Qualitative Health Research
1–13

DOI: 10.1177/1049732315619380
qhr.sagepub.com
SAGE

Living in Limbo: Contested Narratives of Patients With Chronic Symptoms Following Lyme Disease

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Abstract

Persistent, subjective symptoms of unknown etiology following treatment for Lyme disease have been termed *post-treatment Lyme disease syndrome* or *chronic Lyme disease* (PTLDS/CLD). The objective of this study was to give primacy to the patient experience of this medically contested condition by eliciting patient illness narratives and identifying emergent issues through semistructured interviews conducted among 29 participants. We used thematic narrative analysis to identify three predominant themes: (a) Physical and social limitations lead to a "new normal" characterized by fundamental shifts of ways of being in the world, (b) disease-specific factors contribute to symptom and illness invisibility that affects social support in nuanced ways, and (c) pervasive medical uncertainty regarding PTLDS/CLD promotes an increased sense of personal responsibility for care. Similar to other contested or medically unexplained syndromes, our findings suggest that the social sequelae of PTLDS/CLD can be equally protracted as the physical effects of this illness.

Keywords

illness and disease, experiences; illness and disease, chronic; illness and disease, infectious; illness and disease, social construction; interviews, semistructured; qualitative analysis; qualitative; United States, Mid-Atlantic

Lyme disease is a tick-borne infectious disease first identified in the United States in the mid-1970s. It is currently the most common vector-borne disease in North America and is endemic in the Northeast, Mid-Atlantic, Upper Midwest, and Northwestern United States, as well as in regions of Northern Europe and Asia (Paddock & Telford, 2011). In recent years, the number of physician-documented cases reported to the Centers for Disease Control and Prevention (CDC) has risen dramatically (CDC, 2013), with estimates of approximately 300,000 new cases per year (Hinckley et al., 2014).

The early symptoms of Lyme disease include a characteristic skin rash known as erythema migrans (EM) that can occur with or without a flu-like illness. Joint, neurologic, or cardiovascular complications may also occur early in the disease, or can appear weeks to months later if left untreated (Wormser et al., 2006). These objective, visible findings constitute generally accepted diagnostic criteria for early or late Lyme disease caused by active infection, particularly when accompanied by a positive antibody blood test (Steere, 2001).

When diagnosed promptly, the majority of patients treated with recommended antibiotic regimens recover such that no ongoing symptoms are experienced. However, a subset of patients (an estimated 10%-50% in prior studies) reports a range of largely subjective symptoms after antibiotic treatment, including diffuse pain, fatigue, mood changes, and cognitive or neurologic complaints (Aucott, Rebman, Crowder, & Kortte, 2013; Marques, 2008; Steere et al., 1983). These patient-reported symptoms usually occur in the absence of observable physical exam or laboratory abnormalities. When these symptoms persist for 6 months or longer in otherwise healthy individuals, they meet a proposed case definition for post-treatment Lyme disease syndrome (PTLDS) introduced by the Infectious Disease Society of America (IDSA) in 2006 (Wormser et al., 2006).

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The underlying cause, severity, and prevalence of PTLDS, as well as effective treatment approaches, remain unknown and have been the subject of substantial and polarizing debate within the field of medicine (Aronowitz, 1991; Ballantyne, 2008; Davis & Nichter, 2015; Feder et al., 2007; Stricker & Johnson, 2008). Reminiscent of the name chronic fatigue syndrome (Jason, Holbert, Torres-Harding, & Taylor, 2004), even the term *PTLDS* remains disputed, with some patients, advocacy groups, and physicians preferring chronic Lyme disease (CLD) instead (Cameron, Johnson, & Maloney, 2014; Specter, 2013). However, CLD is frequently criticized in the medical literature and is at times presented in quotation marks in peer-reviewed publications, lending additional tenuousness to the term (Baker, 2008; Greco, Conti-Kelly, & Greco, 2011; Hassett, Radvanski, Buyske, Savage, & Sigal, 2009). The label CLD is primarily criticized for its lack of specificity, and the implication of antibiotic-resistant infection as a potential underlying cause of the symptoms (Auwaerter & Melia, 2012; Feder et al., 2007; Lantos, 2015; Sigal & Hassett, 2005), a hypothesis not supported or adopted by IDSA guidelines (Wormser et al., 2006).

There has been very little qualitative research conducted among patients with either acute infection or PTLDS/CLD. A recent study among patients self-identifying with the diagnostic label of CLD revealed that symptoms significantly affect social and physical functioning, as well as doubts about the future, and negative perceptions of mortality and debility (Ali, Vitulano, Lee, Weiss, & Colson, 2014). Drew and Hewitt (2006) focused on the diagnosis experience of a small sample of patients prior to treatment and found that frustration, financial stress, and "a long road to diagnosis" were common themes. Both studies found that the diagnosis itself provided a sense of relief, personal validation of symptoms and in early disease, hopefulness for the future (Ali et al., 2014; Drew & Hewitt, 2006). Mechanic and Meyer (2000) found that patients living with CLD were almost twice as likely as those with breast cancer or mental illness to speak about loss of trust in their physician, and that literal or implicit rejection by a physician was identified almost exclusively by this group.

The symptomatology and sociocultural context of PTLDS/CLD overlaps significantly with other medically unexplained or contested syndromes characterized by diffuse pain and fatigue, particularly fibromyalgia and chronic fatigue syndrome (Ablin, Shoenfeld, & Buskila, 2006; Patrick et al., 2015). Contested illnesses, which also include syndromes such as Gulf War Illness and multiple chemical sensitivity, are characterized by a lack of known biological cause or abnormality, and uncertain or ill-defined treatment paradigms (Brown, Morello-Frosch, & Zavestoski, 2012; Hart, 2014; Moss & Teghtsoonian, 2008). These traits often result in a disputed disease status for patients, and significant discord between sufferers and modern biomedicine (Conrad & Barker, 2010; Dumit, 2006). Despite similarities to other contested illnesses, PTLDS/CLD has not been traditionally included in this literature, and there has been a particular lack of research that considers such factors as a backdrop for the individual, lived experiences of these patients.

In a general sense, we conducted this research from the a priori position that despite the ongoing contested reality of PTLDS/CLD, it can be experienced as and therefore can also be situated in the literature on chronic illness. Understanding illness as a social construct that is distinct from the biological effects of disease (Conrad & Barker, 2010; Kleinman, 1988) is a fundamental concept in the social sciences. Our reading of the transcripts was informed by Charmaz (1983, 2000) and Kleinman (1995) who have criticized purely medicalized understandings of chronic illness limited to physical signs and symptoms in favor of a broader understanding of lived experience. In this framework, chronic illness can be a significant event—a specific type of biographical disruption (Bury, 1982) that "challenges prior meanings, ways of living that have been taken for granted, and ways of knowing self" (Charmaz, 2000, p. 277).

As previously described, contested illnesses represent a unique type of chronic illness (Conrad & Barker, 2010). Nettleton (2006) identified three themes from previous research that are characteristic of medically unexplained, contested illnesses, and we also relied on these concepts in the current study. First, struggles for illness legitimacy in both medical and social settings are frequently identified (Hyden & Sachs, 1998; Nettleton, 2006), particularly as patients seek to reconcile their symptom experience within a biomedically disputed disease context (Barker, 2002). Second, patients often actively resist psychological explanations of associated symptoms, which are seen as dismissive and further delegitimizing (Nettleton, Watt, O'Malley, & Duffey, 2005; Ware, 1992). Finally, embedded in contested or medically unexplained illnesses is a large degree of doubt and uncertainty which is uniquely embodied by patients living with these conditions (Nettleton et al., 2005; Shriver & Waskul, 2006; Swoboda, 2005–2006).

As a way of interpreting our findings, we also relied upon Frank's (2013) typology of three chronic illness narratives (restitution, chaos, and quest). According to Frank, the restitution narrative dominates popular culture and is least often found among sufferers of chronic illness, as the general plotline is concerned with a return to health without significant life disruption. By contrast, the chaos narrative is one that lacks recognizable structure and easily assimilated plotlines, that stems from a profound experience of events "without sequence or discernible causality,"

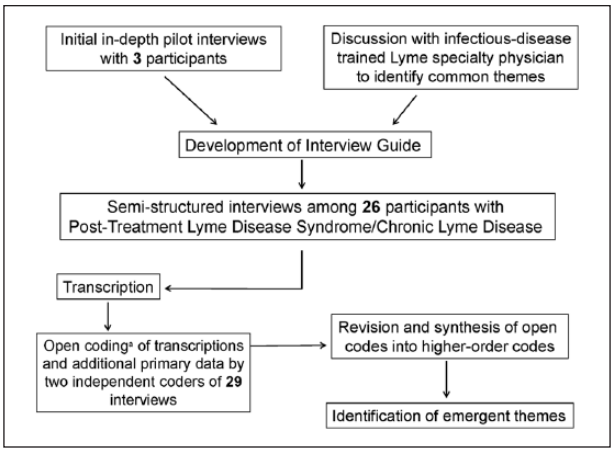

Figure 1. Study design and analysis process.
[1]Strauss and Corbin (1990).

and that is disconcerting for the teller and listener because it challenges social norms of control, resolution, and predictability (Frank, 2013, p. 97). Finally, the quest narrative is one in which the narrator plays an active part in utilizing the illness itself as a driver for personal gain or growth (Frank, 2013). This typology has been previously utilized to understand experiences of patients with medically unexplained neurologic symptoms (Nettleton et al., 2005), chronic fatigue syndrome (Whitehead, 2005), and fibromyalgia (Swoboda, 2005–2006).

The goal of the current study was to gather illness narratives to contribute to the small body of qualitative research that gives primacy to patients' experiences and ways of making sense of PTLDS/CLD as a medically contested, chronic illness. However, given the prior lack of qualitative inquiry into the lived experience PTLDS/CLD, analysis of these narratives also allows the opportunity to meaningfully improve previously unappreciated challenges faced by patients living within this illness context. Consequently, we also conducted this study to examine how patients' experiences could inform an understanding of the personal and social cost of this illness, and assist in setting future research priorities.

Method

This manuscript is based on data from an in-depth qualitative study conducted in two phases. In 2007, a small pilot study was performed to collect exploratory data and inform interview guide development, and in 2012–2013, a larger interview study was conducted (Figure 1). The Institutional Review Board of the Johns Hopkins School of Public Health approved both phases of the research, and written consent was obtained from all participants prior to initiating study activities.

Semistructured Interviews

In 2007, we conducted open-ended, in-depth interviews among three individuals with PTLDS. The resulting transcripts were interpreted in conjunction with a primary care physician with infectious disease training and a specialty in Lyme disease. This allowed us to refine key themes and develop an interview guide which contained initial questions and follow-up probes loosely structured around four major thematic lines of inquiry: illness history, effect on daily life, coping strategies, and relationship to the medical system. In this article, we focus largely on the first three; relationships to the medical system, particularly with health care providers, raised distinct issues and will be analyzed separately.

Between August 1, 2012 and March 31, 2013, an additional 26 participants were interviewed. The interviews lasted approximately 45 to 60 minutes and took place in either a private room in a clinical setting or at the participant's home. Roughly half of the participants were interviewed again for approximately 30 minutes when follow-up questions arose or participants indicated they had more to discuss. The interviews began by asking questions such as "How did you come to find out you had Lyme disease?" or "Tell me how your symptoms began?" These open-ended questions frequently elicited extended accounts upfront, an approach to narrative interviewing described by Riessman (2008). The interviews were semistructured; however, participants were encouraged to address additional issues they considered important at any point.

Although the interview process was not identical for the two samples, questions elicited in the larger sample of 26 participants were based on themes identified in the pilot, and we found broad similarities in many of the issues raised. Consequently, although our findings derive primarily from the larger sample of 26 interviews, we also drew from relevant passages in the pilot transcripts and a combined sample of 29 interviews was included in the final analysis.

Study Sample

The study sample was drawn from the clinical practice of one of the authors. Participants were invited to join the study if they tentatively met a case definition for PTLDS: specifically, if they had an initial Lyme episode marked by either (a) the presence of an EM rash or (b) a positive blood serology, and concurrent objective signs consistent with late Lyme disease and/or unexplained flu-like illness. All participants were adults, had been ill for a period of 6 months or more, and none reported preexisting health conditions that could explain their symptoms.

There was substantial variability in the clinical histories and current symptom severities detailed by our participants. Some described a waxing and waning of symptoms over both a short (hour-to-hour) and long (month-to-month or even year-to-year) time frame, whereas others described symptom persistence on most days. Despite heterogeneity of clinical course and current severity of illness, however, all participants described their symptoms as currently affecting or having previously affected daily life, oftentimes to a substantial and widespread degree. Some participants identified with the diagnostic label PTLDS, others preferentially used CLD to describe their illness, and others did not identify with a distinct diagnostic label but rather spoke of individual symptoms. For the purposes of this article, we use the term *PTLDS/CLD* to describe our participants' illness.

Three invited patients declined to participate, and response rate for the study was 91%. Our sample was 52% women, had a mean age of 54, and reported symptoms for a mean of approximately 7 years at the time of the interview. Table 1 shows symptom characteristics of the participants interviewed for this study. Participants frequently described symptoms consistent with those included in the proposed case definition for PTLDS (Wormser et al., 2006), namely, fatigue, pain, and cognitive complaints (Table 1). A more severe initial illness course and a longer duration of illness prior to the initiation of antibiotics have been previously identified as risk factors for the development and persistence of symptoms following exposure to Lyme disease (Marques, 2008). Our participants were drawn from a community sample seeking care from a Lyme referral specialist, and many had histories consistent with these risk factors.

Table 1. Symptom Characteristics of 29 Participants With PTLDS/CLD.

Participant	Illness Duration, Yearsa	Pretreatment Symptoms[b]	Posttreatment Symptoms[c]
1	2	F, FV, H	F, P, H
2	12	R	F, P
3	1.5	R, P, F, FV	F, P, FV, I, LA
4	5	R, F, FV, NS	F, C, FV, H, LA
5	27	R, F, JSW	F
6	4	R, F, C	F, P, C, H
7	5	R, P, C, A, I, V	P, C, A, IN, H, HP
8	7	F, C	F, P, C, H, B, BP
9	21	R, P, F	P, IN
10	4	R, F, NS, I	F, C, FV, I, V
11	8	R, F, VS, DZ	F, P, DZ, H
12	2.5	P	F, P, LA
13	10	R, P, F	F, P, HP
14	4	P, H, DZ	F, P, C, H,
15	2	F, C, A, MW	F, C, T, MW
16	8	R, P, FV, NS	F, P, C, A
17	12	R, P, F	F, P, IN, JSW, H
18	3	R, P, F, FV, H	F, P, H
19	10	R, P, C	F, P, FV, H
20	2	V, H, N	P, C, HP, H
21	3.5	R	F, P, C, IN
22	14	P, F, FV, H, C, JSW	F, P, JSW
23	2.5	R, H	F, P, C, H, A
24	4	R, P	F, P, C
25	5	R, P, F, FV	F
26	13.5	F, N	F, P, N
27	4	R, P, BP	F, P
28	3	FV, F	F, H
29	7	R, N, HB	F, P, C

Note. PTLDS/CLD = post-treatment Lyme disease syndrome or chronic Lyme disease; F = fatigue; FV = fever; H = headache; P = pain; R = rash; I = irritability; LA = loss of appetite; NS = night sweats; C = cognitive complaints; JSW = joint swelling; A = anxiety; V = vertigo; N = numbness; IN = insomnia; HP = heart palpitations; B = balance loss; BP = Bell's palsy; DZ = dizziness; MW = muscle weakness; T = tremor; HB = heart block; VS = vision sensitivity to light.
[a]Defined as time from symptom onset of first episode of Lyme disease to time of interview, including any intermittent symptom-free periods.
[b]Symptoms pretreatment defined as those listed by participants as having occurred prior to initiation of recommended antibiotic treatment for early Lyme disease (Wormser et al., 2006).
[c]Symptoms posttreatment defined as those listed by participants as having occurred following initiation of recommended antibiotic treatment for early Lyme disease (Wormser et al., 2006).

Data Analysis

Although many definitions of narrative exist, one key component in Salmon's definition is the meaningful transformation or linkage of events into a broader understanding of past or future experience (as cited in Riessman, 2008). Narrative inquiry is based on the premise that humans are "storytelling organisms who, individually and collectively, lead storied lives" (Connelly & Clandinin, 1990, p. 2); consequently, narrative methods attempt to preserve such stories in the analytic process as a way to gain unique insight into how individuals make sense of and interpret their experience (Andrews, Squire, & Tamboukou, 2013; Riessman, 2012). Within the realm of narrative inquiry, thematic narrative analysis is a common approach that is "suited to many kinds of data; it can generate case studies of individuals and groups, and typologies" (Riessman, 2008, p. 74).

Thematic narrative analysis was chosen as a means to examine the contested illness experience of PTLDS, as it represents a case-based approach which emphasizes individual agency and complexity (Byrne, 2009; Mishler, 1996). In addition, we found the transition from uncontested, acute infectious disease (early Lyme Disease) to

contested subjective syndrome (PTLDS/CLD) to be of interest, and the temporal element of this shift is preserved in this and other forms of narrative analysis (Riessman, 2008). Finally, thematic narrative analysis is also characterized by an exclusive focus on content ("what" is being said) rather than structure ("how" it is being said; Riessman, 2008, p. 54). This aspect allowed us to thematically address patient experiences in an applied manner, which we found particularly important in an illness setting such as PTLDS/CLD where limited prior research exists.

All interviews were audio recorded, transcribed, coded, and analyzed in several stages (Figure 1). First, two independent coders performed open coding (Strauss & Corbin, 1990) on all transcriptions and any additional interview notes and related documents with the assistance of ATLAS.ti qualitative data analysis software (version 7.1.8). After this process was complete, the list of open codes were then critically reviewed, modified, and synthesized into higher order codes through discussion between the two coders and the rest of the study team. The transcripts were then re-reviewed by members of the study team for consistency in light of the final identified themes. We provided two individuals with PTLDS/CLD (one a member of the study cohort and the other not) a copy of the manuscript and solicited feedback as a small measure of respondent validation.

Findings

The findings from this study share many similarities to themes previously identified in the chronic disease and contested illness literatures. The major themes identified in our interviews are as follows: (a) Physical and social limitations lead to a "new normal" characterized by fundamental shifts of ways of being in the world, (b) disease-specific factors contribute to symptom and illness invisibility that affects social support in nuanced ways, and (c) pervasive medical uncertainty regarding PTLDS/CLD promotes an increased sense of personal responsibility for care.

New Limitations and Shifting Identities: "Then All of a Sudden, You Are No Longer Who You Were"

Participants often described experiencing profound physical, emotional, and social limitations during the course of their illness, reflected in frequent stories of altered participation in meaningful activities or relationships due to fatigue, pain, or other symptoms. In the following quotes, two men illustrate this shift.

> I had season tickets to the [symphony], the Opera, and the [theater] and I used to go to all those, and when I was sick I couldn't go at all, so I'd give tickets away. When I started feeling better, I started going again, but I would have to leave at intermission and go home because I was so exhausted. So I ended up not subscribing to those and just giving that up as well. It really has changed my life dramatically. Activity-wise. And socially.

> I've gone out and tried to cycle and I get tired and I just can't, and I had a very difficult time dealing with that. . . . When I get on the bike and you know, putting on the spandex it's good and it's bad. It's good that I feel like well, at least I'm on this bike. It's bad that it makes me think about where I was before this happened.

Similarly challenging were cognitive or mood changes. Symptoms such as anxiety, depression, irritability, memory changes, difficulty concentrating, or "brain fog" were not uniformly understood to be physical manifestations of the disease or emotional responses to newfound limitations. Rather, they were seen as interrelated aspects of the illness experience that were of unknown origin and were distinctly different before and after Lyme disease. One participant explained the effect of his cognitive symptoms and the subsequent coping strategy he had implemented.

> The side effect from the memory loss is worse because it ruined my confidence. You try and deal with people on a business level and you got something in the back of your mind going "Am I right?" It's very unsettling. So I've taken to writing everything down. Taking her [referring to his wife] with me everywhere.

Some participants specifically mentioned how their relationship to and engagement with nature (as one woman put it "my beloved woods") was altered not only by symptom limitations but also by its association with the initial source of their current illness and risk for future disease.

> One of the most severe consequences of having Lyme disease it that it has tainted my love of the outdoors. Because it's something I always think about. . . . It's like you can't enjoy it if you're worrying that you're going to get bitten by a tick.

Even those with less severe symptoms or those who considered themselves largely recovered introduced "new normal" narratives of baseline health and daily life activities. The concept of a "new normal" state that bounds daily experience has been described in other chronic disease settings such as rheumatoid arthritis (Orbai, Smith, Bartlett, De Leon, & Bingham, 2014). It also implies a distinct loss that triggers shifts in fundamental ways of how patients see themselves in the world. One man indicated feeling distanced from a more global, intuitive sense of his former self: "The old me? He's not around. He's coming back, slowly, hopefully." Similar to

patients with other chronic illnesses (Anderson & Spencer, 2002; King et al., 2003), our participants often depicted Lyme disease as a marked turning point by contrasting "who they were" before and after the onset of their illness. One woman spoke of what she called "Lyme rage" and how it made her feel: "The least little thing, like if one of the dogs knocked over a bowl of water, I'd just lose [it]. I'd be standing there, and it was almost like this out-of-body experience and I'd go, is that really you?"

Awareness of physical boundaries and the symptom-based consequences of pushing beyond them were mentioned as a common coping strategy to reassert a degree of predictability and thus power. As one participant stated, "I now feel more in control and I almost feel more comfortable maybe saying no, and backing out of things." Another participant described this ongoing trial and error process in terms of spoonfuls of energy, a framework used by patients living with a range of chronic illnesses to depict fatigue in daily life (Miserandino, 2010).

> You're going to get X spoonfuls of energy and I want you to think about how you're going to use it? And then the price that you pay if you do want to go out and do those active things; this is how your body responds.

Particularly for participants with more severe symptoms, daily activities were managed in this way to a degree that was unnecessary before the onset of their Lyme disease and the establishment of a "new normal." Despite this, some participants described their "stubbornness" in defying limitations imposed by their illness. An athlete spoke of completing a triathlon: "I'm going to prove that I don't care how crappy I feel. I'm going to finish this despite everything. And I know I'm going to pay the price." One woman described the process of occasionally challenging boundaries as "inherent . . . it's that strong desire to go back to feeling the way you felt, when you do start to feel a little bit better you just push and it backfires."

For participants who described a "new normal," if only transiently while symptoms were at their peak, acceptance of limitations was also frequently described as a means to cope with a sense of loss or powerlessness. One man explained what had helped him: "Accepting things for the way they are. You aren't going to be who you thought you were going to be. You're just going to be different. Change the plan. Make a new plan." For a few participants, acceptance was one component of a renewed or newfound positive engagement with religion or spirituality that they directly linked to their illness experience. Alternatively, acceptance was also portrayed as a necessary part of moving through the illness experience: "You got to accept that either you're going to throw in the towel or you're going to accept that it's there." The following quote is illustrative of several participants who reflected on the lengthy and often transient or incomplete process of acceptance.

> I'll say oh I know I'm accepting it much more but I realize that when I hit a wall again and I get really disappointed all over again, I realize you weren't accepting this as much as you said you were. I mean I think we can kid ourselves.

Invisibility and Social Support: "You Don't Understand What Kind of Tired I'm Talking About"

The majority of participants we interviewed had initial objective, clinical signs of Lyme disease that were visible to others, including the EM rash and/or neurologic or joint system complications. Consistent with the clinical literature on Lyme disease, these signs often resolved with appropriate antibiotic treatment. However, the post-treatment symptoms that remained were more likely to be invisible to others.

> When you can see a bandage, you can see something hurt, you can see somebody getting treatment, you can see the effects; it's there. But when you see somebody that looks normal, do you know what I mean? It's a little different and I think sometimes, that can be the hard part.

Symptom and illness invisibility emerged in the interviews in different ways. Participants spoke of the ubiquity of fatigue, pain, headaches, sleep disruption, and other symptoms among their peers and in the general population. As a result, some felt that their symptoms were perceived as exaggerated or "whiny" to others: "There are those that think you're just complaining, blaming it on Lyme." Alternatively, some participants expressed how they themselves had questioned the nature and severity of their symptoms, at least temporarily, during the illness process. Many participants expressed frustration in conveying that their symptoms were qualitatively and quantitatively different from the aches, pains, and tiredness of everyday life. One man echoed the incongruity between patients' PTLDS/CLD experiences and the common perception that Lyme disease is easily treated and cured without long-term sequelae:

> And people said, well it's just a little tick, my kids got well from it. Yeah, oh well, 99% of you probably are going to get well from it. It's the other percent who feels left out or not right.

The theme of illness or symptom invisibility and its relationship to perceived social support and validation from close family and friends also appeared in participants' stories. Many described unconditional support, whereas

others felt physically and emotionally isolated. However, support also seemed to vary across participants, fluctuate throughout an individuals' course of illness, and was often presented as nuanced. As one woman described,

> I also had this feeling like people do not believe me about how bad I feel. I mean, even the supportive people like my husband and my mother were sort of like, you just kind of need to buck up and you know, try a little harder. I hate to accuse them of thinking that I was just being like malingering and being lazy, but I think there was some of that. I think that sometimes they really, you just need to quit whining and put your happy face on and act like everything's going to be okay and it will be okay and I was like, you don't understand what kind of tired I'm talking about.

The distinction between "support" and "belief" appeared important to many participants. Disappointment, hurt, or anger arose when participants perceived that close family or friends did not recognize the profound effect of their symptoms or perhaps more critically, invalidated the authenticity of their illness. One man known for fearless outdoor adventures described a fellow daredevil's response to his illness.

> He actually called me a coward. He thought that would fire me up and get me out there. I said, all you did was make me lose respect for you, for not finding out what my situation [is]. Him and I haven't spoken in a long time. . . . And I said look, you and I have [to have] a little talk before we ever get back together to do anything, I said but right now I can't. That means I can't. I said, have you ever heard me tell you I can't at anything ever? They should know that I can't. Because I wouldn't put other people at risk trying to save my sorry butt.

This account emphasizes an important distinction between laziness and physical inability, with the former particularly upsetting when suggested by others. Some participants had experienced multiple chronic illnesses, and comparisons with other, noncontested illnesses highlighted struggles of symptom invisibility and illness legitimacy in PTLDS/CLD. In the following quote, one participant described having had PTLDS/CLD for over a decade while also receiving a cancer diagnosis during that time.

> [Cancer] is obviously a very recognized disease. And at that point, all of a sudden I got the recognition and sympathy and support that was lacking because, you know, there was a chance I wasn't even going to make it. . . . Being a person of science, [my spouse] went okay now I know you really have something. And she couldn't have been better or more supportive to this day. But that was kind of a turning point in the psychological aspect because up until that point it was like oh yeah c'mon, tough it up, you're a guy, you can do this, blah blah blah. Because it gets that isolating where you just feel like your body's stopping to function and no one will listen. It's hard enough when you're declining and you get everybody's love and support. But to do it without anyone believing you is I think one of the most difficult things to deal with, as far as the psychology of the illness.

Likewise, one woman who had breast cancer years before Lyme disease stated that "people really tried to be helpful, and they understood [breast cancer]. They don't understand this. . . . It takes too much energy to explain."

Interviewees named personal experience with PTLDS/CLD or a close relationship to someone who has experienced it as key determinants of receiving empathy and support from others. One participant recounted that his employer's medical department had allowed him to work a flexible schedule because "the director was very familiar with Lyme and she was aware of the [symptom] fluctuations." This was presented in contrast to his supervisor who had overridden his doctor's medical instructions. Participants described validation and support from interaction with others experiencing PTLDS/CLD, helping to cope with and resist feelings of isolation and uncertainty by "sharing our experience" and "being a sounding board for each other." For most participants, the nature of this contact was through existing personal networks. Notably, none of our participants regularly attended in-person or online support groups and most did not express interest in doing so. Some also felt they had unintentionally become de facto lay experts in Lyme disease, a finding also identified in interviews among women with fibromyalgia (Swoboda, 2005–2006). One woman explained that "for people who have just been diagnosed, I can provide kind of what I've been through, what they can expect, that sort of thing. So it's good for both parties." A woman who had not come across others with PTLDS/CLD described wanting that connection. "I am probably looking for somebody to link my story to. . . . But that, oh my gosh somebody else actually is going through this or has gone through this."

Medical Uncertainty and Personal Responsibility: "Really, No One Has Clear Cut Answers"

It has been previously recognized that doubt and uncertainty are important components of the contested illness experience, both for patients (Dumit, 2006; Nettleton et al., 2005; Shriver & Waskul, 2006; Swoboda, 2005–2006) and physicians (Swoboda, 2008). We found that these themes also appeared in our interviews in various ways.

An absence of available, established treatment and disease prognosis guidance from the medical system was

mentioned by many participants and often led to uncertainty regarding expected future duration of symptoms and questions regarding whether PTLDS/CLD would be a lifelong, chronic illness. One woman struggled with the recent return of her initial symptoms.

> Here we are, we're getting to the end of October, and I still don't feel real good and it came out in May. So I mean, I don't know if that's a long time or not. I don't know if this is going to keep going on? If this is going to be forever? Or if it's going to be for just a longer period of time? Whether it's ever going to go into remission? I don't know. And that kind of bothers me too, that really bothers me.

In this quote, a lack of information regarding what might be expected led to an inability to gauge the normality of her own experience in this illness context. Another participant drew upon the disease trajectory of a broken bone to contrast this commonly recognized restitution narrative (Frank, 2013) with the indefinite and unpredictable nature of PTLDS/CLD.

> Even if you fracture your arm in thirteen different places, they put the halo in you, they put the pins in you, you lose function, you go in two months later, they take it off, then you got the paranoia after you broke the thing where you don't want to use it and then you do the therapy, and six months later the memory starts to fade and you're on to normal use. You may have a little problem here and there but this . . . this is like a huge monkey on your back that you're carrying around that's like God, is it going to hit me hard today? . . . This monkey never gets off. It kicks and kicks and kicks and kicks.

Likewise, participants expressed uncertainty as well as degrees of frustration and fear regarding not only the duration of their illness but also what and how to think about their future health. This included severity and impact of symptoms, the need for and decision to pursue additional treatments or therapies, and "worst-case" scenarios of severe physical and emotional decline. As one man questioned, "I live in fear, am I going to be a cripple? Am I going to go nuts?" At times, expressions of hope and despondence coexisted in the same patient narrative, characterized by Nettleton and colleagues (2005) as "merry-go-round" accounts that lack a concrete progression.

Uncertainty also marked some participants' past illness narratives, specifically the extent to which health events occurring after their initial Lyme exposure were attributable to PTLDS/CLD, to some other disease process, or would have happened regardless (e.g., "maybe I'm just getting older"). In medicine, PTLDS/CLD currently falls in the contested space between an acute and a chronic disease, as well as in the traditionally dissimilar realms of an infectious disease, an autoimmune illness, and a psychological condition. Depictions of medical ambiguity were particularly present in stories surrounding the transition from acute illness to PTLDS/CLD, or rather what happened as patients' symptoms persisted and they entered a new, contested illness context. In one such account, a man described his experience with two physicians who had been treating him for idiopathic pain following early Lyme disease.

> But the older guy . . . [he] said I've never seen anything like this before. He said if I were you, I would stick with the Lyme type thing, but it's your call. . . . There was a younger doctor who sort of threw in the towel early on. Yeah, like I don't know what this is, I don't have a clue, so like what do you want to do now? I'm looking at him like, well I don't know what do you want to do now? And then I don't know where that went, it just didn't go anywhere.

As in the above quote, realization of the medical uncertainty inherent in PTLDS/CLD often appeared to relate to further recognition of interphysician subjectivity. Participants described receiving a range of diagnosis and treatment plans offered by different physicians at different points in their illness, and even perceived that basic recognition of their symptoms was individually determined; "sometimes doctors, depending on who they are, may not even believe what I'm saying."

The participants whom we interviewed were generally aware of the contested nature of PTLDS/CLD, either through firsthand encounters or while seeking information on their condition. For a few, it was challenging to contend with the realization that the context of PTLDS/CLD was not as straightforward as other illnesses. As one woman summarized,

> The thing that upset me the most about the whole thing was what a political football it is. That just flipped me right out. And it took me a long time to sort of grapple with that? And try and make a decision about what to do.

Likewise, another participant recounted the first time she became aware of the medically contested nature of her illness while at a dinner party seated next to an infectious disease specialist.

> We were having dinner, and I had the PICC line in [a small IV used to administer intravenous antibiotics worn in the arm for the duration of treatment] . . . he asked me what was going on and I explained and I said you know I have chronic Lyme disease, and his immediate reaction was just sort of to pull back from the table and he said well, who told you that? And I explained you know, what had been going on and all this time and he said well, I don't think that evidence supports what you're doing. We didn't have a lengthy conversation about it because we were at a table with other people, but that surprised me.

Particularly among participants with a greater awareness of the medical uncertainties and controversies surrounding PTLDS/CLD, we often found a strong sense of self-reliance rather than turning to physicians for their care and future navigation of the illness landscape. Participants described this as an unwelcome but necessary shift following situations such as in the earlier quote when a participant was told "it's your call" or asked "what do you want to do now?" by his physicians. This sense of personal responsibility for future health also seemed to be fraught with feelings of both empowerment and self-doubt. In the following quote, a female participant appeared responsible, ambivalent, and questioning toward her decisions regarding duration of antibiotic treatment.

> So you second-guess yourself, you think, well should I be insistent that I keep the PICC line? Gone another month? Would that have made that three-month hiatus from antibiotics not as devastating physically as it was? I don't know. I don't know. I don't have enough confidence in my own decision making about that because this is kind of an overwhelming disease.

Discussion

Through this study, we seek to provide insight into the illness experience of patients with chronic, Lyme disease-associated symptoms who met a proposed case definition for PTLDS. Within our sample, we found variability in disease course and physical impact of symptoms, with many participants describing significant current or past physical limitations that had continued for an average of 7 years at the time of the interview. These findings are similar to previous qualitative studies among patients with CLD which identified themes of significant life impact, uncertainty, and chronicity (Ali et al., 2014; Drew & Hewitt, 2006). This is in contrast to much of the medical literature that generally considers PTLDS to be "mild and self-limiting" (Feder et al., 2007, p. 1422). Our findings suggest that the social experience of these symptoms can be equally and distinctly challenging, particularly in contrast to noncontested disease states such as cancer, where a patient's suffering is well accepted.

The loss of control described by many of our participants, heightened by the distinct perception that perhaps no one is in control in this contested setting, was experienced as a pervasive and often sprawling uncertainty. Similar to Nettleton and colleague's (2005) depiction of medically unexplained symptoms, many of our participants lacked a discrete and predictable illness trajectory once their symptoms fell outside the scope of early, objective Lyme disease. This was succinctly depicted by one participant in a "monkey on your back" analogy, in which the turmoil of an uncertain and persistent illness is contrasted with the clear beginning and ultimate restitution of a broken arm narrative. The extent of this ambiguity is reminiscent of the "existential uncertainty" described as a key component of the patient experience of idiopathic disease by Adamson (1997, p. 134), the experience of "embodied doubt" described by Nettleton (2006, p. 1169), and ultimately of the fluid, "bottomless" sense of trouble that characterizes Frank's (2013) chaos narrative (p. 99).

Jutel (2011) describes clinical diagnosis as a "road map in the middle of the forest" that is transformative in its ability to explain and clarify the way forward for patients (p. 1). However, although some participants we interviewed had been given the label *PTLDS* or *CLD*, the diagnosis is still largely contested and their symptoms remain clinically unexplained. In this case, the diagnosis itself does not translate to clarification regarding disease pathophysiology and expected course, nor a validated treatment protocol. The similarities in patient experience between our sample with a clinically unexplained condition and those with other contested or medically unexplained symptoms suggest elements of a shared experience independent of specific biologic etiology. It also suggests that perhaps the diagnostic label in and of itself is not as important to patients as the clinical implications it carries; a shared context for communicating their illness and gaining understanding from others—including both clinicians and members of patients' social and familial networks.

Here, we also borrow from previous work discussing Parsons's (1951) sick role theory in idiopathic or contested conditions. This framework describes illness as a form of socially sanctioned deviance that allows the patient to blamelessly withdraw from their normal roles with the expectation that they in turn will seek appropriate help and comply with the medical system to exit the sick role as soon as possible (Parsons, 1951). The process of clinical diagnosis legitimizes illness and allows for entry into the sick role (Jutel, 2011); however, those without a diagnosis or with a contested diagnosis such as PTLDS/CLD are precluded as a result (Glenton, 2003; Nettleton et al., 2005). Furthermore, we found that invisibility of symptoms such as fatigue was an important theme in our interviews, particularly as it relates to perceived level of social support. It might be that in this context, to be visible is to be known, or to have an experience that is recognizable to others and thus allows for entry into a socially understood sick role. Otherwise, the perceived authenticity of the illness experience is called into question, as was evident both in one participant's distinction between support and belief from others (with the latter being equally if not more important), and the contrasts drawn between the PTLDS/CLD and cancer experiences.

Narratives might become increasingly chaotic as inability to enter a commonly understood sick role also renders patients unable to recognize and make sense of the illness experience for themselves as well as for others. Patients with PTLDS/CLD are faced with a deep uncertainty regarding the nature and expected duration of their physical symptoms, and they may perceive that the traditional rules for enacting and navigating illness do not apply, thus preventing an ability to uphold their expected sick role responsibilities (Parsons, 1951). Likewise, "what should have happened" statements were common in these interviews. Such statements reinforce the sense of separation from a more cohesive, relatable narrative, but they also highlight an important feature of our sample: There was a biologically based, infectious trigger that initiated their illness experience. This is notable not only because it marked symptom onset for many participants but also because early Lyme disease, as with many infectious diseases, is traditionally expected by physicians and the public to lend itself to restitution rather than chaos narratives. A significant degree of uncertainty and invisibility is felt when personal experience strays not only from expected clinical outcomes but also from broader, socially understood illness narratives, as was described in our interviews. In clinical terms, this argues for conveying appropriate disease expectations upfront to mitigate some of the frustration and uncertainty surrounding any persistent symptoms that do arise, an approach shown to facilitate improved outcomes in other disease settings (Hanson et al., 2015; Moore et al., 2014; Williamson, Nichols, & Lamb, 2014).

We found the specific ways participants described actively and effectively making sense of their experience and turning chaos into quest narratives (Frank, 2013) to also be of importance. Specifically, these data illustrate how feelings of validation and connectivity are strengthened by listening to and recognizing patient stories. Likewise, honoring the chaos story is an important, even moral obligation as described by Frank (2013). In addition, the notion that the experience and knowledge gained could be useful to others or serve as a catalyst for change was described as a positive consequence. This active repurposing of illness into a force for personal or societal gain is instead more characteristic of Frank's quest narrative (Frank, 2013). It also suggests that peer-to-peer counseling or other structured small group settings might be helpful, as has been implemented in other chronic diseases (Dennis, 2003; Schwartz & Sendor, 1999). Second, participants described ways of grappling with uncertainty on a personal level by incorporating spiritual or other mind-body modalities, such as mindfulness meditation. Finally, participants reported tempering uncertainty through close tracking of symptoms and an understanding of anticipated responses to daily activities. Health behavior interventions that are focused on symptom management have been shown to reduce the impact of the symptoms on daily life and might afford patients the opportunity to learn skills for actively managing their symptoms (Carbonell-Baeza et al., 2011; Cicerone et al., 2011; Okifuji & Ackerlind, 2007).

This study does have limitations, perhaps most notably that all interviewees were recruited from a single Lyme referral practice. Whereas participants did have a range of prior experiences, initiating care at this practice likely influenced how participants spoke of their current illness in unknown ways. This factor also limits generalizability, as participants included in our sample might reflect more homogeneous geographic and sociodemographic characteristics than the larger population of patients with PTLDS/CLD. In addition, our semistructured interviews focused on broad topics, as prior qualitative research among patients following Lyme disease is limited. We feel that this allowed us to gain a wide range of insights, but future research will need to explore emergent themes in greater depth.

Finally, by necessity, any analysis of these accounts must acknowledge uncertainty of whether patients' current illnesses are specifically due to their prior history of Lyme disease rather than other, subjective syndromes such as idiopathic chronic fatigue syndrome or fibromyalgia. Our findings suggest that this uncertainty is central to how this illness is experienced and understood—even by those living with it. We therefore relied on the only tool currently available to physicians to make this distinction: a detailed clinical interview documenting symptom onset following CDC-defined Lyme disease. Moreover, our findings highlight shared aspects of the social illness experience, identifiable across various subjective syndromes, which might render specific etiology less important. Given the increasing emphasis in recent clinical research on patient-centered outcomes, acknowledging and incorporating the patient experience will be increasingly important. Ware (1992) argued over two decades ago that patients with chronic fatigue syndrome face a form of psychic suffering that is largely driven by the delegitimation of their illness experience. Our findings among a sample of participants with similar experiences agree that challenging and reshaping the social construction of PTLDS/CLD could effectively improve ways for physicians, peers, and the community to better care for and serve patients suffering from this illness.

Acknowledgments

We gratefully acknowledge the participants who agreed to share their stories with us. We would also like to thank Dr. Veena Das for assistance with the pilot study and Allison Kirkpatrick for assistance with coding.

Declaration of Conflicting Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and or publication of this article: This research was supported by the Lyme Disease Research Foundation and the Kenney Family Foundation.

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