

COMMUNICATIVE WORK AND SHIFTING ILLNESS TRAJECTORIES: AN
EXAMINATION OF INDIVIDUALS COPING WITH CHRONIC LYME DISEASE

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ABSTRACT

Invisible Illnesses are unseen to the eyes of others and require disclosure by the ill in order to seek social support. Invisible illnesses fall under a rather large umbrella that includes both mental and physical illnesses. These illnesses in particular prompt communicative challenges including disclosure and support seeking. This study is guided by the theory of illness trajectory and the concept of work which aims to describe the individual's experiences of chronic illness overtime. Work describes the numerous intricate tasks couples coping with a chronic illness must manage over the course of an illness. The four types of work outlined by this framework are illness work, biographical work, everyday-life work, and communication work.

This study employs a qualitative approach to explore how individuals living with chronic invisible illnesses effectively negotiate the stressors associated with communicative work within a romantic relational context. Using chronic Lyme disease as a specific focus, this study employs a semi-structured interview process to gain knowledge of the patient's illness-related turning points and perceptions of relational satisfaction at each point in order to investigate how relational partners facilitate or hinder the patient's coping with changes in the illness trajectory. As chronic Lyme disease persists over an indefinite span of time for individuals, directly impacting their relationships and health related quality of life, it is important to examine the ways in which patients and their support networks cope with the variety of stressors involved in managing this chronic lifelong illness.

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) estimates that as of 2010, half of all adults are living with chronic health conditions (“*Chronic*,” 2016). In the year 2010, seven of the ten top reported causes of death were chronic in nature (“*Chronic*,” 2016). When symptoms of chronic health issues are not immediately visible to others, these conditions are considered to be invisible illnesses (Higgins, 2000; Matthews & Harrington, 2000; Horan, Martin, Smith, Schoo, Eidsness, & Johnson, 2009). Invisible illnesses fall under a rather large umbrella that includes both mental and physical illnesses, and elicit a variety of communicative challenges for individuals attempting to manage these illnesses (Matthews & Harrington, 2000).

Horan et al. (2009) speculate that individuals suffering from chronic invisible illnesses often experience uncertainty due to their health status and worry about their quality of life post-diagnosis. Additionally, Horan et al. (2009) propose that these individuals often experience changes in their daily routines. Research indicates that these individuals report having higher contextual ages than their similarly chronologically aged healthy peers as a result of their illness experiences (Kundrat & Nussbaum, 2003). In other words, chronically ill individuals often have different life experiences than their comparatively healthy peers due to the responsibilities demanded by the management of their illness (Kundrat & Nussbaum, 2003). The responsibilities involved in illness management processes tend to influence the perception of likeness to one's peers for a chronically ill individual, and may create the inward and outward perception that the individual is older than his or her chronological age (Kundrat & Nussbaum, 2003). A qualitative study and thematic analysis of participant's reports of chronological ages for

individuals with outwardly invisible heart disease revealed six illness themes that span across the illness experience. These violations included age violations in which patient's life experiences were unusual for their chronological ages, perceived differences in capability between the invisibly ill individual and others of the chronological age group, self-realization regarding the ill individual's identity reformation through the illness experience, other's concern regarding the ill individual's health status, perceived similarities between the two groups, and perceived differences in social treatment of the ill individual during the adolescent life-stage (Kundrat & Nussbaum, 2003, p. 340).

In effort to combat feelings of uncertainty and negotiate life changes brought upon by the experience of chronic illness, individuals often seek various forms of social support from their established interpersonal relationships (DiMatteo, 2004; Doherty & MacGeorge, 2012; Donovan-Kicken, Tollison, & Goins, 2012; Reich, Olmsted, & van Puymbroeck, 2006). MacGeorge and colleagues (2011) defined social support seeking as "intentional communicative activity with the aim of eliciting supportive actions from others" (p. 330). Existing literature in the communication discipline examines social support in terms of both action support, which includes informational or tangible support, and nurturing support, which includes esteem, emotional and network support (Gray, 2014). Action support is demonstrated through behavior such as providing favors, giving advice, and information gathering, whereas nurturing support is provided through acts such as offering reassurance or compassion to another person (Gray, 2014).

Because invisible illnesses are unseen by others, the illness experience prompts the ill individual to make decisions regarding whether to disclose or conceal their health status. Diagnosed individuals may opt to disclose to relational partners in attempt to seek

social support (Matthews & Harrington, 2000). The disclosure requirements associated with receiving social support in the context of invisible illness may conflict with an individual's desire to protect their privacy and maintain a public self-image.

Communication Privacy Management Theory (Petronio, 1991) explains that individuals presume a right to privacy and have a choice in the information that they choose to disclose with others, with whom they share private information, and when they share it. The nature of invisible illness and its associated disclosure implications may threaten this right to privacy for individuals managing chronic invisible conditions such as chronic Lyme Disease (CLD).

Although existing interdisciplinary works have focused on the concept that individuals receive social support via their interpersonal network and established relationships, little is known about the dyadic nature of the support process in the context of chronic invisible illnesses. To truly understand the process of coping with chronic invisible illness, it is imperative that studies focus on the unique communicative challenges presented by invisible and contested conditions such as CLD. Recent investigations have examined the complexities of the communication events which arise as result of invisible illnesses; however, the literature has been limited to contexts such as HIV, cancer, and heart disease. Thus, a major goal of the current study is to broaden the scope of the communication literature to include an investigation of the communicative consequences patients and their relational partners encounter in the context of CLD. This study will situate CLD as an invisible illness as it meets the conceptualization of this variable because the disease's associated symptoms are largely non-apparent to others (Higgins, 2000; Matthews & Harrington, 2000).

CONCEPTUALIZING CHRONIC LYME DISEASE

Lyme disease is the most common vector borne inflammatory disease in the United States (Johnson, Aylward, Stricker, 2011). Lyme disease is caused by the spirochete *Borrelia burgdorferi* and is transmitted to humans through the bite of an infected tick (“Lyme Disease,” 2015). While there is no formal definition for CLD (Ali, Vitulano, Lee, Weiss, & Colson, 2014), patients diagnosed with this condition commonly experience “chronic musculoskeletal pain, neurocognitive symptoms, or both that persist after antibiotic treatment... [and] have considerable impairment in their health-related quality of life” (Klempner, Hu, Evans, Schmid, Johnson, Trevino, Norton, Levy, Wall, McCall, Kosinski, Weinstein, 2001, p. 91).

The CDC reports that symptoms after the initial infected tick bite include rash and flu-like manifestations which may progress to include severe headaches and neck stiffness, arthritis, severe joint pain, Bell’s palsy (muscle weakness on one side of the face), intermittent pain in tendons, joints, and bones, inflammation of the brain and spinal cord, nerve pain and problems with memory (“*Signs and Symptoms*,” 2015). Many patients’ symptoms continue after the initial four to six-week antibiotic regimen and may lead to persistent fatigue, memory difficulties, issues with cognitive processing and difficulty completing ordinary tasks as a result of the comorbidity of patients’ persisting symptoms (Andrews, 2004). While it is possible for Lyme disease to be cured with antibiotic regimens if diagnosed and treated early, one study found that 84% of participants’ late diagnosis was a major factor in the development of CLD (Aucott, 2013).

According to the CDC (2015), 30,000 confirmed cases of Lyme disease are reported to state health departments annually. As only a fraction of Lyme disease cases are reported to state health departments, this estimate is not representative of the number of individuals infected with Lyme disease in the United States annually (“*How many*,” 2015). For instance, based on figures from the CDC in 2008, it is estimated that between 240,000 and 444,000 infections occur annually among patients who submit a laboratory specimen for testing (“*How many*,” 2015). In the United States, eighty-five percent of the nation’s health spending is associated with chronic conditions (Anderson, 2010). One study concluded that the annual economic impact of Lyme disease in the U.S. based on the 23,767 Lyme disease cases reported to the CDC in 2002 was approximately \$203 million dollars (Zhang, Meltzer, Hopkins, Wroth, Fix, 2006). However, since the number of Lyme disease cases annually is highly underreported and the number of reported cases has grown since 2002, this estimate is thought to be low (Zhang et al., 2006).

In addition to the national burden to the economy, Lyme disease is financially draining for patients as the cost to treat the disease exponentially grows as the condition progresses to a chronic state (Andrews, 2004). While the initial treatment costs associated with early Lyme disease are approximated to be \$1,600, CLD patients incur expenses of \$20,000 annually due to medical costs, nonmedical costs (such as productivity losses) associated with the pursuit of treatment to manage their chronic symptoms (Zhang et al., 2006). The process of obtaining adequate medical care in order to effectively manage the comorbid symptomatology of CLD often places these chronically ill individuals at risk of losing their jobs and as a result, their health insurance, ultimately creating a “cycle of

disability and deficient care” between patients and their healthcare providers (Johnson, 2011, p. 69).

In addition to the management of physiological symptoms and monetary burden associated with Lyme disease, patients also may experience psychological symptoms as a result of their infection. As CLD progresses, previous studies have demonstrated that the condition is likely to attack the nervous system and has been linked to the development of learning disabilities, mood swings, anxiety, depression, panic attacks, obsessive behaviors, sudden rage, and other psychiatric disorders in patients suffering from the illness (Andrews, 2004). According to Igenex, a research laboratory specializing in clinical and research testing for Lyme disease, “Psychiatric Lyme has been linked with virtually every psychiatric diagnosis and can affect people of all ages. Family members are baffled by [Lyme patients’] transformations” (Andrews, 2004, p. 4). The combination of physical and psychological symptoms associated with Lyme disease may leave patients prone to increases of irritability, flares of anger, and tendencies to withdraw from social situations, as well as higher instances of divorce, family dysfunction, and domestic violence (Andrews, 2004). Igenex also reports that patients’ symptoms often worsen as Lyme bacteria grow, activate, and begin to reproduce (Andrews, 2004). This process causes symptoms to often occur in cycles which may be exacerbated by the patient’s experience of stress throughout the diagnostic and treatment processes (Andrews, 2004).

While early Lyme may be cured by a course of antibiotics, no cure currently exists for patients who experience CLD. No single antibiotic or combination of antibiotic treatments has the capability of eradicating the infection of *Borrelia burgdorferi* in Lyme patients, and illness relapses or treatment failures are reported with all regimens (“Lyme,”

2015). As CLD persists over an indefinite span of time for individuals, directly impacting their relationships and health related quality of life (health related QoL), it is important to examine the ways in which patients and their support networks cope with the variety of stressors involved in managing this chronic invisible illness.

LITERATURE REVIEW AND RATIONALE

Little research currently exists regarding communication between patients with CLD and their social networks. Instead, the literature has focused predominantly on common themes of financial stress, frustration, and diagnostic uncertainty (Drew & Hewitt, 2006). When patients do receive the diagnosis of CLD, they often experience a sense of relief, personal validation of symptoms, and hopefulness for the future when received in the disease's early stages (Drew & Hewitt, 2006). However, because Lyme is known as the "great imitator" due to its wide range of associated symptoms, few patients actually receive this diagnosis when the disease is in its infancy and when treatment regimens would be most beneficial (Pachner, 2006). Unfortunately for CLD patients, it is commonly understood that the process of obtaining a diagnosis for their multitude of simultaneous symptoms is often complex and shrouded by uncertainty (Dumit, 2006).

SOCIAL CONSTRUCTIONISM, STIGMA, AND CONTESTED ILLNESS

According to the Social Constructionism framework, illnesses have both biomedical and experiential dimensions (Conrad & Barker, 2010). The framework asserts that certain illnesses have social or cultural meaning attributed to them which adhere to the illness experience and may have consequences for a patient's health care (Conrad & Barker, 2010). In other words, social constructionism examines the ways individuals or

groups collectively create perceived social reality and knowledge (Berger & Luckman 1966). For example, some illnesses such as CLD are stigmatized or contested while others are not. These distinctions impact the way the illness is experienced, how it is depicted, responded to socially, and how policies are created regarding the illness (Conrad & Barker, 2010). Additionally, stigmatized understandings of contested illnesses such as CLD tend to influence patients' communicative interactions with their healthcare providers as well as the diagnosis and treatment of the disease's symptoms (Dumit, 2006). Contested illnesses require "hard work" by patients to achieve diagnosis and acknowledgement (Werner & Malterud, 2003, p. 578). Previous work by Dumit (2006) explains this idea by stating, "the amount of constant struggle [to achieve diagnosis] suggests that these emergent, contested illnesses can best be described as illnesses you have to fight to get" (p. 578).

Communication research involving the management of stigma states that its negative impacts often incite lowered self-esteem, achievement, and health, including increased anxiety and sustained illness for the stigmatized individual (Meisenbach, 2010). In the case of HIV/AIDS, stigma has been shown to limit access to treatment, as well as affect relationships and identities (Weitz, 1990). The Social Constructionism framework states that illnesses are not inherently stigmatizing, however, it is the social response to a condition and its manifestations, or a certain type of individual who may suffer from the condition that contribute to the stigmatization of illness. For example, using Predicted Outcome Value (POV) Theory (Sunnafrank, 1986) Horan and colleagues (2009) examined POV judgments by providing participants hypothetical scenarios for targets

with HIV, cancer, or no illness to determine how learning of an individual's ill-status may affect relational development between partners.

POV theory focuses on initial interactions and proposes that during these interactions, individuals make value judgments about future interactions and relational outcomes with the ill individual (Sunnafrank, 1986). POV judgments for HIV positive individuals were significantly lower compared to POV judgments of cancer or healthy individuals (Horan et al., 2009). Previous research in the context of HIV/Aids suggests that misinformation about transmission of the disease (Reeves, 2000) and a form of emotional burnout associated with omnipresent issues known as compassion fatigue lead to decreased interest, emotional arousal, and information seeking toward the ill individual by others (Kinnick, Krugman, & Cameron, 1996). Results of Horan et al.'s (2009) study indicated that individuals forming POV judgments forecasting relational development with HIV positive individuals were cognizant of stigma perceptions associated with the condition, and perceived the disclosure of HIV as non-normative communication in the formation of a relationship. This study highlights the complicated communicative decisions invisibly ill individuals must navigate in terms of disclosing their illness to others. The combination of stigma and public misinformation may leave these individuals lacking support from both their families, peers, and the medical community largely due to the medically-contested understanding of the diagnosis (Asbring & Narvanen, 2002; Barker, 2002).

The concept of contested illness is particularly informative to the controversial nature of the CLD diagnosis. By definition, contested illnesses are those "where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as

distinctly medical” (Conrad & Barker, 2010, p. S70). Social Constructionist Theory indicates that sufferers of contested illness themselves, physicians, and or the public often “question the legitimacy of the symptoms and mental stability of the sufferer” (Conrad & Barker, 2010, p. S70). The symptomatology and sociocultural context of CLD intersects with several other medically contested syndromes characterized by diffuse pain and fatigue such as fibromyalgia and chronic fatigue syndrome (Ali et al., 2014). Patients experiencing these symptoms may feel stigmatized due to mistreatment by health care providers or public perception of the condition (Conrad & Barker, 2010). Because sufferers of CLD are burdened by a medically contested illness, this influences the communicative implications of patient’s access to a diagnosis and healthcare, the various support responses of others to one’s problems, and the identity of the sufferer (Conrad & Barker, 2010).

Two distinct schools of thought have emerged regarding how Lyme disease is initially transmitted to humans, what symptoms may occur as a result of infection with the spirochete, and ultimately how the disease should be treated. One side of this debate is represented by the views of the CDC and Infectious Diseases Society of America (IDSA). Because the CDC and IDSA claim the spirochete is transmitted only by one specific tick species, they maintain that Lyme is a rare illness that is localized to well-defined areas of the world (Johnson et al., 2011) and specifically concentrated in the Northeastern United States (“*Data and Statistics*,” 2015). In discussing healthcare access and burden of care for patients with Lyme disease, Johnson and colleagues (2011) describe the IDSA’s stance on Lyme:

The Infectious Diseases Society of America maintains that [Lyme] disease is ‘hard to catch and easy to cure’ because the infection is rarely encountered, easily diagnosed in its early stage by distinctive clinical features and in more advanced stages by commercial laboratory tests, and effectively treated with a short course of antibiotics over 2-4 weeks. In the IDSA’s view, chronic infection with the Lyme spirochete is rare or nonexistent.

On the opposing side of the argument is the International Lyme and Associated Diseases Society (ILADS) and several other tick-borne illness patient advocacy groups. These groups assert that Lyme disease is not rare, and because the spread of *Borrelia burgdorferi* is facilitated by deer, birds, and rodents, the disease can be spread unpredictably around the world. (Johnson et al., 2011). Johnson and colleagues (2011) describe ILADS’ view of Lyme disease as follows:

Tick bites often go unnoticed, and commercial testing for Lyme disease often yields inaccurate results. Consequently, the disease is often not recognized, and may persist in a large number of patients, requiring prolonged antibiotic therapy to eradicate persistent infection with the evasive Lyme spirochete.

The greatest difference in thought between ILADS and the IDSA is the recognition of CLD as a legitimate disorder. While the CDC does acknowledge that Post treatment Lyme disease (PTLD) may leave individuals who have completed a prescribed course of antibiotics with residual symptoms for up to 6 months, the organization discounts the possibility of Lyme disease continuing to impact individuals’ health and quality of life after a period of time exceeding 6 months as they assert residual symptoms associated with PTLT should be cured within this timeframe. For instance, the CDC suggests “that patients with PTLT almost always get better with time; the bad news is that it can take months to feel completely well” (“*Post-treatment*,” 2015).

The CDC and IDSA’s denial of CLD coupled with their influence over the infectious disease protocols followed by hospitals and medical professionals is a major

barrier to receiving adequate healthcare for patients experiencing chronic Lyme symptoms months or years after completing antibiotic treatment regimens. Johnson and colleagues (2011) designed and distributed a web-based survey in attempt to understand the challenges patients with Lyme disease faced in regards to acquiring adequate care for their conditions.

The study collected responses from 2424 patients in which half of the respondents reported seeing at least seven physicians before their diagnosis of Lyme disease was made (Johnson et al., 2011). Nearly half of the study's respondents had Lyme disease for a period of time exceeding 10 years, and many traveled over 50 miles to obtain treatment (Johnson et al., 2011). Most respondents experienced symptoms lasting six months or longer despite receiving at least 21 days of antibiotic treatment, a quarter of respondents had been on public support or received disability benefits due to the management of their CLD symptoms, and over half of the study's participants had visited an emergency room at least once as a result of these symptoms (Johnson et al., 2011). Johnson and colleagues' (2011) results confirm that patients diagnosed with Lyme disease frequently experience extensive delays in obtaining an initial diagnosis, have poor access to healthcare, and suffer a severe burden of illness.

A subsequent study by Johnson and colleagues utilized CDC health related QoL indicators to compare the burden of illness across several chronic conditions including Congestive Heart Failure, Fibromyalgia, Stroke, Post-Traumatic Stress Disorder in military veterans, Systemic Lupus, and others (Johnson et a., 2014). Respondents rated their overall health and answered questions regarding how often in the previous thirty days they had experiences of poor mental health, physical health, anxiety, sleep

difficulties and the number of days which activity was limited due to pain or poor mental health (Johnson et al., 2014). The study found that the burden of illness for CLD patients as compared to other chronically ill individuals or the general population was significantly greater in regards to symptom disease burden, the number of poor mental and physical health days, increased utilization of medical services and resulting medical costs, and greater impairment in activity limitations and ability to work (Johnson et al., 2014).

In sum, patient-reported symptoms associated with CLD often occur in the absence of outwardly observable physical symptoms or laboratory abnormalities (Rebman, 2015). CLD is frequently criticized in medical literature, and at times appears in quotations within peer-reviewed journals (Baker, 2008). These representations of Lyme disease within literature which establishes policy and medical opinion diminishes and invalidates the illness experience of patients with CLD as well as the credibility of the condition. Criticism of CLD primarily stems from the disease's lack of specificity regarding symptomatology and the implication of antibiotic resistant infection as a cause for symptoms (Auwaerter & Melia, 2012). Furthermore, the contested nature of illnesses such as CLD may result in physicians refusing to treat patients as well as insurance companies denying reimbursement for treatments associated with the condition (Conrad & Barker, 2010). As a result of stigma associated with CLD in the medical community, patients are often left unsatisfied with their care in conventional healthcare settings and experience disconfirming, dismissive, patronizing and condescending communication or attitudes from healthcare professionals (Ali et al., 2014).

The minimal presence of research regarding the implications that invisible and contested conditions such as CLD have upon sufferers' illness trajectories is part of the rationale for this study. These gaps in the literature invite the opportunity for theoretical development using traditional social science techniques. The next section of the manuscript will detail this study's theoretical framework which is designed in attempt to better understand the impacts and complicated interplay of the previously discussed factors involved in the CLD experience upon the patient's health related QoL and relational satisfaction with the patient's romantic partner. This study views the aforementioned illness phenomena through the theory of illness trajectory and concept of work.

THE THEORY OF ILLNESS TRAJECTORY AND CONCEPT OF WORK

Originally proposed by Corbin and Strauss in 1986, the chronic illness trajectory framework aims to describe the experience of the individual and their support network in regards to the chronic illness over time. Corbin and Strauss (1986) originally identified three lines of work associated with the numerous tasks couples coping with a chronic illness must manage through the duration of the illness experience. These three lines of work include illness work, biographical work, and everyday life work. *Illness work* involves managing tasks directly related to the illness such as attending appointments or routinely taking prescription medications (Corbin & Strauss, 1988). *Biographical work* involves individuals re-forming personal identities around the disruption of chronic illness in their lives. Biographical work may involve the CLD patient's acceptance of their ill-status and resulting physical limitations due to the condition. Lastly, everyday-life work refers to daily task work that individuals are expected to perform (Corbin &

Strauss, 1988). In the context of CLD, this line of work may present itself as the re-negotiation of household and family responsibilities as illness symptoms related to the condition may prevent the patient from completing tasks which were previously a part of the individual's routine.

Donovan-Kicken et al. (2012) furthers this theory by discussing a fourth line of work known as communication work. Rather than treating communication as a “means to an end”(p.642), she argues that interpersonal communication holds a critical role during illness. Donovan-Kicken et al. (2012) define communication work as, “a demanding and time-consuming activity” which involves “[talking] to others, [managing] information, and [dealing] with people's questions, comments, emotions and anxieties” (p.644) whilst simultaneously managing the health issues caused by the patient's ill-status and its treatments. She states that without seeking and sharing information, or coordinating duties, accomplishing the other three lines of work would not be possible. Her theory of communication work aims to shift the focus of communication as a background process that enables the other lines of work to occur, to a foreground process that allows the essential exchange of messages and achievement of meaning to occur between individuals who are attempting to cope with a chronic illness.

In the context of CLD, this study speculates that communication work will be a crucial element involved at all stages of the illness trajectory which occurs between all members incorporated in the patient's illness experience. This study aims to extend the literature concerning the theory of illness trajectory and the four established lines of work by considering the implication of these work and communication factors upon the CLD

illness trajectory. Thus the following research questions will guide the design and execution of the qualitative processes outlined by the remaining manuscript:

RQ1: How do individuals living with contested illnesses effectively negotiate the stressors associated with communicative work within a romantic relational context?

RQ2: How do romantic partners facilitate or hinder the patient's coping with changes in the illness trajectory?

METHODS

This study employs a qualitative approach to explore how individuals living with chronic invisible illnesses effectively negotiate the stressors associated with communicative work within a romantic relational context. Using CLD as a specific focus, this study will employ a semi-structured interview process to gain knowledge of the patient's illness-related turning points and perceptions of relational satisfaction across the illness trajectory in order to investigate how relational partners facilitate or hinder the patient's coping with changes in the illness experience.

PARTICIPANTS

The sample was composed of four participants who had received a diagnosis of CLD and were treated by a physician for their continued resulting symptoms. The researcher employed multiple methods in acquiring eligible individuals to participate in the study. First, after receiving IRB approval, the researcher contacted several Lyme disease patient advocacy groups in the central Texas area via email in order to inquire about eligible participants. Next, network sampling occurred in order to reach out to the local Lyme disease community. Finally, snowball sampling occurred in which individuals participating in the study were asked to recruit others in their respective social networks

who might be interested in participating. The duration of the illness period for participants in the study lasted between 6 months and 50 years. The relational duration for participants and their romantic partners in the study ranged between six months and 20 years. The age of participants ranged from 22 years to 50 years, with an average age of 34.5 years. Participants reported ethnicities in the study were Caucasian ($n = 3$) with one participant self-identified as both Caucasian and Hispanic ($n = 1$).

PROCEDURES

Data collection for this study occurred over a one-month period. Patients signed up for a scheduled interview and were asked to meet with the principle investigator to complete an interview. The interview process took on average 1-2 hours to complete. Prior to beginning each interview, the principal investigator explained the purpose of the study to the participants, obtained consent to audio and video record the interviews, and informed them of their anonymity. To protect the anonymity of the participants, the label participant and a corresponding reference number are used within this report to refer to each interview conducted for the sample.

This study utilizes the Retrospective Interview Technique (Huston, Surra, Fitzgerald, & Cate, 1981) in which participants plotted their personal illness trajectories on a blank graph provided by the researcher. The horizontal or x-axis of the graph was used to represent *time* while the vertical axis or y-axis was used to represent the participant's *health-related quality of life* perceptions and their perceived *relational satisfaction* with their romantic relational partner. These variables were both measured along the y-axis on a zero to ten scale with zero being the lowest and ten being the highest indicator of either health related QoL or satisfaction. Participants were asked to

first plot one point on the graph which represented their health-related quality of life (QOL) status at the onset of initial symptoms. This point was placed on the y-axis as an anchoring point for the graph. At the conclusion of the graphing exercise, participants were asked to indicate their current QOL as a second anchor point.

As suggested by Thompson et al. (2016), the suggested number of turning points provided by the participant was limited to minimize the possibility of participant fatigue during the interview process. The interviewer instructed the participant to plot up to five points which they considered to be the most major turning points in relation to the illness trajectory. Participants reported between seven to thirteen significant turning points depending on the complexity of the individual's illness trajectory. The turning point is a unit of analysis which allows for the understanding of relationship processes and is defined as "any event or occurrence that is associated with change in relationship" (p. 470), turning points are essential to change in any trajectory (Baxter & Bullis, 1968).

The retrospective interview technique was the preferred method for this study as it allows participants to reflect upon and identify significant points in time. After participants completed plotting the significant turning points of their illness trajectory, they were then asked to repeat this process by indicating when they met their romantic relational partner during the established trajectory, and by indicating their perception of relational satisfaction with the partner at the time of relational-establishment. Then, the participant continued the retrospective process in which turning points of relational satisfaction around significant illness turning points were plotted.

Next, an interview guide and probing questions were used to discuss each of these points individually in attempt to discuss the specific details of the work processes which

occurred in the participant's experience and aimed to identify memorable messages received by the participant. The interviews conducted were semi-structured in that wording of the questions slightly varied in delivery each time they were asked, and follow up questions were adjusted to best coincide with the participants answer to the initial question. All interviews were audio or video recorded, and then transcribed for data coding purposes. In sum, 102 single spaced pages of data were transcribed, which documented approximately five hours of interviews. Following the conclusion of each interview recording, participants were debriefed about the purpose of the research study and provided an opportunity to ask the researcher any questions that arose as a result of their participation in the study.

This study is based in the grounded theory method and utilizes both emic and etic approaches to qualitative data analysis. According to Keyton (2005), grounded theory is an approach to analyzing qualitative data in which theory is created from relationships between emergent categories. Using grounded theory, a multistep process of data analysis occurred. First, the principle investigator determined an organizational system for how data was to be coded in attempt to increase coding reliability. Once the coding process was decided, data analysis began as all transcriptions of the study's data were thoroughly reviewed. Next, several passes through the data took place where open coding was used to select data as pertinent to the initial research question. Next, axial coding occurred during which significant data were linked through emergent categories in a meaningful way (Keyton, 2005). On the second and third stages of data analysis, the constant comparative method was utilized and recurrences in participant quotes were color coded and then tallied. Eight initial categories emerged from the data. During the fourth stage of data

analysis, axial coding began and categories were collapsed as they were linked in meaningful ways (Keyton, 2005).

RESULTS

The illness themes that emerged from the data suggested several communicative challenges that helped further the understanding of communication work along the illness trajectories experienced by CLD patients in this sample. The following themes were informative to the understanding of the original three lines of work in this specific contested illness context: illness work for CLD patients was found to be cumbersome and demanding, biographical work was linked to an increase in the patient's awareness of their mortality, and disruptions in everyday-life work processes for the study's participants concentrated on productivity interruptions in both the home and workplace. Distinctions were found between communicative work strategies employed by the patient and the patient's relational partner when communicating about challenges involved in CLD experiences. Although patient and their relational partners enacted different communicative strategies, both ultimately adopted the role of advocate during the patient's illness experience. Namely, these themes have been identified as patient's adoption of the communicative role as self-advocate, and the partner as protector and primary support provider as compensation for deficits in the extended network's capability to understand the patient's illness experience and inability to provide adequate social support.

TRAJECTORY COMMONALITIES

Between all participant trajectories captured by this study, 36 health related QoL trajectory turning points and 19 turning points of participant relational satisfaction were

reported throughout the individual trajectories. Commonly, downturns in the illness trajectory were reportedly linked to degradation of health status due to recurrent symptoms participants experienced, stress, and largely to the lack of access to effective medical regimes as a source of symptom management. In this sample positive turns in relational trajectory most frequently occurred after participants' trajectories dropped to their lowest turning points regarding health related QoL after which participants reported finding medical treatments which partially alleviated or began to help manage their illness related symptomatology.

Participant perceptions of relational satisfaction throughout the course of the trajectory tended to follow the upwards or downward turns of the participant's health related QoL. Often participants' relational satisfaction lowered during periods of uncertainty tied to their quest for a definitive diagnosis to explain the myriad of symptoms they began to experience caused by their infection with Lyme disease. These uncertain and turbulent periods for the participant's health related QoL and relational satisfaction often occurred in the middle portions of their illness trajectories. In this sample, differences occurred during this stage on a trajectory by trajectory basis.

Participant 1 reported high levels of consistent relational satisfaction with her husband throughout the entirety of her illness experience, indicating her satisfaction at a nine on a possible scale of zero to ten. Participant 2 indicated that her partner decreased communication and de-escalated relational commitment as he perceived that she was attempting to use her illness-status as a form of relational manipulation.

Participant 2 stated:

I remember us, we weren't romantically involved, we were just trying to be friends with one another because we just broke up, but some of it was him just being like you're convincing me to get back with you. And I was like, ok, whatever. We need to take a break. I can't. You're back to thinking that I'm planning and all this stuff and it's just, guys do that sometime and he does that a lot. And it's just really annoying. So, he, we kind of stopped talking. It kind of went back up, like during that time he was there I wasn't really excited that he was back, I'll be honest and maybe I was secretly wanting him back in my life. I can't say that I didn't. Cause I was always happy with him. But we weren't in a good stage. We had a tough Summer.

This decreased her relational satisfaction, until the next turning point when her symptoms were manageable and her corresponding health related QoL began to improve. Participant 3 discussed the "rocky times" which occurred within her marriage during this mid-trajectory period. She discussed that a disconnect began with her partner during this time because he was unable to fully comprehend her illness experience. Participant 3 stated that she felt "totally alone" during this time. Further, she explained:

I mean you're just alone. You know, your spouse isn't on board so I'm sitting here you know, fighting a dragon and he's thinking I'm just, you know, off on some little project or something.

During the uncertain middle stage of her trajectory, Participant 4 recounted assessing her life choices due to the biographical work involved in her illness experience caused by her shifting trajectory. Participant 4 severed her relational connection to her partner after he proposed the couple should marry. When discussing this relational severance, Participant 4 stated:

I felt scared, and I felt so bad. We actually broke up because he proposed to me. That's when I realized, I was like I don't see a future with him. . . . I was sad to let him go, but I knew that it was the right thing. . . I still enjoyed his company, but I just didn't know if I was in love with him, or if I saw a future with him.

Excluding Participant 4's relational termination with her romantic partner, all participants in this sample reported drastic increases in relational satisfaction as they were

able to receive proper medical treatment and experienced upward shifts in their health related QoL statuses. The increasing relational quality satisfactions for participants one, two, and three were cited as perceptions which returned to or approached the level of relational satisfaction preceding the middle-trajectory period. Again, it is significant to note that these increases in satisfaction accompanied the participants' upwardly increasing health related QoL statuses. Visual depictions of the participants' illness trajectories which detail these shifts and turning points in trajectory are included within the appendix section of this manuscript.

ILLNESS WORK

Illness work involved in the initial diagnostic process and required by attempts to manage the comorbid symptomatology experienced by CLD patients was found to be cumbersome and demanding. For example, participants in this sample reported experiencing illness symptoms throughout the CLD trajectory which required management-efforts that included: presence of the typical Lyme bullseye rash, Bell's Palsy, seizures, infertility, brain fog and clouding of mental faculties, loss of speech, lapses in consciousness, meningitis, and critical suppression of the immune system which left the body vulnerable to infection. Participants in the sample most commonly reported that these management demands presented themselves in the form of attending doctor appointments, trying expensive and often ineffective medical regimens, self-administering medications, managing symptoms, and information seeking as a form of self-education when help could not be adequately obtained from medical professionals.

For example, Participant 1 discussed the biological anomalies caused by her symptoms which affected her resulting infertility as follows:

My adrenal glands, my kidney glands, my kidney hormones, my pituitary hormones, everything was working at a snail's pace. So my metabolism was low, that's why I had infertility problems. Doctors didn't know what to do about it. They were confused about it because it's not normal to have everything low. Your body is supposed to work differently. It's kind of like an automation, you know, when this is low this is high and so that tells the doctors what to treat and that wasn't the case with me.

Additionally, Participant 4 stated:

The symptoms started when I was in eighth grade. It started with fatigue, and then I got mono when I was a freshman. The main symptom that affected me the most is that I would get sick, and then I wouldn't be able to fight it off. I would get sick with things that only people that have severe immune disorders get. I got a black mold infection in my sinuses, and had to be hospitalized, because the medicine wasn't working. I would get sick with things that only people with HIV would get sick with, because your body should be able to fight off things like that. . . My doctor was like, "If it spreads to your blood like you could die, but oh, you don't have to worry about that, because only people with like major immune deficiency have to worry about that, like AIDS patients." I was like, "You don't get it. Like, my immune system is non-existent." He was like, "No, you're fine." . . . Then I just had like chronic sinusitis. I had like four sinus surgeries, and then an appendectomy. It's just like I was always getting sick with something, and my body wasn't able to fight it off. That was my main symptom. From eighth grade to senior year we went and we saw everyone. We went to California, we went to Houston just to try and get a diagnosis. We saw all these infectious disease physicians and no one could figure it out. Finally my mom basically [diagnosed my Lyme] herself when I was a senior.

To cope with the stigma and uncertainty of their conditions, these participants discussed information seeking as a form of communication work which occurred throughout the trajectory. Further, Participant 4 described one of the lowest turning points of health related QoL in her illness trajectory around the age of 20 by stating:

I was really scared at this point. I was like I'm going to die if I don't find something. . . Then I started doing all this research, and I started doing intravenous ozone therapy, and it helped a lot. I was like, okay I'm getting better, but I don't think this is going to cure me. I spent about a month just researching.

Three out of four participants in this sample reported leaving their home state of Texas to seek specialized medical treatment, and one participant traveled internationally to meet with a German Lyme specialist in attempt to discover an effective medical

regimen to restore her health to a state of “normal” functioning. Throughout the interviews conducted for this study, participants repeatedly discussed their experiences of frustration involved in following their physician’s treatment protocols while experiencing little improvement regarding their health related QoL.

When asked about attempts to manage her symptomatology, one participant stated that she felt that she was “[putting] Band-Aids on things, but [she] worked really hard at improving [her] health.” In addition to the burden of physically attempting to manage persistent symptoms, participants discussed financial costs of treatment, and obtaining access to medical care from a physician who viewed the contested condition as legitimate as significant barriers to illness work processes. Often, participants discussed having to leave the state of Texas to seek treatment for their declining health status due to the CDC’s geographic definition of where Lyme disease can and cannot be contracted. Regarding these barriers to care in the southern region of the United States, Participant 3 stated:

Many people in Texas and in the southern states, we are not educated on Lyme, we’ve heard of it, maybe but really don’t know what that means and of course, our doctors are not educated on Lyme as they believe it’s not in the south. So, the way that I, after being very ill with many different symptoms, going from doctor to doctor for different ailments, diagnosed with things from depression, rheumatoid arthritis, MS, chronic fatigue, I needed attention. All the, you know, typical misdiagnosis, even ankylosing spondylitis was one I got diagnosed with, and none of those seemed to fit totally with what I was dealing with. It never answered all the questions. Each diagnosis I would have gladly taken one and wanted to treat.

It is obvious that these barriers of care significantly complicate CLD patients’ diagnostic quests and attempts to medically address their illness conditions. These complications not only affect CLD patients’ illness management work processes, rather, these consequences are seen in all forms of work throughout the illness trajectory. The

next segment of this manuscript will demonstrate how these barriers create significant disruptions in CLD patients' every-day life work processes as well.

EVERYDAY-LIFE WORK

Participants in the sample discussed the complex nature of symptom management and relapse common to the CLD experience as a “rollercoaster.” Disruptions in everyday-life work processes for the study's participants concentrated on productivity interruptions in both the home and workplace. When discussing the challenges involved in incorporating the overwhelming management of symptoms into her daily life, Participant 3 (a small business owner and the mother of four young children) stated, “I went from working full time and running around to not being able to get off the couch. I used to have a store and a boutique and I had to close them because I was so sick.” Further, this participant stated,

I could [no longer] manage my body... the way Lyme works, it waxes and it wanes. It comes in and out and I kind of got to the point that I'd took care of myself during the day, took it easy, then I'd have a few hours where I could kind of get the dinner ready, and get everyone where they needed to be. Take care of the kids and go to bed early, and I would wake of of course feeling like I had drank a bottle of whiskey or something.

Participant 4 reflected back upon her high school career when her health related QoL was at one of its lowest points and stated:

I missed three straight weeks of school, because I had [Aspergillus black mold in my sinuses], and then I had pneumonia, and then I had a mono relapse, and I think that I had to go to the school board, because I calculated it and I missed about 70% to 80% of my senior year. My teachers hated me because they thought I was faking it.

The two married participants in this sample reported every-day life work challenges most often revolved around managing household and parental responsibilities.

Participant 3 stated that she “lost half the things [she] was able to do...all while having a family.” Participant 1 described her caretaking role as everyday-life work by commenting, “I was a stay at home mom for 17 years and my full time job was to treat myself for Lyme Disease and my kids.” Participant 3 explained that fatigue due to her experience of CLD greatly impeded her ability to carry out tasks within her family’s home. She stated that because of her symptoms, her husband was required “to step up to the plate a bit more and help [her] because [she] was always saying ‘I’m so tired, I need to lay down’.”

This loss of normal ability or disruption of the everyday life routine were discussed by participants in this sample as a source of frustration and dejection. Because their physical or mental abilities were hindered by their condition, participants reported experiencing changes in their cognitive thought processes or worldview. The next section of the manuscript details their discussions of the re-formation of their identities around the incorporation of the CLD experience into their self-concept.

BIOGRAPHICAL WORK

Participants in this sample linked the identity management processes inherent in biographical work to shifts in prioritizing a health conscious focus in daily life, and an increase in the patient’s awareness of their mortality.

Because of these biographical shifts which placed health consciousness in the forefront of participant’s minds, at the lowest points of health related QoL along the CLD trajectory cognitive assessments of mortality often occurred in the sample. At one point during the interview, each participant discussed the fear and hopelessness associated with

the feeling that their symptoms would lead to death if drastic improvement in the trajectory did not occur.

Participant 3 contracted meningitis which triggered painful symptoms while she was watching her son's soccer game. The CDC defines meningitis as, "an inflammation (swelling) of the protective membranes covering the brain and spinal cord known as the meninges. This inflammation is usually caused by an infection of the fluid surrounding the brain and spinal cord" ("Meningitis", 2016). The condition can be life threatening and requires immediate medical attention ("Meningitis", 2016). When Participant 3's symptoms began to present themselves, she described the event as follows:

All of a sudden started to lose, it's very hard to explain, but I started to feel like I lost the reality of my surroundings, and I realized that I needed to go to the bathroom. It felt like my inner being was shrinking, like the essence in me was just going away like I was a shell of a person and I waved to my husband and I was in the bathroom I was in west university, in the field and I walked to a little restaurant. I just remembered shuffling my feet and my neck was jerking and twitching, and I got to the bathroom, splashed water on my face and I vaguely remember, it was getting kind of dark, passing some woman at a table and thinking that I need to ask them for help... and I wanted to say I had Lyme, but it was just a weird feeling of knowing, I don't know what to say was wrong with me 'cause it's not anything that anyone understand.

Upon returning home from the hospital after this traumatic episode, Participant 3 reported:

I had no control over my body and I think that was the first kind of scary turning point, and yeah actually that evening, or the next day... I couldn't turn the lights on, you know the Lyme affects your eyesight and you know you have light sensitivity, and I was sitting in my husband's office in the dark and I wrote an email to a handful of my friends saying if something happens to me, here's what to do, and I told them where I wanted to go. I said my husband would be very focused on the children, I said my mom's gonna want to get me to a doctor here in Houston. There is nobody. Please get me up to... it was the feeling of I'm not going to be able to speak anymore or tell anyone what's wrong with me, 'cause I was already losing my speaking faculties so I was trying to tell everybody what to do with me if something like that happens...that was three months that held in and out of you know feeling like I was gonna die and lay around and you just the pain was incredible. I would stay up all night in pain. It felt like dogs were biting my

knees and sometimes my brain I would think I was on top of the ceiling looking down. You know and so... I felt like I was literally going crazy.

In this sample, the stress of illness management work, changes in the participant's routine inherent in every-day life work, and the biographical work processes which led to health conscious assessments of health related QoL or mortality defined individual's' illness experiences. Because of the complicated interplay of these factors upon the CLD patients' trajectories, it is important to consider the ways in which patients and their partners enact communication work as a means to cope with shifting trajectories within this context.

COMMUNICATION WORK

In this sample, distinctions were reported between communicative work strategies employed by the patient and the patient's relational partner to manage these communicative obstacles between varied relational partners (i.e., romantic partners and external members such as family, friends, and medical professionals) in the CLD patient's life. Previous work by Donovan-Kicken et al. (2012) determined that the line of communication work, "places emphasis on communication as more than a component of illness, biographical, and everyday-life work," (p. 650) because communication work illustrates the demands inherent in talk about the illness experience.

Participant 3's aforementioned inability to reach out to the woman she passed at the soccer stadium due to her perception of anticipated stigma surrounding the understanding and validity of CLD despite her desperate need for assistance highlights the communicative complications involved in living with and managing this invisible, chronic, and contested condition.

REPORTED PATIENT COMMUNICATION STRATEGIES

To negotiate the communicative challenges often involved in the diagnostic process of CLD, physician-denial of the condition, and stigma from the outside support network, participants reported adopting a communicative role as self-advocate. Patients in the sample enacted this role via understanding their health condition, knowing their rights and responsibilities as a person with a disability, and being able to communicate and assert one's needs which have been established in previous research (Test, Fowler, Brewer, & Wood, 2005). Participants in this sample demonstrated a vast knowledge of complicated medical terminology and understanding of the body's biological processes. To compensate for the contested nature of the illness and the lack of medical consensus participants discussed the need for self-education in which they turned to online research from credible sources for information. Previously established literature suggests that the internet is frequently used as a conduit for information seeking behaviors in this way. This type of health information seeking behavior has been demonstrated to positively affect patients' coping mechanisms and informed decision making processes regarding treatment options (Nelson, Kreps, Hesse, Croyle, Willis, Arora, Rimer, Viswanath, Weinstein, & Alden, 2004).

When speaking to medical professionals or friends and family members, self-advocacy was often demonstrated through the use of medical jargon in attempt to bolster the credibility of the patient's illness experience. When asked about specific communication moments with her romantic partner during the illness trajectory, Participant 1 discussed the tendency to respond with incredibly detailed explanations of her body's physical symptoms and scientific processes involved in physician-

recommended medical regimens that perhaps suggests this is how she preferred to communicatively navigate the discussion of her illness experiences.

In this sample, participants reported the need for their communicative self-advocacy often resulted from physician denial of this invisible and medically contested disease. Because her physicians were reported as turning to CDC published literature which views CLD as an acute rather than chronic illness to inform their understanding of the condition, Participant 1 felt that:

[She] had to school them because they're all told...very false information. The doctor actually opened up the, this humongous journal from the CDC that explained um, Lyme Disease, um, and how, you know, easily curable it is with...30 days of antibiotics, which was a big fat lie.

Attempts to inform the network or medical professionals were primarily discussed as unsuccessful, and participants often voiced their frustration at members of the outside network's inability to understand their experiences.

For example, Participant 1 described her attempts to discuss her illness experience with individuals other than her relational partner as follows:

I do think that [CLD] causes divorce and people get tired of hearing about it. Because it consumes your life. You know, you feel bad every day because you have it, um, people get tired of listening to it, talking about it, hearing about it. You suspect everyone else in the world has it because you see the symptoms in other people. And I just kind of came to the conclusion that I can only talk about it to people who had it or understood it. And I quit talking about it with everyone else.

Participants 2, 3, and 4 reported similar frustrations in managing communication work in the context of CLD. Participant 3 stated that to compensate for her inability to successfully communicate her experience to others in the social network, her husband became an echo chamber-like resource for her venting about frustrations regarding her

illness in response to other's who did not understand her condition. Participant 3 stated that her "complaining," eventually took a toll on the collective relational satisfaction of their marriage and lead to "rocky times" for the couple.

In addition to these communicative barriers and burdens, participants' feelings of isolation and loneliness were exacerbated by the perception of communicative obligation to inform others about the changes in trajectory, outcomes of medical appointments, or new treatment regimens. In this sample, participants' sense of burden regarding these communicative responsibilities was heightened when the participant perceived a lack of understanding from friends or family members regarding the multitude of symptoms they experience on a daily basis. These findings are in accordance with work done by Donovan-Kicken et al. (2012) which concluded that communication work included strategic message design for how cancer survivors "packaged and delivered their messages" (p. 647).

Participant 3 illustrated these concepts when she discussed her initial disappointment after traveling out of state in her search for a definitive diagnosis which would encompass her mysterious symptomatology. After Participant 3's new physician dismissed the possibility of CLD being contracted in her home state of Texas, she explained:

I said, would you please run the western blot, because at that point, I had only been given the ELISA test, and he said, no if you had the ELISA that would just be the only test that you need and I kind of begged for that, please at least give me the western blot... kind of demanded that, so he went along and ran that test, and walked out the door. So...that was a huge turning point, because that was my hope. I collapsed to the ground, sobbing my eyes out, because I had realized that I was not going to get help there... and I had all friends and family waiting for me to come home and tell them some kind of good news, that yes I got diagnosed, and yes I'm getting treated, because at that point I had said this is what I have,

Lyme, it's so obvious. I have all of the symptoms. So, then I went home and I felt like I had lost some, I didn't really want to talk about it anymore.

To address and update the network about these trajectory-related shifts, participants reported the use of scripts as communicative tools to ease the burden of repetition involved in describing their experiences to the network. Describing scripts as a tool to overcome this communicative challenge in her experience, Participant 2 stated:

I wish my doctors and my professors were all on the same page. I wish they all, instead of me going and actually trying to go and explain to every single one of these people, I wish I could have just said it once and everyone kind of just do their job and understand how terrifying it was for me. (Later) Towards the end, I've said this so many times, that I know this literally frontwards and backwards... Yeah, let me just show you and here's the picture. And it's basically me selling myself so that they would take me seriously.

Due to the largely invisible nature of this chronic and contested condition, this study speculates that the demands of communicative work associated with CLD include the patient's ability to address the burden of proof being placed upon their shoulders during their search for diagnosis and subsequent communicative interactions with the network about the illness. On several occasions participants in this sample discussed the feeling of hope experienced when any physical and outwardly visible representation of the illness occurred. Participant 3 recounted the following regarding the observability of her symptoms:

Bell's palsy was a real physical sign of my illness, which as scary as that is, it was almost a blessing because I had something physically wrong with me that you could actually see – outwardly see.

In this sample, participants used the observability of their symptoms as nonverbal communication tools to aid in addressing the burden of proof when communicating their physicians or extended networks about their condition. Because participants with

observable symptoms were able to document them, the participants were more likely to be successful in bridging this communication gap with their physicians.

This concept emerged again during the interview with Participant 2. She reported that she had an observable bull's-eye rash which she photographed and used as a nonverbal communication tool to increase the validity of her illness claims when communicating with her physicians during the early stages of her diagnostic search. Participants reported that due to the invisibility of CLD, their nonverbal appearance conflicted with others' perceptions of the participant's credibility when discussing their suffering. All participants discussed the concept that the invisibility of their illness exacerbated personal feelings of invalidation and isolation as they experienced discrepancies between the visual presentation of their illness and commonly held "images in [other's] heads" of what a sick person "should look like."

All participants in this sample reported the consequences of misunderstanding leading to lack of adequate support from their network during low points in the health related QoL trajectory. This is especially detrimental to the participant's health related QoL as these moments are likely when such support would have been most needed and beneficial to the participant. Participant 1 stated, "it blows my mind. It almost makes me wish they got it, a bad case of it so just they would understand. Which is a horrible thing to, I wouldn't wish that on anyone." When reflecting on her lack of network support, Participant 2 explained she often thought, "Why are you not here for me! I'm suffering!" Further, she stated:

It was terrible...I wanted someone to be there and take care of me and no one was and my doctors didn't care and my Mom was [in a different city in Texas] and it was just, I felt very like, I don't know, alone.

Participant 4 discussed her issues with communication work involved in maintaining relationships with her social network during her high school years by explaining:

I felt like they just didn't really understand, because I looked fine. When I went to school I wore makeup. My parents, at that point they kind of let me do whatever I want, because I was so sick. I remember they would let me throw parties, and stuff like that. When I was feeling good I was fine, but then when I was sick I don't think people really understood, and I was just so depressed that I didn't really want to talk to anyone, and I was just kind of isolated at my house.

Additionally, younger participants in the sample commonly discussed the fear of death or further declining health related QoL due to their inability to manage their illness related symptoms. These concepts were discussed in association with the desire to seize control of the illness trajectory. When discussing these control desires, participants reported an accompanying increase in perceptions of self-efficacy related to achieving this goal. Participant 2 stated that because of her illness, she “realized she only had [herself], and had to be [her] own best friend.” She cited her reason for seeking counseling to guide her through her illness experiences as, “I just wasn’t good at that. I didn’t know how to do that. So, I basically asked someone to teach me how to do that.”

REPORTED PARTNER COMMUNICATION STRATEGIES

One theme which emerged from this sample revealed that in the face of stigma and misunderstanding the patient experienced throughout the illness trajectory, partners commonly adopted communicative roles as defenders of the patient to the extended social network. Additionally, partners became primary support providers as means for combating the stigma and invalidation participants often experience from others in their social networks. Specifically, the romantic partners enacted the role of defender through tangible and emotional support.

Action support tangibly provided by partners within this sample was identified through the contribution of financial assistance to the patient. For the married participants in this sample, these monetary resources were used for treatment or diagnostic purposes and for hiring individuals who came in and assisted with management of every-day life work in the household. Participant 1 explained the financial support that she received from her husband as follows:

The only challenges we had was, you know, it was expensive. The tests were expensive to pay for out of your pocket 'cause insurance didn't cover them. We didn't have the money to be paying for that kind of thing and he supported me. But you know, it's like you're asking your husband, 'Can I go blow a couple hundred dollars on a blood test?' Most people are going to say 'No! You're crazy! Go use the insurance.' And he didn't do that. He allowed me to do what I needed to do.

Participant 3 described the tangible aid from her husband as manifesting in his management of their children and activities involved in the negotiation of the couple's everyday-life work. When asked how her husband was most able to help her along the trajectory she stated:

The children. If I had to, especially on treatment, I was going to bed sometimes at 5:00 or 6:00[pm]. And he would handle the children. I also had full time nannies so I was in Denver when I was going through treatment, which was you know... very fortunate, so I would say he was very helpful with children when he was there and when he traveled, I had help... and financially I was able to afford everything which is not for most people, so that... you know he provided for me, and he listened.

The younger unmarried participants in this sample reported that tangible aid was offered when the partner's physical presence was required in appointments, during treatment procedures, or at times of emergent situations. Participant 4 discussed her gratitude for her partner's presence during her treatment procedures as follows:

Going through the treatment was really rough. I'd have a fever. I would shake... He was just being there for me. It's such a scary experience. You're throwing up.

You can't breathe. You're shaking so bad, and you have a high fever. It's hard to move. You're in so much pain that it's unbelievable how much pain you're in. It's just the worst. He would just be there, and he would hold me, because you're freezing, and your fever is like 105. You're just freezing your butt off. He would cuddle with me, hold me, and try to keep me from shaking, and bring me water, which of course I always threw up, but whatever. That's how he helped me through it.

When questioned about partner support during her time of illness, Participant 2 recalled that despite their recent decision to terminate their relationship, her partner drove from another area of the state to check up on her health status when she took herself to the emergency room in search of medical assistance and asked to remain updated on her evolving health condition.

Patients' discussed their partners' support providing behaviors in a myriad of ways. In this sample, partners' support was most commonly discussed in terms of action support. An interesting theme emerged through participants' discussion in which tangible support was perceived by the patient as means of symbolic emotional support and validation from their partners. To illustrate this concept, Participant 1 discussed her husband's willingness to preemptively treat himself with antibiotics for Lyme disease despite showing no outward indications of having contracted the disease. In this segment from her interview transcription, Participant 1 also discusses a theme found throughout this sample; The relational partner as the patient's defender:

I think he supported me with other people in our lives like his parents... he was on board with me. He was an advocate for me... but he would have taken up for me, um, as far as like my brother and sister in law they didn't believe in it. My husband took up for me and my parents. And you know...did we consider him a positive patient? No. I did. He himself, I'm not sure if he did or not. Probably not. But just as a precaution, he treated himself. Because I was scared. I didn't want to re-infect myself after what I had been going through.

Participant 1 further explained that due to her partner's positivity and the rapport inherent in their relational closeness, the couple was often able to use humor as a means of coping in times of stress caused by shifts in the illness trajectory which she perceived as benefiting her long term QoL outcomes. Participant 1 stated, "because I was so supported, we could be that way. When you don't have that support then you don't have that."

This statement from participant 1 illustrates the importance and necessity of effective communication during the illness trajectory. These participant testimonials detail the work functions inherent in the CLD illness experience. Participants in this sample reported using communication behaviors as conduits for information sharing and coordination of tasks involved in work processes throughout their illness trajectories. In accordance with Donovan-Kicken et al.s' (2012) findings, this study asserts that the communication work involved in the CLD illness context is in fact laborious and an influential component of the patient's illness trajectory (p.649) regarding sufferers' health related QoL and perceptions of relational satisfaction.

DISCUSSION

The theory of illness trajectories (Corbin & Strauss, 1988) and the four proposed lines of worked involved in the chronic illness experience (Corbin & Strauss, 1988; Donovan-kicken et al., 2012) have informed the understanding of the complicated nature of work involved in CLD patients' illness management demands across their often turbulent illness trajectories. The purpose of this study was to investigate how shifts in individuals' illness trajectories and corresponding health related QoL influenced the patient communication processes with romantic relational partners. This study sought to

extend existing social science literature regarding illness trajectories and the theoretical concept of work to the context of contested illnesses which affect sufferers' lives for indefinite periods of time.

To truly understand individuals' health-related experiences within this context, this study focused on the unique communicative challenges presented by invisible and contested conditions such as CLD. An underlying belief of this study's rationale was that because of the contested and invisible nature of CLD, work processes, especially communicative work functions, would be influenced by stigma and public misconceptions of the disease.

The research questions posed by this study sought to understand how relational partners facilitate or hinder the patient's coping with changes in the illness trajectory by exploring patient's illness-related turning points regarding health related QoL in relation to corresponding perceptions of relational satisfaction. Several key findings emerged from the semi-structured interviews conducted in this sample.

The interview data revealed that partners often adopted communicative roles as defenders of the patient to the extended social network. Because of the unique implications of the CLD illness context, participants in the sample discussed the ways in which their romantic relational partners became primary support providers as means for combating the stigma and invalidation participants often experienced from others in their social networks due in part to the invisible and contested nature of the condition. This theme supports previous research which suggests that in the context of chronic illness, partnership-models of communication may be adopted where communication becomes more equal and open (Young, Dixon-Woods, Windbridge, & Heney, 2003).

Additionally, this research indicates that close relational members involved in the illness experience are often used as a resource to manage communication, which may function to “facilitate or hinder communication” (Young et al., 2003, p.307). In this sample the facilitation or hindrance of communication emerged through the participant’s discussion of support related to communication work. Namely, partners provided tangible aid, and supportive messages to the participant throughout the illness trajectory.

Further, this study asserts that tangible aid provided by the partner often symbolically functioned as a form of emotional support for the patient. This concept was best illustrated by Participant 2’s discussion of her partner’s willingness to treat himself preemptively for Lyme disease to provide her solace in a time of uncertainty and fear due to her declining health related QoL trajectory.

This study’s use of visual trajectory comparison between patient’s health related QoL trajectories and corresponding relational satisfaction allowed for unique analysis of the ways romantic partners may help or hinder the chronically ill patient’s ability to cope with shifts in illness trajectory. By examining the patient’s illness and relational trajectories in tandem, this study was able to draw conclusions in order to determine how the lines of work have influenced both trajectories, and additionally, how these trajectories function together to create a comprehensive view of the patient’s illness and relational experience. Through the analysis of the collected trajectories in this sample, attention has been drawn to the communicatively complex mid-trajectory phase of this illness context. During this period, trends in reported trajectories revealed the tendency for declining relational satisfaction as the CLD patient struggled to obtain diagnosis and adequate medical care for the multitude of symptoms they were experiencing. However,

patterns in the patient's relational satisfaction mirrored health related QoL turning points towards the end of this mid-trajectory period as the patient's health related QoL trajectory saw improvements. After careful consideration of these trends in trajectory similarities, this study speculates that variables such as intimacy, relational closeness, enacted methods of partner support, and relational affection may account for individual differences in trajectory outcomes regarding satisfaction.

LIMITATIONS

Although this study provided much needed insight into the communicative circumstances involved in this illness context, it is important to discuss the limitations of this study to fully place its findings into perspective. One major limitation of this study includes time constraints for the project which placed restraints upon participant recruitment while the principle investigator waited to receive IRB approval to contact Lyme disease patient advocacy organizations in the South Central Texas area. However, IRB approval for these recruitment methods has since been obtained, and this study will be expanded upon as more data is collected to inform the emergent themes found in this sample in attempt to achieve theoretical saturation. This limitation restricted the sample size to four participants who were primarily Caucasian. Additionally, the sample included only women which may have influenced the results presented here. Future recruitment should aim to include male participants' viewpoints so that the understanding of their experiences are simultaneously considered and reported. Future studies should consider these limitations and seek to expand the participant pool to expand a variety of gender and cultural perspectives of the chronic invisible and contested illness experience.

FUTURE DIRECTIONS

Emergent themes discussed by this sample indicate the significant need for the addition of extant theory and literature regarding patient-physician communication in this unique illness context. In this sample, participants repeatedly discussed the experience of physician communication invalidating their illness experiences and symptoms. This pattern of physician denial ingrained in the invisible and contested illness context may impact the sufferer's illness trajectory, as this denial often impedes the patient's ability to gain access to medical care and treatment. Additionally, literature in this area would be benefited by the understanding of the partner's perspectives of these communicative processes along the illness trajectory. Future researchers should take these limitations and needed directions into consideration when constructing studies which focus on the communicative work enacted by patients in their encounters with their physicians.

CONCLUSION

This investigation has informed our theoretical understanding of interpersonal communication features in the contested illness experience. Prior research on chronic and invisible conditions illuminated tasks associated with illness management demands which were conceptualized as work. Through discussion with individuals living with Chronic Lyme Disease, this study extended the understanding of theoretical work functions throughout the trajectory to bring attention to this medically contested condition and its implications for relational partner communication. These findings place emphasis on the need for social support during the illness trajectory to aid sufferers' coping capabilities and illness management attempts. By focusing on both health related quality of life and relational satisfaction as key components throughout the illness trajectory, we are better

able to understand how effective interpersonal communication processes may facilitate enhanced patient psychosocial and physiological health outcomes.

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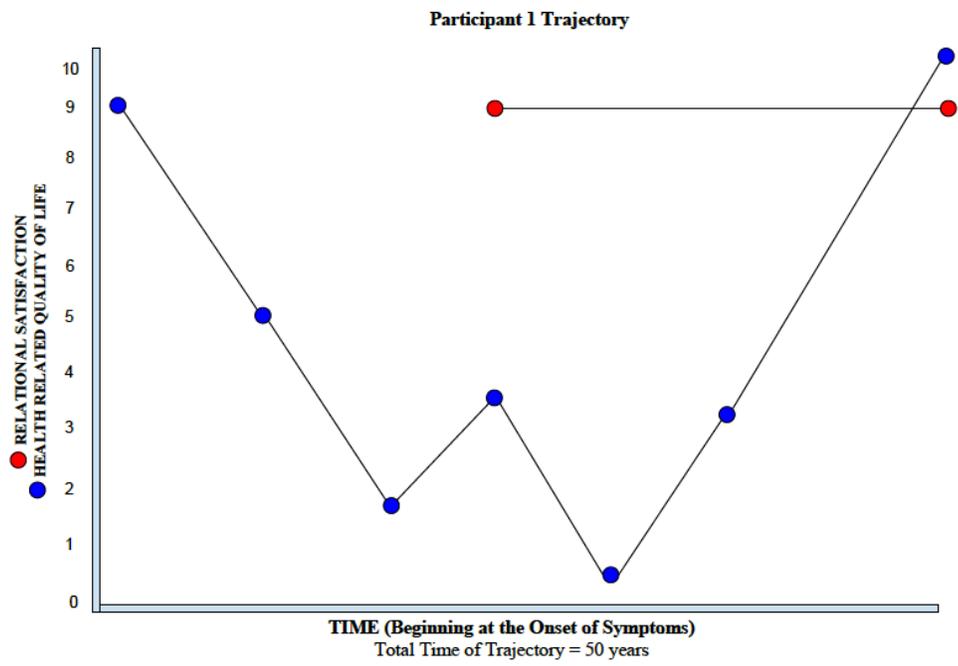
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APPENDIX



Participant 2 Trajectory

