

REVISITING THE SICK ROLE: PERFORMING REGIMES OF PATIENTHOOD IN THE 21ST CENTURY

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ABSTRACT

Beginning with the sick role, sociologists of health and illness have characterized how illness behaviors and experiences are deeply social (Bury 1982; Charmaz 1991; Corbin and Strauss 1988; Williams 1984; Williams 2005). Building on the emergent use of patienthood (Erikainen, Pickersgill, Cunningham-Burley, and Chan 2019; Kerr and Cunningham-Burley 2015; Sosnowy 2014; Vinson 2016) and regimes of practice (Bell 2009; Klawiter 2008, 2004), we develop the concept regimes of patienthood to theorize how illness behavior is socially constructed, connecting individual biographies and social structure in historically specific ways, with power and resistance visible at all times. Drawing on analysis of 45 in-depth interviews conducted with United States [U.S.] residents living with autoimmune illness, we argue that contemporary regimes of middle-class patienthood emphasize four main strategies: 1) becoming a knowledgeable patient, 2) cultivating collaborative relationships with clinicians, 3) using a broad repertoire of healing techniques to manage and limit symptoms, and 4) putting themselves first. These illness behaviors are produced by and contribute to structural forces such as the cultural emphasis on the active patient, the digitization and decentralization of knowledge, the valorization of collaboration, and individualism. Although intimately intertwined with social forces, use of the four strategies allowed participants to manage unpredictable illness conditions and regain a sense of control over their bodies and lives.

INTRODUCTION

With the introduction of Talcott Parsons' (1951) concept the sick role, sociologists began to understand that the way people behave when ill is a socially produced role. It is not ahistorical or natural, but, like other roles, is comprised of social norms and interactions. These insights led to research that investigated how the sick role varies by gender and ethnicity (Mechanic 1964; Zola 1966, 1973), how chronic illnesses vary from acute illnesses (Fox 1989; Parsons 1975), when and why people adopt the sick role (Mechanic and Volkart 1961), and how power structures relations between clinicians and patients (Hahn 2001; Stiggelbout and Kiebert 1997; Young 2004). Although some still use the sick role (e.g., Glenton 2003; Mik-Meyer and Obling 2012; Varul 2010), its use declined in the 1990s. The move away from the sick role occurred for many reasons, including that it did not prioritize patient perspectives and experiences (Reir 2010), its perceived ties to structural-functionalist sociology (an approach that sociology has moved away from), and that it had been generative, creating a rich body of research. Sociologists, like society, move onto to new ideas and topics including a focus on health instead of illness, medicalization,

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and the experience of illness (Burnham 2012; Gerhardt 1989; Williams 2005). And, although researchers expanded the sick role to highlight how such roles vary, the concept still carries the legacy of Parsons' very precise definition, which may have hindered the term's ability to evoke the varied, changing practices of societal expectations for illness behaviors. The concept is known as *the sick role*, after all, seemingly not open to the possibility of variation despite scholars' efforts.

As the sick role fell out of use, sociologists continued to investigate the norms that comprise illness behavior, but they did so as part of their important investigations of broader trends in medicine such as medicalization (see, for example, Barker 2008, 2014; Bell and Figert 2012; Clarke et al. 2003; Conrad 2007). In this literature, the norms that comprise illness behaviors was part of the larger project of examining the rise of pharmaceutical companies and the creeping expansion of diagnostic categories and interventions, showing how the expectations of and for patients shifted in the wake of changes in medicine. These analyses did not center the patient experience, instead they showed how social forces shaped the conditions of possibility for becoming a patient.

Other scholars have turned to the concepts patienthood (e.g., Erikainen et al. 2019; Kerr and Cunningham-Burley 2015; Sosnowy 2014; Vinson 2016) and regimes of practice (Bell 2009; Klawiter 2008, 2004) to describe the norms and expectations for one's behavior when ill. As with the sick role, patienthood calls attention to how the response to illness is socially structured. Coming primarily from anthropology, the concept patienthood draws on the discipline's use of the term personhood to describe how the self is socially constructed and varies across time and regions (Appell-Warren 2014). Patienthood highlights the varied, social processes that constitute how a person responds to illness as well as how a person might resist such practices and norms (Landzelius 2006). In contrast to the sick role, where researchers had to open up the concept to show variance, patienthood has a legacy of openness that evokes how illness behavior varies across time and place, and this term is beginning to be used by sociologists (see, for example, Erikainen et al. 2019; Kerr and Cunningham-Burley 2015; Vinson 2016). Regimes of practice, developed by two sociologists, Dr. Susan Bell (2009) and Dr. Maren Klawiter (2008, 2004), conceptualizes how people's way of performing illness and treatment is situated in larger social structures. This concept highlights how individual behaviors and choices are informed by institutional practices, knowledge, cultural contexts, collective identities, and policies and regulations, and how these behaviors in turn can reinforce or transform institutional practices, cultural contexts, collective identities, and regulations. Both concepts—patienthood and regimes of practice—are slowly materializing in the literature yet scholars have yet to explicitly situate their use as replacements for the sick role.

Building on the emergent use of patienthood and regimes of practice, we develop the concept *regimes of patienthood* to evoke how illness behavior is socially constructed, connecting individual biographies and social structure in historically specific ways, and highlighting power and resistance. Combining the two concepts ensures that the anthropological emphasis on the varied cultural construction of self (patienthood) and that the sociological focus on power and structure (regimes of practice) is integrated and foregrounded. Such a move addresses some of the reasons the sick role fell out of use while simultaneously providing a theoretical tool to understand the social construction of illness behaviors in the 21st century.

Drawing on a grounded theory commitment to generate theory by analyzing people's experiences and knowledge, in this article we investigate the norms and practices that structure contemporary illness behavior in the United States [U.S.] by investigating how people live with autoimmune illnesses. Autoimmune disease has become a salient way of categorizing a range of chronic diseases. More than 80 illnesses are considered autoimmune or autoimmune related—these include illnesses such as lupus,

multiple sclerosis (MS), type 1 diabetes, rheumatoid arthritis, and Crohn's disease, as well as less known illnesses such as mixed connective tissue disorder (MCT) and Guillain-Barré Syndrome (GBS). As lifelong conditions that may have complex diagnostic processes, unpredictable cycles of symptoms, and medical treatments that at best manage (not cure) an illness, autoimmune illnesses provide a rich site for sociological analysis of the norms and practices that comprise contemporary regimes of patienthood.

In this article, we draw on 45 in-depth interviews conducted with U.S. residents living with autoimmune illness to show how contemporary regimes of middle-class patienthood emphasize four main strategies: 1) becoming a knowledgeable patient, 2) cultivating collaborative relationships with clinicians, 3) using a broad repertoire of healing techniques to manage and limit symptoms, and 4) putting themselves first to promote health. These behaviors are both produced by and contribute to structural forces such as the cultural emphasis on the active patient, the digitization and decentralization of knowledge, the valorization of collaboration, and individualism. Research that investigates regimes of patienthood advances sociological inquiry *and* creates knowledge that will help patients, clinicians, and policy makers navigate illness and health.

THE RISE OF AUTOIMMUNE ILLNESSES

Autoimmune processes began to be documented in the 1950s and 1960s (Anderson and Mackay 2014; Mackay 2010). Autoimmunity describes how a person's immune system attacks healthy parts of the body (Rose and MacKay 2013). It was initially difficult for research scientists to accept that autoimmunity exists; the idea that a person's immune system might attack healthy cells and tissues seemed counter to evolutionary logic (Silverstein 2001). Early scientists thus characterized autoimmunity as a case of "misfire," that is, a case in which the body's immune system goes awry. Scientists now argue that low levels of autoimmunity may be beneficial, providing a mechanism for a rapid immune response in an infection's early stages and for clearing dying cells supporting the body's maintenance (Callier 2016; Schwartz and Cohen 2000).

Although autoimmune processes occur in healthy people, such processes can lead to illness, affecting different parts of the body, including the skin and connective tissues, the central nervous system, blood, and gastrointestinal and endocrine systems. The illnesses included under the autoimmune umbrella vary widely in their presentation, but their common thread is the immune response: a person's immune system attacks his or her healthy cells, tissue and/or organs. In some cases, such as celiac disease, where the cause is known (e.g., ingesting gluten sparks an immune response that targets the small intestine), treatment involves removing the item that triggers the immune reaction (e.g., gluten). In most cases, though, both a cause and a cure are unknown. Instead, most medical treatments aim to dampen the body's immune response to prevent the reaction from continuing; this process aims to manage symptoms (not eliminate the underlying cause), and can entail a lifetime of treatment.

Autoimmune illnesses are well documented in Europe and North America, with increasing incidence rates of autoimmune illnesses such as type 1 diabetes, multiple sclerosis, and rheumatoid arthritis (Agmon-Levin, Lian, and Shoenfeld 2011; Lerner, Jeremias, and Torsten 2015; Ramos-Casals et al. 2015). Estimates suggest that 3.2–9.4 percent of the population may be affected with autoimmune conditions depending on study parameters (Cooper, Bynum & Somers 2009). In the U.S., for example, the National Institutes of Health estimates that autoimmune illnesses affect more than 23.5 million Americans (NIEHS 2012; HHS 2012) whereas AARDA, a patient foundation, estimates the number to be higher, suggesting that approximately 50 million people live with autoimmune diseases in the U.S. (AARDA 2017).

AARDA's estimate is higher than the NIH's estimate because NIH's estimate only draws on 24 diseases for which rigorous epidemiology studies were available (instead of the 80 plus diseases believed to be autoimmune related). Autoimmune diseases involve multiple organ systems, including the central nervous system, blood, skin and connective tissues, and gastrointestinal and endocrine systems. Many autoimmune illnesses disproportionately affect women (Ngo et al. 2014; Pollard 2012). For people who live with autoimmune illness, navigating the illnesses' chronicity and medical treatments requires considerable work and care. Such work and care follows patterns that bring together agency and structure: in this article, we show how these patterns comprise a contemporary regime of patienthood.

RESEARCH METHODS

This research draws on 45 in-depth interviews with people who live with autoimmune illnesses in the U.S. Participants were between 20–67 years old. Autoimmune illnesses disproportionately affect women in the U.S., and as such our interviews were conducted primarily with women: of the 45 people interviewed, 35 were women and 10 were men. 40 participants identified as white, 2 identified as black, 2 as Asian, and 1 as Latinx. All participants were diagnosed with at least one autoimmune related illness at the time of the interview, e.g., celiac disease, Crohn's disease, Guillain-Barre syndrome, Hashimoto's thyroiditis, IgG1-related sclerosing disease, lupus, mixed connective tissue disease, multiple sclerosis [MS], psoriasis, and type 1 diabetes. The majority of participants self reported white collar, middle class occupations and were insured; 7 participants were students who reported that their parents have white collar, middle class occupations. 2 participants, who held white collar occupations in the past, were supported by social security disability income. Most participants had a four-year college degree, or were in the process of attaining one. Some had graduate level education.

Table 1: Self-Reported Age, Race, and Gender of Participants

Age	White		Black		Asian		Latinx	
	Men	Women	Men	Women	Men	Women	Men	Women
20–29	7	8	0	0	0	2	0	1
30–39	1	6	0	1	0	0	0	0
40–49	0	6	0	0	0	0	0	0
50–59	0	4	0	0	0	0	0	0
60–69	1	7	1	0	0	0	0	0

Participants were recruited by word of mouth, flyers posted about the study in community centers, and at patient foundation events. Participants were considered eligible for the study if they had been diagnosed with an autoimmune-related disease, were at least eighteen years of age at the time of the interview, and currently living in the U.S. To ensure regional diversity, participants were primarily recruited from California, Pennsylvania, and Virginia. Each interview lasted between 60 and 140 minutes, and included open-ended questions that asked participants to describe their diagnostic process, how they manage their illness, where they get information about their illness, and if and how living with illness has impacted their relationships, identity, and work. Interviews were conducted in person, over the phone, or over Skype by one of four research team members. The initial research team included a medical sociology professor, two graduate student research assistants, and one undergraduate student research assistant. After the undergraduate student and one of the graduate students graduated, the remaining team members continued to collect and analyze data. All interviews were recorded and transcribed and personal identifiers were removed from the data. The study protocol was approved by the Office of Research Institutional Review Board at Drexel University. ATLAS.ti was used to manage and code interview data. To ensure intercoder reliability, the two authors independently coded interview transcripts following the grounded theory tradition. Grounded theory methodology is an inductive, qualitative

approach in which researchers develop codes, diagrams, and memos to identify themes and concepts from data (Charmaz 2014; Strauss and Corbin 2008). Codes that emerged from analysis included the knowledgeable patient, the importance of collaboration with clinicians, the use of a range of techniques to manage illness, and an emphasis on putting themselves first to limit symptoms. All proper names of individuals, doctors, or hospitals have been changed to ensure confidentiality except for names on publicly available materials. All quotes used in this article have been edited to remove false starts and filler words for ease of reading.

REGIMES OF PATIENTHOOD: LIVING WITH AND MANAGING AUTOIMMUNE ILLNESSES

Regimes of patienthood identify the patterns of how people manage illness in a particular moment in time, linking these to larger structural factors. Patienthood, in other words, is socially situated, connecting biography and history in particular ways. Power and resistance are central to the practice of patienthood. In this article, we outline the four main activities used by the majority of participants, regardless of their age, race, or gender, to manage symptoms and cultivate health while living with uncertain, heterogeneous chronic illness. These include: 1) becoming a knowledgeable patient, 2) finding a collaborative physician, 3) using a broad repertoire of healing techniques to manage and limit symptoms, and 4) putting themselves first to promote health. Together, they comprise the regime of patienthood for participants in our study. Given the demographics of participants, this is a classed regime—one that evokes the values and practices of middle class, white collar people. Following scholars who study how social class operates and is cultivated, we define middle class by occupational and educational attainment to categorize our participants (Calarco 2014; Condrón 2009; Lareau 2003). Given that middle class values often operate as the unacknowledged social norm in a variety of arenas (e.g., education, medicine, law), investigating middle class values sheds light on broader social expectations.

As chronic conditions that require lifelong management, people who live with autoimmune illnesses struggle to adapt to the changes in their bodies and to the construction of a new, often invisible to others, way of life. Many participants highlighted the unpredictable component of living with autoimmune illnesses: flares and attacks often happen without warning. Similarly, what may be a trigger for a flare for one person with the same illness label might not be for others who share the diagnosis. The unpredictability and heterogeneity of autoimmune illnesses, coupled with lifelong medical treatments that usually aim to dampen the immune response, means that individuals bear the burden of figuring out strategies to live with and manage their illnesses (Stockl 2007). Individuals come to be experts on their bodies and conditions through developing a rich set of strategies that allows them to live well in the face of chronic illness.

RESULTS

Becoming Knowledgeable Patients

A key dimension of the regime of patienthood involved becoming what we call a “knowledgeable patient.” In the face of uncertain diagnostic processes, unpredictable cycles of flares and symptoms, and unsatisfactory experiences with clinicians and treatments, participants, regardless of gender, race, or age, described how they became knowledgeable patients. A knowledgeable patient is one who investigates their condition by researching and experimenting with strategies to manage symptoms and flares, and by building networks with others to learn and share knowledge. The search for knowledge included consulting physicians, using the Internet and libraries, talking with friends and family, and collecting and

crosschecking information in an iterative manner. When arriving at homes or places for interviews, participants would often bring out an expandable file that held test results, key articles, and/or correspondence with physicians. In our study, the expandable folder became an evocative object—one that visually evokes the experience of chronic illness in the 21st century.

Becoming knowledgeable patients was motivated by multiple factors, but often the uncertainty and dissatisfaction experienced during doctor visits coupled with the desire to feel better sparked the research quest. Autoimmune illnesses are heterogeneous and uncertain, and the impact of treatments varies. Because of this, patients often struggled to be heard by their physicians and to identify interventions that alleviated symptoms. Becoming knowledgeable or “doing research” as participants described it, became a way to fight feelings of disempowerment and identify paths toward recovery. As a participant living with Crohn’s explained, “It wasn’t until the mid 90s that I started researching [on my own] because at first I just said, ‘Well, okay, I’ll just follow what the doctor says.’ And that’s probably the best thing to do. But then I realized, okay, they don’t have the answer. I need to take responsibility for myself.” Further exemplifying this response, a participant living with IgG1 noted, “When you have a disease that’s outside the norm. [My doctor] is very good. They’re very dedicated. But here’s something that they’ve never seen. They don’t know what it’s about, and they don’t have the time to spend to research it. You’ve got to do that. You’ve got to do your own homework.”

Part of becoming knowledgeable included working with clinicians (in our data, most participants saw clinicians trained as medical doctors and referred to them as physicians). The knowledge quest often began by reaching out to physicians. As a participant living with MS noted, after experiencing symptoms, she “started going to doctors. I asked them what was going on.” Or, as a participant living with lupus noted, “I go in with questions [to my doctor]. I get all my answers. And he knows where to go for resources.” All participants included interacting with physicians as part of the process of doing research.

Reaching out to clinicians, though, was not enough. Because autoimmune illnesses can be difficult to diagnose and the impact of treatments varies, becoming a knowledgeable patient required additional work. To manage their illness, individuals used a range of strategies to learn about their condition, becoming experts in identifying and advocating for a range of possible treatments and interventions. First and foremost, participants highlighted the importance of using the Internet as central to becoming a knowledgeable patient. Exemplifying this response, a participant who lives with Guillain-Barré Syndrome stated, “If I want to know something, I Google it.” Or as another participant who lives with rheumatoid arthritis explained, “I do everything on the Internet.”

Although participants liked that the Internet has a wide range of sources, participants were critical consumers of web-based health information, commenting frequently on the need to pay attention to the quality of sources. Exemplifying this point, a participant living with lupus noted, “If I have a specific question, I might do my own search in articles, Google topics, but I’m also careful which websites I use.”

Although the Internet was the primary search tool, approximately one third of participants (14 participants) turned to libraries, patient foundation newsletters, magazines, and/or books to become knowledgeable about their illness. A participant living with lupus noted, for example, how after her diagnosis, “The first thing I did was go to the library and get a book on lupus.” Or, as a participant living with GBS explained, “I like their [GBS Foundation] newsletter. I think they put it out quarterly. So that’s nice to have.” Most participants, though, relied on virtual sources of knowledge over printed materials.

Online videos accessed through platforms such as YouTube were another valuable source of knowledge that participants used to acquire expertise. Participants used YouTube to watch other people use technologies and techniques, which in turn helped them learn how to use these techniques on their own. A participant living with Crohn's exemplified this pattern when she explained, "I've learned a lot. I give credit to the people who put the videos on YouTube and showed me all the tricks on how to change it [the ileostomy stoma bag], how to keep it from leaking. All of these things. They are all young people—twenty something—who were brave enough to do it."

Similar to how online videos were used, three participants explained that they used online message boards strategically to find answers to particular questions. A participant living with Crohn's explained, for example, how she used, "those boards to figure out ways to come up with ideas about how to stop different problems like leaks. Those things were valuable."

Participants also drew upon friends and family's knowledge to increase their expertise. When asked what are your best sources for information about your illness, a participant living with mixed connective disorder answered put it succinctly, stating "Friends and google." Or, as a participant living with MS explained, "I have a friend who's a nurse whose husband has MS. She gives me a lot of information." A participant living with GBS explained, "My niece has a friend that has it [GBS]. As soon as he heard that I had it, he came to see me right away." For participants, friends and family were an important resource; friends and/or family members may live with or know of people who live with a particular illness and can share strategies and information. When diagnosed, many participants described how friends and family put them in touch with others who had the same diagnosis, highlighting the importance of biosociality in regimes of patienthood (Rabinow 1996).

As participants acquired information, they would fact check it against other sources. The process of becoming a knowledgeable patient was one where participants were critical consumers of information, iteratively checking information against other sources in order to evaluate techniques and treatments. Exemplifying this iterative process, a participant who lives with type 1 diabetes explained how a speaker at an event "talked about how he was going to try to change that (the device) to check people's blood sugars as well. So instead of having to prick my finger to get blood out and put it on the test strip, I could just kind of like do a breathalyzer type thing into my iPhone, which would definitely—it would be a lot easier. It would be a lot more convenient but—when I hear about things like that, it's kind of interesting. I definitely go on the Internet and look it up." As this participant learned about a new technique, he further researched it to see whether it was worth pursuing.

Participants overwhelmingly rejected social media as a key information source. When asked if they used social media to learn about their illness or create community, most participants simply said no. Exemplifying this response, a participant living with MS explained that "I have never tweeted. I have a Facebook page. But Facebook has never helped me with MS." Another participant living with type 1 diabetes noted, "I don't really learn too much about [it] over social media." When asked directly if she uses social media, a participant with GBS stated, "Nah, nah. If I want to know something, I google it."

Although four participants actively participated in and benefited from support groups, the majority of participants did not use online or in person support groups to become knowledgeable patients, contrasting with previous research that has shown how Internet support groups for chronic illnesses such as fibromyalgia are an important part of the illness experience (Barker 2008). For many participants, support groups were perceived in a negative way. Groups were places where people lived *in* the disease, instead of *with* it. A participant living with Crohn's exemplified this viewpoint when she said, "It was all

too touchy feely for me. I am not into that kind of thing. I tried it. It was just a bunch of whiners. I mean, that's how I looked at it. A bunch of people who wanted to go on and whine about what their problem of the day was. I just found it to be very annoying and disempowering." Support groups were perceived as places where people complained instead of coped. Still other participants noted that they did not participate in support groups because group activities were not their thing. A participant living with lupus illustrated this pattern when she noted, "I'm not really a groupie." For this subset of participants, group activities were less appealing in comparison to one-on-one interactions. Although the reasons for rejecting support groups varied, the majority of participants in our study reported that they did not participate in support groups: it was not part of their quest for becoming knowledgeable patients.

In all, participants reported that they had to do research and become knowledgeable to regain a semblance of health, wellbeing, and control. Highlighting the link between knowledge and control, a participant who lives with mixed connective tissue disorder explained, "I believe very strongly that if you want to be in control of something you have to be knowledgeable, because you're just going to lose control of who you are to someone else." Or as a participant living with MS noted, "I know a lot of people, several people that have the diagnosis of MS, and have just said, 'Okay I'm going to sit on the sofa and watch TV until I die.' And basically, that's what they've done. They've gotten worse and worse and worse. When I get worse and worse, I fight it. I start doing research, start doing something new." Information from clinicians, Internet searches, books, articles, online videos, and personal networks were crucial to this effort.

Collaborating with Clinicians

Scholars have described how the cultivation of cultural health capital (CHC), that is, learning and performing biomedical intelligence and communication skills, is important in encounters with physicians. Patients who develop CHC are able to optimize their clinical encounters by demonstrating a proactive stance toward health, a knowledge of medical topics and vocabulary, and relevant communication skills, among other attributes. In doing so, they are able to have more satisfactory experiences in healthcare settings (Shim 2010). Certainly, participants in our study developed CHC throughout their knowledge quest and positionality as middle-class adults (Lareau 2003; Shim 2010), but importantly they also developed their own expertise about their conditions and sought providers who respected this knowledge. They sought physicians who would be partners in their care, developing long-term relationships with doctors who recognized their bodily knowledge and experiences as valuable and credible.

Most participants in our study saw multiple clinicians in various specialties and traveled many miles before finding a physician with whom they could work. Because of the unpredictability and variability of autoimmune illnesses, medicine's limited knowledge about the causes of and treatments for autoimmune illnesses, and the emphasis on compliance and efficiency in healthcare, it can sometimes take a while for patients to find what they call the "right" doctor. But, what do participants mean by the "right" or a "good" clinician? Across all interviews, participants articulated their view of the ideal clinician—one who listens and thinks outside of the box, employs modes of communication beyond the face-to-face visit, and participates in a partnership where patients are seen as experts about their bodies. We call this ideal physician a *collaborative physician*, highlighting participants' emphasis on partnership, communication, and trust.

For participants, the ideal clinician is one who listens and is willing to try different strategies. Highlighting this dimension of a "good" doctor encounter, a participant living with MS explained how her doctor "would ask all the questions that she needed to ask me. I would tell her everything I could tell

her...she is a doctor that thinks outside of the box. She doesn't say, 'Okay I went to medical school and they say 'if you have MS you've got to do this and this.' And so I would say, 'These are my symptoms,' and she would say, 'Why don't you try this for this symptom? And why don't you try this for another symptom?'" Honesty was a crucial component of communication with doctors. Participants depended on the ability to be straightforward so that a productive discussion could occur.

Being honest and open meant being able to tell the doctor when they did not comply with medical instructions. As a participant living with Crohn's explained, "I actually called my doctor and sort of fessed up about what had been going on. Told him. At that point, I was afraid that I had gone so long that he was going to be really mad that I hadn't called him. Or mad that I hadn't been treating with the prednisone and all these things. He was just glad that I called. He got me into to the emergency room and he met me there." Participants reported that it was important to be able to tell the doctor when they did *not* follow medical advice, and, in that telling, have the doctor respond without judgment or scolding.

The ability to contact clinicians outside of scheduled face-to-face visits was emphasized as central to a collaborative relationship. Highlighting this point, a participant living with type 1 diabetes stated, "Sometimes I'll email my doctor. You know he's always asking about—because your body is so dynamic where your insulin resistance changes so much. So with careful monitoring, you can record how these changes happen [and] then your doctor can make some adjustments to your insulin regimen and switch some things around. So that's kind of helpful. Being able to shoot emails back and forth." Yet another participant living with psoriasis explained, "The doctors that I have worked with, I've worked with for so long, are pretty wonderful. I hear back pretty much instantly. Also some of the doctors I have now have online portals and I can chat them." Such exchanges help manage illnesses with unpredictable symptoms and treatment responses, keeping people out of hospitals and clinics.

Finally, the collaborative physician is one who participates in a partnership. Participants emphasized the importance of finding a physician who views patients as partners *and* as knowledgeable experts about their bodies and conditions. As a participant living with Crohn's summarized, "One of my doctors once said to me, 'You know more about this than I do, so I'm taking your lead.'" Or, as a participant living with mixed connective tissue disorder related, "My grandmother taught me, who had chronic illnesses as well, is that you have to learn to say, 'No and stop.' You need to be able to hold to that and not bow to the sense of authority or power that doctors have. They simply have that because we've imbued them with a lot of power and significance within our culture. I think it's important that I answer that. They're supposed to be a partner. They are not supposed to be a director of what happens."

Participants acknowledged that clinicians who were willing and able to listen and communicate were hard to find—it took time and effort. A participant living with lupus emphasized this when she stated, "It is hard to find a doctor that understands what you need." Or as a participant living with Crohn's concluded, "A lot of doctors don't like patients who are not going to follow their directives. I met a lot of doctors who are like, 'If you don't want to do what I am telling you to do, then find another doctor.' And, I'd say, 'Fine.'" When participants found collaborative physicians, they developed longstanding relationships with them. They saw collaborative physicians as critical to their wellbeing and deeply respected doctors who respected and valued them.

Using a Broad Repertoire of Healing Techniques

The third dimension of the regime of patienthood highlights the variety of strategies and techniques participants used to manage symptoms and create health. For participants, medicine was just one of the many strategies they used to cultivate health and wellbeing. Low-tech practices such as heat,

self-massage, rest, meditation, and prayer were central to living with autoimmune illness. While the majority of participants in our study regularly visited clinicians and took some type of prescription medication to manage their symptoms, their management routine included learning how to incorporate low-tech strategies such as heat and sleep to manage pain, inflammation, and flares. This rich combination of low- and high-tech practices were critical to living with autoimmune conditions and being able to participate in daily life. Such a combination, where medicine is one of many strategies used, has also been found in how old people manage aging (Loe 2010) and queer women try to achieve pregnancy (Mamo 2007).

Participants regardless of gender, race, or age explained how simple, low-tech strategies such as heat and self-massage were crucial to managing pain and participating in their lives. Exemplifying this use of low-tech techniques, a participant living with lupus remarked, "Your joints ache. It takes you a little longer to get ready. So, usually I get up 5:30 [in the morning]. You take a nice warm shower, get your bones warmed up, have a heater in the bathroom, bring your clothes in there with you so when you leave the bathroom, you're dressed." Yet another participant living with GBS mentioned, "I just try to rub it or massage it. Or the same, sometimes if I get them [spasms and tingles] in the legs. Which I really don't, but if I do, sometimes patting helps. If I get one in my foot, really just tapping and massaging."

Rest and slowing down was another strategy articulated by the majority of participants. When asked how she manages her illness, a participant living with MS exemplified this pattern when she explained, "You need to slow down and listen to yourself. You need to slow down and listen to your body." As part of slowing down, she, like other participants, prioritized sleep, naps, and rest. Further highlighting the importance of pacing oneself, a participant living with lupus stated, "I would sleep on Saturdays and Sundays and rest. So again, it's a balance." Paying attention to one's body and making the time to rest were key components of managing illness.

Approximately one third of participants (16 participants) described how they use contemplative practices of prayer, meditation, and/or yoga to manage their illnesses and to cultivate hope and strength. Exemplifying this practice, a participant with lupus noted, "I am lucky I have a very good foundation in scripture and prayer and theology and some theologians that have buoyed me up over the years." Another participant living with lupus stated, for example, "Because I got it in my mind that the Lord is on my side, and I was going to make it. I have a great faith in Jesus Christ. That's who I depend on." Another participant living with MS found peace in the practice of yoga: "The doctors confirmed that things were not, you know, going to hell in a hand basket. So I started doing yoga. And it made a huge difference. It made a huge difference in my life." A woman living with lupus explained how yoga "helped directly with the lupus as well because of the joint problems. And also the relaxation. You know all of that really helps to calm the whole body. With lupus, when you're in a flare up, your body is not calm. Everything is awry it seems. And so if you can get to that place, that deep breathing, I really do think that it benefits the joints and calming the flare of the rashes." Although not used by the majority of participants, prayer, meditation, and yoga allowed some participants to access quiet and calmness in the face of pain and discomfort.

Approximately one fifth of participants (10 participants) described how they tried complementary health techniques such as acupuncture, Ayurvedic medicine, chiropractic, or healing touch to try to manage their illnesses. Of these techniques, acupuncture was the most popular with six of the ten participants reporting having tried it. Highlighting how acupuncture helped her, one participant living with lupus explained, "The acupuncture was immediate relief of pain and it seemed to help. Out of the three [chiropractic, acupuncture, massage], I'd say acupuncture helped me probably more but it was so expensive. I didn't go back." Commenting on the power of healing touch, another participant living with

lupus reported, “It really worked...I can show you better than I can tell you. They run their hands down to your hips and to your feet. Then they keep doing it. Then they feel where the clog is and then they work that area. They smooth it out. You can feel a difference.” For the most part, though, participants did not use complementary health techniques to achieve wellbeing.

In all, participants developed and used a rich set of strategies to manage and limit symptoms. Summarizing the importance of using a variety of therapeutic techniques, a participant living with lupus pointed out that people needed, “to have a more open mind about it, explore different ways of dealing with disease—with lupus and other autoimmune diseases. The people I know are the healthiest, are all people who have tried alternative ways of helping themselves... a lot of them have tried certainly with diet and acupuncture, meditation, yoga. All of my friends are into those kinds of things and exploring outside the medical profession. None of them are averse to taking a medication if they feel they need it. But given what we know about the side effects of a lot of these medications, I think a lot are wiser about that—at least my friends are. I’m sure a lot of people are.” In our study, participants used biomedicine *alongside* a range of other, often low-tech, practices such as heat, self-massage, and rest to promote health and minimize flares. A subset of participants also reported using contemplative practices and complementary medical technique to manage symptoms. Such a broad repertoire allowed participants to regain a sense of control over their lives and make living in their bodies more bearable.

Putting Themselves First

The final dimension of the regime of patienthood that participants articulated was making empowering life changes in order to put themselves and their wellbeing first. For example, participants described how they ended relationships or quit jobs in order to support a calm life. They hoped that such a lifestyle would minimize symptoms and flares. Although medical sociology literature has portrayed chronic illness in a negative light emphasizing how a sense of time becomes restricted (Charmaz 1991), a sense of self is lost, or how biography is disrupted (Bury 1982), participants in our study repeatedly called attention to how illness served as an impetus to make what they perceived as needed life changes. Calling attention to medical sociology’s tendency to accept hegemonic understandings of illness as disempowering, Williams (2000 p.41) writes, “the critique, from within the disability movement itself, of ‘personal tragedy’ views of illness—in which medical sociology is said to be complicit—and the call for a more thorough-going model of disability as ‘social oppression.’” For participants in our study, their experiences with autoimmune illnesses empowered them to make major life changes; while their lives may have needed to change in order to manage their illness, they found purpose and meaning in the changes they chose to make.

The majority of participants highlighted the need to make changes in their lives to reduce stress and create a lifestyle that was more likely to cultivate health. Exemplifying the need to make life changes, a participant living with MS explained, “You will probably need to significantly change some aspect of your life in order to live well.” Others talked about putting themselves first, and learning to say no. Exemplifying this, a participant living with lupus emphasized, “I actually have to say no. I can’t do it anymore. You have got to say no. And it’s okay. It’s a lifestyle change.” Making life changes is an important strategy participants used to put themselves and their wellbeing first.

Most participants reported making drastic changes to their diet and alcohol consumption after becoming ill. “I completely changed my diet and lifestyle,” explained one participant who lives with lupus, “I became vegetarian and gave up smoking and drinking. Anything like that. I decided I needed to be as healthy as I could.” Although most participants aimed for a well-balanced diet that included fresh, varied foods, some explored removing gluten and sugar from their diet, for example, while others embraced

foods perceived as anti-inflammatory. Exemplifying this pattern, a participant who lives with mixed connective tissue disorder noted, "I'm vegetarian. One of the things that we know very much is that autoimmunity disorders react to red meat. I've always been a vegetarian. I'm thin. I keep my weight down. What we're now learning is that sugar, sugar is this huge inflammatory. Since I don't eat a lot of that anyways, that's really helped me a lot in the past."

Among participants, there was no sense, or desire, that such strategies would allow one to go back to the pre-illness life. Instead, participants articulated an awareness that they were creating a new normal for themselves. A participant living with Crohn's illustrates this when she explained what she would say to people newly diagnosed with the illness. She noted, "Be prepared to have to give up certain things in your life to deal with the disease. Because if you think that you are going to be able to go and live your life normally after that diagnosis, you are not. Things will change." Echoing this point, another participant living with lupus stated, "I'm not going to conquer it (the illness). I'm not going to feed it but to learn to live with it, with some kind of peace."

Such changes allowed participants to put themselves first and to take care of their health and wellbeing. Importantly, our participants did not see these life changes as necessary concessions as a result of their illness; instead, they explained these life changes as being positive and meaningful changes in their lives. Unforeseen changes, perhaps, but not ones that brought shame or the pursuit of the pre-illness self.

CONNECTING ILLNESS BEHAVIORS TO SOCIAL STRUCTURE

Regimes of patienthood connect patterns of individual behaviors to larger structural forces. The patterns identified above are supported by cultural contexts that reinforce the societal expectation that these behaviors are the morally appropriate ones. The patterns in our data, in other words, do not exist independently of larger social contexts. The key societal factors that help normalize these behaviors are: the cultural emphasis on the active patient, the digitization and decentralization of knowledge, the valorization of collaboration, and individualism. In a reciprocal relationship, these social forces contribute to patterns of individual behaviors, which in turn shore up and influence social contexts; working in tandem, the two produce a regime of patienthood.

Contemporary cultural contexts emphasize the desirability of active patients (Andreassen and Trondsen 2010; Timmermans and Oh 2010). The moral message is that people should learn about their illness, do their homework, and advocate for themselves or loved ones. The emphasis on being an active patient comes from many changes in society including the rise of health social movements (Bell 2009; Brown and Zavestoski 2004), media stories encouraging people to learn about particular illness and treatments, and the pharmaceutical industry's advertising and self diagnosis campaigns (Ebeling 2011). In this study, participants become active patients, but they do so in particular ways that reflect their class position and broader social contexts.

One of the primary ways participants became active patients is through their pursuit of knowledge about their condition. As Foucault (1973, 1977) and others have argued, knowledge became a key site of power and resistance in the 20th century. Experts using knowledge (e.g., physicians, lawyers, social workers, teachers) aim to control populations through norms, timetables, and architecture. Given that knowledge is now a key site of power and identity, one way that people can participate in or challenge society is through the terrain of expertise. Although people may resist becoming active patients (Henwood

et al. 2003; Lupton et al. 1991), participants in this study reflect this broader trend in their pursuit of knowledge about their conditions.

At the same time that becoming knowledgeable patients taps into this larger disciplining practice where patients are rewarded for their proactive maintenance of health and health knowledge, becoming knowledgeable also provides a way for people to feel in control of their illness. This was especially important with autoimmune illness where medical knowledge about cause and treatment are limited. For participants, becoming knowledgeable patients, or “doing research,” became a way to fight for their lives. Participants in our study developed expertise over their bodies; their pursuit of knowledge enabled them to get better care both within and outside healthcare settings and to manage their symptoms in the face of limited medical interventions. It also kept them from, as one participant put it, “running out of hope.”

The emphasis on becoming a knowledgeable patient is reinforced by media and by patient foundations and government agencies. Newspapers and magazines print articles that educate people about autoimmune illnesses and how to diagnose and treat them (see, for example, O’Rourke 2013; Park 2011; Travers 2016; Walk-Morris 2018). Resources provided by AARDA and the U.S. HHS Office of Women’s Health suggest that people experiencing symptoms keep track of their family health history, record any symptoms, and seek out multiple opinions from doctors who take complaints seriously (HHS 2012). AARDA suggests calculating one’s “autoimmune quotient” (AARDA n.d.). Patient foundations such as the Lupus Foundation of America and the National MS Society regularly offer face to face events and webinars such as “Clinical Trial Education,” “Managing Progressive MS,” and “Living with Lupus: An Insider’s Perspective” that are free and open to the public. These materials are not provided for the purposes of self-diagnosis, but rather to encourage people to become “knowledgeable patients” who advocate for themselves when they seek the help of healthcare professionals (AARDA 2017).

The pursuit of knowledge as a way of becoming an active patient is made possible through the digitization and decentralization of knowledge (Clarke et al. 2003; Lemire et al. 2008; Mechanic 2008). With the diffusion of the Internet and the availability of medical journals and open access repositories online, people are now able to access knowledge that was previously stored in spaces with limited access (e.g., medical school libraries in particular geographic locations, subscription-only journals). Patient foundations have a visible online presence that features a range of resources (including clinical trials, medical studies, patient advocacy opportunities), as do magazines, newspapers, Facebook groups, and other outlets. The availability of decentralized, digitized knowledge does not mean that people will have the skills to read and analyze the data available (Fox et al. 2005). Though access and comprehension are two different things and must not be conflated, participants in this study clearly engaged in meaningful transformation through knowledge production and dissemination. Compiling data in an expandable folder, participants pursued knowledge via the Internet, physical libraries, as well as other sources.

Collaboration, like knowledge, is a central way to become an active patient. In our current moment, collaboration has been held up as a moral good (Vinson 2016). Silicon Valley companies’ emphasis on open floor plans and collaboration (Klett 2015), team or group assignments in university curricula (Tsay and Brady 2010), and the rise of team science and interdisciplinarity (Frickel et al. 2016; Stokols et al. 2008) all signal the high value placed on collaboration as a form of social action. Participants regardless of age, gender, or specific illness diagnosis sought out physicians with whom they could be honest, sharing when they did not want to follow treatment protocols or wanted to explore other treatment options, and whom they could contact easily by email or phone. Traditional clinician-patient encounters still offer a site of unequal power dynamics, though new practices such as group medical visits are disrupting some of these longstanding power imbalances (Thompson-Lastad 2018). Managing

unpredictable conditions that have few impactful treatments requires checking in with physicians and making adjustments. And, when treatments and adjustments do not work, it means living with the pain created by flares.

Finally, all four strategies used by participants—becoming a knowledgeable patient, cultivating collaborative relationships with physicians, using a broad repertoire of healing techniques to manage and limit symptoms, and putting themselves first to promote health—support and are supported by individualism. Individualism highlights the primacy of the individual, stressing individual initiative, action, and interests. In such an ideology, it is the individual's responsibility to pursue health (Becker 1997; Bell 1996; Nettleton 1997; Rose 1996). Linked to a desire for self-control (McClellan 2005), the individual is imagined as the key actor, a move that benefits governments because it emphasizes individual choices and actions instead of structural change. As Fraser (2004 p.200) summarizes, "Contemporary liberal democratic society produces the subject as an autonomous, self-governing, enterprising individual who exercises rational thought and choice in managing life. This approach benefits government as it devolves responsibility for maintaining health and well-being to the individual subject, rather than to the welfare system or other government structures." Participants in this study exemplify the primacy of individual action as they pursue strategies to minimize and manage symptoms. Although not impossible, collective action and structural change are hard to imagine or pursue in such a context.

CONCLUSION

Identification of the sick role sparked a rich body of sociological work that recognizes that how people manage and live with illness is a social process—one that is socially structured by norms, expectations, agency, and power. A key expectation of the sick role is that people should work with medical professionals to restore health (Parson 1951). As research has shown, people use a range of strategies to try to create health, and these strategies can vary across time and place, and by gender, race, ethnicity, and class. To counter the decline of the sick role's use in the sociological literature, we introduced the concept regimes of patienthood. Regimes of patienthood highlights how illness behavior is socially constructed, connecting individual biographies and social structure in historically specific ways, with power and resistance visible at all times. Regimes of patienthood opens up the space for continued sociological input into the norms that comprise illness behaviors and the political consequences of such norms now that the sick role, despite Williams' (2005) call for its return, is no longer widely used.

This article demonstrates how people who live with autoimmune illnesses participate in a particular middle-class regime of patienthood, one that involves becoming a knowledgeable patient, finding a collaborative doctor, using a range of techniques to promote wellbeing, and putting themselves first in order to manage symptoms and create as much of an independent life as possible. These strategies relied on individual initiative and interactions, not group activities or collective change. Future work should study other class positions to investigate if the patterns identified in this article vary across classes.

Studying the norms that structure patienthood demonstrates how patterns of individual behavior and social structure are connected. Social forces such as the cultural emphasis on active patients, the digitization and decentralization of knowledge, the value placed on collaboration, and individualism create the conditions for particular illness behaviors yet these behaviors are also empowering for people who live with unpredictable, heterogeneous illnesses. Investigating illness behaviors demonstrates how much work people who live with autoimmune illnesses do. They do not sit back, follow the doctor's orders, and let the illness take its course. Instead, they are active patients—ones who aim to manage and limit

symptoms so that they can enjoy daily life and being in their bodies as much as possible. Indeed, this article shows how patients are producers of knowledge and should be viewed as sources of expertise, particularly in situations where medical interventions are limited.

Although this study focuses on how people live with autoimmune illnesses, this study also offers insight into how the organization of medicine can support people who live with chronic illnesses more generally. Building on how participants practice patienthood, policies and practices that cultivate the development of knowledgeable patients and collaborative clinicians, as well as healthcare providers more broadly, can support people as they live with illnesses that are marked by limited medical knowledge and uncertainty. Although there is a risk that clinicians will use collaboration and knowledge claims to convince patients to comply, and indeed this has happened (Robertson et al. 2011), knowledge and collaboration can be explicitly integrated and supported into healthcare to support people as they navigate health and illness. Many health care facilities are already doing this, but it could be implemented more evenly and robustly if patients' values and ideas are prioritized.

Making the norms and expectations that structure patienthood explicit also allows people such as caregivers, family, friends, and clinicians, to be aware of moments when people are *not* performing the expected roles. As scholars have shown, some patients do not want to or cannot become active participants in the management of their illness (Henwood et al. 2003, Lupton et al. 1991) or to cultivate cultural health capital (Shim 2010), and this should not result in the provision of inferior care. Understanding that there are multiple ways to practice patienthood, and being open to these as socially legitimate, may offer a way to support people who do not perform the regime of patienthood described in this article. Making a regime of patienthood explicit can create an openness to identify and support the other ways people practice patienthood.

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