Exemplar

A Qualitative Approach to Understanding Patients’ Diagnosis of Lyme Disease

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Abstract

Objectives: The purpose of this study was to explore the lived experience of becoming diagnosed with Lyme disease. Design: A qualitative, phenomenological study was conducted to investigate the experience of becoming diagnosed with Lyme disease. Sample: A purposive sample of 10 participants diagnosed with Lyme disease were interviewed and tape-recorded. Data saturation guided the size of the sample. Methods: The interviews were transcribed verbatim. Key words or phrases were extracted and clustered; clusters were interpreted into themes. Analyzed data were confirmed with the participants for trustworthiness and reliability. Results: Six themes emerged from the interviews. Participants expressed feelings of frustration during the long road to diagnosis. They endured multiple diagnostic tests and were seen by numerous health care providers. Participants voiced financial stress. They expressed the need for self-advocacy and felt validation when a diagnosis was made. Despite the chronicity of their illness, the participants voiced a sense of hopefulness for their future. Conclusion: A deep understanding of the lived experience of becoming diagnosed with Lyme disease allows for nurses to prioritize health care interventions and strategize ways to implement quality improvement systems as clients enter the health care environment.

Key Words
Lyme disease
phenomenology

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Lyme disease is the most prevalent vector-borne disease in the United States. It is caused by the bacterium Borrelia burgdorferi and transmitted to
humans by the bite of a tick such as *Ixodes scapularis* (commonly referred to as the deer tick). The number of annually reported cases of Lyme disease in the United States has increased 25-fold since national surveillance began in 1982. In 2001, 43 states reported a total of 17,029 cases to the Centers for Disease Control and Prevention (CDC) yielding a national incidence of 6.0 per 100,000 population. In 2002, the number of reported cases increased to 23,763 (a 40% increase from the previous year), resulting in a national incidence of 8.2 cases per 100,000 population (CDC, 2004).

In the United States, the disease is particularly localized in the Northeastern, Mid-Atlantic and upper North Central regions, and in several counties of Northwestern California. Because the CDC relies on voluntary reporting by physicians and laboratories, the agency admits that reported cases may account for only 7–10% of actual Lyme disease cases (Jossi, 2001). One of the reasons for underreporting may be due to the lack of standard diagnostic and reporting practices among states (CDC, 2004).

Symptoms of Lyme disease are numerous and nondefinitive. Often, the patient’s history of the disease is difficult to ascertain. The classic bull’s eye rash [*erythema migrans* (EM)] diagnostic for Lyme disease is reported by less than 50% of patients (Donta, 2002). The EM rash usually resolves spontaneously, with or without treatment, in 2 days to several weeks. The rash is often followed by dissemination of the bacteria to vital organs leading to a variety of symptoms. Many patients with Lyme disease do not recall receiving a tick bite, due to either the size of the tick (less than 3 mm) or the attachment of the tick to the body in a location difficult to visualize.

Diagnostic criteria of the disease are difficult and vary greatly. Currently, there is no serologic test that can definitively confirm or rule out Lyme disease. More than 75% of patients with chronic Lyme disease have negative enzyme-linked immunosorbent assay results and positive Western blot assay results (Donta, 2002). Additionally, these tests may check for antibodies to the bacterium that causes Lyme disease; however, they may be falsely negative if testing is done too soon after the tick bite, before the antibodies can mount a response (Bunikis & Barbour, 2002).

A delay in the diagnosis of Lyme disease, with devastating long-term consequences, can impact a patient’s quality of life. The chronic form of Lyme disease is supported by epidemiological studies showing that 30–50% of patients, even if treated, later develop multisymptom disorders of fibromyalgia and/or chronic fatigue syndrome (Donta, 2002).

The severity of the disease and the long-term sequelae of Lyme disease have important implications for nurses working with patients. Nurses should try to understand the lived experiences of patients in order to prevent misunderstandings and inaccuracies in communication. From this
understanding, nurses may form a trusting relationship with their patient. Enhanced communication will then ultimately improve patient outcomes and is an integral part of the nurses’ role of caregiving (Finch, 2004). Based upon this guiding principle, the investigators embarked upon the phenomenological journey to uncover the experience of becoming infected with Lyme disease. A literature review with a focus on this patient aggregate was performed, and it was discovered that there had been no empirical research undertaken in this area.

Methods

Qualitative research is useful in the early stages of knowledge development (Cirgin Ellett & Beausang, 2002). Phenomenology describes the human experience as it is lived and explores the full nature of the phenomenon (Cirgin Ellett & Beausang, 2002). In addition, phenomenological research is a descriptive style of qualitative research which attempts to understand the meaning of the lived experience. Designing a qualitative study was indicated by the lack of information on the subject. Phenomenological study uses an in-depth interview with participants as the main source of data. The investigator helps the participants describe their experiences without leading the discussion and attempts to learn about the experience through observation and introspective reflection (Wimpenny & Gass, 2000).

In keeping with the aims of qualitative research, the sample for this study was not selected based on the need to generalize findings but by the desire to achieve rich data about the experience of becoming diagnosed with Lyme disease. A purposive sample is defined as “participants who have specific characteristics or features” (Higginbottom, 2004). The sample of participants was chosen from a home infusion company’s database of patients with the diagnosis of chronic Lyme disease. The patient database was accessed only after all HIPAA regulations were reviewed by the infusion company’s management. Inclusion criteria were (a) patients with the diagnosis and (b) patients who were able to articulate their experience of becoming diagnosed. The sole exclusion criterion was being under the age of 18 years.

After approval from the Institutional Review Board, each participant was contacted by telephone for verbal consent and to determine a time and place for the interview. Prior to the interview, signed informed consents were obtained from all participants. Demographic data were collected on a data collection tool which was developed by the investigator. Participants were de-identified on the demographic data collection tool, the cassette tapes, and the transcriptions. Only the investigators had access to any patient health information. All interviews were conducted in participants’ homes where it was hoped they would feel at ease to tell their stories.
After written informed consent was obtained, each participant was asked to respond to the following statement: “Tell me about your experience of becoming diagnosed with Lyme disease.” At no time during the interview was the participant prompted with such leading statements as, “that must have been frustrating,” or “that must have made you feel angry.” To allow the full story of the lived experience to emerge, the investigator engaged in empathetic listening without interruption. An interviewing technique described by Price (2002), utilizing a laddered format of questioning to deepen or expand upon a point, was used by the investigator.

In phenomenology, there are no formulas to determine sample size. Participants continued to be enrolled in the study and interviewed until emerging patterns appeared. There were two investigators; however, one conducted all interviews, in order to reduce potential bias based on subjects’ response to individual interviewer style. Some of the participants feared they would have little to say during the interview, but as their stories unfolded, they came to relive their experiences and quickly filled 1–2 hr of interview time.

The data were analyzed using Colaizzi’s (1978) method for phenomenological analysis (Table 1). Using this method, the first step was to read the transcripts and obtain a feel for them. While reading the transcripts, pre-existing personal experiences, preconceptions, beliefs, and attitudes are set aside in order to gain an understanding of the phenomenon and to view it in a clear and pure form (Priest, 2004). The data were then analyzed by bringing together components of the experiences which might otherwise seem meaningless when read alone. The investigators identified significant statements by extrapolating key words and phrases that reflected the participants’ intensity and depth of their experiences. Similar significant statements were then clustered into themes.

Uncovering thematic aspects from the transcriptions was undertaken by reviewing the data carefully and repeatedly. These themes are not the exact words but are the meanings implied and inferred from words. A theme captures the meaning of the experience and brings identity to recurrent experiences (DeSantis & Ugarriza, 2000). Understanding the concept of theme is critical to accurate data interpretation (Beck, 2003). Formulated meanings were derived from a group of similar significant statements. The investigators compared each of the significant statements and themes for accuracy and completeness. As a final step, the themes were shared with the participants to ensure accuracy of the data.
Table 1  COLAIIZI’S (1978) METHOD OF DATA ANALYSIS

<table>
<thead>
<tr>
<th>Read the written transcriptions</th>
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<tbody>
<tr>
<td>Extract from each transcript significant statements and phrases that directly pertain to the phenomenon being studied</td>
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<tr>
<td>Formulate meanings from these significant statements and phrases</td>
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<tr>
<td>Organize the formulated meanings into clusters of themes</td>
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<tr>
<td>Integrate the results of the data analysis into an exhaustive description</td>
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<td>Validate the description by the participants</td>
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Results

The standard practice in qualitative research is to enroll participants and collect data until redundancy of the data occurs; the investigators find that no new data are emerging or nothing new is heard in the case of interviewing (Tuckett, 2004). To truly determine data saturation, ongoing data analysis is critical. While this was not formalized in this study, the primary data collector was ever cognizant of the need to assess for data saturation. The investigator did begin to hear repetitive patterns after 10 interviews were conducted. Each investigator formally analyzed the data individually after all 10 transcriptions were completed and then compared findings. This allowed for a collaborative process of analysis.

The sample included seven women and three men. Their ages ranged from 28 to 57 years, with a mean age of 45.5 years. All were Caucasian.

While quantitative researchers have a widely accepted method for communicating the results of their research, qualitative researchers do not. The words and themes from phenomenological research include recurring events as a singular thread running through all the transcripts (Sandelowski & Barroso, 2002). From the 10 transcribed interviews, 192 significant statements regarding the lived experience of becoming diagnosed with Lyme disease were extracted. These statements were then merged into the following six major themes. By using the term “themes,” the authors describe a recurring event or emotion with a unified element from all 10 of the interviews.

**Theme One: Frustration**

All participants identified feelings of frustration while undergoing the long process of becoming diagnosed with Lyme disease. A high rate of falsenegative serologic tests, the insidious nature of their symptoms, the extremely small size of the tick, and the lack of the definitive EM rash all added to the difficulty in obtaining a diagnosis.
The following excerpt is from the interview of a middle-aged woman whose primary concern was how her disease would impact her ability to raise her small children. She describes her frustration in the following way:

Feeling like I’ve had enough . . . feeling like I’ve got to get better because I just, I can’t stand feeling like crap every day. It really makes me mad because it’s not diagnosed easily and that’s the frustrating part. . . . It’s a horrible quality of life. I was frustrated. I was crying.

Another example to support this theme is found in the following interview by a young woman who had lived abroad for 2 years and was initially evaluated for a variety of tropical diseases:

It was just so maddening because here I finally after three and a half years got a diagnosis. It’s just like unreal the stuff people have to go through, when they have Lyme, you know, just to get a diagnosis.

Another participant who had seen numerous health practitioners from out of state and had endured multiple testing expressed the following:

They kept doing all this blood work over and over and over and everything, liver, kidneys, immune, everything they could do and everything is coming back negative . . . extremely frustrating.

**Theme Two: Long Road to Diagnosis**

Participants described the process of becoming diagnosed as lengthy and exhausting. Often, it took months or years before a diagnosis of Lyme disease was confirmed. It was not uncommon for participants to undergo multiple diagnostic tests while being seen by many health care professionals from numerous subspecialties, thus extending the time to diagnosis. This delay could lead to a worsening of symptoms as the spirochete becomes sequestered in brain and muscle tissue.

A 43-year-old husband and father described his long road to diagnosis by stating the following:

I’m ten months into it and I’m diagnosed with Lyme disease. One of the hardest things on the patients is the lack of one place to go to for care. I was forced to leave the state and seek out these Lyme specialists in other states because they had treated three thousand, five thousand, six thousand Lyme patients and were familiar with the disease.

Other participants made similar statements:

Six years from tick bite to diagnosis.

I saw a cardiologist, an internal medicine, and infectious disease specialist, another internal medicine doctor, a family practitioner. So I guess that was five doctors before I had a diagnosis.
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**Theme Three: Financial Stress**

Participants often expressed financial worries and its impact on their family. All were middle-aged productive citizens whose lives were devastated by the chronic nature of untreated Lyme disease. These men and women suffered a loss of work due to their illness and faced increasing medical expenses, often not covered by their insurance. One participant described how she and her family had once owned a magnificent home but were forced to give it up as medical bills mounted:

> Mortgaged the house, couple times, you know, just to get through financially. So financially it’s been devastating. Devastating. Had to live off the equity of sold assets to pay for everything and just to survive and pay our medical, monthly medical coverage.

Another participant, a former state employee who had lived with the disease for over 8 years, was now on permanent disability. She stated the following:

> The bills were astronomical. Insurance company doesn’t pay for doctors out of state if you’re on an HMO, so I had to pay for those. (My doctor) didn’t accept insurance and most of his treatment and tests were deemed experimental, so those don’t get paid for. So you’re talking $300–400 dollars a whack.

This next example is from a participant who was formerly employed as a commercial fisherman on the West Coast and relates the following:

> I had to quit my job because I worked on a ship and I just couldn’t stand up. I collected unemployment for a while, so it’s been quite devastating in terms of your work. It’s changed everything.

Another quote supporting this theme is:

> We are seven thousand dollars in debt right now, by paying things out of our pocket. Our savings is gone. That is a tough thing to swallow cause I can’t work and keep up with the bills. So we do have a stack of bills right now, that we can’t pay.

**Theme Four: Self-Advocacy**

Throughout their medical workup, it became clear to the participants that they needed to become their own advocates. They researched their symptoms by use of the internet, medical libraries, and through networking in local support groups. Many took information they obtained back to their primary care provider to discuss the possibility of Lyme disease as a differential diagnosis. They also felt a responsibility to educate others about their experiences with Lyme disease. A 37-year-old-woman bitten by a tick on her property while clearing trails to ride her horses stated the following:
So you really have to be your own advocate... and educate yourself and educate everyone around you so that people are aware. In fact, all along I had to be my own advocate.

A 27-year-old woman working in the health care field related how she advocated for herself and others:

I put pamphlets out for all my patients and all my coworkers and all my coworkers are in the process of educating people.

The following excerpt was shared by a self-employed middle-aged man who had recently relocated to this state:

The coordinator is the patient. I felt like I was my own general contractor, marshalling all my subs. A very difficult thing. I’ll say it’s a disintegrated health care system. It’s the patient that’s got to make it all happen.

**Theme Five: Validation**

Participants expressed relief when finally given a diagnosis of Lyme disease. Although not happy to have Lyme disease per se, participants felt having a diagnosis to be tangible. Despite the possibility of long-term sequelae of chronic Lyme disease, they felt they finally had validation and an explanation for their host of symptoms.

This middle-aged gentleman was originally from Connecticut, a state where the general public is well educated about Lyme. He became even more knowledgeable about it during his work-related Occupational Safety and Health Administration training, becoming highly familiar with how the disease is transmitted and what the symptoms are. The following is taken from his interview:

So we came back to these seven voice mail messages that said, “Don’t be alarmed but get to the emergency ward.” Apparently the test for Lyme disease was through the roof, I was off the charts. There was no doubt I had Lyme disease. I felt like, at least they’re on to something.

Other participants expressed their feelings of validation in the following quotes:

He tested me for it and it came back positive. I was pleased. I can hold this now. I can deal with it. We’re gonna treat it. It’s not this invisible thing anymore.

She said, “Of course we need to get a Western blot... you probably do have Lyme disease.” She spent an hour with me, like in the most compassionate way. And I just felt like, oh my God, someone believes me.

... A Western blot Lyme disease test and that came back positive for Lyme disease... I came back home, went around, told my friends. I said, “I’ve got Lyme disease, this is great.” I’m thinking, this is what’s wrong with [me].
Theme Six: Sense of Hopefulness

All of the participants expressed a sense of hopefulness for their future despite the nature of their illness. They became optimistic for recovery once treatment began. They all hoped that one day they would resume their lifestyles, thus regaining normalcy in their lives. Some of their comments were:

I take the attitude that I feel pretty good now you know, it may come back but I’ll just kind of file that away in the back of my head and deal with it if it happens.

I fully intend to go back to work. I would love to be able to work. and hopefully this year God willing . . . we’ll finally emerge from this and we’ll take antibiotics for a while . . . and hopefully we’ll emerge and continue with our lives.

Discussion

One of the limitations of this study is the small number of eligible participants who were purposefully chosen from a home infusion company’s database. Another limitation is that both investigators were engaged in the formal analysis of the data after it was collected. However, the use of one researcher to conduct all interviews and the informal process of postinterview reflection did lead to a phenomenological process of collecting and interpreting data. Future research would be interesting with a cohort of Lyme patients who have experienced a shorter time to diagnosis. As with any qualitative research, these findings may not be generalizable to other groups of patients with Lyme disease or those with other vector-borne diseases. Given that when Lyme disease is not recognized and treated early, it can progress to a chronic form with long-term consequences. The authors hope the results of this study will raise public health nurses’ awareness of the impact that Lyme disease may have on the patient’s life. The Lyme patients in this study have experienced a great deal of frustration with a long time to diagnosis.

Qualitative research has grown over the past several years and has made significant contributions to nursing. However, the value of qualitative research to determine patient interventions and outcome measurements has been lacking (Morse, Penrod, & Hupcey, 2000). Nurses are often the first health care professionals with whom patients interface. Much of what nurses do is qualitative in nature acting as supportive and informative advocates for their patients (Cesario, Morin, & Santa-Donato, 2002). Amassing a body of knowledge about the experience of having Lyme disease can promote improved nurse understanding and heighten sensitivity of the complexity and difficulty of living with Lyme disease. By providing a
therapeutic alliance, health care professionals can make a difference in keeping high-functioning patients from becoming reduced to a state of disability (Connolly-Taylor, 2000). People living with Lyme disease need compassionate clinicians able to constantly support them through all phases of their illness.

Over the past 50 years, chronic disease has replaced acute disease as the major health problem in the United States. Chronic disease is the principal cause of disability and the major use of health care services, consuming 78% of health expenditures (Holman, 2004). Due to the chronicity of Lyme disease, health care management is best provided by a coordinated team of health care professionals able to develop a unique relationship with the patient based on a comprehensive understanding and anticipation of potential sequelae. This study emphasizes this critical need. Over time, the Lyme disease patient will be seen by many health care providers; therefore, continuity of care is critical.

As with many chronic illnesses, the role of the nurse changes from that of advisor to one allowing sharing decision authority with the patient. To be better able to perform this new role, the nurse must come to understand what it is like to experience this chronic disease and how to mold a specific treatment plan tailored to each patient.

Upon developing a trusting relationship with the Lyme disease patient, the public health nurse may provide effective self-management support and referrals to appropriate community resources. With these resources in place, patients and families will be better able to cope with the challenges of living with their disease. The chronic care model as described by the Institute for Medicine may be a successful strategy to employ for Lyme patients, as it has been for patients with other chronic diseases such as multiple sclerosis and diabetes.

Historically, patient education has been practiced using didactic methods for knowledge acquisition. Recently, these methods have come under scrutiny for their lack of concern for issues of behavioral changes, self-management, and improved disease control. The focus today is to match the patients’ knowledge of disease to his/her ability and confidence in managing their condition. A partnership model is crucial to managing illness, identifying barriers to care and strategizing ways to overcome those barriers (Wagner et al., 2001).

Conclusions
Patient–nurse interactions occur within the context of an ever increasingly complex health care system strongly influenced by the social, political, and physical environment (Glasgow, Davis, Funnell, & Beck, 2003). An
understanding of the themes of this research yields a heightened awareness of the patients’ experience. From this, the public health nurse may be better able to assess a patients’ place on the chronic health care continuum. Strategic health care interventions and quality improvement systems may be better prioritized when understandings are generated from a comprehensive knowledge of the complexity and challenges of the “lived experience of Lyme disease.”

Acknowledgments
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References
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**Profile and Commentary**

In reading this profile and commentary, it is important for you to go back and forth between what is said here and the study report so that you come to truly understand the report. Moreover, the issues explained in the commentary will make more sense when considered in light of the specifics of the report.

**Study Purpose**

The study’s stated purpose is to uncover the full nature of the lived experience of being diagnosed with Lyme disease. Thus, the purpose is not to understand the symptoms of Lyme disease, instead, what it feels like to not be able to get a definitive diagnosis and treatment for a lengthy period of time. The authors state that a literature search did not uncover any research focused on this topic.
Methods

In the report, the authors explicitly identified the study as a qualitative study using a phenomenological framework. Their research methods relied on in-depth, semi-structured interviewing and theme identification. Most certainly, phenomenological methods are appropriate to the research question.

At this point, I would like to provide a more in-depth description of phenomenological research. To get a real sense for human experiences of illness or health care treatment, research methods that allow persons to speak for themselves are invaluable. Such methods allow the participants to say what they are experiencing and what it means to them, rather than impose concerns, issues, assumptions, or answer choices on them. Persons’ experiences of illness, life transitions, and medical treatments are topics that when studied in this way yield insights that would not come forth had the researchers decided in advance what to ask about. For instance, to capture the experience of having a serious allergic reaction at home, letting persons who had the experience describe it is more likely to lead to insights regarding the experience than would a series of scaled questions (e.g., 1 = strongly agree to 5 = strongly disagree) about issues health care providers think are important.

Phenomenological methods of conducting research are rooted in the complex philosophic tradition of phenomenology. There have been many phenomenological philosophers across the 19th and 20th centuries. The ones you are most likely to recognize are those in the existentialism school: Søren Kierkegaard, Jean-Paul Sartre, and Albert Camus. What all phenomenological philosophers share is an interest in “being” and the interpretive nature of human thought (Dombro, 2007).

To understand a person’s experiences of a health or illness condition, it is necessary to enter the person’s life-world, to understand not only what happened, or is happening, but also what events and social interactions in that life-world mean to the person. Each person’s life-world is made up of the givens of birth family and inherited traits; cultural, social, and physical environments; relationships with others; bodily and psychological experiences; and sense of time (Munhall, 2007b). The researcher gains entry into this complex and unified life-world by interacting with participants in the following ways (Munhall, 2007b):

- Suspending preconceptions
- Being fully present in explorative dialogue with the person
Respecting the complex, emerging nature of every person’s life

• Helping the person become aware of the subtle aspects of the experience
• Asking the person to clarify what experiences mean, or meant, to him or her

By using investigative tools such as in-depth conversations, diaries, storytelling, or looking at pictures or calendars, the skilled researcher comes to understand the experience in a way that closely approximates the way the person feels and thinks and remembers the experience. Many phenomenological researchers use transcripts of their conversation with participants so as to be able to immerse themselves in the accounts participants have given.

Sample

Potential participants for the Drew and Hewitt (2006) study were identified from the database of a home infusion company by searching for persons with a diagnosis of Lyme disease. Potential participants were contacted by phone and asked to participate in the study. Steps were taken to obtain an ethically sound informed consent to participate; the records and interview tapes were handled in ways that protected personal identity and privacy. After 10 interviews, the researchers concluded that they were hearing stories with elements that were similar to what they had already heard, and that truly new aspects of the experience were not coming forth. As a result, they stopped recruitment of additional participants.

Drew and Hewitt’s approach to sampling is typical of that used by many qualitative researchers. Phenomenological researchers select their sample because they have had or are having a particular experience. The sample size is not determined in advance, rather sampling ceases when no new information is forthcoming and all major issues are understood; this point is called data saturation.

Data Collection

In keeping with the phenomenological approach to interviewing, the researcher who talked with participants used a progression, or laddered, approach to questioning. First, the interviewer asked about the experience in general terms, “Tell me about your experience of becoming diagnosed with
Lyme disease." Then, slightly more probing questions were asked or requests for the person to expand on a point were made. These requests most likely brought forth more description by the participant of meaning, feelings, and values. By starting with a request for an account of the experience, listening without leading comments or questions, and gradually proceeding to requests for more in-depth information, the interviewer refrained from imposing a perspective on the person’s account yet accessed areas of interest. In short, to get into the experiences of other people requires a great deal of skill and immersion in what the other person is saying, implying, and not saying.

Importantly, data collection and data analysis are not sequential activities. Rather, in reading transcripts or listening to tapes of interviews that have already been done, the researcher identifies an issue that several persons have alluded to but that no one has expanded on, and the researcher might decide to ask future participants about that issue. Thus, data analysis shapes data collection.

Data Analysis

Transcripts of the Drew and Hewitt interviews were produced, read several times, then key words and phrases that captured concerns, causal thinking, associations between events, barriers, and strong feelings were noted. This analysis was done after each interview with reference back to interviews already done; both researchers did data analysis. The key words and phrases were listed and then examined across all cases to identify clusters of similar statements. Thus, Drew and Hewitt produced interpretations of what participants said and meant. Note that data analysis did not wait until all participants had been interviewed; rather preliminary analysis was done after each interview. This intermingling of data collection and analysis allows subsequent data collection to build on what was learned in earlier interviews—it is a common approach in qualitative research.

Commonality and Difference A challenge in phenomenological analysis is to look for commonality and uniqueness across the participants’ accounts. The attempt to capture commonality must be balanced with recognition of unusual or opposing experiences, perceptions, and meanings assigned to experiences. Importantly, the interpretations must not strip away the context of what the person has said or experienced; instead interpretations should portray the complexities that resulted in variations on the experience. Many researchers using qualitative methods show their
interpretation to the participant and ask if it is accurate. Some phenomenological researchers keep lists or count how many persons mentioned a particular issue; this provides a sense of how often various issues were part of the experience and enables the researcher to portray it as common, frequent, or rare.

Phenomenological researchers differ widely in the extent to which they interpret participants’ accounts (Munhall, 2007b). Some do very little interpretation, whereas others move from the participants’ accounts to summative descriptions, theme identification, or even to coherent theories about the experience. These interpretations may be accomplished by a series of coding that proceed from the concrete phrases to clusters of phrases, to more general concepts or themes that encompass several of the clusters. For example, in a study of persons with a particular disability, concrete codes from sections of two participants’ narratives might be, “I do the best I can” and “I’ve figured out some ways of living with this.” Recognizing the commonality in these two phrases might lead to a general theme called “strategic daily living.”

Concrete to Abstract An important characteristic of qualitative research involving theme identification is that the researcher be able to describe for others how she moved from concrete statements to the more abstract concepts, themes, and theories. Toward this purpose, many qualitative research reports include direct quotes illustrating each theme. These quotes often give the reader a sense of whether the themes indeed arose out of the data or were imposed on it.

Results
Six themes became the findings of the Drew and Hewitt study: frustration, long road to diagnosis, financial stress, self-advocacy, validation, and hopefulness. Each theme was supported in the report by several examples or quotes that led to creating that theme. The examples convey the devastating nature of having health problems that evade diagnosis and treatment, and thereby erode the quality of one’s life over a long period of time.

Discussion
Note that the authors acknowledge several ways in which the study could have produced biased results: the way patients were recruited, and the
roles the researchers played in doing the study. They go on to say what they think the contributions of this study to nursing practice are.

This report nicely describes a qualitative research approach to understanding a health experience that has not been extensively studied. The knowledge produced by this study serves to highlight the frustrations and stresses experienced by persons who eventually are diagnosed as having Lyme disease, as well as some of the coping mechanisms used to deal with the drawn out difficulties.

There is an odd conundrum related to the use of these findings. Essentially, many nurses have interaction with a person who has Lyme disease but are not aware of this fact until the diagnosis is made, which is often after many months of medical appointments, tests, and uncertainty. So, from the medical diagnosis perspective, the knowledge produced by this study is in a sense after the fact and after many contacts with nurses.

Still, the researchers express the hope that the results will help nurses who deal with these patients at the time of diagnosis to be aware of what these people may have experienced and how this could still be affecting them. The findings of this study illustrate how qualitative research produces understandings that can be used in practice to be sensitive to what patients are experiencing, to communicate better with them, and to design care that is truly helpful. Of course, as Lyme disease becomes more prevalent in a geographic area, clinicians will think of it more often when patients have vague symptoms. The result will be less uncertainty and delay in getting a diagnosis; thus, this description of the experience will become less typical.

Perhaps the knowledge produced by this study will be useful when providing care to any person who has vague symptoms and is undergoing a number of diagnostic tests that have not resulted in a diagnosis. For instance, persons who are diagnosed with chronic fatigue syndrome or celiac disease could have experiences similar to those of persons with Lyme disease, because they too often have long roads to diagnosis. However, this suggestion extends beyond the findings of the study and should be confirmed by studies of these other groups.

References


**Additional Reading about Qualitative Research Methods**


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