

ORIGINAL ARTICLE

Diagnosis and the practices of patienthood: How diagnostic journeys shape illness experiences

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Abstract

Sociologists have a rich history of studying the process of diagnosis and how people experience illness. Yet, the sociology of diagnosis and illness experience literatures have seldom been fully integrated. Instead, these literatures highlight one element of the illness journey, wherein scholars either primarily study diagnostic processes and categories or people's illness experiences. Drawing on empirical studies that examine diagnosis and experiences of illness in varied settings (diagnosis during breast cancer surveillance, diagnosis and experience of autoimmune illness and incarcerated women's experiences of diagnoses and illness), in this article we build on our concept of *regimes of patienthood* to explain how diagnostic journeys, and the relations and power dynamics that manifest during this time, shape the illness experience and practices of patienthood. We construct a classification of diagnostic processes grounded in our empirical research that span (1) sudden diagnoses, (2) long, changing diagnostic journeys and (3) diagnostic journeys marked by disbelief and denial of care. Our findings demonstrate how diagnostic journeys and illness experiences are intertwined, with

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different diagnostic pathways impacting how illness is experienced. Analysing these categories collectively demonstrates that diagnostic journeys, while heterogeneous, shape the practices that patients develop to manage health conditions and navigate unequal health-care encounters.

KEYWORDS

autoimmune illness, breast cancer, chronic illness, diagnosis, illness experience, incarceration

INTRODUCTION

Sociology has a rich history of studying health and health care from the perspective of people who negotiate and live with illness. Sociological analyses of illness experiences tend to focus on people as they experience illness over a period time that can include pre and post diagnosis or through changing diagnostic labels. The centre of analysis is the person's experience of their bodies, their lives and their care. In another significant body of work, the sociology of diagnosis scholarship has long considered the diagnostic moment—in which a diagnosis is uttered to a patient—a critical social moment in patients' experience. Sociology of diagnosis highlights how professional and cultural contexts and power co-create the diagnostic moment. Yet sociology of diagnosis and experience of illness literatures have largely focussed on one slice of the illness journey, wherein scholars are *either* studying the diagnostic process *or* the experience of people living with illnesses (Joyce & Jeske, 2019). The diagnostic journey is an overlooked or bracketed period in the illness experience literature even though it may be when patients begin to test illness management strategies, develop relations with health-care providers and intimately interact with health-care institutions. Indeed, these experiences occur long before patients achieve diagnostic labels, yet they profoundly shape how patienthood is practiced. And for those who never arrive at a diagnosis, the persistence of medically unexplained symptoms defines the illness experience (Nettleton, 2006). The focus on the diagnostic moment sidelines the temporal aspect of living with illness and how this may change overtime. In this article, we connect these two crucial bodies of scholarship to demonstrate how the diagnostic journey itself is a critical and profoundly influential part of the experience of illness across multiple diagnostic categories, attending to the temporality of illness experiences.

To make this case, we draw on evidence from several empirical studies rooted in varied experiences of illness in the United States (US): a study of 21 women diagnosed with breast cancer during a screening study, a study of 45 mostly white, middle class people living with autoimmune illnesses and two studies which include 24 women diagnosed with chronic illness while incarcerated. We combine insights from our individual qualitative studies to increase theoretical power. Drawing on this work, we construct a classification schema to demonstrate how the diagnostic experience is not separate from patienthood, but rather a profoundly important shaping experience that impacts how people navigate illness. This classification, rooted in our empirical cases, includes (1) diagnostic experiences where patients feel healthy but learn of a diagnosis through surveillance screenings, (2) diagnoses achieved through long journeys, often marked by prolonged uncertainty and shifting diagnoses and (3) instances wherein pain and symptoms are never taken

seriously by health-care providers even though they are profoundly experienced by individuals. We pair this with an analysis of the extant literature to develop a framework for understanding diagnosis as a crucial part of patienthood experience and vice versa. We use the term patienthood to highlight how social structure and individual experiences are connected (Joyce & Jeske, 2019; Joyce et al., 2020). Throughout our analysis, we foreground issues of intersectionality, power and inequality. We find that the process of diagnosis—particularly the relationships patients develop with care providers, engagement with biomedicine as well as rejections of it and expectations of patients—impacts how people practice patienthood, and how these practices contribute to inequalities in health care.

LITERATURE

Diagnosis as a social process

Since the late 20th century, there has been a call for a sociology of diagnosis, raising investigations of diagnosis as both a category and a social process (Blaxter, 1978; Brown, 1990, 1995; Jutel, 2009; Jutel & Nettleton, 2011). Scholars in this tradition view diagnosis as ‘a prism which absorbs and reflects a panoply of issues central to the experience and practice of medicine and health care’ (Jutel & Nettleton, 2011, p. 793). Studies of diagnosis have revealed how diagnosis is a social process in which multiple social factors and relations converge, including the clinician-patient relationship; power, authority and the construction of expertise; resource allocation and (un)certainty and meaning making (Blaxter, 1978; Brown, 1995; Jutel, 2011, 2019; Pickersgill, 2014). Scholars have shown how diagnosis is imbued with power: it can be a means of social control (Burke, 2011; Dobransky, 2011; Waggoner, 2017), diagnostic labels at times legitimise and at others (and also simultaneously) stigmatise (Barker, 2005; Campbell, 2021; Nettleton, 2006) and is deeply tied to resource allocation (Brown et al., 2011; Lane, 2021; Petryna, 2013). Diagnostic categories and the process of diagnosis are also spaces in which interests are acutely visible and where a diverse set of social actors fight for them (Brown, 1990; Smith-Morris, 2015; Whooley, 2014). Studies have focussed on the diagnostic tools themselves, providing in-depth analyses of the production of a diagnosis and the process of achieving one (Ebeling, 2011), the political mobilisation that is needed to secure a diagnosis in the case of contested illnesses (Brown et al., 2011; Dumes, 2020) and how people resist and challenge diagnostic labels (Burke, 2011; LeFrançois et al., 2013).

Sociology of diagnosis has attended to the power of diagnosis, including how the diagnostic utterance shapes patient narratives and the social and political importance of diagnostic labels, but it has typically not questioned how the diagnostic journey—that is, the time beginning when a person begins experiencing symptoms, to the eventual diagnostic pronouncement (or in cases where this never occurs)—shapes illness experiences. Our intent in this article is not to downplay the importance of the diagnostic moment nor the attention to the construction of diagnostic categories, but rather to elucidate how the diagnostic journey itself shapes how patienthood is practiced. We argue that the experience leading up to diagnosis must be understood as part of the illness experience and demonstrate that it shapes relations with health-care providers and the practices that patients develop. While the literature has shown that for uncertain illnesses this has long been the case (Cox et al., 2003; Nettleton, 2006), we combine insights from the sociology of diagnosis and the sociology of illness literature to better understand how the process of diagnosis shapes and is shaped by the illness experience. This move advances the sociology of

diagnosis literature by showing how the period before and after diagnosis is integral to (not separate from) how people navigate illness in contemporary health care.

Experience of illness and subjectivity

Experience of illness scholarship has focussed on the ways in which illness shapes one's identity and sense of self, their social relations and how they participate in daily life and work (Bury, 1982; Charmaz, 1991). Early illness experience scholarship moved sociology away from structural functionalist depictions of illness, dominated by Parsons' concept of the sick role (Parsons, 1975) and a focus on clinicians and patient compliance. Instead, through taking up a more interpretive, inductive approach, early work demonstrated how chronic illness diagnosis created 'biographical disruption' (Bury, 1982). Bury theorised that the disruption caused by chronic illness had three parts: first, the disruption of taken for granted assumptions and behaviours and an attention to bodily experiences and states that would otherwise go unnoticed; second, a rupture in one's biography and concept of the self, and in the 'explanatory systems' that would normally be available to them; and third, a response to this disruption involving the mobilisation of resources (Bury, 1982, pp. 169–170). Biographical disruption centred the changes to social relationships, activities and resource mobilisation. Other foundational work on the experience of chronic illness examined how people's sense of time and self changed when living with chronic illness (Charmaz, 1991). Charmaz's work showed that the self was reconstructed *through* illness experience and captured how this evolved over time. Frank (1991, 1995) analysed how people used storytelling as a way to make sense of illness. Humanising the illness experience, Frank called for an ethics of reciprocity where it was important to listen to people's narratives and not silence them. As we discuss later, such insights underscore the importance of studying illness and diagnostic experience over time, as opposed to cross-sectionally.

Building on this scholarship, sociologists have investigated how people practise narrative reconstruction to explain the cause of their illnesses and their connections to the social world (Beard, 2016; Bell, 2000; Nowakowski, 2016; Williams, 1984, 2000). Other work has attended to how those experiencing illness use the internet and form online support communities (Barker, 2008; Conrad & Stults, 2010; Pitts, 2004; Sosnowy, 2014); and when and how social movements form around shared illness experiences (Bell, 2009; Brown, 2007; Brown et al., 2011; Klawiter, 2008). Others have examined how intersecting forms of oppression, like ageism, sexism, racism and xenophobia impact illness experience (Heaton et al., 2016; James, 2016, 2021; Komaromy et al., 2018; Mendenhall et al., 2010; Monaghan & Gabe, 2015; Sanderson et al., 2015). Intersectional scholarship on illness experience has documented how social stratification shapes relations with clinicians, and how experiences with racism and various forms of stigma in health-care settings shape patients willingness to seek care and receive equitable care in these encounters (Joyce et al., 2020; Shim, 2010). As an analytical approach, intersectionality attends to interlocking forms of oppression such racism, sexism and classism, demonstrating the heterogeneity of experiences within groups and how various forms of oppression and privilege mutually construct one another (Collins, 1990; Collins & Bilge, 2016; Crenshaw, 1989). Scholars in this arena have also described how patients shift power in clinician–patient relations in order to move away from paternalistic communications that have dominated medicine towards more collaborative relations (Joyce & Jeske, 2019; Timmermans, 2020; Vinson, 2016).

Situating illness experiences in social structure, we developed the concept of *regimes of patienthood* (Joyce et al., 2020) to evoke the socially constructed nature of illness behaviour,

underscoring how individual biographies are linked to social structure in historically specific ways and to highlight power and resistance in illness experiences and health-care interactions. Advancing this as an intersectional concept, we showed how regimes of patienthood are always regimes of power *and* resistance, wherein forms of resistance—and the performance of resistance—may look different based on individuals' positionality. In this article, we explicitly bring the diagnostic journey into this framework to demonstrate how this critical period shapes how the practices of patienthood.

METHODS

We draw on four of our empirical studies, all based in the United States, to demonstrate how diagnostic journeys shape the experience of patienthood and the ways it is practiced. Combining our studies increases the theoretical power of each qualitative study. Each study was an in-depth interview-based study that captured participants' experience of illness and the diagnostic journey. In this section, we provide brief overviews of the studies and explicate how we brought the studies together. All demographic characteristics were self-reported by participants.

First, we draw on James' study of 21 women¹ recently diagnosed with breast cancer during participation in a screening study. Participants ranged in age from 45 to 74 with 12 identifying as white, 6 as white and Hispanic, 2 as Asian or Pacific Islander and 1 as Black. All participants had health insurance and the majority were middle or upper middle class with the majority having a college degree. These women were participating in a study comparing annual mammography to risk-based screening; half of these participants were given a recommended breast cancer screening schedule based on their personalised risk for breast cancer. This study focussed on understanding the experience of being diagnosed with breast cancer while participating in this study. Participants were asked about their perceptions of breast cancer risk before and during participation in the trial and how they made decisions about how often to screen. Participants reflected on their diagnostic journey and the meaning of being diagnosed through routine screening, particularly for those participants who had been given a recommendation by the trial to screen less often than they had in the past.

Second, we draw on Joyce's study of people living with autoimmune illnesses. Our analysis of autoimmune illness experiences (Joyce & Jeske, 2019, 2020) explored how people living with autoimmune diseases navigated long periods of uncertainty as well as how to manage notoriously difficult illnesses. This study included 45 mostly white, middle-class people living with autoimmune illnesses. Participants ranged in age from 20 to 67 years old. All participants were diagnosed with at least one autoimmune related illness at the time of the interview, for example, coeliac disease, Crohn's disease, Guillain-Barré syndrome [GBS], Hashimoto's thyroiditis, lupus, mixed connective tissue [MCT] disease, multiple sclerosis [MS], among others. Autoimmune illnesses disproportionately affect women in the United States (Ngo et al., 2014; Pollard, 2012), and as such our interviews were conducted primarily with women: of the 45 people interviewed, 35 identified as women. Forty participants identified as white, 2 identified as Black, 2 as Asian and 1 as Latinx. The majority of participants self-reported white-collar, middle-class occupations and were insured. Two participants, who held white-collar occupations previously, were supported by social security disability income at the time of interviews. Most participants had at least a 4-year college degree or were in the process of attaining one.

Finally, we draw on James' two research projects that study the experiences of women diagnosed with chronic illness while incarcerated. The first involved 13 formerly incarcerated

Black women who were over the age of 50 and had at least one chronic illness. The second study included 11 women who were incarcerated and released during the COVID-19 pandemic; women in this study were over the age of 40 and all had at least one chronic illness they faced during incarceration. While the second study focussed on the COVID-19 pandemic and COVID risk mitigation measures inside prisons and jails, both studies asked participants to reflect on experiences accessing health care inside. Each participant was asked to describe her diagnostic journey, perceptions of health and illness, patient provider relationships and any structural barriers to accessing care.

These studies used various methodological approaches including ethnography, grounded theory and Black Feminist Epistemological Methodology (James, 2016), and data were analysed for each study using techniques based in constructivist grounded theory (Charmaz, 2014). For the analysis presented in this article, we drew on discussions from our previous collaboration (Joyce et al., 2020) and brought together codes from each of our studies that captured our participants diagnostic journeys as well as how they discussed the diagnostic process in relation to illness experiences. Bringing these studies together, we show how across varied settings, the diagnostic process shapes the experience of patienthood and the practices that people develop to manage their health and navigate complex health-care systems. Critically, all of our studies were cross-sectional in their approach. Given our findings, alongside Charmaz's insights about temporality and the lifecourse of illness experiences, it is critical for future studies to examine how people experience illness over time through longitudinal approaches.

FINDINGS: DIAGNOSTIC JOURNEYS SHAPE HOW PATIENTHOOD IS PRACTISED

Case 1: Sudden diagnoses

One type of diagnosis occurs when patients suddenly learn that they have an illness through surveillance screenings. Such screenings may lead to the diagnosis of cancer, type 2 diabetes or high blood pressure. In these situations, patients often experience their bodies as normal and healthy but learn that there is disease following routine screening. To illustrate this category, we draw on a study of women who were diagnosed with breast cancer as part of a screening study. While for some patients, diagnosis follows a lengthy symptomatic journey, as discussed in latter categories, disease diagnosed through screening diagnosis often comes as a surprise. People are often living their lives, *feeling* healthy. As scholars have shown (Salter et al., 2011), such diagnoses are jarring in part because they do not match patients' experiences; they felt healthy prior to diagnosis and, for some, continued to feel healthy after. This disconnect shaped their experiences of illness and self. In our case, focussing on the 'whirlwind' of care appointments and treatments that followed diagnosis, participants often did not integrate the illness into their self-identity and initially experienced a lack of control as their lives were taken up with medical appointments. However, upon later reflection, many were grateful for the intensity of this time period; they felt that the fast-paced push towards intervention and management of disease offered a sense of control within a new and unfamiliar place of illness.

One participant explained that when she was diagnosed, she did not feel sick and that this disconnect led to some denial. She said,

[It's] almost like a disconnect. It's really weird. One of the doctors, they asked me—actually, one of the radiologists, when they were doing an ultrasound they said, “Did

you feel it?" And I said, "No. Should I have?" And they said, "No, you really couldn't have."... So that's the disconnect of it mentally, is like well I feel the same but you're telling me that I'm not. It isn't like you break a leg or something, [there] you know and there's really evidence.

For this participant and others, the speed of the cascade of interventions that follows a diagnosis—alongside the jarring nature of the diagnosis—led some to not consider the meaning of the diagnosis until much later, and many did not feel, at least initially, like they were in control of the situation. The weight of a cancer diagnosis was not always immediately present given the intensity of beginning treatment, and many participants did not report feeling like they were in fact cancer patients:

I was diagnosed in August. I had a mastectomy in September.... everything just happened so fast in those first six months. It's like you go in and then it's like, oh, I have this little lump. And then three days later you find out 'oh, my gosh, I have cancer.' And then you're meeting with the oncologist and you're meeting with the plastic surgeon and you're going and getting all these tests done and the genetic testing and this test, that test, getting ready for surgery, getting all that scheduled. [...] There was just so much going on. I honestly really didn't think about oh, I have cancer. I was just going through the motions... I didn't really think about it that much and then probably like, I don't know, I want to say like February, March, all of a sudden it just... the realization was sort of like oh, wow. Okay, had you not caught this or had it been worse or had it gotten out, you know, into your lymph nodes or into your system, you could've died. I mean, the mortality thing kind of hit me in the face.

Because participants were not feeling ill or dealing with the process of seeking care to alleviate specific symptoms, the abruptness of their diagnostic journeys led to a different kind of illness experience, one in which they never felt ill but were introduced to a 'lightning speed' relationship with biomedicine and health care. For some, this caused a delay in processing the news of this diagnosis as there was an immediate shift from diagnosis to action. As one participant described, 'It was a shock. [...] I kind of like wallowed in it for a little bit, and then it's like okay, what's the next step? We need to move forward.'

Diagnosis of the condition did not come as a relief or as validation, but rather introduced doubt: doubt about if this diagnosis was indeed correct, about their futures and how it was possible that they had no previous signs of an illness. Because participants had not been feeling ill, their diagnosis and subsequent treatments felt in opposition to their health narratives. Moreover, many described not having time for the diagnosis to be disruptive to their identity. As the participant above explained, the lightning speed of care quickly moved her past the diagnosis and on to treatment. The diagnosis and treatments were of course disruptive to daily life, but there was a sense that it was happening to someone else or perhaps to a disembodied version of themselves. For some, because it had been such a surprise and often because their cancer was early stage, their cancer diagnosis did not become a defining feature in their life. Instead, often what is defining are the physical effects of the diagnosis which vary based on staging and treatment:

Some people, afterwards, [cancer] really defines them and becomes such a part of them. But it's like I told a girlfriend, I said, "I don't see myself as, you know, when

people say ‘I’m a cancer survivor’, I don’t really feel that.” And maybe it’s because I had such a, “quick and easy” time through this process. It was really cut and dried [...] I know some people I know are really, it weighs heavily on them I think forever, and it changes and really shapes everything that they do and how they look at things. I don’t know. For whatever reason, it hasn’t for me. [...] Mentally, I don’t like dwell on it. And the only reason why I would think about it now is just because of the physical therapy, just ‘cause of the lack of range of motion with the arm and some lingering pain and a little bit of like changes still. [...] But other than that, I know some people think about it on a daily basis, and I don’t know. I don’t hide it but I don’t dwell on it.

For patients learning of diagnosis through screenings like these, the sudden emergence of diagnosis resulted in a particular experience of illness: one marked by swift intervention and medical attention. Unlike the cases that follow, the ‘cut and dried’, as this participant put it, nature of the screening and treatment meant that this illness experience, like that of the diagnosis, was marked by shock and disbelief as opposed to relief or validation. Participants explained the speed and routinisation of the diagnosis and treatment protocols meant that they did not have the chance to grapple with their diagnosis and often did not process the meaning of the diagnosis and illness as part of their identity until much later in the process, if at all. In this scenario, people’s sense of control was initially off-balance as appointments and medical interventions took over their daily lives. They eventually found a sense of control by seeking care from trusted institutions and by utilising the medical establishment for legitimacy and interventions.

Case 2: Long, changing diagnostic journeys

The second category of diagnosis includes those experiences marked by prolonged uncertainty, and long—often years long—periods of seeking diagnosis. Here, we draw on the case of people living with autoimmune illnesses, a diagnostic category that encompasses over 80 diseases, including illnesses such as lupus, multiple sclerosis, type 1 diabetes, rheumatoid arthritis and Crohn’s disease. Autoimmune illnesses are categorised this way because they are thought to share a common underlying mechanism that initiates the body’s autoreactivity (Anaya et al., 2007; Davidson & Diamond, 2013). With the exception of type 1 diabetes, which has a clear diagnostic pathway, patients with these illnesses often present with symptoms that are challenging to classify, and typically their diagnostic journeys are long. Participants described diagnostic journeys that lasted years, where they often had ‘working diagnoses’ to find treatment plans. Because of this, finding ways to manage symptoms and prevent flares was a common practice for participants in the absence of a diagnosis. Even once they had a diagnosis participants continued using such techniques in conjunction with biomedical care regimens (Joyce & Jeske, 2019).

During the diagnostic journey, participants were often met with resistance from providers who questioned their experiences and often failed to take their symptoms seriously. Over her years long diagnostic journey, one participant living with Crohn’s disease explained,

They’d say, “Oh it’s the flu, we don’t know, viral, nothing.” At some point, most of the time I was getting really, really ill. I had blood drawn and was slightly anaemic at that point. I was told, “Oh, you’re female, you’ve got your period, blah blah blah.” And actually when I was finally diagnosed, emergency surgery in the hospital, I was really anaemic and had a blood transfusion.

Such experiences led participants to seek new care providers until they found clinicians who took them seriously (Joyce & Jeske, 2019). These providers, whom they described as collaborative and respectful, were often ones with whom they eventually achieved a diagnosis. The practice of advocating for oneself in clinical encounters developed long before participants had diagnostic labels and extended beyond clinical encounters. Participants often conducted their own research on their illnesses and symptoms, developing ways to manage them on their own. One participant put it this way, 'At first I just said, 'Well, okay, I'll just follow what the doctor, you know, says,' and that's probably the best thing to do. But then I realised, 'Okay, they don't have the answer.' And I need to take responsibility for myself.' Another participant explained,

You want to try to manage it, and you don't want to lose your job, and, you know, it's like maybe if I hold tight enough, I won't succumb. After I was first diagnosed and did all my research... it's never ending—I thought I figured it out, not that I was secure, but I was like 'alright, next time, if there is a next time, I'll know what's happening, I'll have my doctors,'

People living with autoimmune illnesses learnt that they must 'take responsibility' for managing their conditions. Most concretely, this resulted in practices like conducting their own research and seeking providers whom they could trust.

In addition to a lengthy diagnostic process, people living with autoimmune illnesses also experience changes in diagnostic labels over the course of living with an illness. Even after a narrow diagnostic label was achieved, the diagnosis could continue to change depending on information produced by tests and the types of specialists consulted. Many participants reported how shifting diagnoses was part of living with illness. Highlighting this process, a participant living with lupus explained, 'I have had ANA positive, ANA negative,' referring to a diagnostic test used to indicate lupus. When the test produced an ANA positive result, it confirmed the lupus diagnosis. When the test produced an ANA negative result, it did not. This is not an example of 'misdiagnoses' becoming 'the correct diagnoses.' The back and forth, or shifting between diagnostic categories, is considered routine in autoimmune illnesses and is documented in the medical literature (Anaya et al., 2007; Davidson & Diamond, 2013). This may serve to normalise this experience for people living with these illnesses for some, but it also underscores the importance of the practices people developed in the absence of, or among shifting, diagnosis. A participant exemplified this experience when she explained her diagnostic journey:

[It was] radically impacting my life. I couldn't get it under control. So I went to a second doctor. I kept the rheumatoid arthritis diagnosis and I think it was about four years into the disease after some doctor had made a mistake on the lupus diagnosis. He had actually tested blood work right after I had done Remicade [medication]. Remicade gives you a false negative for lupus. It was my fourth doctor that finally said, "Oh my God. You've got mixed connective tissue disease." It was about four to five years into the diagnosis that I finally actually heard about mixed connective.

Over the course of those years, she tried multiple different kinds of pharmaceutical regimens, as well as enacted changes to her diet and pursued acupuncture. With this illness experience, people feel unwell and unable to participate in their lives (e.g., relationships, activities, work) like they previously did, which is why they seek medical advice. Well aware that something is wrong, they seek providers who are comfortable with diffuse, changing symptoms and work

with them to secure a diagnostic label that may change overtime. Here, the illness experience is marked by long time horizons—our participants did not describe a sudden disruption of one's biographical self when diagnoses were achieved. Instead, the diagnosis was valued because it provided a steppingstone to legitimacy and to access medical treatments and societal support (e.g., disability insurance) as others have described (Halpin, 2021; Nettleton, 2006). Patients work to gain control from the onset of their illness journey, researching symptoms, possible causes and providers. The diagnostic label, which may change over time, is just one of many markings that is embodied and shapes the lived experience of illness (Zola, 1991). Living with illness becomes central to participants' identities.

Case 3: Diagnostic journeys marked by disbelief and denial of care

The final case we turn to is one in which patients feel that their pain and symptoms are not taken seriously by health-care providers, leading to lack of and/or prolonged diagnoses and tense health-care relationships. While we draw on studies of previously incarcerated women and their health-care experiences to illuminate how this experience shapes practices of patienthood, this pattern is likely also found in other totalising institutions, such as mental health facilities and nursing homes, where people are particularly vulnerable (Ben-Moshe, 2020; Goffman, 1968).

For many incarcerated women, diagnoses occurred after they were released from prison even though they experienced symptoms throughout their time in prison. As with the previous example, people noticed changes in their bodies long before achieving a diagnosis and seldom had their experiences taken seriously early on. But this denial was exacerbated for incarcerated women, who had to create illness identities with delayed or nonexistent interventions by clinicians and within a punitive environment. Reflecting on their experiences, participants reported a range of emotions. Some felt angry—very angry—that they were treated this way by a system, especially when they remembered friends who died due to poor medical care or neglect. Others approached this more matter-of-factly: this was the reality in their community. They did not expect that they would or could access more timely or responsive care. One participant described waiting for care, saying:

You go to sick call, 7 o'clock in the morning. [At] 3 o'clock in the afternoon, you're still sitting in the clinic. You ain't been seen yet. You haven't even had your vitals taken yet. Because they [are] doing so much. So the overcrowding, the mass incarceration created a lot of these medical situations that we have because they didn't have enough people to give us the care that we needed.

In both this case and the case prior, patients who are unable to receive a timely diagnosis feel the structural limitations of both biomedicine and fragmented health-care systems. In both cases, patients may feel dismissed or that their experiences of illness are not taken seriously. In this case, the waiting was less about the uncertainty of diagnosis and more about both the structural limitations of prison health care and the lack of humanity and care many patients feel is embedded in the system. While some patients in the free world may experience this lack of care (and perhaps for the first time) during a diagnostic journey, incarcerated patients are always already treated as a not-to-be-believed other in their daily life. Beyond just waiting for care, which may be based on real structural limitations outside of the control of health-care providers, achieving diagnoses was perceived to take longer based on their incarcerated status.

Patients described not being treated with humanity and respect in care settings; they were treated as *less than* by the system and that extended to health-care interactions:

[When] you're in there, you don't have no rights. They are going to do what they want to do because they can get away with it. That's what they think.... You know, doctors and nurses are supposed to be caring people. If they had people that were really like that, things could change.

Like this participant, other participants perceived a lack of control in the clinical encounter and explained that they had little autonomy in their care decisions. Moreover, there was a pervasive idea that prison health care serves to treat symptoms rather than diagnose illness and that the care they did receive was 'limited.' As one participant put it, they 'just give you the medication to control your cholesterol, to control your high blood pressure and that's it.' More complex diseases, and in particular illnesses where pain was a primary symptom, would often go undiagnosed and undertreated with only over the counter medication such as acetaminophen offered as the primary intervention. This led many patients to markedly demonstrate the severity of their illness or what they called 'Going Hollywood' in order to trigger a diagnostic workup. A participant described,

We had this phrase, "Go Hollywood" you know, so that somebody will listen to what really is wrong with you. Because if you just tell them you're having a hard time breathing, they are not really going to pay attention to you... You had to go to extremes and really explain to them... "I'm having difficulty breathing, I'm having heart palpitations." And make it really extreme, dramatic so that they would listen to you.

Because it was a challenge to be taken seriously and not have one's symptoms dismissed, many participants became accustomed to dealing with pain or symptoms without care. Another participant explained it this way:

It's hard because people sort of get reputations in there. And if your reputation is of being a malingerer, you could have a broken arm and they'll say, "oh, come on, you're just trying to miss work," you know. It's tough. It's hard.

If a patient has a negative reputation, her symptoms may not be believed; this is especially difficult in an environment where everyone is viewed as an 'inmate' first and a patient second (James, 2021). Nearly all participants described being told 'nothing is wrong with you' over and over again, often within the context of an assumption that a patient was reporting symptoms in order to miss work or 'cheat' the system in some other way. Thus participants felt they had to 'prove' their illness. One woman described how a simple illness such as bronchitis, gone undiagnosed and undertreated, led to a much worse condition. As she described,

I got bronchitis. I had issues with bronchitis my whole life so I know when I have bronchitis, I know when I don't. But I went to the doctor and I told her, 'okay, I've got bronchitis. Help.' And the doctor told me, 'no, you don't have bronchitis, you have a cold.'

Her doctor refused to treat her bronchitis and she experienced months of worsening symptoms before finally being seen struggling to walk and breathe by another doctor in the hallway. This doctor insisted she have a chest x-ray, which confirmed bronchitis.

This experience of substandard care—and the constant assumptions that incarcerated women are undeserving of care or not in need of care—has consequences beyond prison where people still feel uncomfortable seeking care. In some cases, these experiences of denial resulted in the internalisation of the belief that they did not deserve care and that nothing was wrong with them or worse that they were fabricating their symptoms. One participant explained that this experience, and how she internalised it, shaped her current health-seeking practices:

I've been told I didn't need this, I didn't need that for so long, I almost started believing it, you know.... So [now] when I have five people tell me to go to the emergency room, I'm like, "I can still walk guys, I'm good." So it's strange for me....I still don't like to make a fuss.

For these participants, their diagnostic journeys—and experience of patienthood—were bound up in their experiences of being under-cared for, under resourced and disrespected. Another explained, 'Yeah, it's still weird. Now I don't do it. Because I still haven't been to [the doctor], because I feel like I'm taking advantage of something.' When asked why she felt this way, she said, resigned, 'I don't know.'

Participants often wondered how much of their illnesses could be attributed to time in prison, and if things were worse because of the substandard care they received. There were no answers to these questions, of course, but the feelings of mistreatment and neglect shaped how they experienced their illnesses. For some, this led to actively seeking health care once released in order to make-up for lost time. One participant explained,

I don't know if it's because I'm 59 years old, if this was going to happen anyway or if it's because of me being in prison and what was going on in terms of the living conditions. I don't know. But I'm trying to get a handle on it and I was able to have my first doctor's appointment yesterday. So she's going to do a battery of tests for me.

Participants compared their experiences of seeking care within and outside of prison with the latter being universally better. One participant said,

So when it comes to medical care, so far, [comparing outside care to inside care] it's night and day. It's night and day. The fact that they said I've had this hernia... Because I've had this pain in my stomach and back, and I had a bleeding problem for a long time. I've had it for about four years... Yeah, the [department of corrections] is negligent... It's very hard to get any type of care there. It's very difficult. And that's why I say it's night and day because I've been finding it pretty simple out here for me to get care.

Experiencing diagnostic journeys marked by disbelief, structural and resource limitations and a constant assertion that 'nothing is wrong with you' led to fraught and prolonged searches for answers post incarceration. In the United States, health-care experiences while incarcerated varies dramatically. The lack of social safety net in the United States means that, for many, accessing any health care at all may offer the opportunity to improve health status when health care

is otherwise financially unavailable (Oser et al., 2016). Indeed, for some prison can be a place where people can reliably access care, and research has shown that many patients are diagnosed with chronic conditions for the first time while incarcerated (Nijhawan et al., 2010; Sufrin, 2017). For those in this study, however, the lack of attention and care led to delayed diagnoses and worsening conditions that, once diagnosed, required more invasive interventions and treatment.

DISCUSSION

Our findings demonstrate how diagnostic journeys and illness experiences are intertwined, with different diagnostic pathways impacting how illness is experienced. All three examples demonstrate how patienthood is experienced by connecting individual biographies with social structures such as the rise of surveillance medicine, the decentralisation of and increased access to medical knowledge and total institutions. Our examples show how the diagnostic utterance is often not an 'aha!' moment, but rather one moment that is embedded in the entire journey of experiencing illness, and more broadly to the social positioning of patients and the regimes in which they are situated. Each of the categories we present demonstrates how the diagnostic journey shapes the practices of patienthood in distinct and overlapping ways.

For those learning of a diagnosis through routine screening, the jolting nature of their diagnosis—and the cascade of intervention and treatment that followed—led to an illness experience in which they often rejected an illness identity. Their diagnosis was jarring because they felt healthy and this dissonance, along with the swift intervention, led some to resist labelling themselves as cancer patients and survivors (Leake et al., 1999). Diagnosed through a surveillance programme, they were quickly taken through a highly biomedicalised treatment plan. They did not feel they had time to really sit with their diagnosis, to make meaning from it, or explore treatment options, because of the whirlwind of interventions that ensued. The diagnosis of breast cancer was swift, and the newly diagnosed participants—now patients—were expected to comply with haste. In many ways, these patients experienced what those in the second case were hoping to achieve through diagnosis: clear next steps and an expected course of treatment to manage the disease.

In stark contrast to sudden diagnoses, for people living with autoimmune illnesses the diagnostic process was a long, grueling journey to establish a care regimen that worked to manage their chronic illnesses. For people who experience symptoms that do not fit neatly into contemporary diagnostic categories, the diagnostic utterance is just one experience that happens during the course of the illness experience instead of marking its beginning (Brown, 1995; Nettleton, 2006). Because diagnoses often came after years of searching and may change over the course of one's illness, while the diagnostic label was meaningful for communicating to others and, for some, validation that their symptoms were real (Barker, 2005; Joyce & Jeske, 2020), it was not always a crucial moment that dictated care regimens. Indeed, patients developed strategies to work with clinicians and to manage their care in the absence of or changes in diagnosis. They quickly learnt how to perform patienthood in particular ways—ones that rendered them 'good' or compliant patients. But they also developed a sense of control over their journey: they learnt how to find collaborative clinicians, communicate their symptoms and experiences in specific ways and developed care regimens that worked for them, drawing on biomedical care as well as beyond it.

Tracing diagnostic journeys marked by the delay or denial of care and a loss of control, we showed how patients in particularly marginalised positions navigated tense health-care relationships and their journeys to be diagnosed and cared for. Here we showed how the ability to

become a patient—and to have one's symptoms and pain cared for even in the most basic sense—is not a guarantee. In this case, illness experiences exist without systematic diagnostic workups or care. The ability to achieve diagnoses and perform patienthood is hindered by the other identities thrust upon incarcerated patients; they are 'inmate' first and patient second (James, 2021). Formerly incarcerated women's experience of seeking care while incarcerated informed how they experienced illness and navigated health-care settings once released. For some, the disrespect and lack of care they experienced during their diagnostic journeys led them to fight for better care once released, while for others these experiences led them to avoid, delay, or altogether reject, seeking care.

Each of these cases highlight the profound role that the diagnosis journey plays in the ways in which illness is experienced and patienthood is performed, and how patients' social positions shape both the diagnostic journey and illness experience. Across our second and third cases, we point to specific practices that people develop to manage living with illness prior to the ascertainment of a diagnosis. In response to interactions with providers in which people felt their symptoms were not taken seriously by providers, in case 1 we observed how this led middle-class participants to seek trustworthy and collaborative care providers and take control over their condition. But in a carceral environment, in case 2, we observed how this was internalised such that previously incarcerated women did not feel worthy of care. We also observed how participants practiced control: in case 2, participants were able to take some control/autonomy back through their development of practices that allowed them to manage their illnesses in the absence of a diagnosis. Comparing case 1 and case 3, the intersectional dimension is particularly stark because in case 1 while there was no control over the immediate cascade of intervention, this led to swift care and treatment of cancer. Lack of control did not mean lack of care. Yet in case 3, this lack of control led to delayed (or never) diagnoses. Alongside the internalisation of the experience of being treated as 'less than,' the denial of care exacerbated illness.

The specific contours of diagnostic journeys shape how these experiences get taken up in one's identity (or not) and how illness experiences are interwoven with biomedical knowledge and health care interventions. Our analysis demonstrates that diagnostic journeys and illness experiences are intimately intertwined and cannot be bracketed. Bringing these two aspects of illness together enables a deeper understanding of how diagnostic journeys and processes impact illness experiences, the regimes that shape the practices of patienthood and the power dynamics that constrain and enable them.

AUTHOR CONTRIBUTIONS

All authors contributed to data collection and data analysis. Jeske, as lead author, took the lead on writing and revising the manuscript; Jeske, James and Joyce contributed to the writing, editing and revising of the manuscript.

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DATA AVAILABILITY STATEMENT

Given the difficulty of anonymising data from the studies in this manuscript, data is not available. Sharing data would breach ethical compromise ethical standards and commitments to study participants.

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ENDNOTE

¹ James' studies recruited cis and trans women, trans men and non-binary individuals. All participants included in the analysis for this article were identified as women. Joyce's study was open to anyone living with autoimmune illnesses and included self-identified men and women, but did not ask about trans status.

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