of the chapter I want to closely describe the heterogeneity in the paths, or se-

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[10] For reference, Figure 8.4 in Appendix B shows the same figure for the top 20 subspecialties in medicine.

quences, that clinicians have followed to arrive at HPM. To do this I use data obtained from doximity.com, a website that hosts public-facing profiles for physicians, NPs, and physician assistants. They boast of being "the largest community of healthcare professionals in the country - with over 80% of U.S. doctors and 50% of all NPs and physician assistants as verified members".[11]

This platform provides information on physicians' current area and/or subspecialty area of practice, as well as any training that they have completed, current certification by state licensure and primary boards, as well as their current hospital affiliations, and recent publications. A comprehensive dataset was generated by scraping all physician profiles on `doximity.com` across all specialties. Though this dataset does not represent the full population of practicing physicians and was not generated through probability sampling, if `doximity.com's` claim of having as many physicians represented on their platform is true, the data provides a substantial view into medicine.

First, I seek to estimate the age distributions across the largest subspecialties in medicine. This provides two important indicators for these analyses: for one, the age distribution in a professional area indicates how successfully that area is reproducing itself with new clinicians capable of both meeting the work demands of that area and providing further training for the next generation of subspecialists. Secondly, in determining the particular sequences individuals follow to arrive at HPM, estimating the age distribution indicates the population of individuals that have entered the field through a non-standard pre-accreditation process.

Figure 4.5 shows the age distributions for the top 10 subspecialties of medicine by the number of members. Doximity does not provide information on the chronological age of its members but using the year in which the clinician graduated from medical school I can estimate the length of the individual's career, providing a rough indicator of age.[12] Figure 4.5 shows some interesting trends in the age distributions across specialties: most of the largest specialties show relatively stable age distributions with roughly similar age cohorts (Adolescent Medicine and Addiction Medicine in particular) while others show "high fertility" and a large number of relatively young clinicians

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[11] Obtained from `https://www.doximity.com/about/company` on 11/21/2023.

[12] For reference, I have also estimated the complete age distribution of all physicians across all specialties in Figure 8.2 in the Appendix B

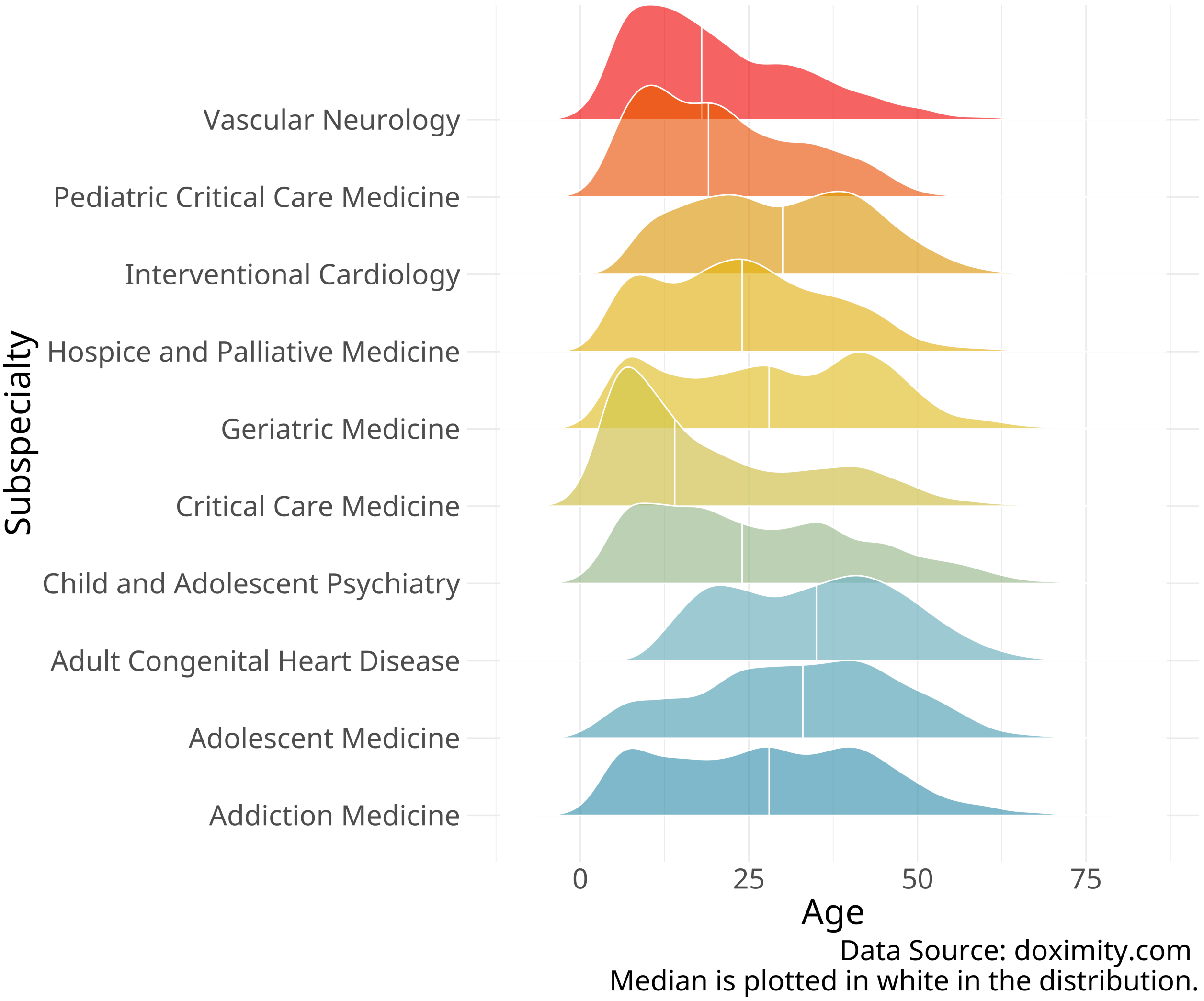
having entered the field within the last 10-15 years (Critical Care Medicine and Infectious Disease in particular). Interventional Cardiology and Geriatric Medicine show some right skewing.

Hospice and Palliative Medicine is unique among specialties with a roughly normal age distribution and median age of 25 years. When precisely these clinicians entered the field is unknown, but besides the mid-career changes that could have occurred during the grandfathering period between 2006 and 2009, few of these clinicians are likely to have entered after accreditation. Examining the specific sequences that individuals followed to arrive at this area will better illuminate to what degree practicing physicians in HPM have gone through the official pathway. This is important as the standardization of medical training will afford greater homogeneity in practice across different sites of practice.

Hospice and Palliative Medicine's area of expertise, as I will explore in Chapter 5, is central to the professional project of medicine, and is the central practical activity that has defined the profession since its inception as a unique area of work. Relating to patients, attending to their being in the face of incurable illness, and attempting to preserve some small amount of comfort in the face of death. The training sequence they follow is relatively short among medical specialties, and as was reviewed above, clinicians in this area can come from a variety of different areas of specialization in medicine. Geriatrics and Pain Medicine, share the characteristic that their central areas of expertise have long defined the medical enterprise; attending to the problems of old age, and the discomfort that results from illness.

To better understand the composition of the HPM workforce, and the specific areas of specialization clinicians pursued before entering HPM, I examine the specific sequences that clinicians followed including their initial specialization during residency and any post-graduate medical training they pursued such as fellowship training. This will help us to understand to what degree there is heterogeneity in the backgrounds of the clinicians currently practicing in this area. heterogeneity in the training backgrounds of HPM clinicians can indicate two things: (1) shared epistemic frames to other areas of medicine that can substantially aid in collaboration, and (2) the degree to which clinicians in this area have narrowly defined their work. This latter characteristic is important as the

Figure 4.5: Age distributions of clinicians in the largest subspecialties.



sociological understanding of the constitution and behavior of professional areas has emphasized that new professional areas first narrowly define their area of expertise to establish a substantial command over an area of work. Many clinicians coming from many different areas, would seem to violate this basic tenet of the sociology of professions. Pain Medicine and Geriatrics are included for comparisons to show whether any uniqueness in HPM is generally shared by new areas of medicine.

Figures 4.6, 4.7, and 4.8 show the top six training sequences individuals currently practicing in HPM, Geriatrics and Pain Medicine have undergone in the course of their careers.[13] The sequences followed by clinicians in HPM and Geriatrics show great affinity, with Internal Medicine and Family Medicine serving as the top two and only forms of previous specialty training the majority of clinicians in these areas have completed. The contribution of other sequences of training to either of these areas is negligible and constitutes no more than 15-20% of the sequences clinicians follow. Internal Medicine and Family Medicine are very large and broad areas of medicine and indicate that general physicians comprise the majority of the workforce in these areas.

The sequences followed by clinicians in Pain Medicine are substantially different, though they are not particularly surprising; Anesthesiology is the dominant area of initial specialization that clinicians in Pain Medicine pass through before joining this specialty, and Family Medicine makes no contribution to the top six training sequences. This indicates that when compared to HPM and Geriatrics, these differences in the training sequences that clinicians follow to arrive at Pain Medicine indicate that it is an area that requires narrower specialization.

4.4 Discussion and Conclusion

HPM is not like other medical specialties; its workforce is composed of clinicians who have not completed specialty training in this area. The sequences that clinicians in this area can follow are varied but largely follow a path that has some stop Internal Medicine or Family Medicine, areas of

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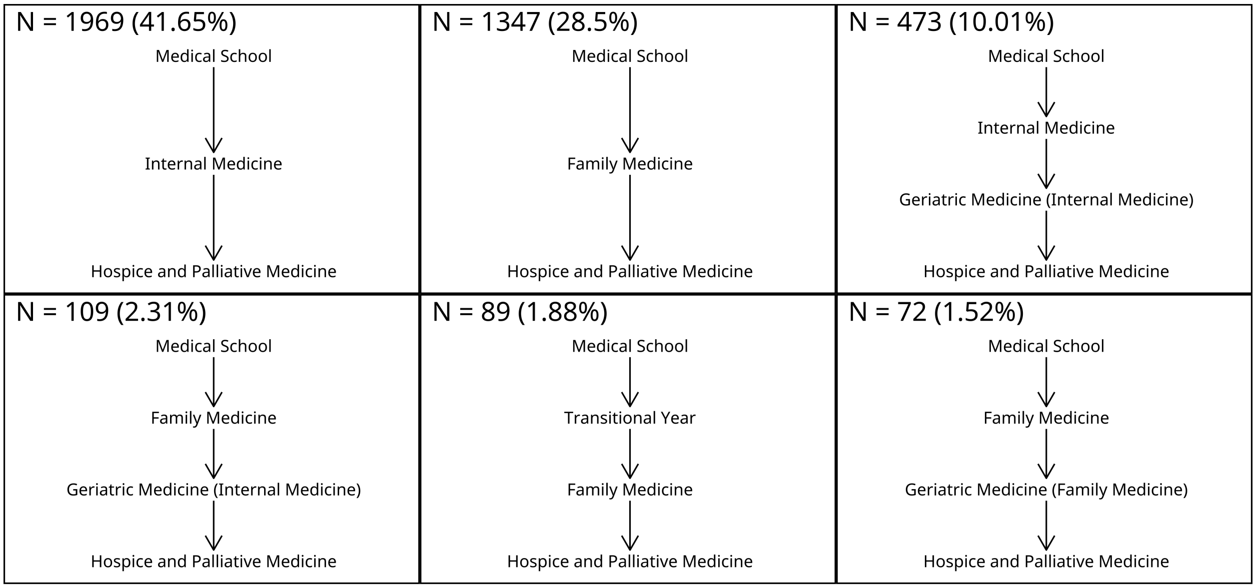
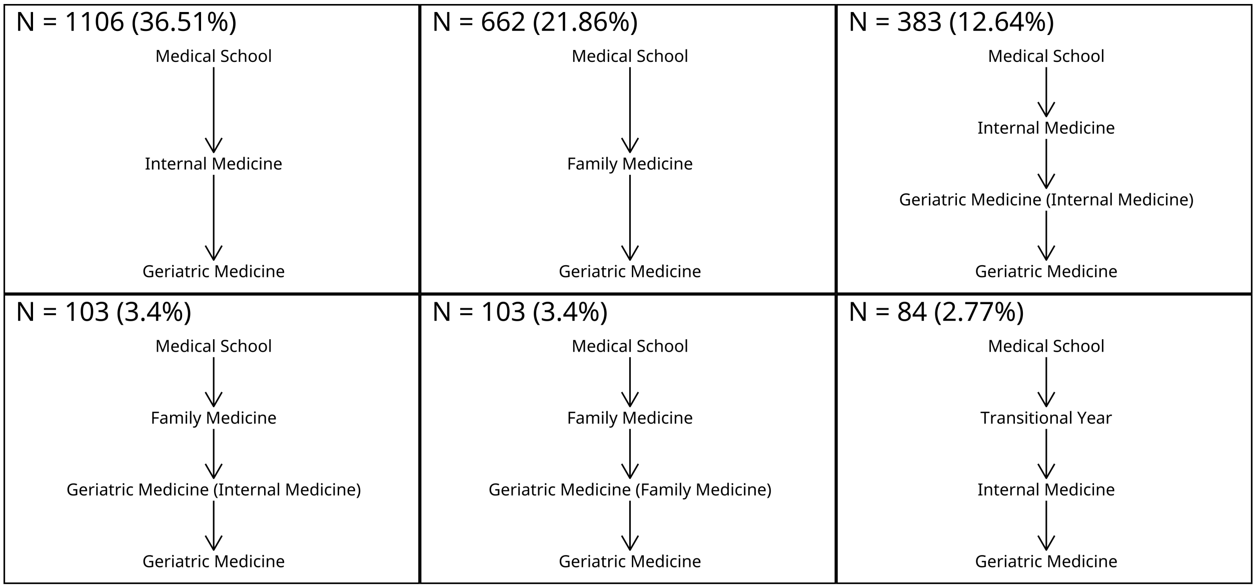
[13] These sequences are drawn from a non-probability sample of clinicians scraped from `doximity.com` and not the population of clinicians in the US.

Figure 4.6: Training sequences followed by clinicians working in HPM.



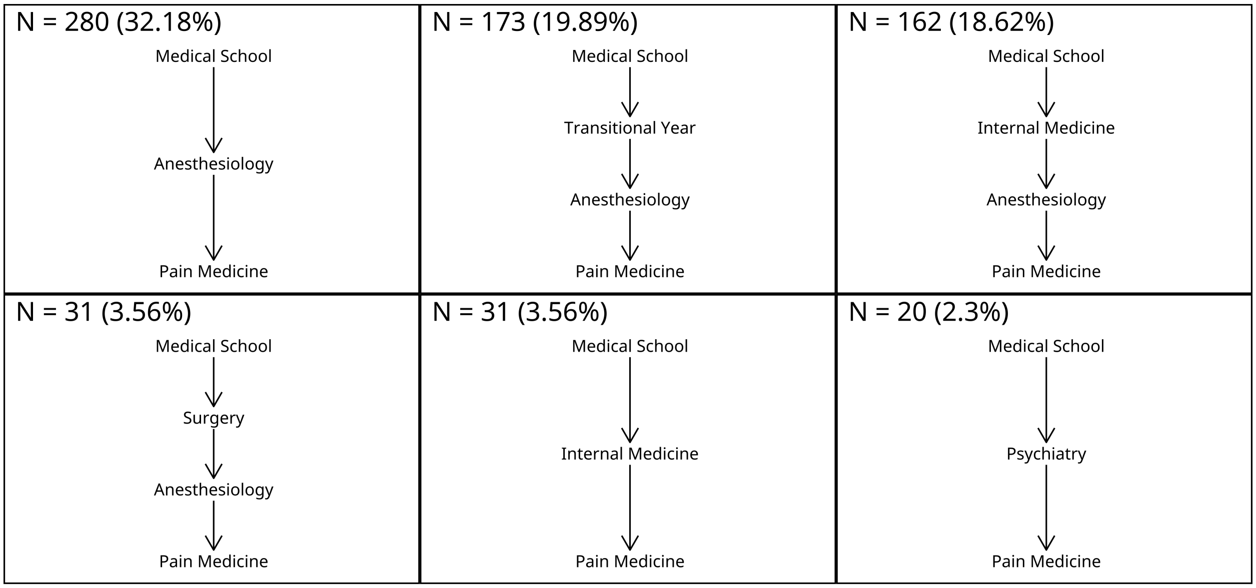
Data Source: doximity.com. Scraped in 2023.

Figure 4.7: Training sequences followed by clinicians working in Geriatrics.



Data Source: doximity.com. Scraped in 2023.

Figure 4.8: Training sequences followed by clinicians working in Pain Medicine.



Data Source: doximity.com. Scraped in 2023.

medicine that have their unique ways of working with patients and intervening in their cases. Its workforce is further diverse in terms of age and has successfully established training programs that are producing new clinicians as the past generation that established the specialty grows older and retires. The most important insight from this chapter is that HPM lies at the intersection of several different areas, occupying an unfamiliar position in the division of medical labor.

CHAPTER 5

‘HOW THE FUCK AM I SUPPOSED TO KNOW?’: GOOD PRACTICE AND BAD RESULTS IN THE CARE OF THE DYING

American medicine first rose to its authoritative position over human health not through technical competence, but through establishing the cultural and political authority to determine who was and who was not the appropriate expert to address illness (Starr [1982] 2017). Only after establishing itself as an institution capable of controlling the authority to decide who could address matters of health, did it establish the efficacy to preserve human lives from trauma and early death. This early period of political and cultural competition for authority over health was difficult for medicine, and its position over health was only fully claimed when it adopted technological and organizational innovations to succeed in the treatment of illness. In the study of work, occupations, and professions, sociologists are concerned with many things: social influences in the systems of remuneration, the individual decisions that workers make through the pedagogical and professional system, as well as the ubiquitous and trenchant sources of inequality in work. But at bottom, when we study the professions, the system of expert labor that modern society relies upon, we are ultimately concerned with how workers achieve success and avoid failure in their endeavors (Timmermans and Oh 2010).

Expert workers are distinguished from their lay colleagues by a process of personal and organizational professionalization, which imbues them with a distinct set of practices and knowledge. Primary to this process of professional socialization is the acquisition of the normative commitments and evaluative criteria professional workers use to determine what they ought to do in the course of completing their work. Rather than a set of definitive rules to which workers adhere, these evaluative criteria are general principles against which workers can compare their activity to structure their practice (Hughes 1951). These strategies for promoting success and avoiding failure, rather than being the product of purposive and logical construction, have been created through a number of stochastic processes that led to a strained relationship to success and failure. In the case of medicine, clinicians value autonomy (Freidson 1988), as well as curing patients of their illnesses (Parsons 1975), and fear causing harm (Anon 2000; Landrigan et al. 2010). These “values” of the profession, and their influence over what professionals aim to achieve and seek to avoid in failure, are further constrained by interactions with the socio-legal environment, as patients, the state, and private insurance companies have gained more and more influence over the work of the medical profession (Light 1991; Pescosolido 2013; Starr [1982] 2017).

Within medicine, the expansion of different medical specialties and their organization into distinct services within hospitals has further complicated how the evaluation of practice occurs. A nascent body of work examines how intra-organizational differences in practice lead to different, and occasionally incompatible, systems of evaluation (Oh 2014). This line of questioning intersects with the growing salience of expertise, particularly the consideration of who is the appropriate body of experts to render opinions on problems and what constitutes expertise itself (Eyal 2013), as well as the renewed interest in medical education (Jenkins et al. 2021). This chapter is motivated by the question of how expert workers assimilate the dominant practices of evaluation in their profession, while also adhering to the social evaluations of their local reference group.

The clinical specialty of Hospice and Palliative Medicine (HPM) offers a unique window into these questions as it occupies a distinct position within modern medicine: many of the patients these clinicians treat are severely and terminally ill, and these clinicians do not have their own exclusive medical interventions like specialists in oncology, cardiology, or nephrology. Patients being seen by HPM clinicians experience a high rate of mortality; death is a consistent part of these clinicians’ work. How then, when the typical touchstones of success in medicine are not available, do these kinds of clinicians know when they have done a “good job”? How do they know they have done a good job, even when their patients die? In this chapter, I will explore the criteria for success and failure HPM clinicians use and how it guides their work and interactions with their patients and colleagues alike. Ultimately I will show that how the clinicians in this specialty view successful practice guides them in establishing a shared set of objectives with patients and other clinical stakeholders to achieve concrete objectives that abide by the preferences of patients.

The professional role, and the organizational niche that HPM occupies, exclude HPM clinicians from engaging in the kind of medical practice that reliably produces medical successes. Many of their patients die, and nearly all are incurably ill and their specialization in decision-making means that they are called to a patient's case when other clinicians have unsuccessfully addressed the needs of their patients. HPM clinicians aim to balance several, at times, competing objectives: they need to align with patients' preferences to create a plan of care while constraining the available choices for future care to the reality of the possibilities of medical intervention. They must also satisfy the work requests of their colleagues who ask for their consultation, while also maintaining their well-being in the face of difficult situations. They are both attempting to relate to their patients as individuals, with a linguistic and interactional repertoire that emphasizes values, while maintaining their authority as medical experts to make recommendations that deviate from both their colleagues' and patients' preferences.

5.1 Success and Failure in the Professions and Clinical Practice

A key means of promoting successful practices is by adhering to the social evaluations of the members of one's "reference group", the individuals to which a person naturally compares themselves due to homogeneity in their task or social role. In the context of work, occupations, and professions, social evaluations of a reference group are themselves determined by the work imperatives they have, a feature of work long noted by sociologists: Everett Hughes, in comparing different professions, noted that "it is very difficult to establish criteria of success or failure, and of mistakes as against proper execution of work" because of the heterogeneity in local imperatives that individual workers orient to. As a simple example, managers seek to establish rigid criteria of quality which requires scrupulous attention to ensure, while workers seek to complete the workday promptly. For managers, success is the production of material that conforms to precise tolerances, while for the worker success is a product that conforms approximately to these tolerances. These not necessarily converging proximate objectives lead to differences in what is considered successful. Hughes further notes that "in medicine, the criteria of success and failure are often far from clear" (Hughes 1951).

Determining when an intervention has been successful is the result of the common normative and evaluative criteria of the profession in which expert workers practice and the local context of workers an individual is embedded. In the process of professional socialization, where individuals acquire the knowledge and practices requisite to complete the tasks of their profession, they acquire the implicit set of normative criteria used to evaluate successful practice (Hafferty 1991; Miller 2013). Beyond education, (the acquisition of knowledge), credentialing (the acquisition of degrees and certificates), and apprenticeship (the acquisition of supervised experience), early career professionals acquire a set of practices that help to structure their work by understanding what they ought to do in novel situations by adhering to a set of shared normative associations. This socialization shapes the professional by shifting from their "prior reference groups to professional reference groups and develops a relationship to the values, norms, and culture of that profession" (Miller 2013:369).

In medicine, a key normative commitment is to provide life-sustaining interventions and to return patients to normal biological states by applying the appropriate medical treatments (Slomka 1992). In the drive to create more sophisticated and efficacious technologies that address patients' pathologies, a "technological imperative" has fused with the "normative imperative" to treat patients (Starr [1982] 2017). The fusion of these two imperatives has led to the development of technologies that have saved many individuals from premature death, but these more sophisticated technologies require clinicians to narrowly specialize in specific and esoteric bodies of knowledge. This internal differentiation is such that the core professional role of clinicians becomes contested as different sub-professional groups have different practices and criteria of judgment to evaluate their unique practices (Bucher and Strauss 1961; Kendall, Merton, and Reader [1957] 2014).

The multidisciplinary organization of the care of the severely ill means that many different kinds of clinicians are working with one another, each with different stakeholders and reference groups they need to attend to in maintaining their "professional legitimacy", authority, and recognition to practice in a given area. Different medical specialties use different strategies for maintaining their professional legitimacy: highly technical areas of medicine, such as oncology and surgery, maintain their legitimacy by appealing to their unique expertise to address patient's illness, while other areas, such as geriatrics, emphasize their ability to address patient's well-being, a much more general feature of patients (Sanders and Harrison 2008; Vale and Good 2020). Despite being organized on a largely not-for-profit model (Gapenski and Reiter 2016), there are still financial and material concerns of hospitals and individual clinicians that influence the evaluative criteria they use to judge their work.

Medical specialties practicing in hospitals, organized into "services" or "sections", need to generate revenue for the organization to justify and maintain the infrastructure they use to practice. The means by which many clinicians are reimbursed is through the production of Relative Value Units (RVUs) [Gapenski and Reiter (2016); p. 58]; these are a means of quantifying the value of medical services based on the complexity, technical expertise required, and resources needed. Highly technical, time and resource-intensive procedures, generate a relatively greater number of RVUs than those that require less expertise and are less time or resource-intensive. The use of RVUs to generate reimbursements and to evaluate different medical services creates unique exigencies and concerns that clinicians orient themselves to. For example, surgical services are incentivized to perform low-risk, high-paying procedures. This can translate into procedures that are not likely to lead to complications, but that might not necessarily improve a patient's overall well-being. Medical services, such as HPM, whose procedures require relatively less training and expendable medical supplies (and not necessarily less expertise) are harder to justify as they generate less revenue for the organization.

The generation of RVUs conforms to the dominant normative imperative medicine to reverse pathological biological states in patients as well as the quality metrics used in hospitals to evaluate the practice of clinicians: complications, unscheduled readmissions, extended hospitalizations, and death are all poor indications of practice and count against medical services that accumulate them. To maximize RVUs and avoid poor quality indicators clinicians may continue to prescribe relatively low-risk, but unhelpful treatments that constitute continued disease-oriented therapy, and prevent individuals from switching to a purely palliative form of care, that generates less revenue for organizations and medical services.[1]

To understand how the practical dispositions of clinicians influence their normative criteria of judgment I examine a specialty in the social world of medicine in which ambiguous problems, uncertain solutions, and equivocal commitments help to reveal the negotiated order of success and failure in medicine. This strategy for understanding how determinations of good and poor practice influence clinical decision-making is in tension with the dominant paradigm by which medical knowledge is produced, organized, and rendered orthodox. Medicine is principally governed by metrics of objective success and failure through the adoption of evidence-based practices (Hogle 1995; Lutfey and Freese 2007; Timmermans and Berg 2010). HPM is a fruitful area to study standards in medicine as the tasks and objectives these clinicians are oriented to, do not conform to the dominant evidence-based paradigm used to determine successful practice.

5.2 The operation was successful, and the patient died

The death of a patient is the clearest form of failure in medicine. Medical protocols and hospitals are designed to ensure that patients are saved from untimely deaths but despite the incredible medical advances of the past 70 years, death remains the inevitable conclusion of life and some illnesses remain impervious to treatment. Despite the reliable failures of medical intervention to save all patients who seek care, clinicians remain intensely focused on providing curative therapies to their patients. Specifically, clinicians focus on the "reversible" elements of a patient's illness and provide therapies that will reverse pathological states to normal ones. Such a mode of treatment, particularly in the care of the chronically and terminally ill, can lead to narrow applications of medical therapies that elongate the dying process and are untethered from a concern for patient well-being.

Death is a ubiquitous feature of the work of HPM clinicians as PAL-PH/A-044 (Male Attending,

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[1] That medical therapies can be "low risk, but unhelpful treatments" means that they are still meant to address symptoms and complications resulting from a patient's illness, but that is not alleviating the total symptom burden of illness, including its social, psychological and existential components. This results from the narrow focus of medical specialties on their unique domains of expertise and specific organizational niches.

East Coast) describes “all of my patients die, most of the time, maybe not all of them.” Rather than an unequivocal indication of failure, the deaths of patients exist on a continuum: “There are better or worse outcomes in certain ways. I think the times that I feel most useful are when I can be of service to people in shepherding them through this difficult time.” Success, instead of being determined by the application of technological interventions that extend longevity, is the result of *social* interventions in the care of their patients: “My role is in being there for people”.

Even tragic cases can admit to this form of successful medical practice. PAL-PH/A-044 describes a case where a patient suddenly and unexpectedly died: “All of a sudden, in the span of a week [the patient] went from getting extremely sick to essentially dying.” Though such a case “And the thing that I think, went well, in a certain way is just that I had built a relationship with him and his brother, that they trusted me, along with the oncologists to make the best decision for him based on what he cared about, and ultimately, he did not want too many aggressive treatments.”

Establishing a relationship with the patient and his family helps HPM clinicians establish achievable and acceptable goals from what other clinicians would consider at risk of failure. Without the rapport and trust of the patient and their caregivers to execute their preferences, the established routines of medicine determine patient care as PAL-PH/A-044 emphasizes: “When something crazy happens like that, the default is always to go towards the aggressive thing, because you can undo that. You can’t undo waiting for him to die.”

HPM has unique criteria to evaluate its practices and the outcomes its patients experience. An outcome that is considered at severe risk of failure is a patient dying in the hospital, an end HPM clinicians strenuously attempt to avoid. PAL-PH/A-044 describes that the case “doesn’t look good from the outside [because] he, unfortunately, ended up dying in the hospital. But he ended up dying with his family feeling like the right decision was made”. HPM clinicians commonly describe their practice as one that attempts to closely abide by the stated preferences of patients, in so far as these preferences represent achievable medical goals. Aligning closely with what patients describe as their goals or preferences requires that HPM clinicians structure the idiosyncratic statements of patients into “values”, normatively laden statements that match the overall moral order a profession establishes as appropriate. In medicine, the moral order is to “do no harm”, but this maxim is now primarily oriented to maintaining the lives of patients by applying technologies and techniques that extend patients’ longevity.[2]

Establishing values that are intelligible to clinicians and that are realistic given patients’ medical status is not a straightforward process. HPM clinicians shape, guide, and re-shape the values of patients in such a way as to make them intelligible to other clinicians. In so doing they are making patients para-medical experts, capable of making decisions that are informed based on clinically relevant information. This process makes patients behave more like HPM physicians, facilitating the coordination of the patient’s care and helping to soften the distinctions between patients with different levels of health literacy. To elaborate on this process I will first outline some of the strategies these clinicians avoid, and common errors made by their colleagues, before addressing how they communicate with patients and attempt to do a good job in the face of the ubiquitous and inevitable deaths of their patients.

5.2.1 The medical menu

HPM clinicians identify their colleagues using an *à la carte* menu of options to establish paths a patient can pursue. This style of providing patients decisions is described as “option-listing” in the sociology of medicine literature (Tate and Rimel 2020; Toerien et al. 2018; Toerien, Shaw, and Reuber 2013). Option-listing without endorsement is viewed by some clinicians as a means of counteracting medical paternalism, but HPM clinicians see it as a failure to provide patients with the clinical expertise they need to make an informed decision. PAL-PH/A-001 (Female Attending, Midwest) describes these different dispositions saying “I used to think probably more paternalistically […] I do try to not offer people a menu”. Providing patients with a menu of options can preserve their autonomy, but they are ill-equipped to meaningfully engage with the substantive dif-

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[2] The current orientation of medicine is not purely the product of broader cultural values, but the interaction of medicine with outside influences. Of particular note is the legal environment: my respondents often mentioned that their behavior and their colleagues’ conduct were regularly influenced by the perception that patients or their families were “litigious”, likely to use a legal recourse were they denied a desired medical therapy or if a death occurred. A fear of being sued often influences clinicians to prescribe more rather than less medical treatment.

ferences between the available choices. Regarding the use of heart therapies and breathing support she describes that "there is more expertise needed, not every really sick patient needs ECMO or a ventilator." Rather than purely providing individuals choices she describes that clinicians "have to get their values and then make a recommendation or give them appropriate choices for treatment, but not just like a menu like say, 'based on what I've heard, these three options are reasonable. And these are the benefits and risks of each' ".

Though every treatment is not guaranteed to address the overall well-being of the patient, clinicians can prescribe a large variety of interventions that attempt to reverse the complications resulting from the patient's underlying illness. These treatments can be uncomfortable and dangerous but are reasonable to offer based on the narrow decision-making matrix of specialists. HPM clinicians emphasize the need to use their expertise *with* patients' values and preferences to make decisions regarding their care. These clinicians frequently reference that their expertise in illness, medicine, and communication provides them the ability to make recommendations that can accord with patients' preferences while not overriding their autonomy to make free choices. PAL-PH/A-002 (Male Attending, East Coast), made this point emphatically saying "[the patient is] trying to make decisions in a realm they don't really understand. So they need your expertise and your expertise includes what I know about [their] disease, and what I've learned about [their] values". A concern for maintaining the autonomy of patients is compatible with the fusion of expertise and understanding of the patient's preferences. The patient is not obliged to accept the advice, PAL-PH/A-002 further notes: "[they] don't have to choose it, because it's going to be [their] call. But should I withhold that because I might overly influence him? I don't think so". PAL-PH/A-002 goes so far as to be critical of the broader movement in medicine to ensure patient autonomy that he sees as largely a form of clinical abandonment: "Where we've gotten really screwed up, in recent times with the patient autonomy movement is that many clinicians will present people with 'Well, we could do chemo, we could do surgery, or we could do hospice, what do you want us to do?' [and the patient says] 'How the fuck am I supposed to know?' You know, I mean really, so they really need guidance in this and guidance doesn't mean you're overly controlling them."

The disposition of this clinician is an instantiation of the broader strategies HPM clinicians use to establish success in the care of their patients. Rather than providing a simple set of choices, HPM clinicians seek to balance both overwhelming patients with choices they can decide between, and controlling the decisions they make for their care. Rather than a menu, they curate a set of choices that are established from the patient's stated preferences and afford reasonable and consequential decision paths.

5.2.2 Substantively identical choices

Overly curating a set of choices runs the risk of denying patients the agency to decide what will occur in their care, such as when clinicians create a set of seemingly heterogeneous but substantively identical choices. One respondent used the example of the inconsequentially different options that he gives his children to give them the impression of agency. Hypothetically asking his children, "Do you want the blue bowl or the red bowl for your cereal? but you're still getting cereal" (PAL-PH/A-018 Male Attending, Midwest). Though the respondent does not use this strategy as a legitimate means of providing choices to patients, he does use it to build rapport with patients by making the patient a social agent in the total institution of the hospital. "I certainly will do that sometimes for patients to try to give them more of a sense of control over the circumstances [...] I'll try to give them like, 'Hey, is now a good time to meet? If not, when do you want me to come back? Hey, do you want the window open, would you want the door closed? Do you want me to sit here or sit there?' "

HPM clinicians describe that providing inconsequential options is more common among their colleagues in other specialties and indicates a failure to sufficiently engage patients to discover what their preferences are:

> "[clinicians] will kind of throw up 'Well, we could try this right. Or we could do this, this is an option if you really want to'." Clinicians who follow such a strategy "haven't elicited the person's goals well enough to realize that these things aren't gonna accomplish that. Or the person's goal is actually different, they never asked what the goal is. They just assumed that the goal was to live as long as possible, and didn't realize actually, the goal was to get home again [...] I think it's usually they genuinely

> believe that there's a chance of this helping, but again, usually I think it's because either the chance is small, they're mistaken as to what the statistics are, or they have not clarified what the goals are. And therefore are offering things which aren't consistent, or helpful."

5.2.3 Pure Translation

Engaging patients and aiding them to make decisions as they face intractable illness requires that HPM clinicians engage the preferences that patients have. However, engaging these preferences and creating a plan that is in accord with them is not a matter of pure translation where predicates are encoded in different systems and unproblematically transcribed from one to the other. Rather, HPM clinicians *shape* the preferences of patients in the process of engaging them. PAL-PH/A-018, still describing the issue of offering an *a la carte* menu of providing patients choices, describes how he helps constitute the patient's preferences as they discuss what they want. Specifically addressing patients requesting that certain procedures, such as chest compressions, be excluded from resuscitation attempts, he describes that hospitals:

> actually make it so that patients can have what I would call 'partial resuscitation' and like I said, there's literature out there to suggest that that is completely ineffective. So that to me would be something that, 'hey, this doesn't make sense clinically, like from a medical standpoint, this has a 0% chance of accomplishing their goal'. So that would be something I would be trying to discourage and I would say, 'Hey, if this is your goal, to live longer, this isn't gonna help you get there. So therefore, I don't think this makes sense at this time, or I don't, I wouldn't recommend you go through this, because I don't think it's ever gonna help you live longer or live better or anything'.

PAL-PH/A-018 is shaping the goals of patients by aligning their stated preferences with achievable medical outcomes. Clarifying what treatments will achieve the preferences they have requires consistent engagement. PAL-PH/A-108 continues saying "The patient says, 'Hey, I want this because I think it'll help me live longer. But I want to avoid the uncomfortable seeming parts'. You know at that point, my goal, right is to confront that a little bit and be like 'I don't think this is going to accomplish that goal'. And usually [...] I mean, it's fear of dying that's often motivating some of these things, like when patients are asking for stuff that is almost certainly unlikely to be helpful in accomplishing their goals usually there's other underlying things that you want to explore there. So me discovering that would be successful and then I would kind of be like, 'there is a tension here. How do I navigate this, and how do I help this person navigate it?' " Clarifying the source of distress and the things that are influencing patients' decisions further clarifies what the necessary and helpful treatment modality is.

HPM clinicians are oriented to helping patients get the things they want, to be comfortable, and to have care that conforms with their preferences, but HPM clinicians are also working to satisfy the work demands of their colleagues who are asking for their consultation on patients' cases. The issue of decision-making and the mechanisms other clinicians use for establishing what patients want to do and what they can do, given their preferences and their condition, is critical in instigating HPM's involvement in a patient's case. For example, PAL-PH/A-001 describes how clinicians' eagerness to provide patients with options can undermine their ability to later constrain patient choices to those treatments and care that will best address their well-being.

> So that's why there's always decisions [...] we actually do let people make a lot of decisions around things that we don't think will help [...] a huge portion of [HPM's] job is we're constantly getting calls from oncologists who say, this patient won't stop chemo. We keep offering it and they keep saying yes. And you're like, 'okay, well that's your problem'. And also they don't know, right. The patients don't know what the benefit is, which the oncologist is sitting there being like, 'I don't know why they keep saying yes'.

Addressing the concerns of patients and the clinicians who care for them, who ask for HPM's assistance, involves a careful balance between aligning closely with patients and maintaining good working relationships with colleagues. In getting their work done, HPM clinicians attempt to find decision paths that are satisficing to the different stakeholders involved.

5.2.4 *Satisficing*

Satisficing describes a decision-making strategy in conditions of computational intractability, lack of information, or the inability to precisely define achievable optima to which individuals can orient to (Simon 1956). Rather than optima that to which some outcome is maximized to achieve, satisficing entails finding an acceptable threshold that can satisfy multiple conditions. In the hospital, rather than computational tractability generating situations in which satisficing is the appropriate decision strategy, the intractability of diseases as well as the established preferences of patients represent obstinate impediments to finding an optimal decision. HPM clinicians' strategy for completing their work is satisficing the work imperatives of their colleagues and the goals of patients.

HPM clinicians work at the request of other clinical specialists, and to continue to receive requests for their services, must demonstrate the ability to satisfactorily complete the work delegated to them by their colleagues. This need can create diverging imperatives for HPM clinicians which PAL-PH/A-002 describes "I think the primary responsibility is to the patient and family, right? [...] When you're invited in to be a consultant by a treating doctor, you also have a responsibility to that person who invited you in, they can invite you out, right? If you piss them off too much, or get too invasive, in your recommendation."

HPM clinicians need to satisfy the needs of patients by closely aligning with them and completing work tasks to the satisfaction of their colleagues. This can create issues for HPM clinicians as the different objectives of satisfying patient needs and completing tasks set for them by their colleagues can be orthogonal to one another. The ultimate concern is the patient's choice, as PAL-PH/A-002 emphasizes: "the bottom line would be your real primary responsibility is to try to do the best by the patient. So its the patient's clinical situation and the patient's values that count the most". If patients are fully informed, cogent, and oriented to goals that are medically achievable but at odds with the values of HPM's colleagues and which obstruct their work, then HPM clinicians have to manage the disagreement to the satisfaction of all parties involved. Diverging paths forward need to be presented to patients in such a way that the expertise of clinicians is communicated, but the autonomy of patients can be maintained. Rather than a menu, HPM clinicians establish the different paths a patient can pursue that accord with their established values through *choice set construction*.

5.2.5 Choice Set Construction

Patients seeking care for life-limiting illnesses have many choices to make in the course of their medical treatment and the number of decisions to make can proliferate as illnesses grow more acute. The kinds of choices clinicians offer patients to choose from are critical as they can set patients on different trajectories for their later illness and death. PAL-PH/A-001 (Female Attending, West Coast) described it tersely saying “oh man, there’s still so much decision-making to happen. I mean up until the bitter end”. These decisions vary from continuing disease-oriented therapies to the level of supportive therapy patients will receive: “Like should [the patient] come back to the hospital? Should you not? […] we honor patient decisions […] We err on the side of autonomy if people are making decisions that don’t necessarily align once we’ve shared information and tried to guide them.” In hewing to patients’ preferences, both shaping and closing aligning to them, HPM clinicians are furthering legitimately achievable goals that accord with what patients admit wanting. As the respondent makes clear, “Our goal is to really honor patient’s wishes even if they seem like very disconnected and to do the best we can.”

This disposition to guide patients, providing them with a choice set that conforms to their preferences and values, distinguishes HPM among clinical specialists. PAL-PH/A-020 helps to clarify the distinct attitude HPM clinicians take to establishing what treatments will be appropriate and beneficial given patients’ unique goals: “The most important thing to me is addressing and finding out what’s important to them, and what motivates them, what keeps them going and what fears or concerns that they have. And then from there, moving to one thing or another makes a lot more sense for that patient, because you’ve already established that framework of this is how we’re going to view these treatments.” Establishing first what the objectives of medical care are (the “framework” the respondent mentions) that accords with the patient’s preferences, allows HPM clinicians to consistently engage patients in decision-making that organizes choices based on how well they match that framework. Failing to establish this framework is deleterious and leads to confusion as to what ends are being pursued and what means are appropriate for achieving them: “A lot of patients view [all treatments] of ‘I’m fighting, these are the ways to fight’ but then it’s like, ’well, what are you fighting for? You're fighting for time with your family, you're fighting for communication with your family. So let's focus on the things that will get you that, and the things that aren't going to get you that."

A key feature of this disposition to decision-making, which diverges from other kinds of clinicians, is the focus on the social circle around the patient and how it determines success and failure: rather than the technical success of a pain regimen, one of the traditional forms of medical expertise HPM maintains, HPM clinicians emphasize how the technical medical achievements in patients' care are constitutive of a larger success in creating an achievable plan that delivers patients concrete changes in their life, such as eating and drinking, gardening, or spending time with their loved ones. PAL-PH/A-001 describes that "patients don't make decisions just based on like what we think our medical reality is. People make decisions based on faith and previous experience." Respecting the perspective of patients and their family members, based on their own experiences and fears, requires that HPM clinicians attenuate the ways they use their own objective and rational engagement with medicine. She continues by saying "I have since become less attached to my own definition of what reality is and much more interested in supporting patients than giving them as much the reality of my scientific world that I can." A key strategy for promoting success and doing a good job that HPM clinicians adopt is to closely engage and abide by the preferences that patients and their social circle have, a behavior I identify as *hewing*.

5.2.6 Hewing

In describing how HPM clinicians engage and abide by the preferences of their patients to create achievable goals, I adopt a metaphor from carpentry. *Hewing* is a traditional woodworking technique that involves shaping and smoothing rough timber or logs with hand tools such as an axe, adze, or chisel. The primary goal of hewing is to create flat, smooth surfaces and straight edges on wooden beams or logs, making them suitable for use in construction or other woodworking projects. The metaphor for the work of HPM clinicians is apt as the word has a further metaphorical meaning used to describe the action of adhering closely to a particular principle, idea, guideline, or standard.

It implies a commitment to staying faithful or aligned with a specific concept or course of action. HPM clinicians establish the goals and preferences of patients by listening to them in interaction, a process that is not accommodated in the work schedules of hyper-specialized subspecialists.

PAL-PH/A-013 (Male Attending, Midwest) describes that the ability to sit with patients and discover their preferences is due to both HPM clinicians' expertise derived from their training: "Different [specialists] have different things that they have either proclivity towards or expertise on […] communication is our procedure, or a family meeting is our procedure". Beyond an aptitude derived from training, the division of labor in hospitals means that HPM clinicians also have more time to complete these idiosyncratic tasks of relating to patients and sitting with them: "There's also an economy of time, right? That I will have more time than an internal medicine doctor who has eight different patients they need to see that afternoon. Whereas I have three patients I need to see for example."

The economy of time that PAL-PH/A-013 describes allows HPM clinicians to engage their patients more than their colleagues in other areas of medicine. "Sitting with" patients, the term HPM clinicians often used to describe interacting with patients for an extended period, allows them to collect and discover the myriad preferences and goals patients have outside the strictly defined medical goals clinicians use to determine the appropriate interventions to use with them. Hewing includes discovering patients' preferences, which PAL-PH/A-013 describes can take on many different forms: "Being home might be valuable, fighting for every last breath might be valuable. Seeing his grandchild born in two months might be valuable. So drawing out what might be valuable to this person in front of me". Confining these preferences to what is medically possible is also critical in this process of establishing patients' preferences.

Once HPM clinicians establish patient's preferences they then work to maintain everyone to those preferences. PAL-PH/A-008 (Male Attending, West Coast) describes this in terms of an ideal-typical patient who desires the full degree of supportive life-sustaining therapies, which "in the palliative care literature is called the 'vitalist' ". Such a patient unequivocally desires the full degree of life-sustaining therapies; "This is a person who, no matter what the odds are, I want you to do everything on earth to keep me alive forever. And I don't care if it means machines, and I'm sitting in a room, and you're just supporting my organs, but I'm never there." When patients unequivocally express their preferences, PAL-PH/A-008 describes that "I'm not going to talk about like, 'should we consider intubation and not using CPR?' Like that, I know the answer, and in some ways, them telling me their narrative if there's such certainty, then I just need to go back to the provider and say, 'Look, this is what they want. It may not be what you think is right. It is what they want' ". Hewing in the clinical context involves HPM clinicians shaping the preferences into achievable medical goals, and smoothing the diverging opinions that can occur between different clinicians and the patient. The primary goal of hewing is to create the basis upon which further medical therapy can be conducted.

To give concrete examples of both the constraints that are placed upon patients and their clinicians, as well as the different behaviors and strategies clinicians from varied specialties use to engage their patients, in the following section I provide an extended example from my ethnographic fieldwork. One case I observed during my fieldwork, is particularly instructive of the distinct approach HPM clinicians have for constructing a choice set that hews closely to the preferences of patients, and exhibits a concern for their social circle and their personal preferences for care, rather than the medical-scientific reality that technically oriented clinicians focus upon.

5.3 Good Practice, Bad Results: An Ethnographic Example

Daniel, a 35-year-old man suffering from abdominal cancer, was hospitalized due to failing liver functions, possibly a result of the pain regimen he was prescribed to control his worsening tumor burden. Daniel's case is a relatively common one in the care of individuals with chronic and life-limiting illnesses. Following the diagnosis of his illness, the proscribed therapies, which were derived from the routine mechanisms for making medical decisions, failed to halt the advance of his illness and a slow decline began. A recent precipitous decline in his well-being indicated that he might not have much time left to live. For many patients, periods of hospitalization can elongate as more and more severe symptoms impede their ability to remain at home, as was the case for

Daniel. Attempts by specialist clinicians to triage the treatment of the most pressing symptoms can lead to diverging treatment imperatives. Remaining in the hospital is alienating and uncomfortable, but not so uncomfortable as remaining at home with worsening symptoms. Interventions that have the promise to alleviate some symptoms pose other complications, and the lingering possibility of further therapy meant to stall the advancement of their disease can incentivize remaining in the hospital longer.

Over multiple hospitalizations, I visited Daniel with Marissa, a palliative care clinician, and he expressed his desire to be discharged from the hospital and to sustain himself at home, where he could be visited by his family and spend time with his wife, Sarah, and their pets. Simultaneously, he was interested in starting a clinical trial for his cancer, which had some small chance of elongating his life. He was also being evaluated for the implantation of an Intrathecal (IT) Pump, which would deliver pain-relieving drugs directly to their site of action helping to control his symptoms. At the same time, the clinicians were attempting to manage his failing liver, which was both keeping him in the hospital and posing a severe risk to further treatment. If he could get his liver numbers better, and get his IT pump, he might achieve the goal of getting home comfortably, but staying in the hospital was the only way of receiving further cancer-directed therapy that might extend his life. Daniel was met with diverging choices that had severe implications for his well-being and longevity. At the same time that he was loath to return to the hospital, which he had emphasized to Marissa on previous hospitalizations, he was unable to maintain his health at home. Though he wanted to ensure that he lived as long as he possibly could, he knew that this would lead to more time in the hospital and more uncomfortable procedures, which other specialists continued to offer.

Daniel had been experiencing what he described as “unquenchable thirst”, and a great deal of pain from his abdomen. Daniel was unable to maintain normal nutrition as it caused him severe discomfort to eat or drink, and he was proscribed total parenteral nutrition, which intravenously provides nutrition, bypassing the usual process of eating and digestion, a life-sustaining but uncomfortable treatment. Describing the most pressing concerns of the medical staff caring for him, Marissa said ‘I think the main concern is your liver function, which is probably what is causing a lot of your symptoms'. The gastrointestinal team was handling the treatment of Daniel's liver, while the pain service was evaluating him for his pain pump, and the surgical oncology team was also seeing him as they had most recently performed surgery on his abdomen. Critically, each team maintained a focus on their specific domain of authority and continued to proscribe treatments that would address symptoms resulting from issues they could both diagnose and treat. On our first visit, as Marissa and I were preparing to leave, Daniel asked, 'I am not sure whether or not it is time for hospice?'

Patients bringing hospice without being prompted by HPM clinicians was an uncommon event in my observations, and usually, the prospect of hospice was only brought up after a great deal of rapport was created between patient and clinician. Marissa, rather than fully endorsing the idea said, 'If we can get your liver numbers better and you want to get to the trial that you can do that. But hospice is always an option for you if you feel you're ready.' Daniel was informed that he was a possible candidate for a trial for a novel cancer therapy and had been considering receiving another round of treatment with it. Marissa was hewing closely to what Daniel admitted his goals were; he had expressed ambivalence about more treatment and hospice would definitively close that option. Remaining in the hospital was a legitimate means of furthering his goals, and wouldn't preclude later adopting a purely palliative option. Further, Marissa was expressing a concern for the wider social circle that Daniel was embedded in.

I asked whether she was surprised at Daniel's question. She described that Daniel had been told that his cancer was incurable and that he very likely had only 'months to live'. I asked Marissa whether she was going to address the goals of care for Daniel or mainly focus on treating his symptoms. 'In this case, I don't think there is a distinction.' She described that 'we are really here just to support the patient, and his wife in particular. Because…' Marissa hesitated before continuing, 'the truth is Daniel is going to die from this and we need to support her. I don't think she will be able to live with herself if she doesn't try or if Daniel doesn't try everything.'

As noted above, the primary difference between HPM and other clinical specialists is that HPM engages nonmedical but clinically relevant information that patients produce, as well as the wider circle of stakeholders in the patient's case. Daniel admitted a preference for eating and drinking naturally, as well as spending time at home. Other clinical specialties, particularly those oriented to performing technically challenging procedures, tend to narrowly focus on features of patients that are specific to the domain in which they specialize and seek to achieve success. This inability to engage with the idiosyncratic and nonmedical preferences patients express can lead to the narrow application of treatments to no definitive and achievable end. When we returned to visit Daniel again in the afternoon our visit coincided with the arrival of a surgeon from the surgical oncology team who had operated on Daniel months ago. He announced that he was making a 'social visit', and immediately drew Daniel and Sarah's attention, both of whom peppered him with questions.

'We know that we are thinking about the clinical trial and waiting to hear about whether he is eligible and the pain people were here to see him but we wanted to know whether you know about what sort of time frame we might be looking at?' Sarah asked.

The surgeon answered 'I gave up on playing god a long time ago, and I can't answer that question. But the primary goal is getting you to treatment. The goal is keeping him comfortable because being comfortable allows you to pursue more therapy.' Cancer is a predictable illness; the increasing frequency and unscheduled nature of Daniel's admissions to the hospital, and his self-reported degradation in quality of life, were key indicators that he might die soon. Marissa would later confide in me that 'these oncologists, or maybe it is just the surgeons, do not give definitive answers to questions when they are asked about prognosis or the state of illness.' The surgical oncologists' failure to disclose or speculate about Daniel's prognosis meant that he and Sarah were making decisions without a relevant piece of clinical information. Euphemistic and obscurantist communication has diverging consequences. A lack of terseness leaves patients and their caregivers ignorant, while being brusque can leave them devastated. The surgical oncologist failed to engage Daniel when he asked about his prognosis, which allowed for discussing a feature of the case that would bear greatly on future decisions: if time was short for him, then he might prioritize his well-being and stop pursuing extra therapy.

The pain service successfully implanted Daniel's IT pump, and it seemed to be giving him some relief as he was less lethargic and more alert. On a later visit with Daniel, Marissa learned that to be evaluated for his clinical trial he had to complete several scans that would require that he be considered outpatient to complete. To do this he would be discharged from the hospital and transferred to conduct imaging before being readmitted to the inpatient unit. When visiting him, a member of the gastroenterology team visited, a specialist that Marissa and I had learned Daniel had developed rapport with and regarded well. After performing a cursory inspection of Daniel's abdomen and paying particular attention to his jejunostomy tube, which delivers food to the small intestine the gastroenterologist announced: 'Well it looks like there is some extra discharge around the J-tube.' She replaced the sheet around Daniel and then pressed the disinfectant dispenser on the wall. 'We are going to have to send you for some scans right away to make sure it is implanted right.' Daniel was devastated by the news as performing the scans was uncomfortable and they could not be used in the evaluation for the clinical trial. When the scans returned, the J-tube was found to be properly placed but his IT pump was discovered to be improperly planted, and the needle that is meant to deliver his medication intravenously migrated in his tissue.

The clinicians providing him care, presented Daniel with different choices to make: attempt to manage his pain with the IT pump, with its risks of complication, or continue attempting oral analgesics and fentanyl patches; pursue an experimental clinical trial or get well enough to go home and discontinue treatment; receive oxygen to support his weakening lung function, and risk dependency on it, or suffer the effects of air hunger. Certain of these clinicians presented treatment options without particular regard to the overall goals Daniel held: the surgical oncologist and the gastroenterologist, presented treatment decisions as necessary to unambiguous but diverging ends. Marissa worked to understand what clinical objectives would promote the well-being and balance with longevity Daniel sought and offered a choice set curated through engaging his preferences and evaluating the reality of his situation. This choice set was oriented not only to his well-being but also to his wife, who wanted both to have more time with her husband, but also wanted to respect his wishes. From the field excerpts above, I maintain that different kinds of specialists are differentially adept or willing to engage in this kind of work. Over my fieldwork, I saw non-HPM clinicians engage Daniel in decision-making, and a common feature of these encounters was a narrow focus on the technical aspects of illness, and reversing symptoms that were the result of his illness, but that would not substantively achieve his goals. The exception was my observations of his encounters with palliative care clinicians who consistently engaged him in global considerations of medical care and his goals.

After being discharged and readmitted from the hospital a number of times, Daniel died in the ER after his heart stopped. Clinicians attempted to resuscitate him, though in the weeks prior he told clinicians he did not want such a procedure. Over the weeks that he was in the hospital and considering the treatments before him and the implications on his well-being he was trying to find a balance between competing desires: living longer, being comfortable, spending time with his dogs and Sarah at home, seeing his family, and eating and drinking. There is no necessary relationship between longevity and discomfort, but oftentimes in the care of patients who are as acutely ill as Daniel was in his final weeks, they are orthogonal to one another.

5.4 Discussion

Daniel's case, despite the best efforts of Marissa, ended poorly. Though she adopted good practices that were in line with her specialty's commitments to hewing closely to patients' preferences and creating choice sets that conform to them, the constraints of medical treatment, the hospital, and the behavior of her colleagues ultimately led to Daniel dying in a way that he had described before as being something he did not want. Though a consequential and unequivocal distinction between a living and dead patient is important, the determination of appropriate practice in medicine is not a straightforward process. Everett Hughes (1951) notes that professionals seek to reduce the risk of failures and mistakes in their practice, though the frequency and repetition of tasks necessarily lead to a greater chance of a mistake occurring. He notes that risk management leads to the need to address the process by which professionals define "what a failure or mistake is in any given line of work or a given work operation. This leads to still another, which turns out to be the significant one for the social drama of work: Who has the right to say what a mistake or a failure is?"

HPM clinicians succeed in their work by closely aligning with their patients' expressed preferences and orienting them to achievable medical goals that are meant to promote their psychological and existential well-being in the face of death. They expand the circle of moral and medical concern beyond the nucleus of the patient to include the patient's family who have a stake in their well-being and who will endure after their death. These clinicians express this concern by hewing closely to what patients say they want and helping to create a curated set of choices that accord with those expressed preferences, avoiding the pitfalls of leaving patients with a simple menu of possible paths forward or prescribing treatments based upon the impartial rationality of the medico-scientific worldview. Breaking out of the rote mechanisms for prescribing "appropriate" or "beneficial" treatments requires that they sit with patients and spend extended periods interacting and contextualizing the patient's experience back into their subjectivity.

Success for these clinicians is abiding by the wishes of their patients, and ensuring that what they express as a preference, in so far as it is medically possible, is pursued and respected by the clinicians who care for them. Failure for them is the breakdown in the social relationships that allow medical therapies to be delivered to patients in a timely and substantial way: if surgeons become disengaged, or patients reject the continued involvement of consequential medical personnel, and their exclusion degrades their well-being, the HPM clinician has unambiguously failed. The maintenance of the social relationships that surround patients is key to not only their medical care but also to the esteem of HPM clinicians.

A continued interest on the part of sociologists in how professionals know when they have done a good job and avoided doing a bad one will endure as an important feature of our studies of work, occupations, and medicine in particular. Not only is the determination of success and failure consequential for worker well-being, but it is also an important feature of the collaborative environment and the network of organizations workers must prove their worth. In the domain of medicine, with its heterogeneous body of medical specialists, all of whom become integral to patient care, understanding when colleagues have done well and when they have performed poorly allows clinicians to maintain the continuity of patient care. An understanding of how the evaluation of colleagues work, allows them to more intelligibly engage differences in practice. What's more, the aging population in many industrial societies, and the rise in chronic life-long diseases, will only lead to more cases that are seen by clinicians in HPM and which are discordant with how clinicians have understood good practice in the past.

5.5 Conclusion

The clinical practice of HPM is unique in medicine because their patient population is among the most acutely sick patients who are seeking care. Their patients are often chronically and terminally ill and in a profession that seeks to maximize the longevity of patients or curing them, this is not a role that is amenable to the classic definitions of good practice. Rather than abiding by the dominant paradigm of success and failure, HPM guides its practice by a set of alternative normative commitments: they seek to promote the preferences of patients for treatment by translating their stated goals into a set of values that are intelligible to their colleagues. They then assemble a set of choices that are appropriate given those values and align the different stakeholders in the patient's case to the goal that accords with those choices. Success in this framework is deceptively straightforward; HPM clinicians simply do what patients tell them to do; HPM clinicians do indeed do what patient's tell them, but in the process of hearing what the patients want, they are structuring these preferences in such a way as to help insulate themselves from the risk of failure. Rather than being a kind of meta-paternalism, where the substantively consequential decisions are taken out of the hands of patients and placed into the hands of clinicians, this process is the form of shared decision-making so often advocated for by the largest organizations that govern the profession.

CHAPTER 6

THE DISCOURSE OF DATA AND THE TALK OF VALUES

When patients arrive at the clinic, they complain of aches, pains, abnormal excretions, or other symptoms that undermine their ability to pursue their daily activities. In the most extreme cases, patients arrive at the clinic in a state of acute medical emergency unable to speak at all. They do not speak in the language of medicine, and instead describe their problems in a multivocal, idiosyncratic, and plural collection of utterances, what some scholars have called the "Voice of the Lifeworld" (Maynard 1991; Mishler 1997; Silverman and Torode 1980). A primary concern of physicians and nurses is to take in these utterances, which lack an intelligible organization to medicine, and translate them into the medical worldview, to arrive first at a diagnosis and then a treatment. In routine medical encounters, the ready-at-hand tools for categorizing and prioritizing the patient's symptoms described in their idiosyncratic vernacular are efficacious for arriving at appropriate and beneficial therapies. In what I call the "Maximization Framework", clinicians evaluate possible treatments, benefits, and side effects based on seeking to maximize the longevity of their patients, by curing or inducing remission in their illness.

When the Maximization Framework fails to produce unequivocal indications for medical treatment due to the patient's advanced illness, clinicians and patients become misaligned in their practical objectives. Patients are the primary locus of decision-making (Emanuel and Pearson 2012; Epstein and Street 2011), if there is discordance between what clinicians advocate patients do and the patient's preference, consensus is achieved by clinicians leveraging the discursive resources of an objective, scientific, and disinterested rationality (Stivers and Timmermans 2020), what I call the "Discourse of Data". Despite momentous changes in the organization of healthcare delivery in the US (Light 2010; Starr [1982] 2017), the fundamental nucleus of the patient-clinician relationship remains the fulcrum upon which healthcare delivery pivots (Timmermans 2020). The different forms of expertise that patients and clinicians bring to the problem of sickness and medical treatment (Prior 2003), as well as how stakeholders in the clinical encounter negotiate decision-making given their uniquely authoritative positions (Tate 2020), bears great influence over the efficacy of medical treatment (Heritage and Maynard 2006; Singh et al. 2017). Growing emphasis on patient autonomy has required that clinicians give greater and greater weight to the opinions and perspectives of their patients while at the same time providing evidence-based care that meets clinical standards (Tate 2019).

Simultaneous to the emphasis on the role of patients in medical decision-making is the growing specialization of medical knowledge and practice, wherein the profession of medicine is more and more composed of a heterogeneous body of narrowly defined specialists (Brotherton, Simon, and Etzel 2002; Moorhead 2010). Networks of collaboration tightly couple different areas of medicine that are further separated by rigid boundaries, with technically incompatible language, practices, and criteria of success and failure. Running through these changes in the patient-clinician relationship is the continued need for clinicians to translate their expertise to colleagues in other areas of medicine and to the lay clients they are treating. This is no trivial challenge, as the dynamics of professional boundary-making purposively insulate experts from lay critique and competitor colleagues alike by abstracting the practical problems of lay people to a recondite domain over which they have exclusive jurisdiction (Abbott 1981).

In this chapter, I will show how clinicians in HPM integrate medical professionals and their patients by synthesizing the linguistic and interactional repertoires patients and clinicians use to talk about illness and treatment and make decisions about what to do by emphasizing shared values and objectives. Particularly in the care of the terminally ill, HPM clinicians help to transition patients and the clinicians that care for them from the Maximization Framework, where the primary objective is to extend a patient's longevity at the expense of short-term discomfort, to a Reconciliation Framework, where the primary objective is to provide patient's social and existential comfort in the face of death. Clinicians in HPM use a particular repertoire of talk, what I call the "Talk of Values", to integrate the otherwise discordant practical activities of the diverse set of clinicians and their patients into a shared goal.

This chapter is distinct in its focus on clinicians working in the inpatient setting, treating the acutely and often terminally ill. Past works have largely focused on clinical encounters in the primary care setting (Bergen and Stivers 2013), as well as solely focusing on mechanisms within the patient-clinician interaction which reliably produce inequalities between different patient populations (Shim 2010). This work extends past research by including how the differences in discursive and interactional resources available to different kinds of clinicians are used to include patients in decision-making. Rather than solely focusing on moments in which patients resist clinician's recommendations (Stivers and Timmermans 2020) or the specific strategies that clinicians use to achieve assent from patients (Stivers and McCabe 2021), this work attempts to theorize both how differences in practical activity inform the linguistic resources available to social actors and how these differences are integrated to establish a working consensus between different stakeholders.

6.1 Background

6.1.1 Professionals in Organizations

Professionals are more and more embedded within organizations that structure their work. Organizations assemble and coordinate the interactions of their professional members to form cycles of collaboration within a division of labor to address the organization's goals encouraging expertise in a task, domain, or technique (Merton 1940; Meyer and Rowan 1977; Nancarrow and Borthwick 2005). Complex organizational problems require a sophisticated assembly of knowledge and practice and internally differentiate into suborganizational groups, or *specialties*, to address client's problems through a further division of labor (Becker et al. 1961; Laumann and Heinz 1977; Muzio, Brock, and Suddaby 2013). Dense cliques within organizations facilitate this work, with clique members frequently collaborating and communicating with one another, and in the course of these cycles of interactions, developing their distinct ways of talking about and doing their work (Burt 2004; DiBenigno and Kellogg 2014; Trotter 2019). Intra-organizational dialects form as a result of the functional differentiation of the organization into specific specialties, with their own sub-tasks and work styles.

Specialties develop *domain-specific* knowledge that is not shared by all members of the profession and devolve specific tasks to specialists to achieve shared goals in a system of interdependence. The development of this domain-specific knowledge through social differentiation leads to a “professional paradox” (Moorhead 2010) as functional differences lead to diverging levels of experience, terminologies, and normative imperatives which undermine the cohesion of the overall profession (Carlile 2004). Despite being united by membership in the overarching profession and possessing a professionally specific common knowledge, diverging practical imperatives of actors organized into different specialties lead to both issues in the translation of their vernacular and coordination of their work styles (Steinberg 1999). The “discursive regime”, the dominant set of linguistic resources available to specialists, structures the ways of talking about work as well as organizes the taken for granted means and ends specialists use to guide their actions. This common language and knowledge bridge the different dialects that form within organizations, but occasionally these specialty-specific dialects bump into one another as the meanings of shared phenomena, processes, or objects can take on distinct meanings, producing confusion and impeding collaboration (Oh 2014).

6.1.2 Translation Across Boundaries and Institutional Talk

Sub-professional groups, or specialties, mutually orient to a set of shared goals, to which specialists can immediately direct their attention and effort. This division of labor requires that different intra-organizational groups develop their domain-specific knowledge, while the social differentiation and dense interactions maintained between group members, and the relatively sparse interactions with out-group colleagues lead to differences in practice and communication that require translation to overcome. Domain specificity can further lead to “cognitive narrowness” (Moorhead 2010), as specialists fail to attend to features of cases, clients, or processes that fall outside their circumscribed area of expertise.

Three characteristics of knowledge and practice between groups structure how the passage of information occurs across the permeable boundaries between groups (Carlile 2004): (1) *Difference* in knowledge can be of degree (such as between a patient and their doctor) or kind such as the specific domains different groups are specialized in (oncologists v. cardiologists). (2) *Dependence* is the degree to which individuals or groups must account for the activities of others to achieve their individual goals. Dependence can be structured sequentially, such as surgeons relying upon anesthesiologists to anesthetize patients, or reciprocal where the activity is completed in parallel, such as the work of oncologists and radiologists coordinating the treatment of their patients. Dependence is matched by an equivalent amount of coordination to ensure that the specialty-specific goals and timelines are aligned. Finally, (3) whether the goal to be achieved is already routinized within the system of collaboration and interdependence established in an organization, or the level of *Novelty* of a task. In the medical setting, these boundaries extend to organize the relationships between patients and the clinicians who care for them.

The presence and degree of difference, dependence, and novelty between intra-organizational specialties structure the boundary between these groups and form *syntactic*, *semantic*, or *pragmatic* boundaries across which knowledge must pass. A syntactic boundary (low difference, low dependence, no novelty) is crossed by a simple transfer of information via a shared lexicon, where the social meanings of words and other signifiers are mutually understood and uncontested. Close working relationships and frequent collaborations, such as in the case of surgeons and anesthesiologists, or oncologists and radiologists, produce ease in crossing such a syntactic boundary. A semantic boundary (medium difference, medium dependence, and low novelty), where a common lexicon is insufficient to transfer knowledge because the meanings of signifiers are contested or unshared requires the translation of knowledge by a deliberate process. Clinicians need to regularly cross this boundary in working with patients who lack medical expertise.

A pragmatic boundary (high difference, high dependence, high novelty) where groups are separated by both functional differences and normative or political differences requires the transformation of knowledge between the domains into a mutually intelligible form.[1]

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[1] The need to translate and coordinate across organizational boundaries is not unique to medicine, but occurs in many distinct domains. A fruitful tradition of "industrial sociology" has explored how intra-organizational boundaries form and are crossed in the process of collaboration (Carlile 2002, 2004) and how structured or institutional talk is critical to the maintenance and functioning of organizations (Boden 1997; Fairhurst and Putnam 2004). In the development of new industrial products, different members of organizations facilitate the creation of different parts of

Bridging the boundaries in knowledge and practice between different functionally interdependent groups can be achieved through technical and organizational innovations. One means of coordinating activity across groups is by the use of "boundary objects" (Star and Griesemer 1989), material or conceptual entities that can move between domains while preserving meaningful information that is intelligible between otherwise incommensurable systems. The Electronic Health Record in medicine was designed to be a powerful mechanism for transforming how patients' medical information was stored and managed, facilitating both collaborations between clinicians and their patients, and improving the ability of patients to actively participate in their care (Tang et al. 2006). Despite the promise of EHRs, persistent problems remain in their use: much of doctor's clinical and office time is spent interacting with the EHR (Sinsky et al. 2016), as well as contributing to burnout (Kroth et al. 2019), and inattention to patients due to doctor's focus on the EHR in the medical encounter can produce risks to patient's safety (Palojoki et al. 2017).

A further organizational innovation to achieve coordination is through the use of expert managers (Freidson 1984a), where professionals specialize in the supervision of different workers. The rise of such a managerial class is not fully efficacious for administering heterogeneous bodies of mutually dependent expert workers (Chandler [1993] 2002), as technical knowledge of the workaday methods employed by the workers is required to effectively manage subordinates (Goodwin 2021). In medicine, reforms to ensure that patients' cases are managed in the inpatient setting have been assigned to subordinated professions such as nursing and social work, and their efficacy in increasing efficiency and quality are disputed (Roggenkamp and White 2001). An alternative to the vertical integration of different sub-professional areas is horizontal bridging by expert workers with functional knowledge of the demands and requirements of different areas, but these professional

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the ultimate product (Carlile 2004). Designers, design objects' shapes, functions, and aesthetic qualities, but are not experts in the industrial processes by which the product will be rendered into a physical object ready for consumption. Fabricators, on the other hand, take in schematics from designers to create processes by which abstract plans are concretized into physical objects. A series of boundary objects (schematics, flow charts, operating manuals) are used to create meaningful connections between the different groups and the products of their activity (Star and Griesemer 1989). The problem of coordination further extends to military science and the need to ensure the different branches of the armed services, both interdependent upon one another and distinguished by different cultures, tactical and strategic practices, are capable of working together to achieve mutual ends (Rubel 2001).

groups are often subordinated due to their perceived lower status (Kellogg 2014). The development of the Hospital Medicine specialty was meant to serve just such a role for hospitalized patients and despite great evidence that they increase the efficiency of medical care, there are persistent questions about whether Hospitalists improve the overall quality of care patients receive (Centor and Taylor 2009; White and Glazier 2011).

Each of these innovations to integrate different specialists is efficacious to a degree but fails to address a fundamental problem in the care of patients with advanced illnesses who are approaching the end-of-life: the routinized mechanisms for making decisions, creating consensus, and synthesizing the practices of different kinds of specialists fail to provide unequivocal indications as to what is the appropriate treatment, if any, and what mode of care to use for patients. In such situations, the specific practical imperatives of specialties organize their engagement with patients: surgeons seek to manage post-operative complications, anesthesiologists evaluate patients for intrathecal pain pumps, pulmonologists monitor weakened lung function, cardiologists weakened hearts, while oncologists attempt to address the spread and severity of tumors without sufficient coordination to achieve any functional improvement in well-being for patients.

These specialty-specific goals are not arbitrary, but evidence-based and organized by scientific medicine, but are ill-equipped to solve the problems of decline and death. The problem of managing the care of the chronically and terminally ill requires an alternative strategy for crossing the pragmatic boundaries that form between and within clinicians and the patients they care for where patient preferences are re-established as grounds for determining achievable goals.

6.2 Navigating Clinical Decision-Making in Chronic and Terminal Illness

Why are divergent practical imperatives produced when a patient's illnesses reach the chronic and terminal phase? The primary decision framework in medicine, used to indicate therapies based on the diagnostic and prognostic information patients produce, the Maximization Framework, is primarily oriented toward increasing longevity, and so takes for granted patients' preferences and goals. This framework productively organizes the work of nurses and physicians in routine cases as the assumptions made by clinicians accord with the taken for granted desires of patients: patients value being alive, they prefer to extend their life, and their instrumental goal is to keep receiving therapy directed at prolonging their survival. The routinized working relations between different specialists are easily integrated with this scheme as their established means for collaborating are sufficient for crossing the pragmatic boundaries that separate their knowledge and practice as they mutually orient to a shared goal.

When a patient's illness is incurable, or increased longevity is no longer an achievable goal, the Maximization Framework fails to produce clear indications as to what to do for patients and clinical specialists pursue narrowly defined instrumental goals to address the novel and complex issues patients present. To re-establish coordination and successfully integrate different work practices across the pragmatic boundaries between specialist clinicians, HPM clinicians work to establish a shared understanding of what is possible for patients and what is desirable for them by taking in their idiosyncratic and unorganized utterances about their goals and translating them into a medical worldview intelligible to the various specialists caring for them. This requires HPM clinicians to be particularly sensitive to the different ways in which social actors talk about and understand illness, treatment, and death.

Clinicians and patients bring fundamentally different discursive and epistemic resources to the clinical encounter and are divided by boundaries that organize their understanding of illness and its treatment (Mishler 1997). Clinicians speak in the Discourse of Data in which impartial objective judgment and anonymous data are used to inform decision-making, while patients use ordinary talk, unscripted and spontaneous language that lacks pre-planning or formal structuring and instantiates their everyday understanding of their own identities, preferences, and concerns (Silverman and Torode 1980). With their language of objectivity and disinterested rationality, clinicians hold the key resources patients seek and successfully acquiring a command over this esoteric language is a critical step in the clinical interaction.

The Discourse of Data instantiates one understanding of illness, and what can be and should be done about it, and while the workaday language and understanding inherent in the ordinary talk of patients, with its messiness and multivocality must be tamed to match the clinical language of medical personnel. With its dual focus on symptom management and complex decision-making, HPM is often called upon when the efficacy of medical treatment has been exhausted, and the taken for granted goals of remission or cure are no longer possible. HPM bridges the ways patients make sense of how they are feeling, the future they have in store for them, and the things they want to do, and produces medically achievable goals from their idiosyncratic desires and aspirations. In doing this they are translating between two languages, the theories of the world that they instantiate, and the frameworks for decision-making they rely upon.

Rather than maximization, HPM clinicians indicate appropriate therapies for patients and the specialists that care for them by using the Talk of Values to translate between patients' preferences and the work-styles and ways of thinking clinicians have. Rather than facilitating a direct correspondence of terms, the Talk of Values takes in information from patients and coordinates them to a vernacular intelligible to the language and work practices of clinical specialists. It accounts for nonmedical but clinically relevant information and broadens the scope of "data collection" to include the individual patient's idiosyncrasies that can help instigate decision-making and a path forward. The Talk of Values is a synthetic language that allows information to pass through the syntactic, semantic, and pragmatic boundaries that form between patients and the specialists who care for them.

6.2.1 Overcoming Syntactic, Semantic, and Pragmatic Boundaries in Clinical Communication

Different social actors in the clinical setting, patients and their families, and the clinicians that treat them, are separated by syntactic, semantic, and pragmatic boundaries as their knowledge of illness and the repertoires of talk they use to discuss them originate from fundamentally different perspectives. Particularly ambiguous clinical situations, where no one or set of treatments are clearly indicated and the goals of medical care are no longer taken for granted, strengthen the impermeability of these boundaries as novel problems which defy established work routines arise. These differences in knowledge extend to different kinds of clinicians who are semantically separated by the technically specific suite of terms and linguistic affordances they use to communicate information related to the treatment of their patients.

CD-PH/A-005 describes trouble coordinating with a general cardiologist about the appropriate treatment to adopt for a patient who CD-PH/A-005 believes has a congenital heart defect where a valve that should close after birth remains open:

> ”There’s a clear indication from the data and from the guidelines to consider closing [the open valve in the heart]. But I can’t convince the primary cardiologist; ’look, I’ve done 1000 of these, this is the textbook patient in whom it should be closed, and then we can prevent future strokes.’ So just like with the patients who may not understand what’s going on. Sometimes other cardiologists don’t understand the specific technical area of expertise that we have.”

More than just a difference in the ‘technical expertise’ of different clinicians as the respondent suggests, this disagreement is rooted in their larger epistemic frames of reference as the respondent continues to explain: “General cardiologists tend to appropriately be driven by data, which is great, but their data is accrued from macro studies. 25,000, 30,000 patients study, which is great, but sometimes they have difficulty, you know, my job is not to take care of all 25,000 but try to take care of the one patient in front of me.”

Relating technical expertise and their fundamental epistemic worldview requires that different specialists sensitize themselves to the work styles and normative dispositions of their peers in other areas of medicine. CD-PH/A-004 (Female Attending, Midwest) describes having to adapt her expertise to that of the Oncologists she closely works with in a cardio-oncology setting:[2]

> ”[the oncologists] were not necessarily excited to have us [cardiologists] around because they thought that we were just going to tell them they couldn’t give any more

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[2] Linguistic and interactional differences between the social actors in the clinical setting are keyed to their particular expertise. There are fewer semantic and pragmatic differences between clinicians from a particular specialty than between. Patients and clinicians have very different and obviously different ways of talking about and dealing with illness while different kinds of clinicians will have different ways of thinking about illness and treatment that are partially hidden by their overlapping lexicon. Differences in thought are often immanent in talk, though differences in thought can persist in shared linguistic resources. These underlying differences can be particularly frustrating when it comes to the standard electronic templates for storing patient’s health information. As the health record grows and specialists from different areas contribute their own notes, a growing body of heterogeneous vernacular is used to describe the same problems a patient experiences.

> chemo [...] but as the treatments for oncology have expanded, astronomically, like in terms of what they can do with chemo and other things like immunotherapy, so too have the cardiac complications: hypertension, coronary disease, arrhythmias, and they need us more and more. Because now there are complications, not just a year down the line, but it's like with each dose sometimes. But it also required really making sure that we understood how they worked and making sure they knew that we were trying to understand their thought process so that they knew that if we said to them, 'You have to pause with the chemo' that we understood what that meant."

Describing a common stereotype about surgeons she notes that they are considered "Aggressive, not necessarily so collaborative. I mean, some of them are, a lot of them are but I mean, there are a lot that I get along with. Again I think it's like when you understand their language, and you understand what their motivations are, that helps a lot. Just like relationships, you know, it's not really any different."

Pragmatic boundaries further structure the collaborative working relationships between different clinicians as the work styles of different specialists influence the features of patients' cases they attend to. Navigating these pragmatic boundaries is critical to the work of HPM clinicians as they occupy a unique position in the network of medical specialties. PAL-PH/A-023 (Male Attending, Midwest) describes an experience that clearly indicated to him the need to remain sensitive to the taken for granted organization of care, particularly how differences between medical specialists' care of the terminally ill can place these patients into dangerous situations. The respondent was caring for a patient, who was not terminally ill but had a life-threatening cancer, in their inpatient palliative care unit. The patient was experiencing severe pain that needed to be managed with "aggressive symptom management". The nursing staff caring for the patient overnight are not palliative clinicians and so abide by the dominant work styles and decision frameworks used in medicine, and did not alert the respondent that the patient was "snowed", excessively, and dangerously sedated with pain medicines. The respondent described that:

> We [HPM clinicians] didn't put her in harm's way. She was in harm's way, make no mistake about it. So that case caused me to think 'You know what, I'm not sure the hospital can hold two things in their mind, right?' They're thinking of the palliative care unit as an end-of-life care unit, where a patient who is over-sedated is fine. And I'm thinking of palliative care as this more upstream concept of we're doing symptom

> management [with] patients still on aggressive anti-cancer therapy and maybe that's a bridge too far right now.

The respondent altered his practice after this case to better match the established decision frameworks in medicine by keeping patients who did not require end-of-life care off their inpatient service to not "confuse the system".

The Discourse of Data primarily focuses on value maximization, with a circumscribed variety of information that can inform it, while the Talk of Values is concerned with a more diverse set of principles that are not easily integrated into the Maximization Framework.[3] The Discourse of Data simplifies human lives to a set of inputs and parameters that then maximize the longevity of individuals while the Talk of Values attempts to contextualize individuals back into their life histories, their community, and their situation before attempting to produce solutions to their illness and death.

6.2.2 The Discourse of Data

The Discourse of Data is the linguistic repertoire that instantiates the Maximization Framework in the speech acts and work styles of clinicians. In this repertoire, clinicians leverage their scientific worldview with a singular focus on the means and ends of medicine to build a working consensus with their patients and colleagues to facilitate treatment and cure. A powerful rhetorical tool in this repertoire is a direct appeal to epidemiological and clinical data. CD-PH/A-003 (Male, West Coast) described his approach to resolving differences of opinion between patients or colleagues, simply saying "I show them the data". In the primary care setting discussing preventive measures for avoiding dangerous heart events due to artery occlusion, CD-PH/A-003 describes relating the patient's location on a chart which displays lifetime risk for a heart attack given particular risk

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[3] That the Discourse of Data by way of the Maximization framework is oriented to value maximization, while the Talk of Values is concerned with values should not provoke confusion for the following reason: value maximization refers to the naive utility maximization that we find in many economic theories and systems, while values are the axiological and normative principles individuals are oriented to in practical activity. Value or utility maximization has its own "values", enhancing the amount and duration of utility, while values *qua* values are laden with moral content in themselves.

factors. He describes “I think data is powerful. And when you show somebody where they are on the line, and you show them where they could be on the line”. Quantifying the status of patients and relating that to broader population-level data leverages the scientific infrastructure to gain patient compliance with a recommendation for treatment.

Similar appeals to population data occur in more acute moments in the inpatient setting as well. HO-PH/A-004 (Male Attending, West Coast) describes adjudicating between treatment options as “here are risks and these are situations where you have to sit down and spend a considerable amount of time reviewing the data with the patient, and also involving the patient in the decision-making process.” HO-PH/A-003 (Female Attending, Midwest), clarifies what this process looks like. Treating a patient who presented with newly diagnosed breast cancer and who was skeptical about the standard treatment protocols for cancer, HO-PH/A-003 presented the case as “we would either swing for the fences and do aggressive chemo, or we talk about hospice and palliation.” The respondent presented aggressive treatment as the appropriate decision saying:

> I was very clear that if we did not start treatment, that she would likely die in the next couple of weeks. And was very, very blunt about it and obviously provided her very objective data that supported that [...] so I tried to present it from a very kind of objective, things that she could relate to, things that she could sense that were getting worse.

The appeal to data is embedded within the decision framework of Maximization, where data from population studies are coordinated to make sense of the experiences of patients. Particularly by referring to things the patient can “relate to”, and “things that could sense that were getting worse.” Many clinical encounters are productively organized in this paradigm as information about the nature of the patient’s illness and its future course clearly indicates a course of action that is likely to help the patient live free of or longer with their disease.

Despite the objective standards that are used to clearly indicate a course of action, patients remain agents in the clinical process of treatment. A fundamental normative precept of modern medicine is that clinicians must engage in shared decision-making to respect the autonomy of patients (Elwyn et al. 2012; Emanuel and Pearson 2012). HO-PH/A-001 (Male Attending, Midwest) describes:

> there always is need for shared decision-making. It's just that the decision is very easy if there's a clear answer, because the patient may reject your advice, right? [...] It's just that the discussions that are required to come up with an answer or decision are, are kind of much easier, straightforward. There's a clear answer, right. So if treatment A is more effective and safer than treatment B We're going to recommend that and we'll say, the reason why we're recommending this is because it's more effective, and it's safer as well. The patient may ultimately reject the advice, but they've heard the data they understand. They understand why we're recommending it. Where shared decision-making is really important is I agree sort of where there's no clear answer. There are paths, and each path has its own risk and benefit and someone's decision will flow based on what they will accept for benefit and what they'll accept for risk.

In routine clinical situations, what ought to be done is simply what can be done given the accepted standards of care and the taken for granted goal of cure or longevity. As the risk profile of treatment becomes less definitive and no treatment is clearly indicated, specialists narrowly focus on the particular features of patients that fall squarely within their own domain of expertise. CD-PH/A-005, describing patient encounters where the technical aspects of their cases need translation, describes that "you're trying to communicate what the risks are. For example, if I go through an artery in the leg, what are the risks of damaging that artery and causing a major bleed? What's the likelihood of potentially tearing one of the arteries of your heart, or embolizing fat or calcium down there?" The issue is not purely one of information sharing, crossing the syntactic boundary to ensure that patients are aware of clinically relevant information, but that they also understand it. This requires further sensitivity to communicating the meaning of otherwise obscure medical terms and the implications for patient's well-being to cross the semantic boundary between patients and clinicians: "Even terms like embolize, I realized, like that I have to kind of step back and say, 'hey, you know if we put a catheter in there, there's a good chance something can fly off, and block it off' ". Such work requires clinicians to emphasize the most pertinent information to patients in an intelligible way, which CD-PH/A-005 relates to when he needs the services of someone with greater expertise:

> I feel the same way when there's something wrong with my car, and I gotta go to the mechanic. And he or she tells me all this stuff that's wrong with whatever, I have no

> clue. I’m like, ’Hey, man, just fix it’. I try to make it as simple as possible, I try to use analogies, like ’imagine a garden hose, imagine stepping on a garden hose or imagine putting your thumb over a garden hose’, I try to think of things that patients may have in their daily lives that they may be able to relate to.

As patient’s problems present themselves, they are treated with the appropriate therapy given the current state-of-the-art understanding of the illness and the therapies on offer. “If an artery is closed, I open it. If there’s a hole in the heart, I close it. If patients need a new valve, I’ll put a new valve in. [...] So in clinic, I’m usually trying to talk to patients about the procedures I’m going to do, what the risks what the benefits are, and what their expectations are” (CD-PH/A-005). In routine cases, the risk-benefit analysis clearly indicates that the risks are worth the benefits. “We know what the path forward is if someone has a urine infection; generally you’re going to give antibiotics and move on, you’re not going to question what are the goals of care” (PAL-PH/A-008). When the risk profile of a treatment becomes less certain, or the personal risk tolerance of a patient lowers, the ability to do something doesn’t clearly indicate what ought to be done. Clinicians in Oncology and Cardiology, meet patients with data-oriented details and means-ends rationality that offers things that *can* be done, without orienting to what *ought* to happen given the patient’s situation. HPM clinicians leverage their repertoire of talk to engage patients and their colleagues in a mutually intelligible framework for decision-making oriented to the normative content of recommendations and the patient’s preferences.

HPM clinicians frequently emphasize the mismatch of the dominant decision framework of medicine to the experiences of patients facing terminal and chronic illnesses. PAL-PH/A-030 (Male Attending, West Coast) describes the default posture of medicine to escalate that care given an equivalent escalation in the level of illness: “when you have a hammer, everything looks like a nail. Which means if you were to show up at a hospital, in a state of *extremis*, the automation of clinical care waterfalls down a series of algorithms, and decision trees such that you will, by default receive care to preserve your life.” Such care “has mitigated early death for a significant portion of the population. However [...] sometimes patients don’t want that care.” Attenuating this escalation of care to preserve the preferences of patients if not their lives requires clinicians to deviate from their routine methods for making decisions and treating patients. “So the onus is on us as clinicians to break out of the automatic mindset of ‘do do do. offer offer offer’ and try to take a step back and think about the big picture.”

The routinization of medicine leads to a cognitive narrowness that obscures this “big picture” to the point that non-HPM clinicians are unable to recognize when their routinized practices for establishing successful interventions have broken down and warrant amending. Medicine has developed the term of art “goals of care” to capture scenarios in which the objectives of medical intervention have become ambiguous and warrant re-evaluation. HPM clinicians note that a request to consult on a patient’s case to address “goals of care” signals a further oversight on the part of their colleagues:

> When someone gets so medically sick and doctors start saying, ’what are the goals of care?’ that is actually code, and they don’t even realize it, for like they’ve hit an uncertain situation and there’s several paths before them and they don’t know which one is best, because we’re no longer on an algorithm of like, this is the best answer. And so they want to know what the patient wants to do. (PAL-PH/A-008)

To resolve such indeterminate situations, HPM clinicians use a deceptively simple technique for resolving what to do: “Reality is that the patients didn’t go to medical school, and they don’t really always know what they want to do [...] if you think of the equation of the medical information plus the patient’s story, often if you bring these together, you come up with a plan of care or a direction to move among in an uncertain situation or among crummy choices as well” (PAL-PH/A-008). Breaking out of the fixed and determinate pathways of decision-making in medicine is a common feature of the work of HPM clinicians and is conducted by assembling the preferences and goals of patients and the medical interventions available to them:

> the thing that makes many of the decisions with our patients ambiguous is the fact that we’re not getting to the heart of the matter. And the heart of the matter is, ’Who are you and what matters to you? And how are these interventions going to affect you?’ If I have a patient with metastatic colon cancer, and I offer them to, go on a new chemo-therapeutic trial, that is experimental and I really don’t necessarily think it’s going to provide any more than a few weeks of life, I have to really ask myself, ’what are those weeks going to be like for them?’, and I have to convey that to the patient, or else I think, I’m not doing my job. Whereas I think sometimes we skip

> that part about conveying to them what the burdens of the intervention will be. And I think sometimes we forget to include that part, because we just want to be able to offer something. (PAL-PH/A-014)

HPM clinicians elicit the concerns of their patients to re-establish a shared set of objectives and bridge the pragmatic boundary formed by the narrow specialization of clinicians and the lack of medical expertise patients have. PAL-PH/A-036 demonstrates this fundamental difference in practice to elicit nonmedical but relevant information from patients such that they can then realign all parties to a shared goal:

> in a 45-minute meeting, there are probably two moments in that entire conversation where asking the right question, at the right time can really steer that conversation. For instance, we may be in an ICU where a patient has multiorgan failure, and there's a very complicated litany of medical prompts to discuss and most conversations up to that point have really dwelling in the weeds. What is DIC? How come somebody would need dialysis if they had a bacterial infection, etc, etc [...] some families really ask those questions because, one, they may not have a sense of how all those come together, but two kind of stalling a bit because they know they've talked to people six days for this in a row now. And when you ask them in that instance, 'Hey, what are you most worried about? They're not going to say I'm worried that the platelets are dropping', they're gonna say, 'I'm worried my loved one is dying'. That pivots the conversation into an emotional space. And we want to be in the emotional space, because we want to talk about issues that are centered on emotions, for the vast majority of patients and their families. And the sooner we can get out of the cerebral, and the sooner we can get into talking about what really matters. That's that's where we can start talking about decisions in a way that feels equal.

Patients and their families are not oriented to their illness in the same way as clinicians and when the medical framework for deciding what to do breaks down because there are unclear diagnostic and prognostic indicators, these idiosyncratic and ordinary concerns serve to establish a shared source of decision-making and requires translation into a medical worldview, crossing the syntactic, semantic and pragmatic boundaries that otherwise confuse the collaboration of clinical stakeholders. PAL-PH/A-030 continues to give a specific example where an elderly patient was "receiving an amount of breathing support that was unsustainable outside of the hospital, and being considered for a series of both heart and lung interventions, procedures, invasive procedures, which would have been very high risk." The patient frequently expressed frustration with being in the hospital but despite this continued to assent to continued treatment when asked by clinicians. “So a lot of doctors have spoken with him about the medical facts. And they’re like, ‘Well, he always says he wants to do it. So we’re just doing what he says’. And because when you talk to him, he says, you know, ‘stop talking to me just do what you have to do’.”

The specialists on the patient’s case have worked on the issues relevant to their specific specialty’s domain of expertise while farming out other issues to the relevant experts. PAL-PH/A-030 describes frustration with the situation as he notes:

> ’So you’re telling me’ I’m asking the hospitalist, ’we’re really looking at a scenario where the stars have to perfectly align, and even then, he’s a high-risk surgical candidate’. But in their minds [...] they have to go through the process. ’Well, when somebody has this problem, I refer to this doctor, and they also have the problem and from that doctor’, and then there’s a bit of diffusion of responsibility, where ’I as a hospitalist don’t want to make this decision on taking these away from him. I want to let the other doctors talk about it, and maybe one of them will tell me instead’.

The respondent noted that the patient’s “chances of leaving the hospital are less than 1%. And even then, with a very long rehabilitation course, for somebody who hated being outside of his own home”. The respondent identified a fundamental ambiguity in the patient’s continued assent to further therapy and his preference to be at home as a means of reestablishing a source of coordination for the patient and the other clinicians. Referencing the patient stating that clinicians should ‘stop talking to me just do what you have to do’ the respondent noted:

> But what does that mean, ’do what you have to do’? And that’s one of the hardest things I think for doctors to hear is, you can fall on either side of the interpretation of that. If you’re, again, if you’re a specialist, you will do what your specialist trading teaches you to do. And then palliativists, our specialists, we’re specialists as well. So we do what we’re trained to do, which is talk with you about, ’hey, what does life look like for you now? What is life gonna look like for you if any of these procedures go right or wrong?’ And it became clear that while he wanted to give it a shot, if the cookie started to crumble, he’s like, ’just get me home, get me out of here’.

6.2.3 The Talk of Values

The ability to relate to patients and coordinate the sets of actors to a shared objective is not evenly distributed across different medical specialties. Different kinds of clinicians have different aptitudes that help them achieve their clinical goals:

> People use the moniker of doctor and think it's the same phenotype or the same sort of person. The reality is, many people go into medicine because they're highly technical. They're actually technicians, they're not actually humanists, they're not actually good at relating to people. Vascular surgeons, as a personality profile, are probably OCD, like pathologically OCD. And that's what makes them so good at operating on little veins in your arms and legs and body. They're not very good at sitting still, and talking to a 99-year-old to understand what's important to her.
>
> (PAL-PH/A-008, Male Attending, West Coast)

Rather than engaging patients in means-ends reasoning with a determinate set of options that assume patient preferences, HPM clinicians incorporate appeals to the underlying constellation of motivations and desires of patients seeking care in their own repertoire of talk, the *Talk of Values* which expands the scope of clinically relevant information to nonmedical features of patients and organizes their idiosyncratic and non-medical desires into a medically intelligible vernacular and plan. PAL-PH/A-013 identifies the unique collection of clinically relevant "data" in their practice when engaging patients in the Talk of Values: regarding how they approach learning more about a patient to aid in decision-making they described that "it's very much exploratory and listening about where they find data, which is a sciency word, but where they find information to make those decisions?" Curiously, HPM clinicians invert the data collection paradigm typically used in medicine; rather than patients being data-generating machines, from which clinically relevant information is collected and then used to indicate therapies, HPM clinicians treat patients as data-collecting engines themselves and seek to orient themselves to the same set of information.

HPM clinicians emphasize that achieving a reasonable plan in ambiguous situations requires a synthesis of patient goals and medical expertise, which is not always easily achieved due to the semantic boundaries that form between different specialists and the patients they care for. Patient preferences are heterogeneous, unstructured, and do not neatly fit into the framework for medical decision-making. They can include making it to a wedding[4], spending time with family[5] or gardening[6]. HPM does the work of constructing patient's values from these preferences.

> [A patient's goals can be] I want to be able to see my grandchildren, or I want to be able to do XYZ, I want to be able to get up in the morning and sit up and read a book. And then here's the well, you have heart failure, you have kidney failure, you have cancer you have etc, you have whichever. And it's sort of in the middle of because sometimes the goals aren't always realistic. You can't have no pain, we can't always achieve those patient's goals. But only the previous way of practicing that I was talking about was it was just the MD bubble. The other way of practicing was just what the patient wanted or thought they wanted about medicine. But really my perspective is that it has to be born of the person based goals because nobody wants to be resuscitated. They don't want any medical procedure or medication. They will want to live well or as well as they can based on their circumstances. And it's this middle piece with figuring out how to do that and you can't do that if you don't ask the patient questions about who they are and what matters to them. (PAL-PH/A-044)

HPM clinicians specialize in integration, synthesizing patient preferences, and medical expertise to coordinate clinicians from different specialties by assembling values that both accord with patient preferences and are permeable to the syntactic, semantic, and pragmatic boundaries that undermine the collaboration of clinical stakeholders. Bridging the Discourse of Data and the ordinary talk of patients requires that they create a mutually intelligible framework upon which the different social actors can coordinate their cognitive and practical activity to a mutual and acceptable end. Doing this ultimately requires that they take in information from both parties and create a working

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[4] "A lot of times what matters most to somebody might be completely different from what everybody thinks it is. They may think, oh, it's most important to this person to continue chemotherapy no matter what. Well, that may not actually be the case. The thing that may be most important to them is getting to their, uh, granddaughter's birthday or, you know, wedding or something. Um, and then saying, okay, well what treatments are on the table? What does life look like based on those things?" (PAL-PH/A-003)

[5] "If the wife tells me what's most important to us now, given these circumstances is to be at home, for him to spend at least a few days with his brothers and sisters who are all coming in from out of state, then I'm going to recommend what I think we need to do to achieve that goal. And then, two days later, they call me back and say, 'Okay, we talked to the wife, and they want to go home with hospice now. So we've decided to go home with hospice, and he died four hours later, so he never got home' " (PAL-PH/A-052).

[6] "let's say we have this patient whose biggest joy in life is gardening, and they love to garden. Then when we meet and talk to them, we illicit the importance, like what's meaningful, what's important to them, and they say, 'gardening is like, it's my life. It's how I define myself, I'm a gardener'. And so then we say, 'let's focus on treatments that can help you be the gardener or maintain that value, that joy'. And so they undergo chemotherapy with the hope of being a gardener for the long term, and we frame it too 'are you willing are okay with brief moments of not being able to garden knowing that you can garden in the long run and like for months, or years', and a lot of them will say yes" (PAL-PH/A-020).

consensus, to mutually engage a shared set of ideas and goals, using language that meaningfully corresponds to one another's understandings of the situation. HPM clinicians do this by integrating different stakeholders in patients' cases, coordinating attention to a shared set of information, sublimation of patient preferences and medical information into mutually intelligible language, and the alignment among the different sets of actors in a patient's case to a common goal. Integrating different stakeholders into a shared basis of action is then constituted through different processes which include *Coordination*, *Sublimation*, and *Alignment*.

Coordination

Coordination at bottom is a matter of information sharing, ensuring that all stakeholders in a patient's case are aware of *what is wrong*, *what has been done*, and *what can be done*, crossing syntactic and semantic boundaries. HPM clinicians first must establish the state of these three attributes of a patient's case for themselves through a variety of means:

> I […] go find a nurse who actually knows what's going on, and talk to the nurse. (PAL-PH/A-052)

> I generally dig intensively through the chart to understand what have other doctors and providers written about this person and what's been documented about their preferences, wishes, do they have any advanced care planning documents? Do they have any sort of written record that I can build from and not make this person have to regurgitate everything once again, to the 10 millionth doctor that they're seeing, because generally I'm seeing seriously ill patients. (PAL-PH/A-008)

> I think it's sort of like an iterative process there to where when we talk to the teams about what the options are, what's possible and what's not, oftentimes, even as the palliative care doctor, I'll be saying, "Well, you know, what, if we did this really aggressive surgery, what's the most likely scenario after that? What, you know, what are the pitfalls that you see of going this way? What are the pitfalls of, of not doing this surgery? (PAL-PH/A-009)

Mismatches in the understanding of the state and likely progression of a patient's illness are a common cause for requests to HPM for consultation. PAL-PH/A-019 (Female Attending, West

Coast) describes that teams are often distressed “Because they’re feeling like, ‘Well, you know, what are we doing? Why is the oncologist still providing this treatment when the patient is actually dying, and it’s not going to benefit them?’ ” To address the ambiguity in the objectives and current state of medical interventions, HPM clinicians answer the questions “Is the patient informed? Does the patient understand where they are in their clinical trajectory? Do they understand what the intention of this treatment is? And are they really making an informed decision,” with PAL-PH/A-019 noting that “one of the most, I would say upsetting aspects of my work is understanding and coming to grips with the fact that so many patients are not making informed medical decisions, because they’re not having that more candid discussion.”

This candid discussion, not only the implication of emotional candor, requires establishing semantic clarity between patients and clinicians by clarifying the complexity of the implications of modern medical therapies. PAL-PH/A-043 (Male Attending, East Coast) describes his frustration with oncologists who fail to fully clarify the implications of their interventions to patients. This is particularly salient for oncology patients at advanced cancer centers that host clinical trials for advanced and exotic therapies. These clinical trials are often available to patients at any time in their therapy but are typically begun after all the most efficacious, predictable, and routine treatments are tried. PAL-PH/A-043 notes, at his institution, that patient’s “don’t come here to get the best palliative care” but are frequently motivated to pursue curative cancer-directed therapy for their illness.

> Oncology has become incredibly complex, right? So it’s very hard to understand sometimes those new trials and what they mean and what those treatments mean, and […] how does that affect my day-to-day? Many patients don’t really get that, you know? and it seems like there’s this disconnect. There’s this gap, um, where, where that it’s not really happening. Um, or communication about prognosis. You know, that’s another thing. Like, rarely you will hear that someone says, you know, ’I’m worried about you. I don’t think you have enough time or, you know, the time is limited or those things, that doesn’t happen very often.

Coordinating shared information establishes a foundation upon which later decisions can be made and is the first step in determining the clinically relevant but unstructured patient preferences needed to determine what to do given the failures of the Maximization Framework to clearly indicate what to do in a patients' case. PAL-PH/A-044 (Male Attending, East Coast) emphasizes that:

> You can't really have this other conversation about goals and values and about recommendations unless you have a shared vision of what's going on and what's possible. So if a patient thinks they're going to be cured when their treatment is just palliative, meaning that the cancer is just being managed, that's a different conversation about what the next steps are.

HPM clinicians have particular rhetorical and interactional techniques to assess what a patient understands about their treatment and what their preferences are. Rather than directing questions to the patient's own understanding of their illnesses, HPM clinicians commonly ask, "tell me what Dr. Smith has told you about your cancer. And that'll give me a good impression of where they think things are […] And if their thinking is not accurate, I might ask them and say, 'Is it okay, if I share my understanding?' And that's my opportunity to sort of correct and say, like, 'well, actually, I think what Dr. Smith meant by this is that we're trying to manage the cancer, we cannot cure it' ".

Coordinating different specialists to overcome pragmatic boundaries in the ways that specialists work and approach patients, entails HPM clinicians orchestrating meetings between patients and clinicians to focus information sharing and avoid confusion. Some go so far as to script the information sharing of their colleagues:

> I asked each of the specialists, what they wanted to convey, and then help them refine that into sort of a single statement or headline that would encompass what they were trying to get across so that it was simple and clear. And I also reinforced to them, you know, this, I think, is our overarching message [...] I actually scripted a little of what was going to happen. And I said, I pointed to one specialist and said, I'm going to ask you this question. How do you think you're going to respond to that? They tell me, and then I'd say, What if you were to say something like, and repeated what they said, but in shorter words, clear, more straightforward. So I actually sort of helped script or dictate a little bit about how the meeting was going to go for the purposes of clarity, simplicity, etc. (PAL-PH/A-029)

Getting clear descriptively about what is going on in a patient's case gives HPM clinicians the opportunity to assess what information needs to be shared by different stakeholders and to begin assessing what is valuable to patients and to begin expanding the scope of clinical consideration to include things that are not directly relevant to decision-making in the common and taken for granted decision frameworks in medicine: “my responsibility is to make sure that everyone has about the same understanding. And then all parties can come together and make sure that the decision, the ultimate decision that’s made is based on consistent understanding, consistent knowledge” (PAL-PH/A-021). These features of patients are laden with normative content in an otherwise objective theater of human interaction and help to adjudicate between the options available to them. HPM serves to integrate these values of patients into the medical worldview from the ordinary talk of patients to the Discourse of Data of clinicians, by organizing preferences as a set of values by sublimation.

Sublimation

Rather than a direct correspondence of terms, as would be the case in the translation of a statement from one language into another, integrating different clinical stakeholders entails that patients’ preferences are constituted into an intelligible vernacular to clinicians through a change of state or sublimation. Preferences that are stated by patients that are free of direct medical relevance are situated into the medical worldview to align clinicians to the patient’s goals. HPM clinicians do this by constituting the patient’s preferences into a medically achievable goal that all stakeholders can work towards.

PAL-PH/A-019 describes the non-obvious character of this process:

> We [clinicians] have this idea of, we don’t want to be in pain, and we don’t want to suffer with symptoms. And, in a way, that’s often true. I mean, the majority of people feel that way. But then there are some people where actually what’s more important to them is that they have the potential of making it to a certain holiday or seeing the birth of their granddaughter or something. And so for us to sort of impart our values on them may cause us more distress. And so helping understand what really is the patient working for, and if they’re making an informed decision, and this treatment, while it may be causing them more symptoms, or maybe causing them more suffering, may provide them a small chance of potentially achieving this other goal. Helping reframe the clinical situation for the teams and for the people who are distressed can be very helpful.

Despite being a domain that emphasizes its evidence-based and rational basis, PAL-PH/A-019 notes that a key feature of their work is avoiding imparting the values of medicine onto the intentions of patients. This reversal is indicative of the larger point, that medicine too has a set of values to which the preferences of patients need to accord.

Sometimes sublimation is not successful as the actions of patients are so inexplicable from the medical worldview as to be un-transmutable into an intelligible set of values for clinicians. PAL-PH/A-019 continues to describe:

> ”I think that there’s a lot of complexity too, for some people they just think that if there’s a treatment, that is going to be helpful, you know, they think treatment means this is beneficial, I should do this, you know, the doctor is recommending this, and sometimes that’s not the case, right? Maybe the oncologist in this case really doesn’t feel like this is going to be beneficial, but feels in some ways obliged to offer something. Sometimes it’s a little bit more complicated and then you know, it does require some more discussion but sometimes it can be as simple as ’Yeah, the patient really is informed, understands, everybody’s talking the same language, but the patient is just making a different decision’”

.

Fundamental normative differences about what ought to be done, that can not be attributed to differences in what is known about a case can cause “a tremendous amount of distress for pretty much everybody involved” (PAL-PH/A-019).

Recounting a particularly illuminating instance where they could not sublimate patient’s preferences to a coherent set of values to organize the activity of clinicians, PAL-PH/A-019 describes a patient “who had a particular kind of cultural-religious belief that the more that they suffered, kind of the higher the reward in their afterlife, the greater benefit. And so for the patient, and their family they sort of were very okay with as much suffering as possible. And so the idea of, ‘well, you know, we could do this, but this would really not be beneficial and would cause harm’ or something, that whole argument failed. And it caused a lot of stress, because the patient was in agony and was screaming, but they were, they had their reasons, they had their, you know, this sort of, they could explain sort of their thought process. So in some ways it was this informed decision, but it was very distressing.”

Sublimating patients' preferences into a coherent set of values to indicate a goal of medical care that accords with the values of clinicians is not an easy process as PAL-PH/A-019 describes: the values of medicine at times must be bent to accord to the proposed values of patients but this is not always achievable and sometimes HPM clinicians need to shift the values of medical staff to accord with patients.

> In the hospital, we often get consults because of team or provider distress. And that distress may come because they feel like they're doing things to the patient that is either causing suffering or isn't helping. They see, they have this sense of futility. And or there has been a fracture of the relationship there, there has been, there's mistrust between patient or family and provider. And they are, they're in conflict more and more, and they want help in navigating that. Now, sometimes the request is for us to try to convince the patient or family to do something different. And that, we try to be very clear that we might end up with a different outcome, if we do what we do. But we might not like we may get to a place where we say we understand why the patient or the why the family's asking for this. It's not unreasonable. And let's instead focus on Yes, this sucks to do, or this is really hard. And here's why. We need to try to meet the patient where they are. (PAL-PH/A-015)

Patients are oriented to a concrete reality and do not have values pre-made and ready to motivate their preferences. Values, in the work of HPM, are constituted through their interactions with patients, as they explore the preferences they hope to satisfy as their illness persists or their death grows imminent. These values need to be intelligible to other kinds of clinicians, who might be primarily oriented to patient care through the lens of the Maximization Framework, to ensure that all clinicians are working toward a shared goal. Otherwise, clinicians might attempt to achieve incompatible proximate objectives. After sublimating patients' preferences into a coherent set of values that accord with medicine, HPM clinicians seek to maintain alignment between all stakeholders to a shared goal in line with those values.

Aligning

After establishing consensus semantically (Coordination) and accord syntactically (Sublimation) HPM clinicians align the different stakeholders in the patient's case to a shared goal. A common juxtaposition between the reputation and actions of HPM is instructive in summarizing the process of aligning specialists and the patient to a mutual end of action; HPM clinicians describe that some of their colleagues believe they tend to transition patients to comfort-oriented treatment plans prematurely when there are still safe and effective therapies that could extend the patient's life. This reputation is so strong in some institutions and among certain kinds of specialists that some respondents note that their colleagues will not allow their patients to be seen by HPM. Referencing the Cardio-Thoracic Surgeons at her institution PAL-PH/A-045 (Female Attending, Northeast) describes that "they just think we kill people".

Despite this reputation, HPM clinicians describe their practice as advocating for the stated preferences and established values of patients who are fully informed of the reasonable alternatives that they can adopt. "If they [the patient] tell me that, [...] 'all I want to do is live for as long as possible and every day matters', well, that's one type of a response, right? Um, uh, but oftentimes they will tell you different things. [...] It's a very dynamic thing that changes all the time. You know, things can change from week to week sometimes" (PAL-PH/A-043). But remaining aligned with patients can lead to discord with colleagues that requires attention. "Most of the time I would say the oncologists have been pretty honest with their patients, and these patients, at least the ones who are choosing to get admitted and readmitted to our hospital [...] are people who have been given options to focus more exclusively on comfort, and they're choosing to seek continued cancer-directed care." In such situations, HPM clinicians work to align the specialists caring for the patients by orienting them to the patient's values: "it's a matter of just sort of reminding the primary teams or the nurses that this is a choice that the patient is making [...] once we offer something, then we can't really get angry at patients and families for choosing it" (PAL-PH/A-056).

Situations in which a patient's decision is discordant with well-established standards of care require that HPM clinicians realign the different clinicians on the case, and reorient their cognitive relationship to the patient's decision. PAL-PH/A-023 describes a patient with "readily treatable lung cancer" who was "electing not to take anti-cancer therapy". At first, PAL-PH/A-023 was worried that the patient's decision was being influenced by concerns over bias rather than an understanding of the efficacy of the treatment. Rather than continuing to advocate the patient adopt the treatment, contradicting their established decision, the respondent reported:

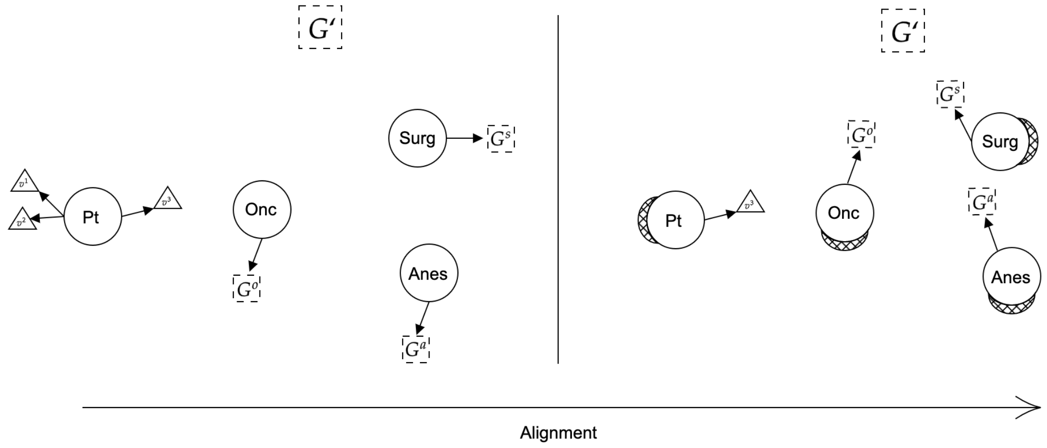
> I allow myself to be convinced that not taking anti-cancer therapy is truly well aligned with his values and goals, not because he was distrustful, which is what I was initially worried about [...] I was convinced that his choice, while at first, I was worried was a product of things that I could have addressed, like bias and other things. It wasn't actually. So I was reassured. So, you know, when I asked the question, 'what should we be doing?' the oncologists are saying, 'This guy, he must not understand because he's turning down, like, a good treatment option. And can palliative care meet with him, because we think he doesn't get it. He's like making a mistake or whatever'. In truth he didn't fully get it but even once he had developed a deeper understanding, I was able to then talk to the team to say, 'Well, actually, in this guy's unique circumstance, because of this, that and the other, I think this makes sense.'

Aligning care across specialists is not always straightforward as united fronts among specialists are vulnerable to defections by different clinicians. PAL-PH/A-030 (Male Attending, West Coast) describes that "What we try to do in palliative medicine […] is we establish consensus among the many different physicians and provider teams working on that patient's case. So in this case, we had talked to everyone individually. And the conversation one on one, on our side was 'yes, this, this isn't something that makes sense. I'm not going to offer this procedure because it's not going to be successful, the perioperative risk is too high'." They successfully developed a consensus among the different clinicians that they would not offer the treatment to the patient.

> So we had a very difficult meeting with them, and in this case more kind of wrenched their arms and really pulled them into a space of thinking about mortality for the, for their loved one. And they were they at the end of the, by the end of the conversation, they were there, they were thinking about it, no decisions were made but they were, they were leaning towards bringing the patient home with hospice care. Understanding that being in the hospital meant there's no bridges to anywhere to be built, we're just eating up his time. Then, because this family was so effective, and, and kind of advocating for him, they were able to convince one of the specialists to offer the intervention that they had previously decided against.

The procedure didn't go well and the patient died after going home with hospice for a day or two, despite this outcome the respondent was equivocal in whether they thought it was a success or not noting that "I think family probably needed to feel like they had exercised as much influence and control over these processes as they could whether they were satisfied with the outcome I don't

Figure 6.1: Aligning different stakeholders to a shared goal.



know. But I think they were more satisfied with the process, and that's as far as my role was just."

The process of alignment is visualized in Figure 6.1. The care of the patient, suffering from cancer, depends upon the collaboration of different specialists including an Oncologist (Onc) a Surgeon (Surg), and an Anesthesiologist (Anes) each of which is oriented toward a specialty-specific goal in the left panel that is unaligned to the patient's values (indicated by the numbered triangles). The oncologist is monitoring the growth and spread of the patient's cancer, and seeks to minimize it, while the surgeon is focusing on preventing and managing surgical complications, while the anesthesiologist is evaluating the patient for the implantation of an ambulatory infusion pump to deliver intravenous drugs continuously.

The patient is oriented toward a diverse set of values that are not couched in the scientific vernacular of medicine nor the linguistic repertoire of the Discourse of Data. The work of the HPM physician (not in the figure) is to identify the preferences of the patient and establish a shared set of values that accord with medicine and indicate an achievable ($G^{\backprime}$) goal that the other clinical specialists can orient themselves to by trimming away those that cannot be shared and integrated as shown in the right panel.

Coordination, Sublimation, and Alignment have been treated as separable and sequentially ordered steps on the path to integrating the different stakeholders in a patient's case, but as is true of many heuristics, they are blurred the closer one looks at their location in the social situations in which they occur. Despite this analytical blurring, they are indeed different phenomena that jointly constitute the integration process, and so naturally bleed into one another. In the process of learning the facts of a patient's case, HPM clinicians can assess their preferences and begin sublimating these preferences into the medical worldview, and in so doing begin the process of aligning them to a new goal that can be shared with the clinicians that are caring for them. So too, with their clinician colleagues, as HPM clinicians express the values of patients and the implications for their care, HPM clinicians begin aligning specialists to a new goal.

6.3 Discussion

Clinical decision-making, particularly in the setting of inpatient care, is both the art and science of diagnosing patients, identifying medical interventions to address their malignancy and side effects, and predicting what the future will look like for them after pursuing, continuing, or forgoing treatment. The science of medicine determines the efficacy of treatments for given illnesses based on randomized controlled trials, clinical surveillance, and the paradigm of evidence-based medicine. For much of medicine, a single moral principle governs clinical judgment: the patient ought to pursue whichever treatment, based on the greatest evidence, will increase their lifespan for the longest time. In this Maximization Framework, longevity is the primary goal and in acute illness, longevity is won at the expense of short-term discomfort. The scientific facts of a case do not always indicate what ought to be done, a distinction long noted by philosophers and ethicists (Black 1964; Hume [1739] 2013; MacIntyre 1959; Searle 1964). Equivocal evidence for diverging treatments, small distinctions in predicted outcomes, or questions about how treatments will impinge upon the patient's well-being through side effects complicate the normal decision framework in medicine. What one can do, does not always clearly indicate what one ought to do.

The art of medicine is less rigid than the procedural standards set by evidence-based guidelines for best practices and requires that clinicians synthesize the personal life histories of their patients and their families to determine what is “valuable” to them and what treatments will allow them to best pursue their goals. Oftentimes, particularly as malignancies progress and the functional ability of the patient and their prognosis degrades, these goals shift from participating in life as they did before being sick to being able to survive a little longer, and, in the last, die a death as free from pain as possible.

In the treatment of the acutely ill, a variety of clinicians are called upon to render their expert opinion on a specific aspect of the patient’s case. Pathologists and radiologists evaluate the state of tumor growth, surgeons determine a patient’s ability to survive the surgery, oncologists determine the overall treatment protocol, and palliative care and pain specialists aid in decision-making and lessening symptom burden. Each is expert in their field, and often “sees” the patient in terms of that expertise, but sickness defies the boundaries of medical specialties, and disagreements about facts, and what to do given those facts, arise. How these specialties see their work will naturally influence how they think about the facts of cases and informs the whys and how they then bring to bear to intervene. As these processes are inherently collaborative, a careful study of the different discursive and interactional strategies they bring to bear will help to clarify the systematic differences and similarities across different domains of medical expertise.

HPM clinicians help patients who are acutely and terminally ill, whose care requires many specialists from different areas of medicine to coordinate their knowledge of illness and integrate their different practical activities to the end of promoting the goals of the patient. This endeavor is difficult as specialist clinicians and the patients they care for have different ways of making sense of illness, and its treatment, and fundamentally different ways of talking about their expertise and practice. The process is further complicated when the goals of this work become ambiguous or unspoken, as the patient becomes more ill and the ability of clinicians to effectively address their illness and its symptoms lessens.

As the very goals of continued medical care become ambiguous, HPM clinicians work to further tighten the set of interactions between the different specialists and the patients they are caring for. As specialists in the integration of different paradigms of care, they then orient the different sets of actors to a shared goal, by helping to elicit from and clarify with the patient their preferences and values. HPM's niche of bridging and integrating different sets of actors contributes to our understanding of important and enduring issues around the role of values in social action. Though values are not a feature of the cognitive processes used in deliberation and decision-making, social actors rely upon value-oriented talk to create a shared understanding of their different goals and the means they will use to achieve them (Martin and Lembo 2021). HPM clinicians bridge social actors who are oriented to the problem of sickness and death with two distinct repertoires (Steinberg 1999); the Talk of Data, the clinical and jargon-filled language of medicine used by and between clinicians to communicate about patients' illness, and the Talk of Values, which highlights patient's self-image, identity, existential and moral concerns. HPM clinicians do not simply translate between these two different repertoires as utterances in one or the other are not completely isomorphic, where the same meanings are encoded in different dialects, but require active clarification between how what can be done for patients relates to what they should do. Connecting this domain of facts, evidence, and instrumental rational thinking and the domain of moral concern requires that HPM clinicians decrease the difference between how other specialties and they work, coordinating professionals who are typically guarded against attempts to restrict their professional autonomy, to mutually intelligible practices and goals. Bridging facts and values reflects the growing need for professionals to orient to the meaningfulness of their work (Grant, Morales, and Sallaz 2009).

Difference and specialization between and within professions is a natural product of a more and more sophisticated society, and as these differences undermine the ability of specialists to meaningfully collaborate, a particularly apocalyptic vision of the future of the professions forms (Stichweh 1997); a necessary and inevitable growth in the number of professions and specialist bodies, more and more rigidly defining narrower and narrower areas of expertise with vernacular inaccessible to generalists and laypeople. With such developments, professionals will be capable of communicating their expertise at such a remove as to prove unusable for lay people. Decisions as to what ought to happen in any given case will then be determined by the exigencies of the organization of professional work rather than the needs of laypeople. Medicine is a particularly consequential area in which this phenomenon occurs.

This study has great importance for the continuing literature in medical sociology around the persistent importance of patient-clinician interactions (Timmermans 2020), as well as the growing but nascent literature on intra-professional collaboration (Boateng and Adams 2016; Conn et al. 2016; Oh 2014; Zetka 2011). Regardless of whether they are held in person or virtually, in the outpatient or inpatient setting, or whether they are about beginning a statin or withdrawing a ventilator, how clinicians and patients interact and relate to one another bears a great deal of influence over how decisions are made about individual's health and medical treatment. This study helps to contextualize previous findings, by emphasizing the different registers of talk in which clinicians and patients, and the different appeals that different kinds of specialists make in the course of building a working consensus with their colleagues and patients.

6.4 Conclusion

Despite numerous changes in healthcare delivery, the organization of medicine, and technological mediation in clinical decision-making, patient-clinician interactions endure as the central context in which decisions are made about what and how much medical care a patient will receive (Timmermans 2020). Autonomy has long been one of the defining characteristics of professions (Engel 1970), and is the ability to determine their own work style and to engage clients on their own terms, free of interference from outside influence due to their sacrosanct authority over a specific social, biological, or technical domain. Despite the concept's central theoretical role in understanding the professions a few features of the work of professionals require that we qualify its importance in understanding contemporary expert labor, particularly the growing importance of organizations and specialization (Leicht and Fennell 1997). A number of scholars have noted the growth in the authority of organizations that have reined in the formerly unequivocal autonomy of professionals (Freidson 1984b; Light 1991). This is particularly true of medicine, where insurance payers, the State, and patient advocacy groups more and more influence the practice of medicine (Light 2010; Menchik 2021; Starr [1982] 2017; Timmermans and Kolker 2004).

An overlooked area in the literature on medical interactions is those that occur between specialists of different types, whose success or failure in collaborating will be highly influential in what can and will happen in the care of patients. Rather than collaboration occurring as a series of sequentially ordered interactions, such as on an assembly line, or occurring in parallel, medical care requires tight cycles of collaboration, information exchange, and alignment, including between experts and laymen. The medical domain, in which morality and scientific rationality come to be fused, helps us to better understand how functional differences, with their attendant differences in worldview, language, and systems of evaluation, are ultimately integrated through the process of sharing information, understanding, and ultimately goals in a joint project.

CHAPTER 7

INTERDEPENDENCE AND DIFFERENCE: NICHE CONSTRUCTION IN THE STUDY OF THE PROFESSIONS AND ORGANIZATIONS

In the previous chapters, I have outlined some of the features of the work of Hospice and Palliative Medicine, as well as its organization, that make it unique among modern medical specialties. It was the product of a competition between a non-medical and medical paradigm of care, the paths clinicians can take to it are varied, and it uses deceptively simple strategies for breaking out of the routine means clinicians have for making decisions when patients are acutely ill. As reviewed in Chapter 5, HPM clinicians work to provide patients choices that conform with the preferences they express, avoiding substantially identical choice sets that seem to provide patients a variety of choices but have the same or similar medical outcomes. They hew closely to what patients express, at the same time forming their preferences in interaction. On the clinician side, as reviewed in Chapter 6, HPM clinicians overcome the linguistic and practical barriers that form between specialties, and which undermine the ability of their colleagues to relate to patients, by using a repertoire of talk that bridges the different schema stakeholders use for making sense of their condition and making choices. On the medical side, there is the Maximization Framework, which seeks to maximize longevity, which clinicians communicate using the Discourse of Data. On the patient side, there is the ordinary, idiosyncratic talk (referred to as the "Voice of the Lifeworld" in the ethnomethodological literature on medicine) which expresses their concerns, fears, and preferences in ways that need to be translated to medical staff.

These practices are not uniquely available to clinicians in HPM, as is the jurisdiction to perform surgeries or the expertise to provide radiological or chemotherapies, and so cannot be said to be exclusively performed by them. Instead, HPM clinicians explicitly say "we do what any doctor can do". Their specific form of competence at work is fundamental to the profession of medicine. This phenomenon is curious as the sociology of the professions has long maintained that new areas of work are established when competing groups determine the authority over novel or unique areas of practice. A special3333ty medicine that establishes itself by specializing in a universal feature of the profession is not easily incorporated into the common theoretical paradigms for making sense of the professions (Abbott 1988; Freidson [1970] 2007; Light 2010; Menchik 2020). In this chapter, I demonstrate that HPM defies the taken for granted logic for understanding professional boundary-making. With its emphasis on collaboration and direct appeal to the central warrant of medicine crosses professional boundaries to constitute its professional niche. Using a theory from evolutionary ecology, niche construction (Odling-Smee, Laland, and Feldman 2003), I argue for a new means of understanding the behavior of certain kinds of professions, ones that coordinate the work of related but functionally distinct areas of work.

The sociology of work and occupations has long organized its studies of professions in terms of competing professional groups who seek to dominate areas of work to the exclusion of other candidates (Abbott 1988; Freidson [1970] 2007; Kellogg 2014; Light 1991). On this view, professionals carefully guard their jurisdiction or turf, fending off claims from without to maintain exclusive epistemic and practical authority over socially valued tasks. This interprofessional brinkmanship, this view further posits, is replicated within professions as specialties arise to address specific professional tasks in a further division of labor. Were a profession or specialty to strive to share its authority and practical activity with other competing professionals, established explanations of professional organization would be badly stretched to account for this aberrant phenomenon, particularly if this occurred at the height of the professional status hierarchy in medicine.

HPM, whose primary domain of expertise is the care of the terminally ill, establishes its central warrant of practice in a set of competencies that are shared by colleagues in other areas of medicine. HPM clinicians say that what they do, “any doctor can do” and frame their competency in terms of what they see as having been abandoned by their specialist colleagues who are more and more narrowly defining their expertise and niche in patient care in terms of the application of esoteric technologies or treatments. Rather than establishing their expertise in terms of exclusive authority over a valued practice, as surgeons do, or over a critical area of knowledge, such as oncologists do, HPM clinicians specialize in a core practice of medicine; talking to patients and establishing what will occur in their care, particularly when the dominant means for adjudicating between diverging treatment paths break down. These clinicians establish their medical interventions as core to how the medical profession defines its primary locus of practice and further attempt to reorient their colleagues to the very same set of practices. Clinicians in HPM express annoyance at having to exist at all and conduct their work in such a way as to attempt to make the need for their expertise obsolete, by altering the work practices of their colleagues.

To be sure, the turf model of the professions does not get everything wrong about the contemporary structure of competition and collaboration in consequential professions in medicine. Growing specialization has led to the atomization of the overarching professional body of medicine with negative consequences for successful patient care (Oh 2014; Stichweh 1997). Specialties in medicine like oncology, surgery, or neurology, collaborate to treat patients, but their narrow expertise and rigid defense of turf undermine their ability to successfully synthesize clinical information and coordinate their practice due to diverging repertoires of talk and action that are not easily coordinated (Conn et al. 2016). Despite the competitive forces that drive medical specialties apart in their different practices, they remain deeply interdependent on one another, and coordinating care across boundaries of practical and epistemic difference is important for the health and well-being of the patients they care for.

In this chapter, I will explore how HPM establishes its practice on what sociologists of the turf model would consider unstable jurisdictional territory, as they claim their expertise in a universal domain of practice, patient-clinician interactions. Further, I will demonstrate how this behavior indicates that students of work and occupations should adjust their theories to better account for this behavior as it occurs in other professional areas. Established based on an ecological metaphor that emphasized competition, predation, and territoriality (Abbott 1988; Freidson 1988), the turf model cannot fully address the behavior of bridging and coordinating specialties such as HPM, which result from pressures that diminish the professional impulse to rigidly guard turf and increases the need for professional convergence. Preserving and revising the ecological emphasis in our sociological theories of the professions, I identify this convergence and cooperation as a form of niche construction (Odling-Smee et al. 2003), where organisms autonomously generate their position within an ecology. Rather than being circumscribed to accounting for pure cooperation on the one extreme and competition on the other, as past theoretical paradigms have emphasized (Stichweh 1997), niche construction can help to account for the full gamut of observed interactions between professionals and professions in the constitution of the ecology of work.

First formed to address the well-being of terminally ill patients, HPM is more and more involved in the planning and management of therapy meant to cure or palliate. HPM developed by focusing on preventing overtreatment, medical interventions that do not benefit patients or that pose a risk of harm that outweighs their benefit (Ooi 2020), by ensuring that patient autonomy, the ability to make decisions about what and how much care patients receive, is respected, particularly as patients approach the end of life. Patient autonomy entails that patients retain the authority to intensify, maintain, moderate or cease medical care as well as influence how they die, regardless of the recommendations of their physicians to do otherwise. However, HPM clinicians work in professional contexts where the normative ideal is to provide patients with *curative* therapies, aimed at extending life and working as consultants for other clinicians, the mandate of their specialty can diverge from the organizational role they are meant to fill. Patients may knowingly request further therapy that will not ameliorate their illness and that presents risks that outweigh the possible benefits. Abiding by a paradigm of medical decision-making that was developed to address overtreatment, where patient's preferences and normative commitments drive medical decision-making, HPM clinicians are sometimes placed in a position where aligning with a patient's values requires that they advocate for medical treatments that undermine their normative commitment to preventing overtreatment.

Navigating these tensions and collaborating with specialists from different areas of medicine leads HPM to occupy a unique niche in the division of medical labor. In part, due to their position in the organization of medical specialties and contrary to our theories about how professionals organize and conduct their work, HPM clinicians attempt to undermine their exclusive claim to a unique area of work by advocating for other clinicians to adopt a work style indistinguishable from HPM, creating an advantageous environment for their practice of HPM. This style of influence defies our taken for granted theories of professional behavior; rather than being oriented to the defense of their jurisdiction and unique style of work, they invite other specialists to participate in their expertise. Further, rather than solely specializing in a set of domain-specific skills or interventions, these clinicians address what they articulate as a fundamental area of clinical practice, one that has long been abandoned by other areas of medicine in the face of the dual influences of technological advancement and increased patient autonomy (Lutz 2019; Stacey et al. 2009): relating to patients, synthesizing information and instigating decision-making through dialogue.

Past theories of the professions primarily emphasized the cooperation or competition of different professions and specialties, while adopting niche construction can better account for the varied forms of interactions adopted by HPM clinicians; intermittently, professions and specialties, draw toward one another and then pull away, influencing one another, resisting parasitization, and welcoming the influence from allied areas, transmuting competition into cooperation through further adaptation. Niche construction as a theoretical development is not completely novel, as is also true in its native discipline of Evolutionary Ecology but follows in the line of ecological theories long influential in Sociology and the Sociology of the Professions. Niche construction fills a necessary theoretical form that developed from the earliest social theorists interested in the division of labor and expert work. This chapter is partially a summary of the previous empirical chapters and seeks to synthesize their arguments toward the end of innovating on established theory.

7.1 Functional Differentiation and Epistemic Difference

7.1.1 Difference with *Interdependence*

The fundamental problem explored in this dissertation is how coordination is achieved between functionally differentiated entities that are interdependent on one another. Understanding this phenomenon is not new to sociology but has a very long lineage in our theories of how society and the professions work. Durkheim, in *The Division of Labor in Society* ([1893] 2008), argued that the interdependence of different parts of society, as individuals become less and less homogenous, leads to a novel form of social cohesion. As traditional sources of order in society are swept away with technological and social advancement, for the continuity of the social order to be maintained individuals need to coordinate their activity and remain symbolically united. Durkheim identified two varieties of social cohesion, *mechanical* and *organic* solidarity. The first is the cohesion of individuals due to their homogenous features and is, he claimed, characteristic of traditional societies, where social bonds can be relatively weak without threat to the overall social order. As society becomes functionally differentiated, rather than homogeneity creating solidarity between individuals it is their *interdependence* that causes them to cohere in both a symbolic and material community.

But the problems of coordination that result from the division of labor are not fully ameliorated by simple interdependence; Fleck ([1935] 2008) noted that membership in different social groups leads to fundamentally different and incommensurable worldviews.[1] The cycles of tight interaction within groups, and the sparse interactions with members of the out-group, lead to internally coherent but externally incommensurable descriptions of the world. Groups with distinct worldviews do not have access to inconsistent external realities, but bring fundamentally different schemas, preconditioned by past interactions with the world and the group, for understanding the mutually accessible material world they share. Differences between groups in their understanding of phenomena cannot be traced to differences in the world but to what they bring to the process of creating explanations from their social organization (Latour 1999).

The paradigm of organic social cohesion, difference with interdependence, is fundamental to the sociology of professions; *professionalization* the evolution of an area of work into a profession is constituted by two distinct processes, *specialization*, in terms of knowledge and practice, and the *differentiation* of the larger body of workers into distinct and official groups, in both organization and identity (Parsons 1939, 1951). Resulting of the emphasis on the differentiation and

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[1] Fleck instead of referring to “social groups” and “worldviews” refers to “thought collectives” (*Denkkollektiv*) and “thought styles” (*Denkstil*), respectively.

specialization of the occupational structure is the recognition that these professions are then further differentiated into intra-professional specialties (Becker et al. 1961; Laumann and Heinz 1977).

Further specialization and sub-specialization are required to address the more and more complex tasks presented by laypeople and produces a fundamental tension in the sociology of professions: in their competition to dominate task areas that require different and more specialized expertise, the professions internally subdivide causing the individual professions to be defined by a core set of competencies with sub-areas weakly interconnected to one another. The specialists and sub-specialists that are instrumental in solving a client's problem will have fewer and fewer means to productively connect their distinct expertise and be unable to address the overall needs of the client as internal heterogeneity grows (Moorhead 2010; Schrepel et al. 2022).

7.1.2 The Turf Model

These lines of theoretical advancement in the Sociology of Professions come into the clearest focus in Abbott (1988); contests for different *jurisdictions*, or *turf*, are settled through local workplace strategies for determining what problems are and what are their appropriate solutions. Key to this is the ability to abstract from a practical problem to a theoretical domain wherein that problem's component parts can be organized and defined in a vernacular inaccessible to the client (Abbott 1981). This affords professionals the ability to remain insulated from lay critique and sufficiently flexible to redefine their practice in the face of novel claims to their turf or a change in the underlying technological environment that establishes their area of work and this ability is key to professional control of a particular area of work and the continued existence of a profession as an autonomous group (Comer et al. 2023; Maynard 1991; Stivers and Timmermans 2020). Professional autonomy is maintained as different areas are symbolically consolidated into superordinate groups (medicine, law, engineering, etc.), and the number of turfs proliferates as task areas are created and identified. Organic solidarity, which theoretically secures this paradigm, requires greater *interdependence* at the same time that individual areas of work are *differentiated*.

Despite being incredibly influential in the study of work and occupations and expert labor, the inadequacy of the turf model for explaining consequential developments in the professions has not gone unnoticed. Menchik (2021) argues that rather than focusing on the domination of jurisdictions as the primary organizing principle of professional conduct, we ought to focus on how professionals build coalitions with various stakeholders to manage "indeterminacy" or the "boundaries of expert knowledge and accepted practice" (p. 11). Key to this work is the emphasis on "tethered venues", the durable connections that form between places where professional work and socialization occur, both inside and outside official professional contexts. This deeply ecological model for the organization of professional work pointedly rejects the turf model for the professions. The turf model provides a powerful theoretical vocabulary for describing, in ideal-typical terms, the organization of expert work, but fails to account for the dynamism and ongoing development of different areas. In particular, such models fail to "offer insight into the ongoing interaction and interdependencies among people who share an occupational project but bring different perspectives" (p. 27). Personal reputation and cooperation between what are typically considered outside influences help to constitute discrete but porous domains of practice (p. 235). In the case of Electrophysiologists that Menchik studied, cooperation between representatives of technology companies that developed the technology surgeons rely upon undermines the sacrosanct autonomy and purity of professional jurisdictions, particularly with such a core skill as surgical technique. However, these ties across professional and intra-professional boundaries are critical to the stakeholders in achieving their distinct tasks.

Kellogg (2014) follows in a similar vein of research, with her work on "brokerage professions" in the implementation of reform in two U.S. medical centers. She found that cross-professional interactions (in her case between Law and Medicine) can be facilitated when the tasks that link them are "low status, low value, and do not enable the target groups to use their specialized expertise" (Kellogg 2014:932). Reforms in the fabric of task areas available to professions, create novel jurisdictions that are left void when the task is unattractive to the professions that would otherwise claim them, and this is particularly the case when reform is meant to establish cross-professional collaboration. Brokerage professions establish "buffers" between professional areas "managing information rather than transferring it, matching meanings rather than translating them, and maintaining interests rather than transforming them" (Kellogg 2014). Rather than being oriented to dominating novel task areas, these brokerage professions serve as a mechanism to bridge different professional jurisdictions.

Menchik (2021) and Kellogg (2014) analyzed professional interactions between different areas (Medicine and Business in the former, and Medicine and Law in the latter case), while Trotter (2019) examined the inter-professional and *intra*-professional boundary work instigated by Nurse Practitioners. Nurse Practitioners are registered nurses who can act in a role similar to physicians, with the ability to "assess patients, make diagnoses, and provide treatment in accordance with their specialties without physician involvement". This poses a threat not only to physicians but also to other kinds of relatively less specialized nurses as "NPs cross boundaries of skill and responsibility that, as RNs, they learned to treat as constitutive of their profession.". To resolve the contradiction, NPs engage in "reparative boundary-work", which "re-centers the primacy of negotiation over direct conflict in the division of professional labor." NPs affirm the boundary between their expertise and that of physicians, maintaining their identity as nurses, while offering a synthesis of nursing and physician expertise in interactions with patients. Rather than an orientation of domination and exclusions, NPs carefully negotiate their role *between and within* different professional entities.

Each of these works indicates compelling shortcomings of the turf model; Menchik (2021) argued for the *cooperation* of professional entities that have been considered diametrically opposed in past work, while Kellogg (2014) emphasized the ways in which novel professions *buffer* established professions and fill gaps in the system of jurisdictional control, and Trotter (2019) attempts to recenter *negotiation* over conflict in the relationships that occur between professions. Though they represent important innovations, each fails to adopt a theoretically and empirically generative framework that breaks with the turf model to understand how difference and interdependence are matched with collaboration that is sufficient for puncturing the boundaries around different working groups between and within professions.

Emphasizing cooperation (Parsons 1951) or competition (Abbott 1988; Freidson [1970] 2007) in our theories of the professions, to the exclusion of other prosaic but decisive forms of interaction between professions and specialties will ultimately fail to address the many ways that these groups do their work while being both independent of but reliant upon other areas in the division of expert labor. A revision to Durkheim's organic analogy will help greatly in both defining the problem at hand and outlining its resolution; rather than analogizing the division of labor in society to the internal differentiation of a single organism, sociologists should appeal to *ecological solidarity*, the differentiation of ecological systems and the interdependence of multiple organisms to make sense of the professional order. Organic solidarity overemphasizes harmony, while the turf model overemphasizes competition and territoriality.

Taking evolutionary ecology and niche construction as models for understanding the interactions of professions and specialties will help sociologists to explain the behavior of expert workers when they are in the intermediate between the two extremes of cooperation and competition. In particular, niche construction helps to understand the work of professionals as both the product of technically specific knowledge of worldly problems and their position within a historically arbitrary organization of work, a synthesis mirrored in the discipline of evolutionary ecology itself.[2]

7.1.3 The Ecology of the Professions

Ecology studies the interactions of organisms with one another and their environment. Evolutionary ecology takes into account the evolutionary life histories of the organisms and ecosystems, and how those histories are shaped and in turn shape the physical environment. Critical to this paradigm is the concept of a niche, the place in the physical environment and the systems of relation where an organism can live, grow, and reproduce (Ghazoul 2020:26) or a species' "mode of life" (Elton 1927). This is meant both literally and figuratively; a niche is a physical location in space, nested within an ecosystem, as well as a non-physical location in several different relational structures,

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[2] The literature on the Sociology of Medicine that follows in the legacy of Parsons (1951), Freidson ([1970] 2007), Abbott (1988) has made important innovations, particularly the "countervailing powers" framework of Light (2010) and "biomedicalization" of Clarke and Shim (2011) but each of these primarily emphasizes the same competitive forces inherent in the turf model of the professions, and of medicine in particular.

such as competition with other species over limited resources (e.g. food and territory). Niche *construction* is where "organisms, through their metabolism, their activities, and their choices, partly create and partly destroy their niche" (Odling-Smee et al. 2003). Organisms, in non-trivial ways, influence their environment such that it alters the selective pressures they and their offspring are exposed to. This can be most obviously seen in the material environment that organisms occupy such as in nest and burrow construction (e.g. beaver dams, termite mounds) which influence the survivability and success of later generations (Odling-Smee, Laland, and Feldman 1996; Turner 2000).

These "extragenetic inheritance" mechanisms (Odling-Smee et al. 1996) enhance the survivability of later generations and act in parallel to standard genetic inheritance. There is the further implication that organisms can influence the evolution of other organisms they share an environment with, and in ways that are advantageous to the focal organism. For example, several varieties of fungiculturist insects have successfully tamed and cultivated thousands of species of fungus, and are now nearly completely dependent upon them as a source of food (Mueller and Gerardo 2002). The fungi these organisms cultivate have changed due to the influence of the fungiculturists, while also in turn shaping the survivability of their tamers. Similar examples of such influence can be found in avian species. Brood parasite species, such as the Cuckoo, which rely on other species' hens to raise their young, have been observed retaliating against parasitized organisms that resist parasitization and reject the brood parasite young (Hoover and Robinson 2007). Over several generations, the retaliation reduced the instances of resistance by the parasitized, likely through selective pressures that altered the behavior of the parasitized species.

Niche construction also emphasizes an important advancement in ecologists' understanding of the adaptation and dynamic matching between organisms and the environment; rather than an inert and unidirectional relationship between organisms and their environment, in which the former adapts to the latter, there is reciprocal and mutual influence. This much more radical claim of the niche constructionists is that organisms and their environments co-evolve, rather than the influence solely flowing from the environment to the organisms that occupy it (Lewontin 1982; Odling-Smee et al. 2003).

Where previously the sole inheritance system identified in biological evolution was genetic, niche constructionists identified ecological inheritance as an important contributor to both the selective pressures organisms are exposed to and a mechanism by which ancestors influence the genetic and phenotypic characteristics of later offspring. These extensions do not undermine the fundamental relationships posited by the standard evolutionary account but add substantive and meaningful elements to the theory. Here, I propose a similar innovation for the study of the professions. Applying niche construction to the study of professions is an extension and refinement of past theoretical paradigms. Just as niche construction extended evolutionary arguments to encompass previously underappreciated phenomena by integrating compatible and standard interpretations of evolutionary and ecological theory, niche construction when applied to the professions, and medicine in particular, helps sociologists to understand the role of specific technical knowledge of professions and specialties and the position of them within the overall network of collaboration.

7.1.4 The Structure of Niches in Specialty Medicine

Rather than adopting the hierarchical and nested taxonomy of Linnaean classification to begin thinking in ecological terms, we should adopt a non-nested system for organizing different medical specialties based on their epistemic, practical, and organizational features. A coarse distinction that helps us to begin to form a taxonomy of different medical specialties is between Proceduralists and Non-Proceduralists, an informal distinction that is used by clinicians to organize themselves in terms of how they intervene in the care of patients. Proceduralists intervene in patients' cases using technologies and techniques that directly target illness, such as with surgery or radiological therapy, while Non-Proceduralists use indirect interventions, such as medications and other therapies, while also focusing on the processes of diagnosis and prognostication.

Non-Proceduralists are sometimes considered too philosophical by their Proceduralist colleagues, prone to questioning the goals of intervention as well as the ontological status of attributes of the patient, while Proceduralists are considered excessively enthusiastic about deploying their interventions regardless of their efficacy for the patient. The surgeon may be able to clean a wound or remove an artery blockage, or the radiologist blast a tumor with radiation and succeed on the terms of their specialty while doing little to improve the patient's overall health or well-being. Non-Proceduralists and Proceduralists are tightly coupled in providing care to patients, despite differences in their orientations to work and possibly grouchy attitudes toward one another, differences which form due to differences in training and disposition to action.

Differences in training and expertise exert a great deal of influence on how physicians relate to one another. In the case of cardiologists, both generalist cardiologists (Non-Proceduralists) and interventional cardiologists (Proceduralists) are certified by the American Board of Internal Medicine to practice as cardiologists, but interventional cardiologists undergo further *sub*-specialization for their practice. The internally differentiated system of subspecialties in medicine both diverge from one another in terms of what they do and how, but also converge in the organizational setting of clinics and hospitals where they care for patients. With greater and greater specialization in an organ system, illness, or technique, there is a degradation in the specialist's ability to address the patient's overall well-being, the course of their illness, and other complications stemming from treatment. Specialists come to rely upon one another to answer questions related to but not directly addressed by the expertise of their domain. The development of the domain-specific expertise and purview of Hospice and Palliative Medicine helps to elucidate this structure.

7.1.5 The Construction of the Niche of the Dying

For much of their history, a doctor's role at the end of life was to pronounce death while neither preventing nor forestalling it (Hertzler 1938). Deaths were the product of unpreventable causes such as natural degeneration due to age or accidental trauma. With the development of novel procedures and technologies, as well as organizational changes within hospitals, the ability of medicine to intervene in emergencies as well as to treat chronic illnesses radically changed the picture of dying in the US. Death ceased to be a domestic event and became a medical emergency, occurring in hospitals with a battery of interventions deployed at the time of death regardless of whether any meaningful functional recovery was possible (Lewis 2007; Timmermans 1999). Within a single century medicine transitioned from a position of helplessness in the face of human mortality to one of efficient and potent intervention.

Death came to nearly solely occur in hospital settings and was incidentally addressed by medical personnel (Cross and Warraich 2019). End-of-life care, a neologism that would come to help define the work of HPM as a distinct area in medicine, did not yet exist. Death occurred in medical settings at the end of a long chain of failed treatments, even in the moments leading up to and following the death of a patient. The curative paradigm, with particular emphasis on longevity, organized the care of the dying and the procedures performed at the time of death which degraded the well-being of the dying without providing any enhanced life span. It was in this environment that clinician's awareness of the suffering of the dying, and of bereaved families, took on greater salience, with noted physician and ethicist Eric Cassell observing that "Basic to understanding the problem of caring for the dying is an awareness that with all its mysteries, death is a concrete event, mostly smelly and mean, preceded and followed by pain" (Cassell 1982).

Hospice and Palliative Medicine gained official certification as a medical subspecialty from the American Board of Medical Specialties in 2006. A Specialty or Primary Board of medicine is an independent organization that certifies clinicians in an area of medicine distinguished by specialization in an illness (e.g. oncologists, allergists), technique (e.g. surgeons, emergency medicine specialists, anesthesiologists), or organ system (e.g. urologists, gastroenterologists, gynecologists).[3] Doctors and nurses practicing HPM specialize in two domains of clinical practice: pain and symptom management as well as complex decision-making (what medical personnel call "goals of care"). HPM clinicians treat patients with a variety of illnesses and are particularly oriented to those suffering from chronic and terminal illnesses. They primarily work as consultants to other medical specialists, rendering recommendations about what other clinicians should do to address the issues a patient is facing. These issues range from the purely medical (symptom burden due

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[3] Several superordinate specialties do not neatly fit into these categories, such as Internal Medicine, Pediatrics, or Family Medicine.

to disease progression), to the purely social (family disputes over how to manage the end-of-life care of a relative). HPM clinicians work as specialists in integration, bridging the worldviews and vernaculars used to talk about them of their colleagues in other areas of medicine and the patients they care for, they must engage in careful negotiation with their colleagues and peers for influence in patient care.

7.1.6 The Place of HPM in the Division of Medical Labor

Within clinics and hospitals, HPM is organizationally dependent upon other medicinal specialties that request consultations from specialists in HPM to advise them about the care of their patients. This organizational subordination is mirrored in the larger structures of medical specialization. As mentioned above, HPM is a medical *sub*-specialty (as opposed to a medical *specialty*) and so does not have an autonomous supervisory organization that can interact with the certifying agency of medical specialization (the American Board of Medical Specialties). As described in Chapter 4, to become a physician practicing Hospice and Palliative Medicine, one first completes a residency program in one of 10 different areas of medicine before then completing a one-year Fellowship program and a board certification exam administered by the American Board of Internal Medicine (ABIM). HPM emerged *between* primary boards, and so multiple specialty boards co-sponsored it, bridging different and disparate areas of medicine.

A brief genealogy of HPM helps to demonstrate the power of niche construction for understanding the structure of medical specialization and HPM's place in it. HPM emerged from Internal Medicine, with a close familial resemblance to Anesthesiology with their expertise in the management of pain. In its earliest forms, HPM was largely indistinguishable from Oncology as its patient population and organizational classification in hospitals was largely Oncological. Over time, HPM began forming ties to other medical specialties in more and more diverse areas of medicine, embedding itself between different areas of practice. Its niche occurs within multiple epistemically and technically distinct ecologies of medicine, unified by the need to facilitate collaboration and mutual understanding between clinicians and patients.

The emergence of and continued relationship of HPM with related but distinct areas of medical practice is unique and indicates a fairly exotic relationship between collaboration, both drawing from different areas and participating in different areas. Further exploring the specific work tasks of HPM will help to elaborate upon its position between different specialties, and the strategies it uses to establish a domain of practice.

7.1.7 The Call to Consultation

HPM clinicians see patients when clinicians working in other specialties "call us and generally, they're stuck. Generally, they're in a place of uncertainty, and they need help navigating it, or there's some symptom or some other thing that the patient is suffering" (PAL-PH/A-008, Male Attending, West Coast). These requests for "consult" with an HPM clinician are instigated by issues in one of two domains: (1) symptom management (physical pain, emotional distress, existential anxiety, family issues) and (2) complex decision-making or goals of care. HPM clinicians are dependent upon the physicians requesting the consults in two ways: firstly, HPM clinicians can recommend that medications and other treatments should be prescribed to a patient but the primary attending on a patient's case can contradict the proposed plan of care. Secondly, HPM clinicians rely upon the goodwill of other physicians to continue getting new consults. They must demonstrate their value in the division of medical labor and maintain long-term working relationships with the physicians they receive consults from.

Pain and Symptom Management

Requests for consultation for pain and symptom management are of a standard form in the professions; different specialists have competencies that uniquely qualify them to address specific problems and are asked by their colleagues to manage them in a division of labor. A common consultation for pain and symptom management includes addressing "really severe cancer-related pain" caused "directly from where tumor is destroying something [...] Sometimes pain is more complicated and more of a total pain picture that may have some physical component, but may also have a strong existential component and social or financial or all these other things that may be funneling into how someone feels they can manage their pain or not manage their pain" (PAL-PH/A-056, Female Attending, East Coast)

Consultations for pain and symptom management can serve as a means of establishing HPM's second domain of work, goals of care, in a patient's cases: "managing complex symptom management and pain [...] gives us a foot in the door to establish some rapport to help someone feel better to demonstrate our competence. And then when we actually do then sit down to be part of discharge planning and goals of care conversations" (PAL-PH/A-056).

Goals of Care

"Goals of care", or "complex decision-making", refers to situations where clinical evidence supporting different medical interventions is insufficient or ambiguous, goals and options are not clearly defined, and preferences are unstated (Epstein and Gramling 2013), and clinicians need to establish the overall objectives patients seek to accomplish from continued medical treatment. Determining goals of care is about locating a patient on a continuum from deploying the full battery of life-sustaining medical interventions to promote longevity, and focusing entirely on comfort to avoid suffering. Goals of care is constituted by both "sharing information or [...] making a decision" (PAL-PH/A-001, Female Attending, West Coast), and include clarifying the status of the patient and then evaluating what the objectives of continued medical treatment should be given the stated and unstated goals and preferences of the patient.

HPM clinicians begin the process of establishing the goals of care in a patient's case by learning how they make decisions and what their values and goals are: "I start by drawing out what might be valuable to this person in front of me and I try to do that on a number of different levels: on a practical level, whether being home, being not home, getting more treatment are important to them. I try to think about his family, if he has a family, and sort of their role in his life and how they figure into decisions or not, identifying what the locus of decision-making is" (PAL-PH/A-013, Male Attending, Midwest).

Patients express confusion about what they should do; an elderly patient is deciding about whether to begin dialysis for their failing kidneys, and continually asserts “I have to decide this between me and my God” or that “me and my God, are going to help me. That’s what’s gonna help make this decision” (PAL-PH/A-013). The patient remained ambivalent about whether they should adopt the treatment and efforts to help resolve the issue were unsuccessful: “Well, is there anything I can do? Or any medical things that I can do or things we can do with your family?’ And it was very hard for [the patient] because he said, ‘No, there isn’t’. And then he kept saying, ‘but I don’t know what to do’ ”.

HPM clinicians do not only serve to clarify the goals of medical intervention for patients. Specialists from other areas of medicine can also be confused and indecisive about what path forward should be adopted in a patient’s case. PAL-PH/A-015 (Male Attending, Midwest) identified this dynamic by observing that “we often get consults because of team or provider distress. And that distress may be because they feel like they’re doing things to the patient that is either causing suffering or isn’t helping. They have this sense of futility or there has been a fracture of the relationship and there’s mistrust between patient or family and provider. And they’re in conflict more and more, and they want help in navigating that.” HPM clinicians consider the goals of care domain to be a *universal competence* for all clinicians, one they ought to have trained for and one which they will use frequently when treating patients. HPM clinicians consider this competence, the ability to successfully and efficiently complete a task, to be at the heart of medical practice or “what every doctor ought to be able to do”. The failure of other clinicians to successfully attend to this competency requires the HPM clinician’s intervention and is justification for the existence of the sub-specialty.

HPM clinicians express frustration with requests for goals of care consultations noting that such requests require that they help their colleagues to complete tasks they should already be equipped to deal with. PAL-PH/A-036 (Male Attending, East Coast), referring to these requests, asked “what does that mean? It’s such a broad thing that like a lot of times what it ends up meaning is that the other teams haven’t spoken to the person at all about what’s going on. And they don’t want to because it’s uncomfortable to talk with patients about the things that are going on with them when we can't make them better, and that the other providers don't feel equipped to do it. And so instead of trying to learn the skills or try to do it themselves, they just say 'I don't want to do it. Call palliative care' ". We would expect professionals, with unique areas of expertise that they carefully guard against incursion, to attend to the boundaries of their and other professionals turf, but a common refrain of clinicians in HPM is that they perform a function that "every physician should be able to" do (PAL-PH/A-020, Female Attending, West Coast). Despite expressing slight annoyance at the fact, HPM clinicians identify goals of care as uniquely defining of the subspecialty as well as the specific "procedures" they perform to address this feature of patient's cases. PAL-PH/A-013 described that "communication is our procedure" and in a similar vein PAL-PH/A-016 (Female Attending, Midwest) described that "the family meeting is kind of the procedure of palliative care" though it is simultaneously identified as something common to the demands of work that all clinicians face. All clinicians ought to be able to communicate with their patients about the issues HPM clinicians are asked to address, and HPM clinicians frequently cite the neglect of this core clinical competency as a justification for their existence as they further nudge other specialists to be more attentive to this aspect of their work.

HPM defies the fundamental theoretical precept that the means of advancing the authority of a profession is to claim and successfully annex areas of work formerly controlled by other professionals or specialists by orienting to what other physicians *ought* to address with all their patients. "Ideally, the primary team would have already had a shot at the patient, talk to them about their goals. Every physician should be able to talk to their patients, and to elicit the patient's preferences" (PAL-PH/A-020, Female Attending, West Coast).

PAL-PH/A-023 (Male Attending, Midwest) recounted an ongoing dispute at his hospital describing that the orthopedic surgeons "would like us to see, preferably at six in the morning, all of their geriatric patients admitted with hip fractures".[4] PAL-PH/A-023 recounted this as a gross violation of the fiduciary responsibility of the surgeons: "What they want to know is 'do we take

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[4] These evaluations would have to be conducted so early in the morning because surgical services start their procedures around 7 AM. That means they are rounding very early in the morning, often before the patient is even awake, further reducing opportunities to communicate with them.

the patient to the OR or not?' And they would like us to tell them whether or not to go fix the hip fracture or not. And my perspective has been, 'yo, you're a surgeon, helping people decide whether or not to have surgery is your job. You can't offshore all of that to me' ". Though HPM clinicians view their role in establishing goals of care as central to their practice they are willing to draw a line at where they are and are not going to take on the role of aiding in decision-making. "They value their ability to fix the fracture, and I value their ability to be a doctor, and they seem to be devaluing their role as a doctor, frankly, as much as possible. They no longer care for their patients before or after surgery, they literally are just doing surgery now. Other doctors have taken over all the other responsibilities. And now they want to give away one more thing, which I see as fundamental to being a doctor". based on established professional theory, we would expect HPM to seize the opportunity to take over what is a core area of another specialty's practice. HPM's emphasis on patient-clinician interaction and communication as a core competency of all clinicians, however, means that it carves out a unique place in medicine but does so upon a universal task of the profession: rather than, as nearly all other specialties do, defining their practice in terms of exclusive expertise in an esoteric domain of knowledge or special technique, HPM clinicians define their work as central to the core values, practices, and history of medicine.

A specialty that frames its practice in terms of the very central problem the profession addresses establishes itself upon epistemic and practical bedrock as it engages in core problems of general concern to its peers. But this can also weaken the hold a specialty has on its task area as other specialists in the same profession have equal claim to it. In describing the conflicting incentives for establishing a palliative care service at his hospital PAL-PH/A-022 (Male Attending, Midwest) noted the skepticism of some of his colleagues saying: "I remember one of my oncology colleagues, which is kind of surprising to me said, [regarding the practice of palliative care] 'Well, you know, it's just common sense. And we can all do it'. Which is true, except that you don't…what we found is that it's beneficial to have somebody 'like, hey, it's your job, to focus on quality of life and spend a lot of time with a family because, you know, you're that subspecialty that does that and therefore has sort of the time set aside to do it' ".

HPM clinicians see this as both core to their unique specialty-specific competencies and what it means to be a clinician. Rather than defining its practice narrowly and discretely, articulating their difference from other kinds of clinicians, they define their practice in terms of what "any physician could do". Not only do HPM clinicians indicate their disapproval of other physicians' inability to do those very tasks that they consider central to their specialty, but they need to, in some cases, decrease the difference between how other specialties and HPM work, precisely because of their need to construct bridges between medical practitioners, patients, and their families. Examining more closely how they conduct themselves in the process of helping patients make decisions and helping other clinicians care for them, we see some of the other ways that HPM is a case that is not easily accounted for by the established theories in the sociology of the professions. In particular, how clinicians in HPM go about *bridging* the taken for granted goals different stakeholders in patients' cases have about what ought to happen. This is most important when working with clinicians from different specialties on particularly intractable cases.

7.1.8 End-of-Life Care

HPM clinicians specialize in pain and symptom management and goals of care, and these two domains intersect in the management of the terminally ill. The care of these patients deprives HPM clinicians of the most common template for success and failure used to adjudicate interventions in medicine — survival. As was previously noted in Chapter 5 When asked to recall a case in which he felt he did an excellent job, PAL-PH/A-044 (Male Attending, East Coast) responded: "[Respondent Laughs] Um, it's funny to laugh at that almost, because like, all of my patients die, most of the time, maybe not all of them." HPM clinicians work on what they identify as the toughest cases with PAL-PH/A-036 (Male Attending, East Coast) identifying a common need to prepare clinicians in other specialties for the worst saying: " 'I think one of the outcomes that you have here is that like, nothing good is gonna come of this'. And that part of our preparation needs to be preparing the medical staff for that."

HPM clinicians treat patients that other clinicians consider to be failures of medical intervention, the dying, chronically ill, or "difficult" to deal with patients, and turn their failures into successes. In part, they do this by defining the outcomes that patients experience as successes by reorienting clinicians and patients to different kinds of goals. HPM clinicians address this part of their work in terms of promoting "goal concordant care" or making "a recommendation that's grounded in [patients] values and preferences" (PAL-PH/A-008 direct quotation, echoed in PAL-PH/A-014, PAL-PH/A-044, PAL-PH/F-046). Orienting both their clinician colleagues and the patients to achievable goals and accord with patients' values requires that HPM clinicians remain aligned with both sets of stakeholders involved in the case, doctors and patients.

Realigning the different stakeholders begins with getting "everyone on the same page" descriptively (PAL-PH/A-021, Female Attending, Midwest), by assessing to what degree each party has the same information, and then, given these shared facts, finding a way forward. They reconcile these different stakeholders, simultaneously trying to get the patient comfortable, get home, or get more treatment while maintaining good relations with the medical staff that originally asked them for help. Getting all relevant parties to share information does not fully resolve basic disagreements about what ought to happen in a patient's case, and HPM clinicians can become caught between two diverging responsibilities: to attend to patient well-being and autonomy and to solve the problems other clinicians perceive as salient to the clinical needs of the patient.

The incentives for HPM clinicians are pulled in different directions, having to balance the desires of patients and those of their colleagues. As PAL-PH/A-002 (Male Attending, East Coast) says, "I think the primary responsibility is to the patient and family, right?… When you're invited in to be a consultant by a treating doctor, you also have a responsibility to that person who invited you in, they can invite you out, right? If you piss them off too much or get too invasive in your recommendation." Balancing their attention to both their colleagues' needs and patients' desires is further complicated by their reliance upon other clinicians to provide information relevant to options the HPM clinician can present to patients. PAL-PH/A-051 (Female Attending, South) describes that "as a palliative care physician, we're there by invite only, which is fine. I want the medical team to assess prognosis and what sort of information they want us to convey. But it takes a variety of different people to really understand the prognosis, and make sure that we're giving good data to the family."

Having to balance their interventions between patient wishes and the possible sensitivities of their colleagues, PAL-PH/A-030 (Male Attending, West Coast) explains the pressures this places upon their work saying that: "at the end of the day as a consulting service in an inpatient setting, my customer, unfortunately, is not the patient. It's the other teams that call on me for help. And so if I'm a firebrand, that does whatever the heck I want, and I alienate all my colleagues, guess what, they're probably not going to call me for help with their patients in the future." They need to both attend to the needs of their patient and satisfy the desires of the providers who asked for consultation. Fortunately, these objectives are aligned much of the time, and addressing the needs of the patient is explicitly what the clinicians requesting the consultation are asking for, but different stakeholders can become misaligned and the consultation request is to address the failure of these social actors to align themselves such that they can make a decision and adopt a path forward.

7.1.9 Bridging Not Brokering

HPM clinicians form connections between, or *bridge*, the critical stakeholders in a patient's case, particularly when the basis for mutual action has been undermined. Often this requires "getting on the same page" (PAL-PH/A-023) where the different stakeholders are made aware of the clinical information currently available including diagnosis, treatment options, and prognosis. Rather than serving as a broker, standing between clinicians and patients, HPM clinicians serve to encourage information to flow between the sets of stakeholders in the case. PAL-PH/A-032 (Male Attending, South) recounted interacting with a patient's wife who had been described to him as "very difficult, and that there was a lot of conflict and that she was sort of hyper-vigilant and fixating on details and…contentious, like arguing about everything, everything was sort of a big deal". He said that visiting the patient and the patient's wife was so taxing that he should save "this patient to the very end of rounds…see them last because they're so emotionally draining." The respondent reported that they approached the patient's wife cautiously but encountered none of the problems his colleagues had communicated about her.

The respondent described that he approached her “from a kind of open posture, just sort of seeing where she’s at” and “when I went to leave, she thanked me and she said, I wish that I’d had you the last two weeks.” The patient’s wife and the other clinicians on the case became alienated from one another, and PAL-PH/A-032’s intervention served to undermine the tension that had been established among the sets of stakeholders. Rather than deploying further medical interventions in the case, the respondent reports that he “literally did nothing, like I didn’t change any medicines. I, you know, like, I didn’t do any medicine, *per se*.”

Such cases highlight some of the most important interventions that HPM clinicians can make in patients’ cases and how they accomplish them: relating to individuals at the same emotional and cognitive register they currently occupy. The respondent described that a common problem he is asked to deal with is when “teams are…not realizing where people are at emotionally, or kind of socially, kind of in their dynamic…they’re missing all that because not all doctors are trained to sort of think [about that]”. Highlighting the importance of this feature of his work, PAL-PH/A-032 relates a moment in which he made this very mistake and its unfortunate consequences for working with the family and his colleagues.

PAL-PH/A-032 was asked to consult on a patient who was at the end of life and being transferred to the hospital’s inpatient palliative care unit which is meant for patients the Palliative Care team will be managing as they die. “I came into the room. And it was just kind of more a matter of fact, like just kind of talking about logistics, and sort of this is how this works. And this is what the unit is like and the palliative care unit is…not a long-term unit. It’s not a residential hospice” and the patient’s wife made “kind of a snarky sort of comment about kind of getting pushed out of the hospital or something. And I sort of missed it and kind of kept talking. And it did not take long that it just sort of blew up…she kind of yelled and said that I wasn’t as helpful as she thought I would be. And that I was ‘welcomed to leave the room’ ”.

The respondent failed to address the caregiver’s concerns about being abandoned, and the continued need for support as her husband died. Where the respondent previously adopted an open posture, that matched the emotional needs of the patient's wife, in this case, he adopted a *closed* posture that didn't account for the caregiver's emotional state and maintained the means-end rationality of the medical team. The respondent failed to bridge the different stakeholders in the case and reconcile their different goals and was unable to recover rapport with the patient's wife.

7.1.10 Reconciling

HPM works to take in the cases that are considered failures by other kinds of specialists and redefines them into successes by providing individuals with the care that matches their "values". This is explicitly the case with dying patients where the primary emphasis is on providing "goal concordant care." This requires shifting or *reconciling* the attention of patients, families, and other clinician colleagues with goals other than cure, ones that can be achieved given the patient's prognosis and well-being. PAL-PH/A-041 (Female Attending, Midwest), a physician who primarily works with pediatric palliative care patients in a neurology ward, describes this as "orienting to the right tragedy", or attempting to match the emotional state of stakeholders in patient's cases to what the HPM clinicians see as productive sources of distress, what is going on right now that they can address and that are likely to cause problems in the near term. Talking about the distress of parents of dying children she describes that "Parents feel like some of the tragedy is that they were not enough, that they did not do enough, that they did not protect enough. And that is not the tragedy. The tragedy is that the child's body was born flawed or acquired something that you know, kept them from living and that medicine is a human system and that their treatments are imperfect." This realignment allows stakeholders to make different decisions, as the meaning of their actions is now in a different schema, where palliation, reducing symptoms, promoting well-being, and avoiding uncomfortable therapies designed to extend life, become an achievable and desirable goal.

However, providing care to patients that is in line with their values does not always mean that HPM patients are always advocating for palliation in the face of death, even as all medical therapies fail. Reconciling the different stakeholders in cases where patients continue requesting treatment up until they die requires special attention from HPM's colleagues in other specialties. PAL-PH/A-

019 (Female Attending, West Coast) describes “I would say one of my pet peeves in the field is this thought that in some ways we are trying to convince patients of something, or we are trying to push them in a certain direction. Sometimes when we’re consulted we will hear the distress of the team. Because they’re feeling like, ‘Well, you know, what are we doing? Why is the oncologist still providing this treatment when the patient is actually dying, and it’s not going to benefit them?’ ” Such instances provoke a surprising role for HPM clinicians: sometimes derided by other clinicians as “death doctors” (PAL-PH/A-019, PAL-PH/A-005) and treated with suspicion that they will attempt to enroll all patients in hospice despite continued efficacy of treatment, HPM clinicians in cases where patients insist on more therapy despite its futility, and in the face of skepticism and distress from providers, will advocate for continued therapy. This reversal of their usual role of advocating for enhancing well-being rather than extending longevity then entails a greater concern for the distress of their colleagues. PAL-PH/A-019 continues to describe that in such instances “part of how we see our role is not only for the patient…but also for the providers and the nurses and you know, we spend a lot of time during our day, talking through and providing that sort of additional support and helping the teams involved to alleviate some of their distress”.

Fundamental to the niche of HPM clinicians is drawing all parties to a working consensus. As long as “patients are making an informed decision, and this treatment, while it may be causing them more symptoms, or maybe causing them more suffering, may provide them a small chance of potentially achieving this other goal” they then “reframe the clinical situation for the teams” (PAL-PH/A-019). This requires “taking that person’s goals, values and preferences and translating that into a medical plan that makes sense clinically” (PAL-PH/A-018) and “assessing values and translating those values into medical recommendations” (PAL-PH/A-026). This need to translate between different registers of talk was most clearly indicated by PAL-PH/A-003 (Female Attending, Midwest): “we’re like medical interpreters. Medicine is its own language…we often get asked to see patients because there is a disconnect in terms of language.” HPM clinicians work to direct patients and the specialists that care for them to a shared understanding in the form of a working consensus when problems arise due to differences in their registers of talk, the constellation of meanings and vernacular used to communicate salient features of the world.

7.1.11 Discourse of Data

In bridging the different sets of stakeholders in patients' cases, clinicians rely upon two different registers of talk to relate diagnoses, prognoses, and treatments to the patients they care for. These two different registers fall along multiple dimensions (e.g. professional/lay, systematized/individuated) but are essentially distinguished by the distinction between normative and descriptive propositions. Descriptive statements, which rely upon the linking verb "is", describe matters of fact ("Earth *is* the third rock from the Sun") while normative statements, which rely upon the verbs "ought" or "should", describe matters of morality ("the Earth *should* be saved from alien invasion") and are not reliably supported by appeals to evidence.[5] Routine medicine is conducted with the taken for granted goal of cure and longevity through the application of evidence-based practices that have evidential support and clinicians do not need to engage in moral talk about what *should* occur in a patient's case. Patients and their clinicians are typically oriented to the same goals of curing or surviving illness but as the ability of clinicians to successfully treat patients and ameliorate their illnesses wanes, the goals of intervention and the information needed to adjudicate between different options become unclear, clinicians must engage in a form of moral talk laden with appeals to the values of patients. Consensus in such moments is *achieved* rather than taken for granted.

Socialization into a specialty and the situations different specialists commonly encounter structure their ability to achieve a working consensus through the use of such moral talk. The "Discourse of Data" relies upon marshaling clinical and epidemiological evidence and situating individual patients' experiences of illness into a larger context, where a standard can be applied and a treatment adopted. One cardiologist (CD-PH-A-003, Male Attending, West Coast) described his approach to resolving differences of opinion between patients or colleagues, saying "I show them the data" while another Cardiologist laments this use of population-level data in clinical decision-making,

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5. Moral claims do require some evidential basis and there is considerable philosophical debate on the distinction between matters of fact and matters of morality. See Black (1964) and MacIntyre (1959) for reviews on the debate about the "Is-Ought Gap" in philosophy.

saying “[my job is] not to take care of all 25,000 [patients] but try to take care of the one patient in front of me” (CD-PH/A-005, Male Attending, Midwest).

Oncologists mention a similar relationship to data and objectivity in how they relate to patients and colleagues. HO-PH/A-003 (Female Attending, Midwest) describes treating a patient who presented with newly diagnosed breast cancer and who was skeptical about the standard treatment protocols in oncology. HO-PH/A-003 presented the case as “we would either swing for the fences and do aggressive chemo, or we talk about hospice and palliation.” The respondent felt the need to present the former as the appropriate decision.

> I was very clear that if we did not start treatment, that she would likely die in the next couple of weeks. And was very, very blunt about it and obviously provided her very objective data that supported that, in terms of her liver numbers getting worse, and she was getting more tired, she had a lot of swelling in her belly, and it was all getting worse, too. And so I tried to present it from a very kind of objective, things that she could relate to, things that she could sense that were getting worse. And that was kind of, you know, again, usually, I tend to build more of a rapport with patients before I get into those heavier situations, but with her we just didn’t have time.

The appeal to data uses a particular discursive regime, wherein empirical data from populations are coordinated to make sense of the experience of the patient. The respondent does this by referring to things the patient can “relate to”, and “things that she could sense that were getting worse.” Relating individual experience to broader population-level data is a powerful tool deployed by clinical specialists in Oncology and Cardiology. CD-PH/A-003 describes that “I think data is powerful. And when you show somebody where they are on the line, and you show them where they could be on the line”.[6] Helping to discover, or helping the patient articulate what their “risk tolerance” is, given their position within the quantification of their present status, and embedding that in a macroscopic vision of patient populations, involves directly communicating with patients. HO-PH/A-004 describes the process of adjudicating between treatment options as “here are risks and these are situations where you have to sit down and spend a considerable amount of time reviewing

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[6] The “line” in question in this anecdote refers to a line graph which relates calculations of lifetime risk for heart attack given age, gender and tests for blood lipids.

the data with the patient, and also involving the patient in the decision-making process."[7]

7.1.12 Talk of Values

The process of bridging the different sets of actors in the patient's case by coordinating clinicians and patients to values is straightforward for HPM clinicians while it requires careful attention to assumptions made by their colleagues. PAL-PH/A-008 noted that "if you think of the equation of the medical information plus the patient's story, often if you bring these together, you come up with a plan of care or a direction to move among in an uncertain situation or among crummy choices as well." The common stance of clinicians in other specialties does not fully address these two features of patients:

> Many physicians ask the question, 'What can I do?' And I think palliative care asks the question, 'what should we do?' When you ask the question that way, you have to consider goals and values, you have to consider the same treatment options. But you have to try to situate them more precisely in a patient's world. If you merely ask the question, 'What can I do?' well, then you're mostly looking at the treatment options. Not necessarily taking into account as much the whole patient story.
>
> (PAL-PH/A-023, Male Attending, Midwest)

The "Discourse of Data", used by oncologists and cardiologists, appeals to the collective authority of the evidence-based paradigm, in which standards of care, generated based on epidemiological studies determine what interventions will be made into a patient's case[8]. It is within evidence-based medicine that the appropriate standards of care are determined for patients, leveraging the normative order of medicine to align patients and other clinicians to a path forward, by posing the question "What can we do?". The "Talk of Values" HPM clinicians use marshals two principles in medicine

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[7] Though some of my respondents from Oncology and Cardiology emphasize the importance of sitting with patients (either literally or figuratively) to figure out what to do given the situation they find themselves in, palliative care respondents mention a general frustration with their colleagues that they are not sufficiently dealing with decision-making in acute situations of need. PAL-PH/A-019 describes that "one of the most upsetting aspects of my work is understanding and coming to grips with the fact that so many patients are not making informed medical decisions, because [other specialists are] not having that more candid discussion".

[8] Standard of care is a technical term in medicine which is "Treatment that is accepted by medical experts as a proper treatment for a certain type of disease and that is widely used by healthcare professionals. Also called best practice, standard medical care, and standard therapy." *Source*: National Cancer Institute

that help to organize treatment: patient autonomy, the recognition that patients remain social agents within the medical system, and shared decision-making, the need for patients to assent to specific treatments and to be an agent in the decision-making process. Both are reactions to the ubiquitous paternalism of medicine in the second half of the 20th century[9] and form a core to what is commonly called "patient-centered care" (Epstein and Street 2011): the need to respect patients as individuals and their right to determine the course of their medical treatment.

Rather than leveraging the rhetorical power of data, HPM clinicians incorporate the underlying constellation of motivations and desires of patients seeking care into their repertoire of talk. HPM clinicians bridge the patient and medical staff by discovering information about patients that is not commonly captured by the instruments of medicine, such as their fears, aspirations, and values, and facilitating the flow of this information between these different stakeholders. By using a mutually intelligible vernacular and highlighting aspects of the case that are important to patients and pertinent to clinicians alike, HPM clinicians coordinate the different sets of actors to both a shared understanding of the patient's present condition and future goals, as well as a means of moving forward. This process begins by collecting "data" from patients. When asked how he approaches learning more about a patient to aid in decision-making PAL-PH/A-013 answered that "it's very much exploratory and listening about where they find data, which is a sciency word, but where they find information to make those decisions?"

Particularly in the treatment of patients with multiple complications, a high symptom burden, or whose illness is becoming particularly dire, the goals of cure or remission are often implausible, and the ways clinicians approach helping patients make decisions about their medical treatment are no longer helpful or appropriate. Despite being ill-equipped to indicate a course of action, clinicians frequently persist in approaching decision-making with the standards and processes that are helpful in routine cases, where evidence unequivocally indicates certain interventions over others. What should be done, in most cases, is that which has the greatest likelihood of extending a patient's longevity. Talk of Values also allows HPM clinicians to reorient different stakeholders in the care

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[9] See Oken (1961) for a contemporary study and Hafferty and Light (1995) for a general overview.

of patients from unrealistic goals, to more directly achievable ones or a “minimally acceptable outcome” (PAL-PH/A-035, Male Attending, West Coast). This tactical retreat in the face of chronic illness, decline, and death, is achieved through focusing on those values patients have and seeking to protect as they decline and die. Such values can be freedom from pain, being home, participating in a family event, or reconciling with a family member. These are actionable and achievable because the medical therapies they involve are oriented to a relative reduction in symptom burden rather than cure or remission. HPM clinicians will seek to reduce the reported intensity of pain, duration, or frequency of pain, or reduce distressing symptoms such as nausea, vomiting, or breathlessness so that patients can engage in meaningful activities as they approach death.

Non-HPM clinicians attribute values to patients, while they attribute the use of data to clinicians as driving their decision-making as to what is both possible and appropriate for patients. The attribution of these features of clinical decisions is sometimes reversed by HPM clinicians: respondents identify the taken for granted values which inform the means and ends other clinicians will advocate their patients to adopt.

> I think we have this idea of, we don’t want to be in pain, and we don’t want to suffer with symptoms. And, and in a way, that’s often true. I mean, most, the majority of people feel that way. But then there’s some people where actually what’s more important to them is that t1 hey have the potential of making it to a certain holiday or seeing the birth of their granddaughter or something. And so for us to sort of impart our values on them may cause us more distress. And so helping understand what really is the patient working for. And if they’re making an informed decision, and this treatment, while it may be causing them more symptoms, or maybe causing them more suffering, may provide them a small chance of potentially achieving this other goal. (PAL-PH/A-019, Female Attending, West Coast)

This quotation and many above display a curious reversal of these attributions: PAL-PH/A-013 mentioned looking for “where patients find data”, and PAL-PH/A-053 (Male Attending, Mountain States) mentioned how the “personal values” of clinicians can influence them to have a “de-escalation agenda”. This is in part contrasted by the unspoken values of HPM clinicians as noted by PAL-PH/A-044: “So often, they can be more aggressive than our field, and we tend to be more on the side of looking more at quality than quantity, which is not always what the patients want, Just to be frank, like, I think we have our bias towards thinking about a life should have more quality than quantity, but for some people they can't, it's hard to see it that way." Where patients find data, who the key decision-makers in their lives are, and what the values that influence the decision-making of other clinicians, are important for understanding a key feature of the work of HPM.

7.2 Discussion and Conclusion

The dominant theoretical framework for understanding professions maintains that expert workers are embedded within systems of competition and mutual definition which create rigid organizational and epistemic boundaries around different groups (Abbott 1988; Freidson [1970] 2007). The puzzling feature of the work of clinicians in HPM is that they advocate for shared authority and for other professionals to participate in their expertise and area of work. Extending the ecological and biological metaphors used by past theorists in the professions literature and sociology broadly helps to explain why these professionals defy the basic need to define exclusive authority over a domain of expertise and carefully guard it.

The field of medicine reveals what is likely to be a more ubiquitous phenomenon: technological and organizational advancement have led to increased internal heterogeneity within professions and to issues of intra-professional collaboration. The problems professions are tasked with offering solutions to require greater and greater specialization within them, and these differences beget specialization in how success is defined for professionals within the same profession. Niche construction, a concept appropriated from ecology, helps to make sense of the relationship of these internally differentiated professions. It can account for the full range of relationships that occur between organisms in a shared environment, from pure harmony and symbiosis to perfect competition and predation. Adopting a more robust ecological account of the interrelations of professions is likely to bear great fruit. Sociologists interested in expert work and the professions, in particular, have too narrowly defined how systems of interrelation develop and structure different professional bodies. It is not the case that HPM is the sole niche constructor in medicine (though it is likely the most unambiguous example of this kind of adaptation) but that niche construction is a more subtle and ubiquitous feature of how professional work is conducted.

Emile Durkheim in the *Division of Labor of Society*, identified the natural differentiation which is consequent to more and more sophisticated systems of production, and further observed their deleterious influences on social solidarity in society. Using Durkheim's distinction between mechanical and organic solidarity as a template, I examine how modern professionals in medicine bridge the wide gulfs in theory and practice internal to their profession. One of the most crucial distinctions that grow between different kinds of professionals within the same profession, is in the normative order which structures their practice. Lawyers define success for themselves in terms of successfully executing or avoiding litigation, while social workers understand success in terms of the advancement of their clients' interests particularly as it relates to making use of the resources of the state. These normative orders are often taken for granted, but if multiple divergent underlying normative paradigms grow within the same domain of work, bridging them becomes of utmost importance to the professionals in that area. Medicine and Hospice and Palliative Medicine afford sociologists the opportunity to better understand the novel dynamics that influence professional structure and behavior, and niche construction provides us with a vernacular to describe them.

CHAPTER 8

THE RELIABLE FAILURES OF MEDICINE: DIVERGENT ONTOLOGIES AND SHARED PRACTICES

Modern medicine is an incredible achievement of science and organization. Doctors and nurses reliably save the imminently dying from acute distress and preserve the sick long past what was formerly possible. Nearly miraculous changes in the prognosis of even very severe cancers are not so uncommon to be unheard of in the personal lives of many individuals. To be certain, we have achieved many great successes in preserving and improving human life from the impartial and rational objectivity of scientific medicine, organized based on principles that oftentimes treat individuals as members of a homogeneous collective of biological systems.

With these reliable successes come reliable failures in the mission of medicine to preserve, sustain, and improve human life. This dissertation was motivated by an engagement with an old question in sociology: what are the unanticipated consequences of purposive human action (Merton 1936)? How do human systems and individual agents, intent on achieving one set of objectives, not only fail to achieve them, but also produce the opposite of the intended consequence? Medicine is one modern institution that is a prime candidate for understanding how purposive action can have unanticipated consequences and ones that are fundamentally at odds with the intended objectives.

Physicians famously take an oath of service, in which they swear to uphold certain idealized values. One common form of this oath includes the line: “May I never see in my patient anything but a fellow human in pain. My goal will be to help, or at least do no harm.” Unfortunately, the medical system, even when it is operating at its peak of efficacy and efficiency, must treat individuals as something other than “humans in pain” and the exigencies of the division of medical labor lead many clinical specialists to view patients as discrete organ systems that require particular interventions to rectify. This tendency to focus on discrete aspects of patients’ cases can become heightened as they grow particularly ill, and there is no legitimate path to restoring them to health, and instead clinical specialists focus on individual and tertiary problems.

Medical personnel in such circumstances fail to uphold the principle to do no harm, as treatments can extend patients' hospitalization, increase their discomfort, or deprive them of the sociality they desire in advance of their death. This isn't the most pressing problem of the modern American medical system but it is one that reliably occurs, and one that seems to be of ubiquitous concern, but so entrenched due to how knowledge and practice are organized as to be insoluble.

8.1 Divergent Ontologies

Many things contribute to the reliable failure of medicine to treat the chronically ill and dying as individuals and to attend to their well-being. As has been noted by past research, economics and the incentives formed by how we pay for healthcare in the US create exigencies that play an important role. But so too do the basic ways in which clinical practice is organized, and how individual clinicians get things done in their work. I identify the ways in which different kinds of clinicians attend to their work as "divergent ontologies". Ontology describes the study of being; what entities exist, their nature, and how they can be categorized and, to some degree, understood. To describe the "ontology" that a particular medical discipline has is to describe the common theory clinicians use to understand what the entities their work is concerned with, their nature, and how they can be understood. In the broadest distinction, between proceduralists and internists, their ontology is differentiated by viewing the entities they work with as either discrete or continuous. Proceduralist ontology describes patients in terms of discrete organ systems and pathologies that can be directly addressed through the manipulation of bodily tissues, while internists have a more holistic view of the patient which requires indirect interventions to address their pathologies. Ontologies can diverge from each other when they begin to have different implications for how specialist clinicians should behave and intervene in patient's cases. Taking the coarsest distinction in medicine, proceduralists will be inclined to recommend procedures, while internists will be more inclined to recommend other less directly invasive forms of therapy.

The most consequential implications for diverging ontologies is not at the coarsest level, as different theories of what entities exist and how they behave and should be addressed between the proceduralists and internists are resolved by establishing universal "standards of care" and "evidence-based practices" that determine the proper protocol for patient treatment. These standards and protocols take decision-making out of the hands of individual clinicians, who then act as nodes in a cybernetic network of data collection and action established through consensus and routine. When these routines break down because they are brought to bear on issues that are no longer easily resolved with their application, individuals again become responsible for making decisions and they must do so without the help of routinized means for determining what ought and ought not be done. But due to the schema and ontologies different specialists have, they will tend to do different things and attend to different features of patients without being able to coordinate their activity.

8.2 Shared Practices

Shared practices indicate the mechanisms that clinicians use to bridge their diverging ontologies, the different theories of patients, and the treatments they have, to get things done. Contrary to the routines that are common in medicine used to handle routine medical encounters, shared practices are largely social, idiosyncratic, and spontaneous results of continued interactions between individuals in different areas that rely upon one another to succeed. They are social as they are the product of interaction, unmediated by the routinized work practices of medicine such as the indication of treatments from standards of care based on diagnostic and prognostic data. Such routines, as mentioned above, largely remove the agency of individuals from the process of determining what is appropriate for patient care. They are idiosyncratic and spontaneous as they are not universal and occur when individuals make the effort to create them. Shared practices, which draw different kinds of expert workers together are not inevitable and largely occur despite the work processes that are typical in medicine.

Shared practices can be the informal calls that clinicians make to one another to ensure that they are on the same page as to what is going on and what ought to be done, or avoiding certain clinicians who have demonstrated an inability in the past to hold to an established plan. Other times, shared practices take the initiative in patient care and orchestrate the interactions that occur between clinicians and patients to ensure that a certain kind of decision is made.

8.3 Implications for Future Research

Several implications for future research can be derived from my work: the first is what future researchers shouldn't do. A great deal of the sociology of medicine which studies similar topics as this work focus upon the use of Advance Care Directives for patients to maintain control over their care as they decline and die. Research has shown that such planning is not effective for changing the kinds of care that individuals receive. The things that determine patient care when patients' cases deviate from those routinized in the medical system are the social relationships that form around patients, not the documents that they have prepared in advance of medical emergencies.

Social scientific work that studies medical decision-making through the study of advanced care planning is missing a crucial and enormous feature of the phenomenon. What happens, how and when is mostly structured by the seemingly inconsequential decisions that clinicians make: to pursue a line of questioning with a patient, or hurry to their next meeting. To catch glimpses of their patient between long periods of examining their electronic health record, or sitting in their room and asking them about how things are going and listening to the long-winded explanations of non-medical but deeply important features of their lives. To better understand what happens when patients are hospitalized, we cannot pay attention to the decisions they have made in the past, but the networks of clinical stakeholders that form around them, the proximate objectives they have, and the means they have at their disposal to coordinate each other to them.

Further, this research indicates that seemingly inconsequential differences between professionals are likely to have consequential influences on what happens in the cases of the clients they are working with. The meanings of words, the salience of particular kinds of data, and the informal social evaluations that individuals orient themselves to are likely to nudge them in different directions, ultimately leading to large differences in outcomes.

Lastly, a few areas are ripe for further study as they are likely to have organizational dynamics similar to medicine which will help us to better understand collaboration. These include architecture, the military, and policing. Architecture and the building professions are unified by a shared goal, constructing habitations and other structures for housing commerce or other important human activities. The regulatory environment, the division of labor, and the status hierarchy within these professions have led to a great deal of internal differentiation, where the meanings of different professionally important tasks are likely different for specific kinds of workers within the profession.

Militaries have long been composed of functionally distinct units: the earliest armies were divided into infantry, cavalry, and archers units and modern armies are more and more defined by functional differentiation that is integral to overall strategic success. Combined or joint warfare, the use of units drawn from different services in a single operation to achieve a strategic objective has its origins in the 18th century, with the rise of professional armies and the projection of force by the major powers of Europe preceding the Seven Years War (Murray 2002).

Scholars of military history have long noted the difficulty of integrating different services (Ferrill 1966); military services not only have different mission priorities due to the modality with which they can engage the enemy and claim territory but also develop a fundamentally different schema for strategy and tactics, while more and more becoming dependent upon one another. The fundamental issue in joint warfare is balancing two distinct enterprises; synergy and specialization, while trying to minimize the deleterious effects on unit cohesion, seen as an essential component of any unit's ability to engage in and sustain combat operations.

8.4 The Art and Science of Clinical Decision Making

Clinical decision-making, particularly in the setting of inpatient care, is both the art and science of diagnosing patients, identifying medical interventions to address their malignancy and side effects, and predicting what the future will look like for them after pursuing, continuing, or forgoing treatment. The science of medicine determines the efficacy of treatments for given illnesses based on randomized controlled trials, clinical surveillance, and the paradigm of evidence-based medicine. But the scientific facts of a case do not clearly indicate what ought to be done, a distinction long noted by philosophers and ethicists (Black 1964; Hume [1739] 2013; MacIntyre 1959; Searle 1964). Equivocal evidence for diverging treatments, small distinctions in predicted outcomes, or questions about how treatments will impinge upon the patient's well-being through side effects complicate the normal decision framework in medicine. What one can do, does not always clearly indicate what one ought to do. But for much of medicine, a single moral principle governs clinical judgment: the patient ought to pursue whichever treatment, based on the greatest evidence, will increase their lifespan for the longest time. In this Maximization Framework, longevity is the primary goal and in acute illness, longevity is won at the expense of short-term discomfort.

The art of medicine is less rigid than the procedural standards set by evidence-based guidelines for best practice and requires that clinicians synthesize the personal life histories of their patients and their families to determine what is "valuable" to them and what treatments will allow them to best pursue their goals. Oftentimes, particularly as malignancies progress and the functional ability of the patient and their prognosis degrades, these goals shift from participating in life as they did before being sick to being able to survive a little longer, and, in the last, die a death as free from pain as possible. The science of medicine is a hard-won epistemic endeavor that has created incredible life-sustaining technologies, and the art of clinical decision-making includes poignant humanism that is unmatched in other modern professional areas. Even though each has an equal part in the ideal model of clinical practice and relating to ill patients, modern academic medicine in hospitals is fairly well dominated by scientistic rhetoric that sometimes eclipses the subtle art of decision-making.

In the treatment of the acutely ill, a variety of clinicians are called upon to render their expert opinion on a specific aspect of the patient's case. Pathologists and radiologists evaluate the state of tumor growth, surgeons determine a patient's ability to survive surgery, oncologists determine the overall treatment protocol, palliative care and pain specialists aid in decision making and lessening symptom burden. Each is expert in their field, and often "sees" the patient in terms of that expertise, but sickness defies the boundaries of medical specialties, and often disagreements about facts and what to do given those facts arise. Though it is true that to decide to do nothing or to fail to decide to do something is in itself a decision, clinicians and their patients are oriented to doing things in the face of illness. How these specialties see their work will naturally influence how they think about the facts of cases and inform the whys and hows they then bring to bear to intervene. As these processes are inherently collaborative, at bottom at least with the patient if not with other medical providers, and mediated through speech and interaction, a careful study of the different rhetorical and interactional strategies they bring to bear will help to clarify the systematic differences and similarities across different domains of medical expertise.

REFERENCES

Abbott, Andrew. 1981. "Status and Status Strain in the Professions." *American Journal of Sociology* 86(4):819–35.

Abbott, Andrew. 1988. *The System of Professions: An Essay on the Division of Expert Labor*. Chicago: University of Chicago Press.

Abbott, Andrew. 2014. *Digital Paper: A Manual for Research and Writing with Library and Internet Materials*. Chicago ; London: The University of Chicago Press.

Abbott, Andrew and Alexandra Hrycak. 1990. "Measuring Resemblance in Sequence Data: An Optimal Matching Analysis of Musicians' Careers." *American Journal of Sociology* 96(1):144–85.

Abel, Emily K. 1986. "The Hospice Movement: Institutionalizing Innovation." *International Journal of Health Services* 16(1):71–85.

Abramson, Corey M. 2017. *The End Game: How Inequality Shapes Our Final Years*. First paperback edition. Cambridge, Massachusetts: Harvard University Press.

Altman, Lawrence. 1970. "A Law Named for Willie Sutton Assists Physicians." *The New York Times*.

American Board of Medical Specialties. 2018. *ABMS Board Certification Report 2017-2018*. Chicago, IL.

American Board of Medical Specialties. 2019. *ABMS Board Certification Report 2018-2019*. Chicago, IL.

American Board of Medical Specialties. 2020. *ABMS Board Certification Report 2019-2020*. Chicago, IL.

American Board of Medical Specialties. 2021. *ABMS Board Certification Report 2020-2021*. Chicago, IL.

American Board of Medical Specialties. 2022. *ABMS Board Certification Report 2021-2022*. Chicago, IL.

Anon. 2000. *To Err Is Human: Building a Safer Health System*. Washington, D.C.: National Academies Press.

Becker, Ernest. 1975. *The Denial of Death*. 1. paperback ed. New York: Free Press Paperbacks.

Becker, Howard S. 1953. “Becoming a Marihuana User.” *American Journal of Sociology* 59(3):235–42.

Becker, Howard, Blanche Geer, Everett C. Hughes, and Anselm L. Strauss. 1961. *Boys in White: Student Culture in Medical School*. Chicago, Illinois: University of Chicago Press.

Bergen, Clara and Tanya Stivers. 2013. “Patient Disclosure of Medical Misdeeds.” *Journal of Health and Social Behavior* 54(2):221–40.

Bettencourt, Luís M. A., David I. Kaiser, Jasleen Kaur, Carlos Castillo-Chávez, and David E. Wojick. 2008. “Population Modeling of the Emergence and Development of Scientific Fields.” *Scientometrics* 75(3):495–518.

Black, Max. 1964. “The Gap Between ”Is” and ”Should”.” *The Philosophical Review* 73(2):165. Retrieved May 24, 2023 (`https://www.jstor.org/stable/2183334`).

Bloom, Samuel W. 2002. *The Word as Scalpel: A History of Medical Sociology*. Oxford: Oxford University Press.

Boateng, Godfred O. and Tracey L. Adams. 2016. “‘Drop Dead … I Need Your Job’: An Exploratory Study of Intra-Professional Conflict Amongst Nurses in Two Ontario Cities.” *Social Science & Medicine* 155:35–42.

Boden, Deirdre. 1997. “Temporal Frames: Time and Talk in Organizations.” *Time & Society* 6(1):5–33.

Bosk, Charles L. 1979. *Forgive and Remember: Managing Medical Failure*. 2nd ed. Chicago: University of Chicago Press.

Brotherton, Sarah E., Frank A. Simon, and Sylvia I. Etzel. 2002. “US Graduate Medical Education, 2001-2002: Changing Dynamics.” *JAMA* 288(9):1073.

Bucher, Rue and Anselm Strauss. 1961. “Professions in Process.” *American Journal of Sociology* 66(4):325–34.

Burt, Ronald S. 2004. “Structural Holes and Good Ideas.” *American Journal of Sociology* 110(2):349–99.

Camus, Albert. [1942] 1991. *The Myth of Sisyphus and Other Essays*. 1st Vintage international ed. New York: Vintage Books.

Carlile, Paul R. 2002. “A Pragmatic View of Knowledge and Boundaries: Boundary Objects in New Product Development.” *Organization Science* 13(4):442–55.

Carlile, Paul R. 2004. “Transferring, Translating, and Transforming: An Integrative Framework for Managing Knowledge Across Boundaries." *Organization Science* 15(5):555–68.

Cassell, E. J. 1982. "The Nature of Suffering and the Goals of Medicine." *The New England Journal of Medicine* 306(11):639–45.

Centor, Robert M. and Benjamin B. Taylor. 2009. "Do Hospitalists Improve Quality?" *Archives of Internal Medicine* 169(15).

Chandler, Alfred Dupont. [1993] 2002. *The Visible Hand: The Managerial Revolution in American Business*. 16. print. Cambridge, Mass.: Belknap Press of Harvard Univ. Press.

Charmaz, Kathy. 2006. *Constructing Grounded Theory*. London ; Thousand Oaks, Calif: Sage Publications.

Christakis, Nicholas A. 1994. "Change in Self-Definition from Specialist to Generalist in a National Sample of Physicians." *Annals of Internal Medicine* 121(9):669.

Christakis, Nicholas A. 2001. *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago: University of Chicago.

Christensen, Garret S., Jeremy Freese, and Edward Miguel. 2019. *Transparent and Reproducible Social Science Research: How to Do Open Science*. Oakland, California: University of California Press.

Clarke, Adele E. and Janet Shim. 2011. "Medicalization and Biomedicalization Revisited: Technoscience and Transformations of Health, Illness and American Medicine." Pp. 173–99 in *Handbook of the Sociology of Health, Illness, and Healing*, edited by B. A. Pescosolido, J. K. Martin, J. D. McLeod, and A. Rogers. New York, NY: Springer New York.

Collins, H. M. 1998. "The Meaning of Data: Open and Closed Evidential Cultures in the Search for Gravitational Waves." *American Journal of Sociology* 104(2):293–338.

Comer, Clémentine, Lucile Benoit, Florence Hellec, and Nicolas Fortané. 2023. "Demedication Without Demedicalization? Redefining the Medical and Economic Boundaries of Veterinary Professional Jurisdiction." *Social Science & Medicine* 116109.

Conn, Lesley Gotlib et al. 2016. "Communication and Culture in the Surgical Intensive Care Unit: Boundary Production and the Improvement of Patient Care." *Qualitative Health Research* 26(7):895–906.

Connors, Alfred F. 1995. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." *JAMA* 274(20):1591.

Conrad, Peter and Joseph W. Schneider. 1992. *Deviance and Medicalization: From Badness to*

Sickness: With a New Afterword by the Authors. Expanded ed. Philadelphia: Temple University Press.

Cross, Sarah H. and Haider J. Warraich. 2019. "Changes in the Place of Death in the United States." *New England Journal of Medicine* 381(24):2369–70.

DiBenigno, Julia and Katherine C. Kellogg. 2014. "Beyond Occupational Differences: The Importance of Cross-cutting Demographics and Dyadic Toolkits for Collaboration in a U.S. Hospital." *Administrative Science Quarterly* 59(3):375–408.

Duneier, Mitchell and Ovie Carter. 2001. *Sidewalk*. 1st paperback edition. New York: Farrar, Straus and Giroux.

Durkheim, Émile. [1893] 2008. *The Division of Labor in Society*. 13. [Repr.]. New York: Free Press.

Elder, Timothy B. and Austin C. Kozlowski. 2023. *Status and Subfield: The Distribution of Sociological Specializations Across Departments*. SocArXiv.

Elias, Norbert. 1985. *The Loneliness of the Dying*. New York: Continuum.

Elton, Charles. 1927. *Animal Ecology*. London: Sidgwick and Jackson.

Elwyn, Glyn et al. 2012. "Shared Decision Making: A Model for Clinical Practice." *Journal of General Internal Medicine* 27(10):1361–67.

Emanuel, Ezekiel J. and Steven D. Pearson. 2012. "Physician Autonomy and Health Care Reform." *JAMA* 307(4).

Engel, Gloria V. 1970. "Professional Autonomy and Bureaucratic Organization." *Administrative Science Quarterly* 15(1):12. Retrieved September 8, 2023 (`https://www.jstor.org/stable/2391182`).

Epstein, R. M. and R. L. Street. 2011. "The Values and Value of Patient-Centered Care." *The Annals of Family Medicine* 9(2):100–103.

Epstein, Ronald M. and Robert E. Gramling. 2013. "What Is Shared in Shared Decision Making? Complex Decisions When the Evidence Is Unclear." *Medical Care Research and Review* 70(1_suppl):94S–112S.

Eyal, Gil. 2013. "For a Sociology of Expertise: The Social Origins of the Autism Epidemic." *American Journal of Sociology* 118(4):863–907.

Fairhurst, Gail T. and Linda Putnam. 2004. "Organizations as Discursive Constructions." *Communication Theory* 14(1):5–26.

Ferrill, Arther. 1966. “Herodotus and the Strategy and Tactics of the Invasion of Xerxes.” *The American Historical Review* 72(1):102. Retrieved September 13, 2023 (`https://www.jstor.org/stable/10.2307/1848172`).

Fleck, Ludwik. [1935] 2008. *Genesis and Development of a Scientific Fact*. Repr. 11. Aufl. Chicago [u.a]: Univ. of Chicago Press.

Freidson, Eliot. [1970] 2007. *Professional Dominance: The Social Structure of Medical Care*. 1st pbk. ed. New Brunswick, NJ: Aldine Transaction.

Freidson, Eliot. 1984a. “The Changing Nature of Professional Control.” *Annual Review of Sociology* 10(1):1–20.

Freidson, Eliot. 1984b. “The Changing Nature of Professional Control.” *Annual Review of Sociology* 10:1–20. Retrieved September 8, 2023 (`https://www.jstor.org/stable/2083165`).

Freidson, Eliot. 1988. *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. University of Chicago Press ed. Chicago: University of Chicago Press.

Frickel, Scott and Neil Gross. 2005. “A General Theory of Scientific/Intellectual Movements.” *American Sociological Review* 70(2):204–32.

Gapenski, Louis C. and Kristin L. Reiter. 2016. *Healthcare Finance: An Introduction to Accounting & Financial Management*. Sixth edition. Chicago, Illinois : Arlington, Virginia: Health Administration Press ; Association of University Programs in Health Administration.

Ghazoul, Jaboury. 2020. *Ecology: A Very Short Introduction*. New York: OUP Oxford.

Gibson, David R. 2008a. “Doing Time in Space: Line-Joining Rules and Resultant Morphologies.” *Sociological Forum* 23(2):207–33.

Gibson, David R. 2008b. “How the Outside Gets In: Modeling Conversational Permeation.” *Annual Review of Sociology* 34(1):359–84.

Gibson, David R. 2011. “Speaking of the Future: Contentious Narration During the Cuban Missile Crisis.” *Qualitative Sociology* 34(4):503–22.

Gibson, David R. 2012. *Talk at the Brink: Deliberation and Decision During the Cuban Missile Crisis*. Princeton: Princeton University Press.

Goodwin, Dawn. 2021. “Describing Failures of Healthcare: A Study in the Sociology of Knowledge.” *Qualitative Research* 21(3):324–40.

Grant, Don, Alfonso Morales, and Jeffrey J. Sallaz. 2009. “Pathways to Meaning: A New Approach to Studying Emotions at Work.” *American Journal of Sociology* 115(2):327–64.

Greenberg, Jeff, Tom Pyszczynski, and Sheldon Solomon. 1986. "The Causes and Consequences of a Need for Self-Esteem: A Terror Management Theory." Pp. 189–212 in *Public Self and Private Self*, edited by R. F. Baumeister. New York, NY: Springer New York.

Gunten, Charles F. Von, Paul A. Sloan, Russell K. Portenoy, and Ronald S. Schonwetter. 2000. "Physician Board Certification in Hospice and Palliative Medicine." *Journal of Palliative Medicine* 3(4):441–47.

Hafferty, Frederic W. 1991. *Into the Valley: Death and the Socialization of Medical Students*. Yale University Press. Retrieved July 21, 2021 (`https://www.jstor.org/stable/10.2307/j.ctt211qv9j`).

Hafferty, Frederic W. and Donald W. Light. 1995. "Professional Dynamics and the Changing Nature of Medical Work." *Journal of Health and Social Behavior* 35:132. Retrieved March 12, 2021 (`https://www.jstor.org/stable/2626961`).

Hallenbeck, James. 2009. "Cutting Through Yesterday's Understanding." *Journal of Palliative Medicine* 12(8):683–85.

Healy, Kieran. 2020. "The Plain Person's Guide to Plain Text Social Science."

Heaton, Janet. 2022. "'*Pseudonyms Are Used Throughout': A Footnote, Unpacked." *Qualitative Inquiry* 28(1):123–32.

Heimer, Carol Anne and Lisa R. Staffen. 1998. *For the Sake of the Children: The Social Organization of Responsibility in the Hospital and the Home*. Chicago, Ill: The University of Chicago Press.

Heritage, John and Douglas W. Maynard. 2006. "Problems and Prospects in the Study of Physician-Patient Interaction: 30 Years of Research." *Annual Review of Sociology* 32(1):351–74.

Hertzler, Arthur E. 1938. *The Horse and Buggy Doctor*. New York & London: Harper & Brothers.

Hogle, Linda F. 1995. "Standardization Across Non-standard Domains: The Case of Organ Procurement." *Science, Technology, & Human Values* 20(4):482–500.

Hoover, Jeffrey P. and Scott K. Robinson. 2007. "Retaliatory Mafia Behavior by a Parasitic Cowbird Favors Host Acceptance of Parasitic Eggs." *Proceedings of the National Academy of Sciences* 104(11):4479–83.

Hughes, Everett C. 1951. "Mistakes at Work." *The Canadian Journal of Economics and Political Science* 17(3):320–27.

Hume, David. [1739] 2013. *A Treatise of Human Nature*. New York: Barnes & Noble.

Hunt, T. 1860. “Palliative Treatment of Cancer.” *BMJ* s4-1(160):47–48.

Jenkins, Tania M., Kelly Underman, Alexandra H. Vinson, Lauren D. Olsen, and Laura E. Hirshfield. 2021. “The Resurgence of Medical Education in Sociology: A Return to Our Roots and an Agenda for the Future.” *Journal of Health and Social Behavior* 62(3):255–70.

Jerolmack, Colin. 2013. *The Global Pigeon*. Chicago: The University of Chicago Press.

Jerolmack, Colin. 2021. *Up to Heaven and down to Hell: Fracking, Freedom, and Community in an American Town*. Princeton, New Jersey: Princeton University Press.

Katz, Jack. 2022. “The Sociological Power of Methodological Rhetoric.” *Sociological Methods & Research* 004912412211404.

Kellehear, Allan. 1984. “Are We a ‘Death-Denying’ Society? A Sociological Review.” *Social Science & Medicine* 18(9):713–21.

Kelley, K. 1995. “The Patient Self-Determination Act. A Matter of Life and Death.” *Physician Assistant (American Academy of Physician Assistants)* 19(3):49, 53–56, 59–60 passim.

Kellogg, Katherine C. 2014. “Brokerage Professions and Implementing Reform in an Age of Experts.” *American Sociological Review* 79(5):912–41.

Kendall, Patricia L., Robert K. Merton, and George G. Reader, eds. [1957] 2014. *The Student-Physician: Introductory Studies in the Sociology of Medical Education*. Reprint 2014. Cambridge, MA: Harvard University Press.

Kroth, Philip J. et al. 2019. “Association of Electronic Health Record Design and Use Factors With Clinician Stress and Burnout.” *JAMA Network Open* 2(8):e199609.

Kübler-Ross, Elisabeth. [1969] 1978. *On Death and Dying*. 13. pr. New York: Macmillan Publ. Co.

Lamont, Michèle. 1992. *Money, Morals, and Manners: The Culture of the French and American Upper-Middle Class*. Chicago: University of Chicago Press.

Lamont, Michèle and Ann Swidler. 2014. “Methodological Pluralism and the Possibilities and Limits of Interviewing.” *Qualitative Sociology* 37(2):153–71.

Landrigan, Christopher P. et al. 2010. “Temporal Trends in Rates of Patient Harm Resulting from Medical Care.” *New England Journal of Medicine* 363(22):2124–34.

Latour, Bruno. 1999. *Pandora’s Hope: Essays on the Reality of Science Studies*. Cambridge, Mass: Harvard University Press.

Laumann, Edward O. and John P. Heinz. 1977. “Specialization and Prestige in the Legal Profession: The Structure of Deference.” *American Bar Foundation Research Journal* 2(1):155–216.

Leicht, Kevin T. and Mary L. Fennell. 1997. “The Changing Organizational Context of Professional Work.” *Annual Review of Sociology* 23(1):215–31.

Lewis, Milton James. 2007. *Medicine and Care of the Dying: A Modern History*. Oxford ; New York: Oxford University Press.

Lewontin, Richard. 1982. “Organism and Environment.” in *Learning, Development and Culture*. New York: Wiley.

Lieberson, Stanley and Freda B. Lynn. 2002. “Barking up the Wrong Branch: Scientific Alternatives to the Current Model of Sociological Science.” *Annual Review of Sociology* 28:1–19.

Light, D. W. 1991. “Professionalism as a Countervailing Power.” *Journal of Health Politics, Policy and Law* 16(3):499–506.

Light, Donald W. 2010. “Health-Care Professions, Markets, and Countervailing Powers.” Pp. 270–89 in *Handbook of medical sociology, sixth edition*. Vanderbilt University Press. Retrieved July 21, 2023 (`https://www.jstor.org/stable/j.ctv16h2n9s.19`).

Livne, Roi. 2019. *Values at the End of Life: The Logic of Palliative Care*. Cambridge, Massachusetts: Harvard University Press.

Loscalzo, Matthew J. 2008. “Palliative Care: An Historical Perspective.” *Hematology* 2008(1):465–65.

Lucas, Samuel R. 2014. “Beyond the Existence Proof: Ontological Conditions, Epistemological Implications, and in-Depth Interview Research.” *Quality & Quantity* 48(1):387–408.

Lutfey, Karen E. and Jeremy Freese. 2007. “Ambiguities of Chronic Illness Management and Challenges to the Medical Error Paradigm.” *Social Science & Medicine* 64(2):314–25.

Lutz, Andrea Giovanni. 2019. “Patients’ Autonomy as a Negotiated Order: An Ethnographic Perspective on the Clinical Management of Childhood Obesity.” *Sociology of Health & Illness* 41(4):772–88.

Lutz, Stephen. 2011. “The History of Hospice and Palliative Care.” *Current Problems in Cancer* 35(6):304–9.

Lynn, Joanne et al. 2000. “Ineffectiveness of the SUPPORT Intervention: Review of Explanations.” *Journal of the American Geriatrics Society* 48(S1):S206–13.

MacIntyre, A. C. 1959. “Hume on ”Is” and ”Ought”.” *The Philosophical Review* 68(4):451. Retrieved May 24, 2023 (`https://www.jstor.org/stable/2182491`).

Martin, John Levi. 2011. *The Explanation of Social Action*. Oxford ; New York: Oxford University Press.

Martin, John Levi. 2017. *Thinking Through Methods: A Social Science Primer*. Chicago ; London: The University of Chicago.

Martin, John Levi. 2018. *Thinking Through Statistics*. Chicago ; London: The University of Chicago Press.

Martin, John Levi and Alessandra Lembo. 2021. "On the Other Side of Interests: The Rise of Values and Their Transformation into Disinterest." *Handbook of Classical Sociological Theory* 671–92.

Marx, Karl. [1867] 1981. *Capital: a critique of political economy*. London ; New York, N.Y: Penguin Books in association with New Left Review.

Maynard, Douglas W. 1991. "Interaction and Asymmetry in Clinical Discourse." *American Journal of Sociology* 97(2):448–95. Retrieved July 11, 2023 (`https://www.jstor.org/stable/2781383`).

Menchik, Daniel A. 2020. "Authority Beyond Institutions: The Expert's Multivocal Process of Gaining and Sustaining Authoritativeness." *American Journal of Cultural Sociology*.

Menchik, Daniel A. 2021. *Managing Medical Authority: How Doctors Compete for Status and Create Knowledge*. Princeton: Princeton University Press.

Merton, R. K. 1940. "Bureaucratic Structure and Personality." *Social Forces* 18(4):560–68.

Merton, Robert K. 1936. "The Unanticipated Consequences of Purposive Social Action." *American Sociological Review* 1(6):894. Retrieved December 3, 2020 (`https://www.jstor.org/stable/2084615`).

Meyer, John W. and Brian Rowan. 1977. "Institutionalized Organizations: Formal Structure as Myth and Ceremony." *American Journal of Sociology* 83(2):340–63.

Miller, Shari E. 2013. "Professional Socialization: A Bridge Between the Explicit and Implicit Curricula." *Journal of Social Work Education* 49(3):368–86.

Mishler, Elliot G. 1997. "The Struggle Between the Voice of Medicine and the Voice of the Lifeworld." *The Sociology of Health and Illness* 295–307.

Moorhead, Richard. 2010. "Lawyer Specialization-Managing the Professional Paradox: LAWYER SPECIALIZATION-MANAGING." *Law & Policy* 32(2):226–59.

Morrison, R. Sean. 2008. “Cost Savings Associated With US Hospital Palliative Care Consultation Programs.” *Archives of Internal Medicine* 168(16):1783.

Mueller, Ulrich G. and Nicole Gerardo. 2002. “Fungus-Farming Insects: Multiple Origins and Diverse Evolutionary Histories.” *Proceedings of the National Academy of Sciences* 99(24):15247–49.

Murray, Williamson. 2002. “The Evolution of Joint Warfare.” *Joint Force Quarterly* 30–38.

Muzio, Daniel, David M. Brock, and Roy Suddaby. 2013. “Professions and Institutional Change: Towards an Institutionalist Sociology of the Professions.” *Journal of Management Studies* 50(5):699–721.

Nancarrow, Susan A. and Alan M. Borthwick. 2005. “Dynamic Professional Boundaries in the Healthcare Workforce.” *Sociology of Health and Illness* 27(7):897–919.

Oddi, Lorys F. and Virginia R. Cassidy. 1998. “The Message of SUPPORT: Change Is Long Overdue.” *Journal of Professional Nursing* 14(3):165–74.

Odling-Smee, F. John, Kevin N. Laland, and Marcus W. Feldman. 1996. “Niche Construction.” *The American Naturalist* 147(4):641–48.

Odling-Smee, F. John, Kevin N. Laland, and Marcus W. Feldman. 2003. *Niche Construction: The Neglected Process in Evolution*. Princeton: Princeton University Press.

Oh, Hyeyoung. 2014. “Hospital Consultations and Jurisdiction over Patients: Consequences for the Medical Profession.” *Sociology of Health & Illness* 36(4):580–95.

Oken, Donald. 1961. “What to Tell Cancer Patients: A Study of Medical Attitudes.” *JAMA* 175(13):1120.

Ooi, Kanny. 2020. “The Pitfalls of Overtreatment: Why More Care Is Not Necessarily Beneficial.” *Asian Bioethics Review* 12(4):399–417.

Open Science Collaboration. 2015. “Estimating the Reproducibility of Psychological Science.” *Science* 349(6251):aac4716.

Open Society Institute. 1998. *Project on Death in America: Report of Activities, July 1994 - December 1997*. New York.

Palojoki, Sari, Matti Mäkelä, Lasse Lehtonen, and Kaija Saranto. 2017. “An Analysis of Electronic Health Record–Related Patient Safety Incidents.” *Health Informatics Journal* 23(2):134–45.

Parsons, Talcott. 1939. “The Professions and Social Structure.” *Social Forces* 17(4):457–67.

Parsons, Talcott. 1951. *The Social System: The Major Exposition of the Author's Conceptual Scheme for the Analysis of the Dynamics, of the Social System*. New York: The Free Press.

Parsons, Talcott. 1975. "The Sick Role and the Role of the Physician Reconsidered." *Milbank Memorial Fund Quarterly* 53(3):257–78.

Pescosolido, Bernice. 2013. "Theories and the Rise and Fall of the Medical Profession." Pp. 173–94 in *Medical Sociology on the Move*. Dordrecht: Springer Netherlands.

Priem, Jason, Heather Piwowar, and Richard Orr. 2022. "OpenAlex: A Fully-Open Index of Scholarly Works, Authors, Venues, Institutions, and Concepts."

Prior, Lindsay. 2003. "Belief, Knowledge and Expertise: The Emergence of the Lay Expert in Medical Sociology: Belief, Knowledge and Expertise." *Sociology of Health & Illness* 25(3):41–57.

Pugh, Allison J. 2013. "What Good Are Interviews for Thinking about Culture? Demystifying Interpretive Analysis." *American Journal of Cultural Sociology* 1(1):42–68.

Roggenkamp, Susan D. and Kenneth R. White. 2001. "Is Hospital Case Management a Rationalized Myth?" *Social Science & Medicine* 53(8):1057–66.

Rubel, Robert C. 2001. "Principles of Jointness." *Joint Force Quarterly* 45–49.

Rytand, David. 1980. "Sutton's or Dock's Law?" *New England Journal of Medicine* 302(17):972–72.

Sander, Levin. 1990. "Patient Self Determination Act."

Sanders, Tom and Stephen Harrison. 2008. "Professional Legitimacy Claims in the Multidisciplinary Workplace: The Case of Heart Failure Care." *Sociology of Health & Illness* 30(2):289–308.

Schrepel, Caitlin et al. 2022. "Who's on Your Team? Specialty Identity and Inter-Physician Conflict During Admissions." *Medical Education* 56(6):625–33.

Searle, John R. 1964. "How to Derive "Ought" From "Is"." *The Philosophical Review* 73(1):43. Retrieved May 24, 2023 (`https://www.jstor.org/stable/2183201`).

Shannon, C. E. 1948. "A Mathematical Theory of Communication." *Bell System Technical Journal* 27(3):379–423.

Shapiro, Susan P. 2019. *Speaking for the Dying: Life-and-Death Decisions in Intensive Care*. Chicago: The University of Chicago Press.

Sheridan, Paige E. et al. 2021. "Cost Savings Associated With Palliative Care Among Older Adults With Advanced Cancer." *American Journal of Hospice and Palliative Medicine®* 38(10):1250–57.

Shim, Janet K. 2010. "Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment." *Journal of Health and Social Behavior* 51(1):1–15.

Silverman, David and Brian Torode. 1980. *The Material Word: Some Theories of Language and Its Limits*. London ; Boston: Routledge & Kegan Paul.

Simmel, Georg. 1964. *The Sociology of Georg Simmel*. edited by K. H. Wolff. New York: Free Pr. [u.a.].

Simon, H. A. 1956. "Rational Choice and the Structure of the Environment." *Psychological Review* 63(2):129–38.

Singh, Sarguni et al. 2017. "Characterizing the Nature of Scan Results Discussions: Insights Into Why Patients Misunderstand Their Prognosis." *Journal of Oncology Practice* 13(3):e231–39.

Sinsky, Christine et al. 2016. "Allocation of Physician Time in Ambulatory Practice: A Time and Motion Study in 4 Specialties." *Annals of Internal Medicine* 165(11):753.

Slomka, Jacquelyn. 1992. "The Negotiation of Death: Clinical Decision Making at the End of Life." *Social Science & Medicine* 35(3):251–59.

Small, Mario Luis and Jessica McCrory Calarco. 2022. *Qualitative Literacy: A Guide to Evaluating Ethnographic and Interview Research*. Oakland, California: University of California Press.

Stacey, Clare Louise, Stuart Henderson, Kelly R. MacArthur, and Daniel Dohan. 2009. "Demanding Patient or Demanding Encounter?: A Case Study of a Cancer Clinic." *Social Science & Medicine* 69(5):729–37.

Star, Susan Leigh and James R. Griesemer. 1989. "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39." *Social Studies of Science* 19(3):387–420.

Stark, Fortney Pete. 1982. "Tax Equity and Fiscal Responsibility Act of 1982."

Starks, Helene, Song Wang, Stuart Farber, Darrell A. Owens, and J. Randall Curtis. 2013. "Cost Savings Vary by Length of Stay for Inpatients Receiving Palliative Care Consultation Services." *Journal of Palliative Medicine* 16(10):1215–20.

Starr, Paul. [1982] 2017. *The Social Transformation of American Medicine*. Updated edition. New

York: Basic Books.

Steinberg, Marc W. 1999. “The Talk and Back Talk of Collective Action: A Dialogic Analysis of Repertoires of Discourse Among Nineteenth-Century English Cotton Spinners.” *American Journal of Sociology* 105(3):736–80.

Stichweh, Rudolf. 1997. “Professions in Modern Society.” *International Review of Sociology* 7(1):95–102.

Stivers, Tanya and Rose McCabe. 2021. “Dueling in the Clinic: When Patients and Providers Disagree about Healthcare Recommendations.” *Social Science & Medicine* 290:114140.

Stivers, Tanya and Stefan Timmermans. 2020. “Medical Authority Under Siege: How Clinicians Transform Patient Resistance into Acceptance.” *Journal of Health and Social Behavior* 61(1):60–78.

Syme, Ann and Anne Bruce. 2009. “Hospice and Palliative Care: What Unites Us, What Divides Us?” *Journal of Hospice & Palliative Nursing* 11(1):19–24.

Tang, P. C., J. S. Ash, D. W. Bates, J. M. Overhage, and D. Z. Sands. 2006. “Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption.” *Journal of the American Medical Informatics Association* 13(2):121–26.

Tate, Alexandra. 2019. “Treatment Recommendations in Oncology Visits: Implications for Patient Agency and Physician Authority.” *Health Communication* 34(13):1597–607.

Tate, Alexandra. 2020. “Invoking Death: How Oncologists Discuss a Deadly Outcome.” *Social Science & Medicine* 246:112672.

Tate, Alexandra and B. J. Rimel. 2020. “The Duality of Option-Listing in Cancer Care.” *Patient Education and Counseling* 103(1):71–76.

Tavory, Iddo and Stefan Timmermans. 2014. *Abductive Analysis: Theorizing Qualitative Research*. Chicago: The University of Chicago Press.

Temel, Jennifer S. et al. 2010. “Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer.” *New England Journal of Medicine* 363(8):733–42.

Timmermans, Stefan. 1999. *Sudden Death and the Myth of CPR*. Philadelphia: Temple University Press.

Timmermans, Stefan. 2020. “The Engaged Patient: The Relevance of Patient–Physician Communication for Twenty-First-Century Health.” *Journal of Health and Social Behavior* 61(3):259–73.

Timmermans, Stefan and Marc Berg. 2010. *The Gold Standard: The Challenge Of Evidence-Based Medicine.* Philadelphia: Temple University Press.

Timmermans, Stefan and Emily S. Kolker. 2004. "Evidence-Based Medicine and the Reconfiguration of Medical Knowledge." *Journal of Health and Social Behavior* 45 Suppl:177–93.

Timmermans, Stefan and Hyeyoung Oh. 2010. "The Continued Social Transformation of the Medical Profession." *Journal of Health and Social Behavior* 51(1_suppl):S94–106.

Toerien, Merran, Markus Reuber, Rebecca Shaw, and Roderick Duncan. 2018. "Generating the Perception of Choice: The Remarkable Malleability of Option-Listing." *Sociology of Health & Illness* 40(7):1250–67.

Toerien, Merran, Rebecca Shaw, and Markus Reuber. 2013. "Initiating Decision-Making in Neurology Consultations: 'Recommending' Versus 'Option-Listing' and the Implications for Medical Authority: Initiating Decision-Making in Neurology Consultations." *Sociology of Health & Illness* 35(6):873–90.

Trotter, LaTonya. 2019. "'I'm Not a Doctor. I'm a Nurse': Reparative Boundary-Work in Nurse Practitioner Education." *Social Currents* 6(2):105–20.

Turner, J. Scott. 2000. *The Extended Organism: The Physiology of Animal-Built Structures*. Cambridge, Mass: Harvard University Press.

Vale, Mira D. and Mary-Jo DelVecchio Good. 2020. "Transcending the Profession: Psychiatric Patients' Experiences of Trust in Clinicians." *Journal of Health and Social Behavior* 61(2):208–22.

Weiss, Robert Stuart. 1995. *Learning from Strangers: The Art and Method of Qualitative Interview Studies*. First Free Press paperback ed. New York: Free Press.

White, Heather L. and Richard H. Glazier. 2011. "Do Hospitalist Physicians Improve the Quality of Inpatient Care Delivery? A Systematic Review of Process, Efficiency and Outcome Measures." *BMC Medicine* 9(1):58.

Zetka, James R. 2011. "Establishing Specialty Jurisdictions in Medicine: The Case of American Obstetrics and Gynaecology." *Sociology of Health & Illness* 33(6):837–52.

Zimmermann, Camilla and Gary Rodin. 2004. "The Denial of Death Thesis: Sociological Critique and Implications for Palliative Care." *Palliative Medicine* 18(2):121–28.

GLOSSARY

Accreditation Council for Graduate Medical Education (ACGME) The organization with the responsibility of accrediting medical education programs in the US, including resident and fellowship programs.

Advance Care Planning Discussions with patients and/or their representatives about the goals and desired direction of the patient's care, particularly end-of-life care, if the patient is or becomes incompetent to make decisions.

Advance Practice Nurse (APN) A nurse who has completed post-graduate training and who has more substantial responsibilities, able to prescribe medications(? need to confirm).

Ambulatory Ability to walk, either with or without assistance.

Aspiration A condition in which food, liquids, saliva, or vomit is breathed into the airways and which can impede breathing, causing death.

Attending Attending physicians are the class of physicians who supervise the overall care of patients and the work of fellows, residents and medical students. Attendings are considered to have the final authority and responsibility for patients. They may further be affiliated with a teaching institution, as is in the case with university-affiliated hospitals.

Curative Treatment These are medical interventions that aim at curing an individual of their underlying illness and bringing them back to full health, or as full as is possible. Curative therapies are identified as separate as palliative interventions which aim to ensure an individual's well-being in the course of receiving care. The difference between curative and palliative interventions is quite complicated as in certain circumstances they can appear quite similar. There are palliative surgeries and palliative radiological therapies, which appear similar to curative therapies. The one place where palliative therapies and curative therapies are clearly distinct and mutually exclusive is in hospice care, where an individual has purposively and expressly forgone curative therapies and only receives palliative therapies or comfort measures.

Cachexia Loss of body weight and muscle mass, and weakness that may occur in patients with cancer, AIDS, or other chronic diseases.

Do Not Intubate Order (DNI) Is a legal order indicating that a patient does not want to receive intubation where a tube is placed in their airway to assist in mechanical ventilation.

Do Not Resuscitate Order (DNR) Is a legal order indicating that a patient does not want to receive cardiopulmonary resuscitation (CPR) if their heart stops beating.

Fellow A fellow is an attending physician who has completed their residency and is now completing a fellowship, an advanced form of medical curriculum similar to residency but geared toward further specialization in one area of medicine. The standard fellowship for palliative care providers in the US is 1 year but other specialties might have longer fellowships.

Full Code A patient is considered Full Code when they are to be given all life-sustaining measures in case their heart stops beating, or they stop breathing. In most hospitals in the US, Full Code is the default code status of all patients unless otherwise contraindicated by a DNR order or a Physician Orders for Life-Sustaining Treatments.

Functional Status the level of activities performed by an individual to realize needs of daily living in many aspects of life including physical, psychological, social, spiritual, intellectual, and roles.

Futility A controversial term that has its origins in legal and ethical conflicts over end-of-life care in the US in the late 80s and early 90s. Futility is meant to identify situations in which curative medical interventions will have no efficacy, and more generally could identify any medical intervention which has no hope of achieving its stated or implicit goal.

Physiological Futility: Is where a treatment is futile on the grounds that there is no appropriate physiological process to intervene on (such as performing CPR on someone with no head).

Quantitative Futility: This form of futility focuses on the probability of achieving the intended goal of a therapy. Closely related to physiological futility it requires the mounting of clinical evidence and establishing a definitive threshold above which a therapy could be considered efficacious.

Qualitative Futility: Shifts the focus from the achievement of a goal to the quality of potential benefits for a patient. This is naturally variable and requires an understanding of patient goals and preferences. A qualitatively futile treatment for one person might be totally efficacious for another it is considered such.

Imminent Demise Futility: These are cases where a person is quickly approaching death and is already in the terminal phase, and where the treatment has no short-term benefit to the patient in advance of their irreversible advance to death.

Gastrostomy Tube (G-Tube) A tube inserted through the belly that brings nutrition directly to the stomach.

Glossary A list of words and their definitions.

Hospice and Palliative Medicine ABMS recognized sub-specialty which practices palliative care.

Hospice a class of palliative care, with a particular population of patients who have received a terminal prognosis and who have abdicated any desire for curative treatments. Hospice patients will exclusively receive comfort care and forgo any treatment that intends to cure them of their underlying disease.

Hospitalist See *Hospital Medicine*

Hospital Medicine A medical specialty that focuses on the care of hospitalized patients. These doctors work solely in the inpatient setting.

Intensive Care Unit (ICU) A specialized department in hospitals dedicated to providing comprehensive and continuous care for patients who are critically ill or have life-threatening conditions. ICUs are equipped with advanced medical technology and staffed by a team of highly trained healthcare professionals, including physicians, nurses, and therapists, who specialize in critical care. The unit is designed to closely monitor, treat, and manage patients with severe or unstable health statuses, ensuring immediate and intensive treatment interventions.

Intubation A procedure involving placement of a tube into a hollow organ, particularly the trachea through the mouth or nose in order to provide a patient with oxygen and anesthesia. A means of delivering life-sustaining treatment.

Non-Beneficial Treatment See Futility.

Nasogastric (NG) Tube A type of medical catheter that's inserted through your nose into your stomach. It's used for limited periods to deliver substances such as food or medications to your stomach or to draw substances out.

Physician Orders for Life-Sustaining Treatment (POLST) Legally binding document which stipulates the forms and intensity of treatment a patient receives. Similar to an Advance Directive but differentiated by the specificity of these orders compared to advance directives.

Remission A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer still may be in the body.

Resident A resident is a physician in advanced training post medical school, typically conducted in a hospital or clinic. Residents collectively constitute what is referred to as "house staff" or the primary body of physician health care providers rendering care to patients. Residents are supervised in their training by Attendings, and are specializing in one branch of medicine. First year Residents are referred to as Interns and are Supervised by second and third year residents, while these residents are themselves supervised by more advanced residents, typically in their last or second to last year of residency. The term Resident has its origin in the notoriously long working hours and their consistent present in the hospital, considered an unofficial residence.

Terminal Prognosis Commonly referred to as a terminal "diagnosis", a terminal prognosis is the an evaluation based on clinical evidence that a patient has 6 months or less to live before they will die. A terminal prognosis is necessary to receive reimbursed hospice treatment from insurance agencies including Medicare and Medicaid.

Standard of Care Treatment that is accepted by medical experts as a proper treatment for a certain type of disease and that is widely used by healthcare professionals. Also called best practice, standard medical care, and standard therapy. *Source*: National Cancer Institute

APPENDIX A: INTERVIEW GUIDES

Interview Theme:

Determining Success and Failure in Medicine

This interview is meant to explore how physicians in the inpatient setting understand when they are doing a good job, have done a good job, done a bad job, and when they aren't doing a good job. The theme touches both on interactions between physicians and patients, but also between physicians and other physicians, even from other specialties. The interview guide is meant to be useable on physicians from any medical specialty, ***with maybe a supplement for the focal specialty of palliative medicine.***

Interview Topics:

1 The cases that they are particularly proud of and what makes them proud of them.

2 The features of their work that are particularly frustrating for them and how they undermine their work.

3 The ways that collaborating with other physicians can go well or poorly.

4 The ways that they think about death and the deaths of patients.

Opening Prompt: I am a sociology student researching patient-physician communication in the inpatient setting. I want to ask you a few questions about a number of topics related to this theme but before I do, do you have any questions about the study? If not…

1) EXEMPLARY CASES:

   a. Ask R [Respondent] about a case that stands out for them, one where they felt particularly good about the outcome or where they knew they had done an excellent job.
   b. Have R walk you through the case, emphasizing the concrete details of what went well. Did R learn something new from that case?
   c. Is that kind of case atypical or common? Was there something about it that allowed R to know it was going to turn out well.

2) FRUSTRATING WORK

   a. Ask R to think of a case that exemplifies the common tensions in their work? Walk me through the case? Is it common for a case to go that way?
   b. Ask them how they felt with the case? What they thought at the end of it?
   c. Is there something that your training didn't prepare you for? Something that they would always teach their students?
   d. What are the biggest things that get in the way of their work? How do get around them?
   e. Can you see them coming in a particular case?

3) COLLABORATION

   a. Which of these do you think your specialty works best with?

b. Which of those specialties your specialty often butts heads with? How? Why?‘ Is there a case that comes to R’s mind which exemplifies this?

c. Which of those specialties does similar work as your specialty?

d. What is the most important thing that distinguishes your specialty from other specialties you commonly work with?

4) DEATH

a. What is a patient that you cared for at the end of life that left a big impression on you?

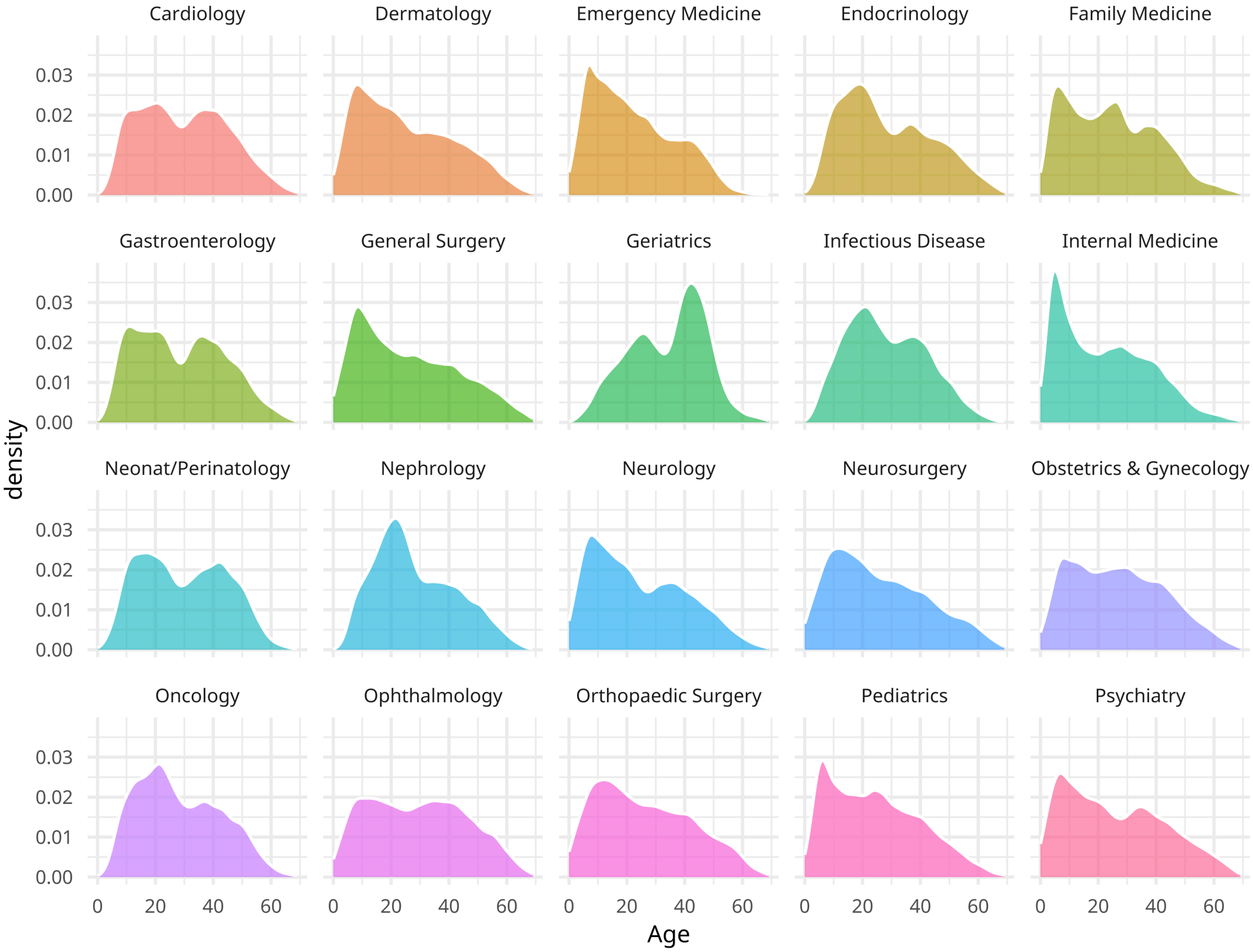
b. Ask R to describe what they understand by the phrase a “good death”. How would R describe the good death to someone they just met at a party?

c. What gets in the way of patients achieving the goal of a good death?

d. Is R more comfortable with death? Less comfortable? Has R thought about death more since starting to practice medicine?

APPENDIX B: SUPPLEMENTAL TABLES AND FIGURES

Figure 8.1: Demographics for largest areas of medicine.



Data Source: doximity.com. Scraped in 2023.
'Age' here is the career age of the respondent:
Interview Year - Year Graduated from Medical School.

Figure 8.3: Histogram of predicted values from Linear Probability Models.

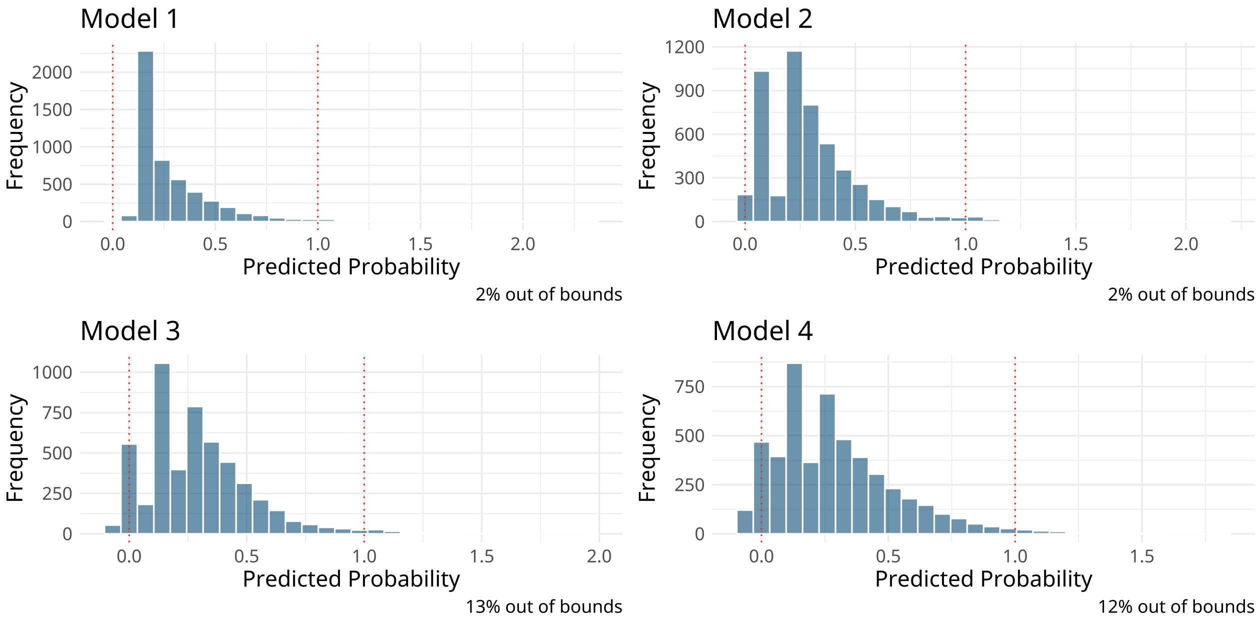
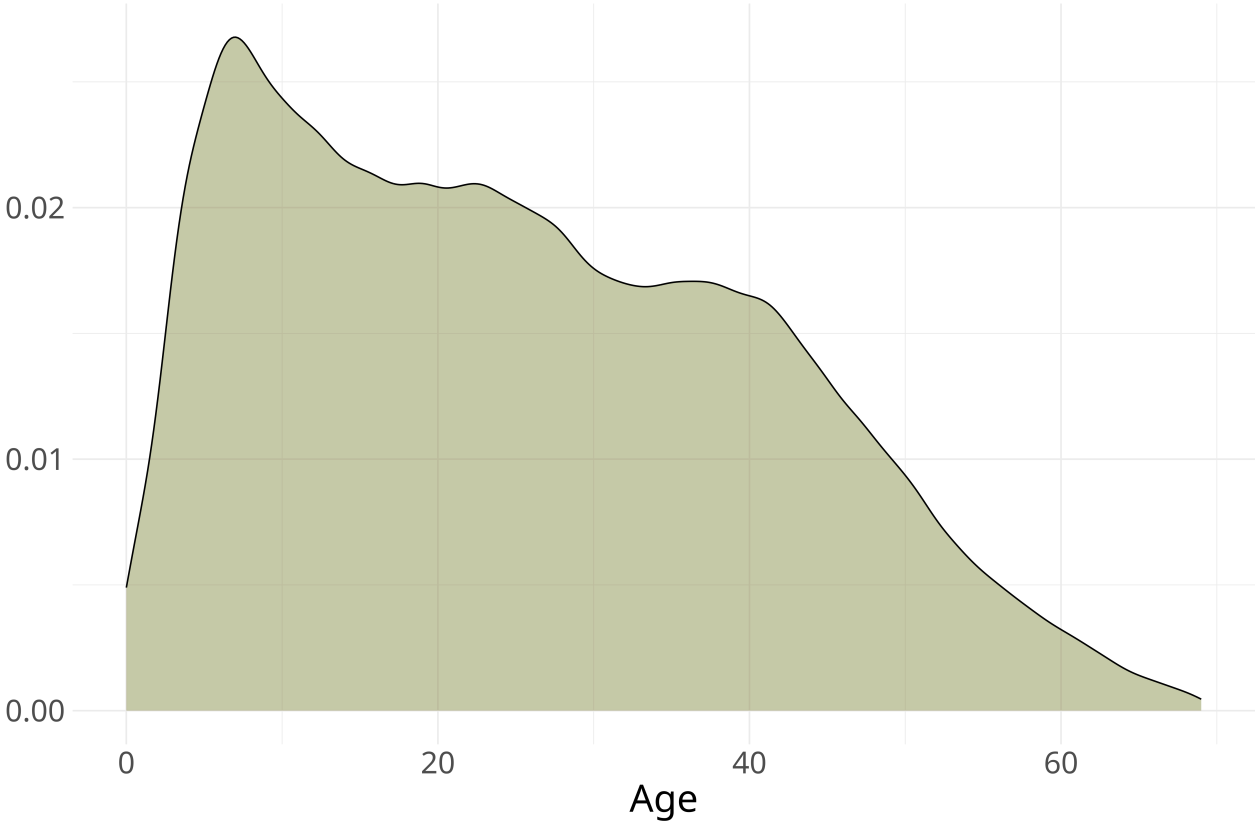


Figure 8.2: Demographics of all doctors on doximity.com



Data Source: doximity.com. Scraped in 2023.

Table 8.1: Residency training length in all primary boards.

Primary Board	Length (Years)
Neurosurgery	7
Plastic Surgery	6
General Surgery	5
Orthopedic Surgery	5
Otolaryngology	5
Urology	5
Obstetrics/Gynecology	4
Pathology	4
Psychiatry	4
Radiology	4
Emergency Medicine	3.5
Physical Medicine	3.5
Anesthesiology	3
Dermatology	3
Family Medicine	3
Internal Medicine	3
Neurology	3
Ophthalmology	3
Pediatrics	3

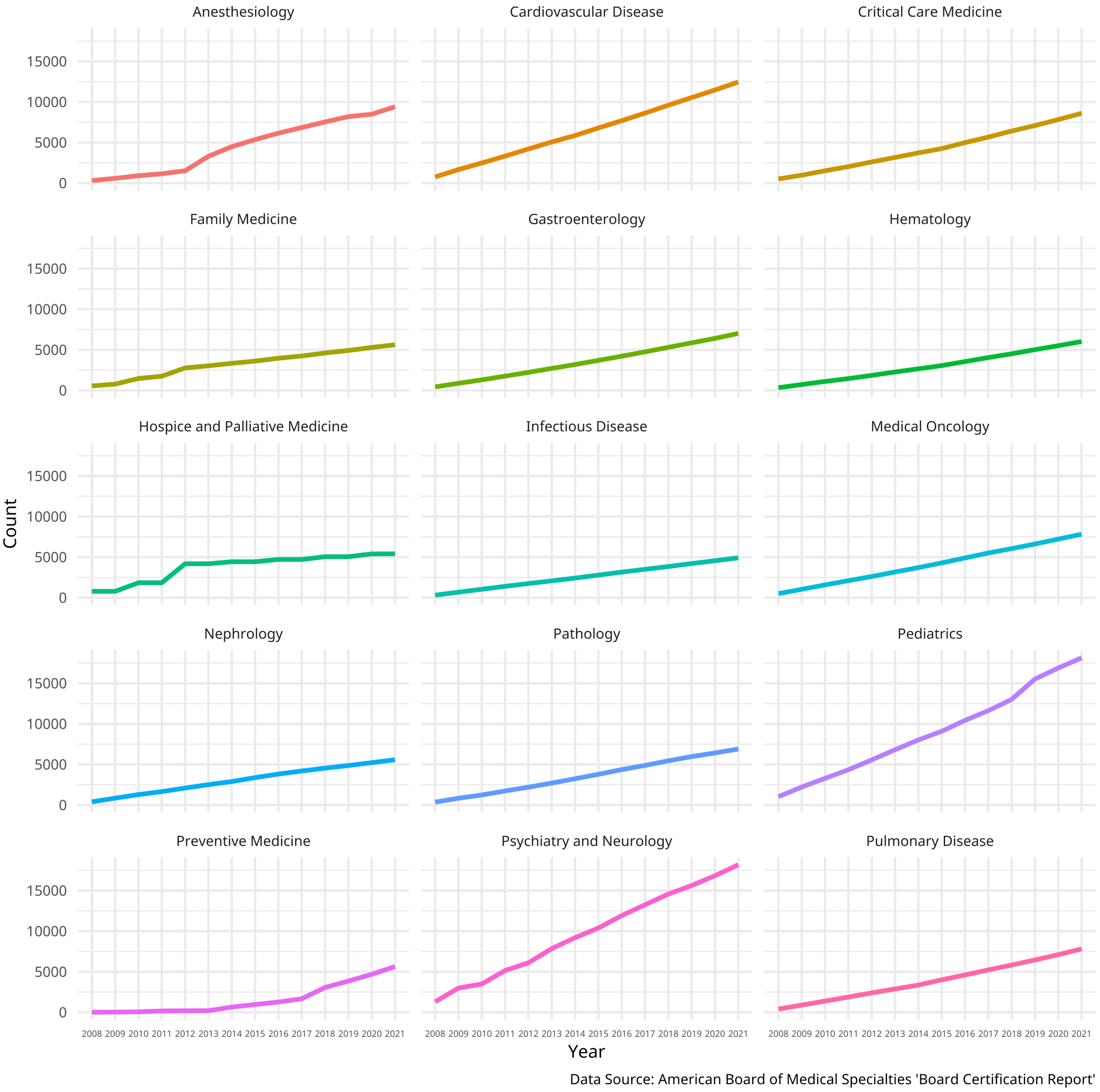
Data Source: ABMS Board Certification Report 2021-2022.

Table 8.2: Raw counts of hospitals, HPM services, and rates of palliative care services and hospitals per capita, across US states.

State	Population	No. of Hospitals	Hospitals with HPM	HPM per Hospitals	HPM per Capita	Hospitals per Capita
Alabama	5049846	97	15	15.46	0.30	1.92
Arizona	7264877	112	16	14.29	0.22	1.54
Arkansas	3028122	85	13	15.29	0.43	2.81
California	39142991	434	128	29.49	0.33	1.11
Colorado	5811297	104	24	23.08	0.41	1.79
Connecticut	3623355	34	19	55.88	0.52	0.94
Delaware	1004807	9	4	44.44	0.40	0.90
District of Columbia	668791	8	3	37.50	0.45	1.20
Florida	21828069	247	86	34.82	0.39	1.13
Georgia	10788029	151	35	23.18	0.32	1.40
Idaho	1904314	46	6	13.04	0.32	2.42
Illinois	12686469	190	72	37.89	0.57	1.50
Indiana	6813532	132	49	37.12	0.72	1.94
Iowa	3197689	135	20	14.81	0.63	4.22
Kansas	2937922	98	3	3.06	0.10	3.34
Kentucky	4506589	108	28	25.93	0.62	2.40
Louisiana	4627098	142	20	14.08	0.43	3.07
Maine	1377238	39	15	38.46	1.09	2.83
Maryland	6174610	54	38	70.37	0.62	0.87
Massachusetts	6989690	86	34	39.53	0.49	1.23
Michigan	10037504	154	52	33.77	0.52	1.53
Minnesota	5711471	132	25	18.94	0.44	2.31
Mississippi	2949586	106	7	6.60	0.24	3.59
Missouri	6169823	126	44	34.92	0.71	2.04
Montana	1106227	65	6	9.23	0.54	5.88
Nebraska	1963554	98	17	17.35	0.87	4.99
Nevada	3146402	45	17	37.78	0.54	1.43
New Hampshire	1387505	30	8	26.67	0.58	2.16
New Jersey	9267961	85	41	48.24	0.44	0.92
New Mexico	2116677	56	7	12.50	0.33	2.65
New York	19857492	209	82	39.23	0.41	1.05
North Carolina	10565885	128	40	31.25	0.38	1.21
North Dakota	777934	53	5	9.43	0.64	6.81
Ohio	11764342	184	94	51.09	0.80	1.56
Oklahoma	3991225	134	31	23.13	0.78	3.36
Oregon	4256301	64	24	37.50	0.56	1.50
Pennsylvania	13012059	187	88	47.06	0.68	1.44
Rhode Island	1096985	12	7	58.33	0.64	1.09
South Carolina	5193266	78	27	34.62	0.52	1.50
South Dakota	896164	58	4	6.90	0.45	6.47
Tennessee	6968351	123	29	23.58	0.42	1.77
Texas	29558864	450	87	19.33	0.29	1.52
Utah	3339113	53	9	16.98	0.27	1.59
Vermont	646972	15	6	40.00	0.93	2.32
Virginia	8657365	104	42	40.38	0.49	1.20
Washington	7740745	111	38	34.23	0.49	1.43
West Virginia	1785526	55	9	16.36	0.50	3.08
Wisconsin	5880101	150	52	34.67	0.88	2.55
Wyoming	579483	31	1	3.23	0.17	5.35

Excludes Hawaii and Alaska. Data Source: Department of Homeland Security Homeland Security Homeland Infrastructure Foundation-Level Data and Center to Advance Palliative Care. Retrieved 2023.

Figure 8.4: New certificates in the 15 largest subspecialties of medicine.



Data Source: American Board of Medical Specialties 'Board Certification Report'

Table 8.3: Descriptive statistics for hospitals.

	N	Mean	Std. Dev.	Min	Max
HPM Present	5024	0.29	0.45	0	1
No. of Beds	5024	169	203	2	2059
Type	5024				
... GENERAL ACUTE CARE	3731	74%			
... CRITICAL ACCESS	1159	23%			
... MILITARY	134	3%			
Owner	5024				
... For Profit	1215	24%			
... Government	1041	21%			
... Non-Profit	2768	55%			
Trauma Center	5024				
... None	3017	60%			
... Level 1	1152	23%			
... Level 2	347	7%			
... Level 3	508	10%			

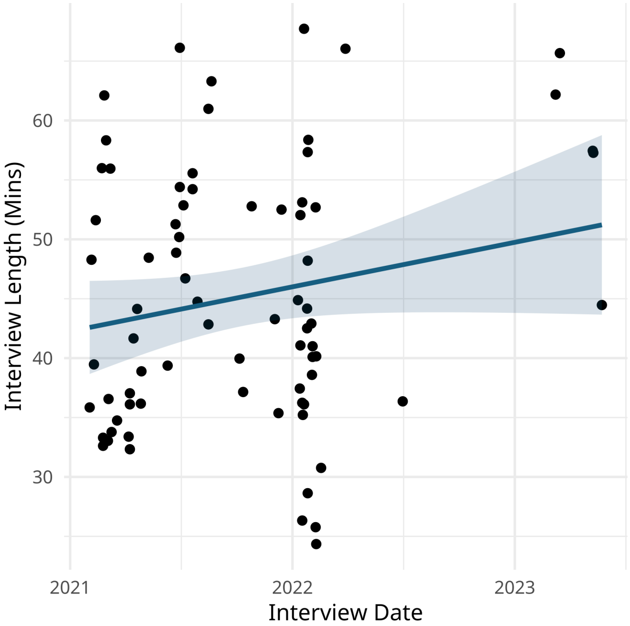
Table 8.4: Estimates from Logistic Regression predicting whether hospitals have an HPM service.

	HPM Service Present				
	1	2	3	4	5
No. of Beds (100s)		$.668^{***}$	$.563^{***}$	$.549^{***}$	$.514^{***}$
		(.024)	(.025)	(.025)	(.025)
Type - Critical Access (0/1)			-1.461^{***}	-1.440^{***}	-1.307^{***}
			(.152)	(.154)	(.157)
Type - Military (0/1)			-1.246^{***}	$-.623^{*}$	$-.532$
			(.256)	(.278)	(.278)
Owner - Government (0/1)				$-.056$	$-.031$
				(.140)	(.141)
Owner - Non-Profit (0/1)				$.895^{***}$	$.881^{***}$
				(.090)	(.091)
Trauma Level 1 (0/1)					$-.254^{*}$
					(.108)
Trauma Level 2 (0/1)					$.843^{***}$
					(.140)
Trauma Level 3 (0/1)					$.486^{***}$
					(.110)
Constant	$-.888^{***}$	-2.104^{***}	-1.717^{***}	-2.247^{***}	-2.285^{***}
	(.031)	(.056)	(.062)	(.093)	(.096)
Observations	5,024	5,024	5,024	5,024	5,024
Log Likelihood	−3,032.378	−2,416.389	−2,342.696	−2,272.273	−2,239.089
Akaike Inf. Crit.	6,066.755	4,836.778	4,693.392	4,556.546	4,496.178
Notes:	*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$				

APPENDIX C: PARADATA ANALYSIS OF INTERVIEW DATA

Paradata is information generated about the data collection process and paradata analysis examines this auxiliary data to ensure its quality. In the case of my interview data, I use paradata related to the length of interviews, the ratio of words spoken by the interviewer and the respondent, and the order in which the interview was conducted to better understand how my interviewing technique changed, and hopefully improved, over time. I further analyze these different features of the paradata and their relationship to the gender and "age" of the respondent to understand if any underlying biases influenced the data collection process.

Figure 8.5: Interview date and length of interview.



Though length is not a straightforward indication of quality in open-ended unstructured interview studies, I think longer interviews do help to get more information from respondents and to explore relevant areas of their work. Figure 8.5 shows the length of interviews (in minutes) across the period of data collection. A slight trend can be observed, where interviews did lengthen as data collection continued.

More important than the length of an interview is the ratio of words spoken by the interviewer and the respondent: effective interviewing requires a parsimony of words by the interviewer, to effectively provide the respondent with the task of answering questions but to avoid participating in the interview themselves. Figure 8.6 shows the percent of words spoken by the respondent in the interview by three different metrics: the interview date, the length of the interview and the career age of the respondent. The left panel, clearly shows that throughout data collection, I became more effective at taking up significantly less of the interview with my speaking turns.

Figure 8.7: Gender Diagnostics

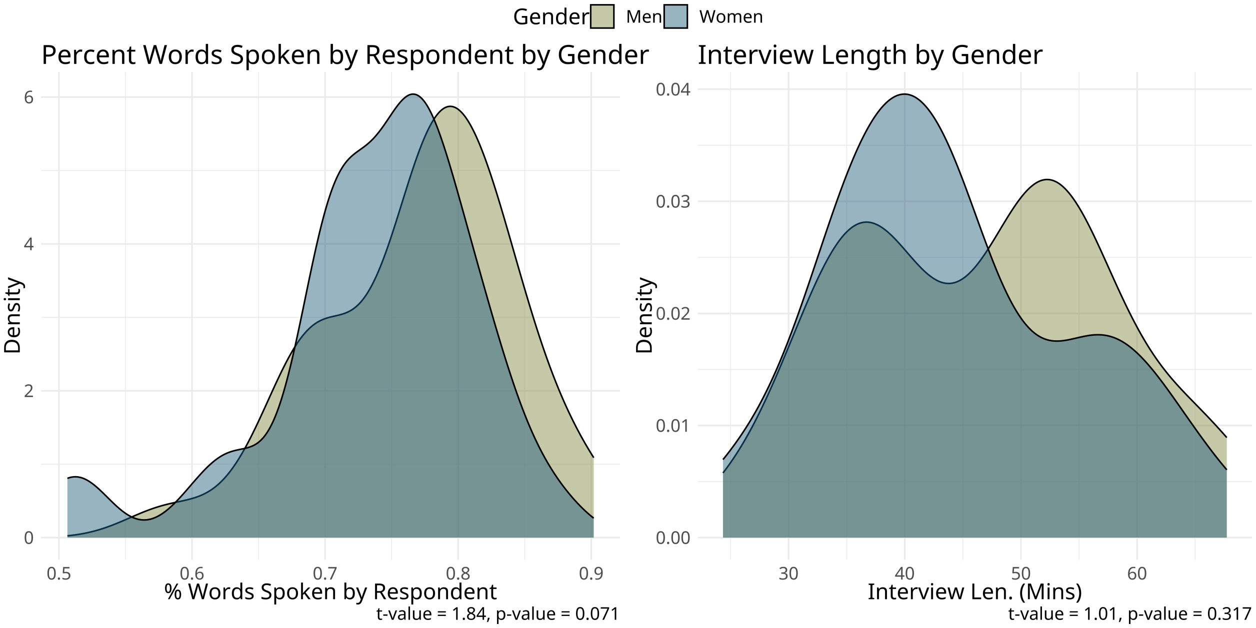


Figure 8.6: Percent of words spoken by respondents by three metrics.

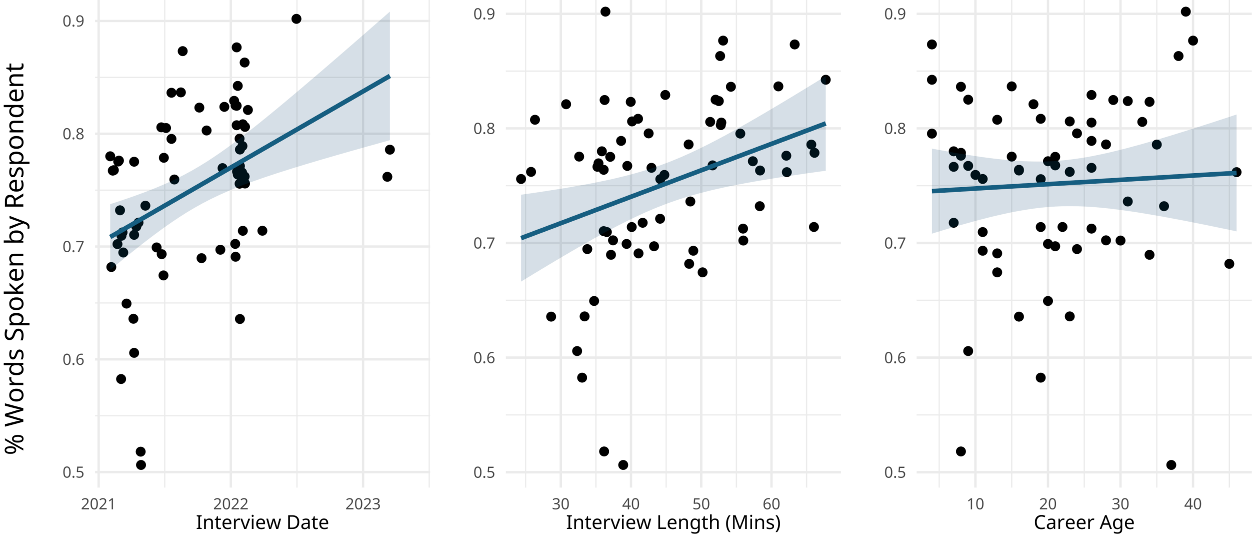


Figure 8.7 shows the distribution of the percent of words spoken by the respondent and the interview length between male and female respondents. A t-test was performed for both and indicates that there are no significant differences between the two groups.