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Walden University
2018

Abstract

The Lived Experiences of Managing Uncertainty in Chronic Illness

by

Amanda S. Brown

MSN, Sacred Heart University, 2013

MSN, Walden University, 2011

BSN, Syracuse University, 2004

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing Public Health Policy

Walden University

March 2018

Abstract

Chronic illness is an increasing concern in the United States as the CDC reports that about 50% of adults have at least 1 chronic illness. When individuals must adjust to chronic illness they may experience uncertainty regarding the illness, prognosis, and symptoms. The purpose of this qualitative, phenomenological study was to explore the lived experiences of individuals living with uncertainty in chronic illnesses. A Merle Mishel's uncertainty in illness theory was the framework used to explore the lives of individuals diagnosed and living with chronic illness. In-depth interviews were conducted with 8 individuals who have chronic disease; data were audio-recorded and transcribed. The data were analyzed using thematic coding, and stored in NVivo and categorized for commonality in results. Results revealed themes that individuals with chronic illness do experience uncertainty and that it impacts almost all aspects of their lives. The individuals expressed changes in daily activities, the need to plan ahead, altering plans based on symptoms, and retraining their minds to accept their new normal. Individuals diagnosed with chronic illness face daily challenges. Obtaining a better understanding of alternate ways to cope and manage uncertainty can greatly impact the individuals quality of life. The information produced from this study will help contribute to positive social change to enable healthcare providers to address the uncertainty at diagnoses and offer ways for individuals to cope and manage the additional stressor. Recommended areas for further research include repeating the study with a larger, more diverse sample, conducting interviews during different times of the year, and investigating the use of a multidisciplinary team approach for chronic illness treatment.

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Chapter 1: Introduction to the Study

The incidence of chronic illness is serious healthcare concern in the United States. The Center for Disease Control (CDC) reported that half of the adults in the United States have at least one chronic illness (Fleming, Phillips, & Kline, 2015). Individuals with chronic illnesses can experience uncertainty and the inability to place meaning to illness-related events, causing significant psychological stress (Sjjadi, Rassouli, Bahri, & Mohammadipoor, 2015). High levels of uncertainty can lead to higher levels of perceived stress, depressive symptoms, as well as poorer emotional well-being (Kurito, Garon, Stanton, & Meyerowitz, 2013). This can lead to the inability to function and maintain relationships; as well as confusion, misunderstanding, and an overall decrease in the individual's quality of life. Not being aware of uncertainty and how to manage it can lead to inappropriate use of healthcare facilities, health-seeking behaviors, and overall poor outcomes for the individuals (Bennell & Taylor, 2013). The confusion and misunderstanding that result from uncertainty can detract from the timely and necessary illness management (Sav et al., 2015). In my search of the literature I identified a lack of knowledge about the strategies used to manage uncertainty and an increased need to alleviate uncertainty in those living with chronic illness. The purpose of this study was to analyze the stories of the lived experiences of those living with chronic illness and analyze the approaches used to cope or manage uncertainty. This will assist in the development of informed recommendations and consistent methods used by subjects or medical professionals to include in individuals' treatment plans upon diagnosis.

This chapter includes a background of the current literature related to uncertainty and chronic illness. The problem statement, explanation of the purpose of the study, research question, and the theoretical foundation used as a framework for the study are also addressed in this chapter. The nature of the study is discussed along with definitions of key terms, assumptions, limitations, and delimitations. The chapter closes with the significance of the study and summary of how the study will impact social change.

Background of the Study

Chronic illness, also known as chronic disease, is used to describe illnesses that can be treated but have no cure; CDC reported that 50% of all adults are diagnosed with at least one chronic illness and one in four have two or more chronic illnesses (CDC, 2014; Center for Managing Chronic Illness, 2011; Fleming, Phillips, & Kline, 2015). Care for individuals with chronic illnesses is currently a top concern raised by the national health agendas and efforts have been put forth to increase self-management and to promote self-care (Martinez-Marcos & De la Cuesta-Benjumea, 2015; World Health Organization, 2009). Chronic illness not only affects the patient but the family, caregivers, and friends who surround the individual, including the public. The number of those diagnosed with a chronic illness is continuing to rise and is becoming a major public health challenge, consuming 75% of the U.S. health care costs (Fleming, Phillips, & Kline, 2015).

Once diagnosed, individuals often undergo surgery, specific treatments, and pharmacological therapies—although the course of treatment and disease process remains uncertain (Giammanco, Gitto, Barberis, & Santoro, 2015). The way individuals cope with

the uncertainty of the disease process, as well as symptoms and diagnosis can vary (Coderey, 2015). When a coping strategy is found to produce a positive experience, individuals' health and quality of life have been found to improve (Kim et al., 2016).

Little research has been conducted on interventions used to cope with uncertainty. Hoth et al. (2013) suggested further research is necessary to examine different factors. For example, factors such as social environment can impact the management of uncertainty and early intervention at diagnosis can improve patient outcomes and quality of life. Giammanco et al. (2015) concluded that although the Mishel Uncertainty in Illness scale (MUIS) (Mishel, 2014) is a valid tool for assessing uncertainty, further studies are needed to deeper explore strategies for coping with uncertainty as patients search for treatment clarity. Medical professionals can identify the uncertainty, but methods for coping are necessary to improve treatment methods. According to Borneman et al. (2014), a case report demonstrated that a woman struggled with her diagnosis and uncertainty and explained it as being similar to being stuck in a "black hole" of questions but being offered no acceptable answers. It is important for healthcare professionals to be aware of uncertainty and the impact it has on patients. Not properly managing uncertainty can lead to further consequences. Patients with chronic illnesses are constantly experiencing uncertainty, which can damage their physical, social, spiritual, mental, and economic aspects of life and daily activities (Sajjadi et al., 2015).

Problem Statement

In previous decades, the most common health emergencies were related to infectious disease and associated with acute illness. However, because of medications

and treatments, people are living longer, but with one or more chronic illnesses (Giammanco et al., 2015). Chronic illness is associated with a variety of clinical manifestations that require individuals to adjust to new limitations caused by the illness, deal with new emotions, and manage increasing financial pressure. The adjustments to chronic illness can lead to uncertainty about the illness, prognosis, and symptoms (Hoth et al., 2015). Uncertainty is defined as a cognitive state characterized by the individual's inability to establish the meaning of events related to the illness (Giammanco et al., 2015). Individuals living with chronic illnesses may experience uncertainty when the cause of the disease or disease progression is unknown, when symptoms fluctuate and are unpredictable, and when there is a lack of knowledge about treatment options and outcomes. The uncertainty experienced by the individuals can lead to seclusion, limited socialization, and a damaged sense of well-being. An individual's behavior, mental state, and social life can also be negatively impacted (Homko, Zamaro, Broden, & Parkman, 2014). Uncertainty can also be perceived as threatening or stressful causing some individuals to rely on maladaptive ways of coping such as worrying, obsessional doubt, compulsions, and avoidance (Renjan, McEvoy, Handley, & Fursland, 2016). In chronic illness, uncertainty and its management are crucial aspects that influence the individual's quality of life (Bloom et al., 2008; Germino et al., 2013; Kornblith, Powell, & Regan, 2007). Researchers have found that uncertainty is experienced but the question remains how individuals manage the uncertainty daily. Individuals living with chronic illness do not always know how, when, or if symptoms will appear. Understanding common

symptom management patterns to help uncertainty can help determine whether there is a trend in coping mechanisms or strategies.

Purpose of the Study

The purpose of this phenomenological qualitative study was to explore the lived experiences of those living with uncertainty in chronic illnesses. Chronic disease symptoms and treatments can be unpredictable and cause uncertainty (Iranmanesh, Tirgari, Tofighi, & Forouzi, 2014). High levels of uncertainty can lead to an increase in psychological distress, anxiety, depression, and powerlessness (Iranmanesh et al., 2014; Livneh & Antonak, 2005). The goal of the study was to better understand uncertainty and chronic illness and how those living with chronic illness manage and cope with uncertainty.

Research Questions

The research question selected for the qualitative research plan is: What are the lived experiences of those living with uncertainty in chronic illnesses?

Theoretical Foundation

Merle Mishel's uncertainty in illness theory (UIT) has informed my work. The UIT advocates that uncertainty occurs when a person is unable to categorize the meaning of illness-related events, such as having difficulty interpreting their physical symptoms or predicting the likely outcome of treatment (as cited by Hoth et al., 2013, p.1171). Uncertainty is a common cognitive state amongst those with chronic illness and the UIT addresses uncertainty related to the diagnostic and treatment phases of an illness with poor expected outcomes (Mishel, 1988, 2014). Later Mishel developed the

reconceptualized uncertainty in illness theory (RUIT) to address the constant uncertainty associated with chronic illness requiring long-term management or illnesses with the possibility of recurrence (Mishel, 1990, 2014). The preferred outcomes from the RUIT are growth and adapting to a new value system. This is opposed to the UIT, which centers on returning to a previous level of functioning (Mishel, 1990, 2014). To better understand the uncertainty and to what extent uncertainty was experienced, Mishel (2014) developed the Mishel Uncertainty in Illness Scale (MUIS) to test the level of uncertainty experienced by individuals.

Three factors can lead to uncertainty, the theoretical concept. Biological factors, including illness severity, symptom pattern, symptom familiarity. Psychological factors such as learned helplessness, emotional state, and cognitive distortions. The last is social factors that can include support systems and education level. Consequences of uncertainty are anxiety, depression, fear, agitation, and anger. All of the above consequences can lead to maladaptive coping, increased psychological stress, and information seeking.

The UIT provides a framework that focuses on the selection of interventions geared toward the psychological and behavioral outcomes of individuals struggling with the conditions of uncertainty (Germino et al., 2014). The purpose of the study, utilizing the UIT as a framework, was to gain a better understanding of the different components those with chronic illness experiencing uncertainty may go through during the initial diagnosis and treatment phases and coping strategies used to improve quality of life.

Nature of the Study

A qualitative methodology was selected for this study to understand the uncertainty experienced by individuals diagnosed with chronic illnesses. According to Polit and Beck (2012), qualitative methodology produces patterns from the data that suggest there are certain comparisons that are relevant to the phenomenon of interest without comparing the subjects. This is a good fit for this study as the goal was to gain an in-depth understanding of the lived experience of those with chronic illness and how they manage uncertainty.

More specifically a phenomenological method was used for this study. Oiler (1982) and Jasper (1994) suggested that phenomenological methods, which capture the experiences of life as it is experienced by the subjects, can complement the participants own experiences on ill health and nursing care (as cited by Bennell & Taylor, 2014). Due to limited research on this topic, the focus included uncertainty in all chronic illnesses rather than selecting a specific illness. This allowed for a greater population pool to obtain an adequate number of subjects for the study. Typically, a phenomenologist utilizes a small sample size and all participants must have experienced the phenomenon and must be able to articulate what it was like to live the experience (Polit & Beck, 2012). Data were collected from individuals diagnosed with a chronic illness until no new trends or patterns were expressed, and saturation was met.

Definitions

Key terms used in the study are defined below as to reduce the possibility of misunderstanding the use of the terms as applied.

Uncertainty: As defined by the uncertainty in illness theory is a cognitive state in which the individual is unable to categorize the meaning of the illness-related events (Hoth et al., 2015).

Chronic illness: Also known as a chronic disease, are terms used to describe conditions that can be treated but not cured (Center for Managing Chronic Illness, 2011; Fleming et al., 2015).

Uncertainty and chronic illness: The uncertainty experienced by individuals with chronic illness can lead to seclusion, limited socialization, and lead to becoming so disabling that the individual's sense of well-being, behavior, mental state, and social life can be negatively impacted (Homko, Zamaro, Broden, & Parkman, 2014).

Assumptions

One assumption was that the participants will provide honest, real answers during the interviews and best describe their lived experience with chronic illness to the best of their ability. To ensure participants were honest, I reiterated that their names or any other form of identification would not be linked with the responses. The second assumption of this study was that uncertainty in chronic illness is not a desirable state and participants desire to manage uncertainty in chronic illness.

Scope and Delimitations

The scope of the study included participants recruited from local medical facilities in the Syracuse, New York, and online sites to capture a greater pool of participants from areas all over the United States. All participants were required to be English speaking, 18 years of age, and diagnosed with a chronic illness for at least six months. There will be no exclusions based on location, race, and gender.

Methodological approaches that I debated but did not select were case study and the narrative approach. Case studies utilize the case itself as the focal point; the researcher uses methods such as observation and delving into related documents and artifacts for analysis while offering no manipulation (Unicomb, Colyvas, Harrison, & Hewat, 2015). Although the case study approach is an interesting method, it would not warrant enough variety of experiences to produce comparable outcomes. The narrative approach is a method where a researcher interviews and uses data obtained to express an individual's experiences of a given situation as related to the topic of interest then the researcher analyzes the data (Rejno, Berg, & Danielson, 2014). This approach is a method for gaining insight into the individuals' lived experience and observing patterns and trends, however, this method requires the subject to drive the study and it was not selected for this reason.

Limitations

According to Polit and Beck (2012), the researcher must be aware of limitations and present them to the audience to preserve the integrity of the results. My own biases as an individual living with chronic illness and experiencing uncertainty may have

influenced the interviews and data analysis. To prevent my biases from impacting results, questions were preplanned and every effort was made not to go off script and try to relate to the subjects. Interviews were recorded and transcribed to use exact wording from the subjects. I did not summarize or put comments into my own words. A second limitation was sample sizes. Phenomenologists focus on smaller sample sizes, and the need to utilize criterion sampling to obtain a diverse group of individuals with different demographic and chronic illness backgrounds (Polit & Beck, 2012).

Significance of the Study

Patients with chronic illnesses experience uncertainty daily related to symptom management. Mishel stated, as quoted by Germino et al. (2013), uncertainty is felt when illness, treatment-related conflicts, and illness-related events possess the characteristics of complexity, inconsistency, randomness, unreliability, and a lack of information in situations that are important to the person.

Individuals can become intolerant of the experienced uncertainty and this can lead to avoidance of uncertain situations as well as the inability to function as the ambiguous situations are viewed as negative and create associated distress (Oglesby et al., 2016). Negative coping strategies can lead to further complications for the individuals. Researchers have consistently indicated that greater levels of uncertainty can cause an increase in psychological symptoms, depression and anxiety, physical symptoms, pain and fatigue, accompanied by an overall reduction in the individual's quality of life (Hoth et al., 2015).

Due to the lack of cures for chronic illness and continuously changing treatments, the focus is symptom management (Dudekula, Rahim, & Bielfeldt, 2014). There is a need for evaluation of the lived experiences of those with chronic illnesses to understand how individuals cope with symptoms and treatments and manage the uncertainty. According to Hoth et al. (2015), self-care knowledge and perceived confidence to manage chronic illness over a long period can improve patient outcomes. This study may have implications for positive social change by potentially providing medical professionals holistic methods of symptom management. Health professionals can then incorporate the strategies into individuals' treatment plans at diagnosis and ultimately improve the individuals' quality of life.

Summary and Transition

Chronic disease is the leading cause of death in the world; in 2008, 63% of 57 million deaths were associated with chronic illness (Sav et al., 2013). Researchers have found that there is a burden linked with chronic illnesses but there is little research to define the burden associated with the treatment and symptom management of chronic illness that individuals experience (Sav et al., 2015). One of these burdens is uncertainty. The inability to predict the events related to chronic illness can cause uncertainty. This uncertainty can worsen when symptoms become unpredictable, not knowing when or how symptoms will start, or for how long the symptoms will last. Treatments are also a trigger for uncertainty, as it is not a guarantee the medications or surgeries will work to improve outcomes.

As the number of individuals diagnosed with chronic illness continues to rise (Fleming, Philips, & Kline, 2015) the need to offer treatment plans to reduce the burden of uncertainty and improve patient outcomes and quality of life is crucial. Individuals diagnosed with chronic illness are offered little to no information on how to manage the ambiguity of diagnosis process, symptoms, and treatments.

In the following chapter I will review literature from the previous five years studying the topic of chronic illness, uncertainty, and Mishel's UIT. I will critique the research strengths, weaknesses, and themes as related to uncertainty management and chronic illness. The need for the study will be clearly defined along with the theoretical framework used to mold the study.

Chapter 2: Literature Review

Chronic illness is a term that refers to illnesses that require continuous treatment and management over long periods of time, years or even decades (Jowsey, 2016). Chronic illness is continuing to increase worldwide along with the demand to improve the care of those diagnosed with a chronic illness (Gibbons et al., 2017). Examples of chronic illness include but are not limited to arthritis, diabetes, and coronary heart disease. Treating and caring for individuals with chronic illnesses has become a healthcare priority as the increasing prevalence adds stress to not only the patient but also the healthcare system (Gibbons et al., 2017). Researchers have suggested that individuals with chronic illness face uncertainty including significant disruption to family life, well-being, and quality of life as they experience unpredictable and incurable conditions (Hurt, Cleanthous, & Newman, 2017). Day-to-day living requires endless decisions which require some degree of certainty for humans to continue to move forward (Brizi, Mannetti, & Kruglanski, 2016). Not knowing if and to what extent symptoms may appear can leave individuals secluded in their homes in fear of extreme exacerbations. Uncertainty can result in a great loss or change in the individual's ability to take pleasure in daily activities (Suzuki, 2012), which can often lead to further problems such as anxiety and depression (Fuemmeler et al., 2001; Gentes & Ruscio, 2011; Jiang & He, 2012).

There is a lack of literature on how those with chronic illness manage uncertainty, healthcare providers are expected to mediate the impact of uncertainty while also assisting in limiting and preventing the negative consequences (Braden, Braden, Mishel,

Longman, & Burns, 1991; Mishel, 2010; Nanton, Docherty, Dale, & Meystre, 2009). The purpose of this study was to explore the lived experiences of those living with uncertainty in chronic illness and to better understand the coping strategies or methods used to manage uncertainty illness.

This review of the literature includes key literature search strategies, theoretical foundation and rationale for selection, and an in-depth review of the current literature related to uncertainty and chronic illness.

Literature Search Strategy

I collected all literature for this review from the Walden University library using several different databases. Nursing related studies were accessed through CINAHL, ProQuest Nursing & Allied Health Source, and MEDLINE. To obtain a wider scope of studies psychology databases, PsycINFO and PsycARTICLES were also searched along with health sciences databases. Key terms used were *uncertainty*, *chronic illness*, *uncertainty and chronic illness*, *impact of uncertainty*, *coping and uncertainty*.

Theoretical Foundation

The theories that have influenced my work are Merle Mishel's UIT theories. Mishel developed the original UIT to address the uncertainty individuals experienced during the diagnostic and treatment phases of an illness with a known downward trajectory (Mishel, 1990, 2014). Later the RUIT was developed to address the feelings of continued uncertainty as experienced by those with chronic illnesses that require continuous treatment or illnesses that have the possibility of reoccurrence (Mishel, 2014).

Both theories serve the same purpose, to describe and explain uncertainty at different stages of illness for practice and research (Mishel, 2014).

Mishel's theory development was personal while caring for her ill father who was dying from colon cancer she witnessed, as he grew swollen and emaciated, he could not understand what was happening to him and began to focus on areas that he could control in order to have some degree of control (Mishel, 2014). Mishel was aware of uncertainty but it was the experience with her father that provided Mishel with a personal understanding of the concept. Lazarus (1974) studied the impact of individuals' encounters with environmental stressors and the psychological processes that lead to coping processes, emotional states, disease precursors and stress disorders. Lazarus's work as well as the work of Norton (1975) influenced Mishel and helped form a framework for her theory. Bower (1978) and Shalit (1977) then further influenced her work as they described uncertainty as a complex cognitive stressor and Buden (1962) who described different sources of uncertainty, ambiguous, and complex stimuli (Mishel, 2014). Lazarus, Norton, Bower, and Shalit all influenced her view of uncertainty and she was able to understand it as a cognitive state rather than an emotional state, which later led to ongoing theory development (Mishel, 2014). After discussions with colleagues, Mishel began to understand her UIT as only addressing uncertainty in the acute and treatment phases and lacked to address the life changes that happen over time for those diagnosed with chronic illness and developed the RUIT. Mishel (2014) stated that qualitative interviews with individuals diagnosed with chronic illness exposed continuous uncertainty and a completely new view of life. Mishel drew, from the influence of

Prigogine and Stenger's (1984) chaos theory, that as uncertain areas of life continue to increase pattern disruption occurs, and the uncertainty feeds back upon itself ultimately creating more uncertainty (Mishel, 2014). Individuals with a chronic illness who continue to feel uncertain begin to lose tolerance and a sense of disorganization begins to take over. The individuals must learn to change their perspective on life from that of predictability and control to a new life filled with changes and unforeseen events (Mishel, 2014).

Previous Theory Use

The UIT has been used as a framework for many studies to understand not only the level of uncertainty experienced, determined by the MUIS, but also the uncertainty experienced by individuals diagnosed with chronic illness and caregivers as well. Hoth et al. (2015) proposed that uncertainty in illness was associated with poorer outcomes in individuals diagnosed with chronic health conditions. Utilizing the UIT as a framework for the study, the researchers also used the MUIS as a key uncertainty indicator in questionnaires mailed out to 406 individuals who met the criteria. The study also requested responses in regard to whether or not the subject attended support groups and if other family members had the same illness. With the goal of the study to better understand the association between the social environment and uncertainty, the authors concluded that the social environment is complex and that multiple aspects of the social environment influence the individuals' uncertainty (Hoth et al., 2015). Coderey (2015) conducted a study to investigate and understand how different members of the specific

population manage uncertainty and health-related risks. Results revealed that the way individuals cope with the uncertainty of the disease process and symptoms can vary. Kurita, Garon, Stanton, and Meyerowitz (2013) utilized the MUIS to better understand the uncertainty in patients with lung cancer. The researchers recruited participants based on specific inclusion and exclusion criteria and utilized the MUIS, along with measuring uncertainty intolerance, the questionnaires concluded that interventions to address uncertainty might help improve individuals' with lung cancer psychological distress (Kurita et al., 2013).

While collecting literature, studies were found that focused on the UIT and RUIT, many utilized uncertainty as a conceptual framework. Jiang and He (2013) explored the effects of an uncertainty management intervention on uncertainty, anxiety, depression, and quality of life, utilizing a randomized controlled study. Over a 10-month duration, one group received a cognitive behavioral intervention and it was found that by providing uncertainty management the quality of life and emotional status would improve in those diagnosed with chronic obstructive pulmonary disease (Jiang & He, 2013). Lastly, Giammanco, Gitto, Barberis, and Santoro (2015) conducted a study to validate the Mishel uncertainty in illness scale (MUIS) as a method for assessing uncertainty in individuals with chronic illness. The researchers concluded that the tool is useful and suggested the need for further study into the strategies used for coping with uncertainty as patients search for clarity of treatment.

Mishel's uncertainty in illness theories were selected as the theories of choice because they not only provided a solid framework to support uncertainty in chronic

illness but also provided a conceptual break down of uncertainty and the MUIS measurement tool to produce an in-depth understanding. Mishel's theories center on the understanding and interventions focused on psychological and behavioral outcomes of chronically ill individuals who struggle with uncertainty (Germino et al., 2014).

The UIT and RUIT support the aspects of the dissertation and the goal of the research phenomenon. The goal of the study was to explore the lived experiences of those living with chronic illness and to better understand how the individuals cope or manage uncertainty. Uncertainty is the central concept of Mishel's theory (see figure 1) and is organized around three main themes as related to uncertainty: antecedents of uncertainty, appraisal of uncertainty, and coping with uncertainty (Mishel, 2014). Theme one antecedents include stimuli frame, which includes the composition or form of the stimuli as perceived by the chronically ill individual, which has three main components: event familiarity, event congruence, and symptom pattern (Mishel, 2014). Cognitive capacity or the ability of the individual to process information and structure resources that are available to assist the individual, such as education, social support, and credible authorities, are both providers of influence for the stimuli frame (Mishel, 2014). Mishel (2014) also describes the two following themes appraisal of uncertainty, the process of placing a value on experienced uncertain events consisting of inference and illusion, and coping with uncertainty, which includes danger, coping, adaption and opportunity. Ultimately, uncertainty is the result of the antecedents and the individual's perception can alter whether the uncertainty is seen as dangerous or as an opportunity. The RUIT is organized around three themes, antecedent theme as in UIT, self-organization, and

probabilistic thinking (Mishel, 2014). Both theories tie into nursing and the phenomenon

of interest as the desired outcome is to understand the cognitive state of the individual,
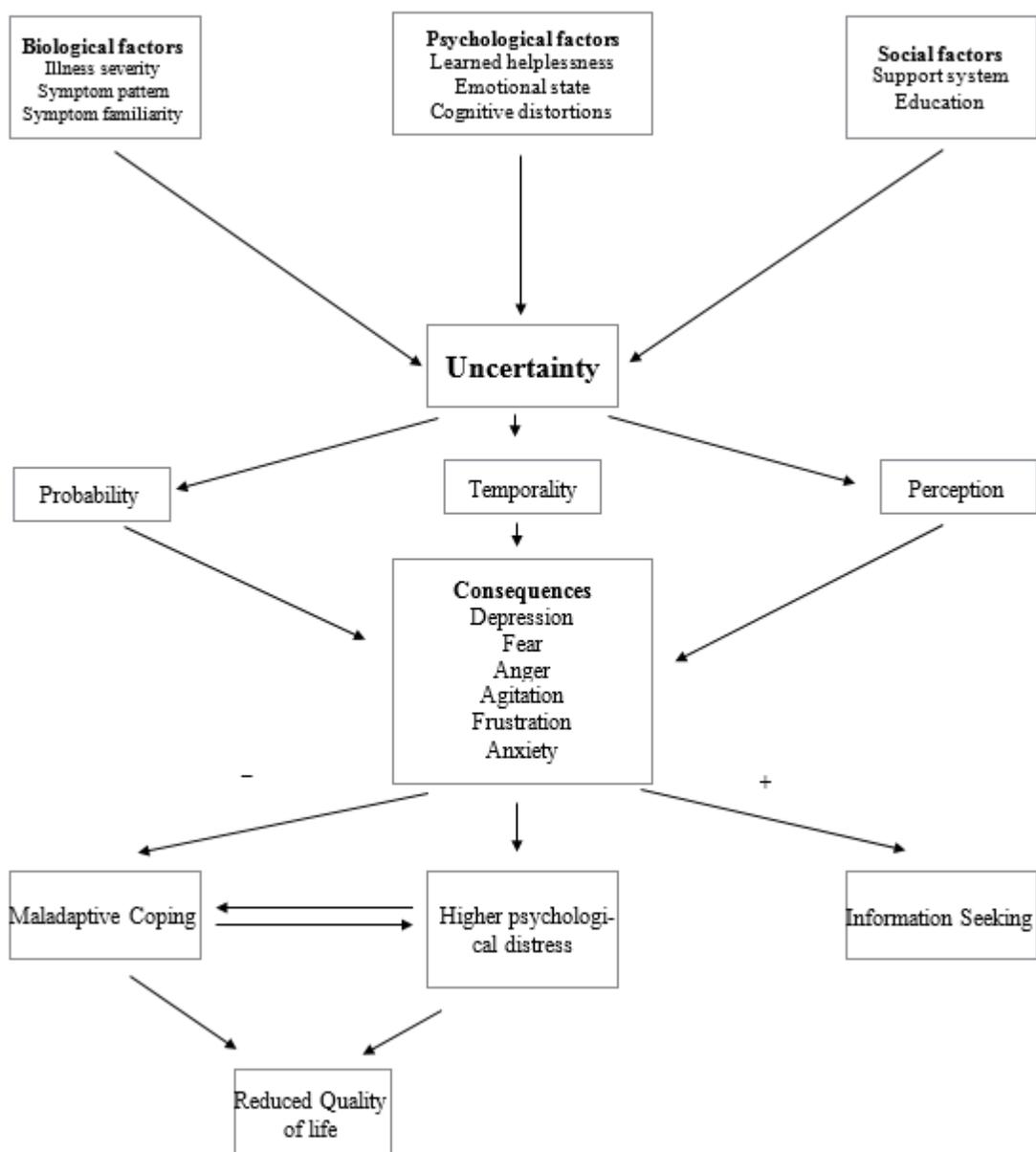
regain individual control, and manage uncertainty.

Figure 1. Uncertainty in Illness

Literature Review

The methodology selected for this dissertation was a qualitative method, phenomenology. When using a phenomenological approach, in nursing research, the desire is to understand the patients' perspectives on illness, suffering, and the care provided (Bennell & Taylor, 2013; Jasper, 1994; Oiler, 1982). Bennell and Taylor (2013) utilized a descriptive phenomenological approach to examine the experiences of individuals living with gastroparesis, a chronic illness. The authors interviewed nine individuals living with gastroparesis; four main themes resulted from the interviews and it was concluded from the in-depth interviews that the chronic illness affects all aspects of the individuals' lives and the uncertainty that the individual's experience can trigger psychological distress and feelings of loss (Bennell & Taylor, 2013). A second study by Inan, Gunusen, and Ustun (2016) used a phenomenological approach to describe the experiences of women In Turkey as they were going through the diagnostic phase of breast cancer. The data for the article were collected through semi-structured in-depth interviews of nine subjects. Four themes were identified from the interviews, facing the diagnosis, uncertainty, avoidance, and holding on to life (Inan, Gunusen, & Ustun, 2016). The authors were also able to conclude that breast cancer patients experience uncertainty about maintaining their role at home as part of the Turkish culture as well as how cancer is viewed within the culture. The methodology of the study allowed the authors to explore into the lives of the women and better understand the lived experiences and how health care professionals should be aware of how the patients psychologically adapt and how to guide them with new information and support. A third study utilizing a

phenomenological approach with purposive sampling was conducted by Coventry, Dickens, and Todd (2014) to explore bodily and emotional consequences of physical and mental multimorbidity in lived time and lived space amongst individuals with different combinations of mental-physical multimorbidity. The researchers recruited subjects with chronic obstructive pulmonary disease from three acute hospitals in Greater Manchester, UK. It was concluded that the lifeworld of those with multimorbidity was characterized by temporal and spatial contraction, meaning that individuals exhausted their energy on coping with symptoms and did not have energy left to spend on social aspects of life (Coventry, Dickens, & Todd, 2014). The examples provide insight into the usefulness of the phenomenological method and benefits of such in-depth interviews toward understanding the lived experiences of those with chronic illness.

The trend I have observed while searching the literature is the majority of studies utilize the MUIS to determine the level of uncertainty experienced by the individuals. For instance, Jian and He (2012) utilized the MUIS to determine the effects of an uncertainty management intervention for individuals diagnosed with chronic obstructive pulmonary disease on uncertainty, anxiety, and depression and quality of life. The use of the MUIS showed that when results were compared the intervention group showed a greater improvement in uncertainty than the control group. Byeong, Choi, Lee, and Noh (2016) studied the relationship between perceived gastrointestinal symptoms, uncertainty, and recovery in individuals diagnosed with gastric cancer post-gastrectomy. Through the use of MUIS the researchers were able to assess uncertainty levels in comparison to perceived recovery time and determined that health care providers should promote

recovery and take into account patients' socioeconomic factors, income, and education ᴡhen providing information and counseling to patients in order to reduce the level of uncertainty (Byeong, Choi, Lee, & Noh, 2016). Another study used MUIS to capture how participants viewed the cues about their cancer. The data discovered that interventions to address avoidance and the intolerance of uncertainty in those diagnosed with lung cancer might help improve the psychological adjustments experienced (Kura et al., 2013). Giammanco, Gitto, Barberis, and Santoro (2015) conducted a study that provided the researchers with a user-friendly and valid tool, MUIS that can help to monitor patients' emotional responses to diagnosis and through the course of the disease and provided insight into appropriate strategies of coping for the patients. An inherent weakness that has been observed in the literature is the lack of studies exploring the uncertainty and how it affects the subjects' quality of life and how the individuals cope and manage that uncertainty. The literature has supported that individuals with chronic illness do experience uncertainty and that health care providers should be addressing the uncertainty at the time of diagnosis. The literature also supports the notion that when educating the individuals it is important to take into account the work, financial, and educational status of the patients (Suzuki, 2012) and that intervention can reduce the levels of uncertainty.

Uncertainty, as defined by Mishel (2014), is "the inability to determine the meaning of illness-related events inclusive of inability to assign definite value and /or to accurately predict outcomes" (p. 56). Studying how the uncertainty impacts individuals over a length of time and how to manage it remains weak in the literature. Perhaps this is

because the UIT, supported by quantitative studies and through the use of MUIS, have

been given a great deal of attention over the RUIT which is supported by qualitative

studies, there is currently a scale to be used to support the RUIT, the Growth Through

Uncertainty Scale (GTUS) that requires further investigation to determine its validity

before it will be available for general use (Mishel, 2014). A study by Germino et al.

(2013) was located that developed an uncertainty management intervention that was

developed and tested in clinical trials for breast cancer patients. Germino et al. (2013)

recruited two groups of subjects, one intervention group and one control group of breast

cancer patients. The intervention group was provided behavioral strategies to control

uncertainty and to promote self-efficacy while coping with recurrence, calming self-talk,

breathing, relaxation, and distraction to deal with triggers of uncertainty. A second

session was developed based on the current literature of young breast cancer survivors

with content that focused on hormone changes, disturbances in body and self-image,

fatigue, and prelymphedema symptoms (Germino et al., 2013). The researchers found

that those in the intervention group reported lower levels of uncertainty because the

subjects felt educated and supported.

In chronic illness how one copes and manages uncertainty can greatly impact the

individuals' quality of life and outcomes. Exploring the lived experiences of those living

with uncertainty in chronic illness is meaningful because the literature lacks in providing

meaning into the lives of those living with chronic illness and how the individuals cope.

There are strategies for decreasing the uncertainty, education, medication, and treatment

side effects, but understanding the methods used by the individuals is the goal of the study.

Summary and Conclusions

To summarize, chronic illness has become an increasing concern in the United States (Fleming, Phillips, & Kline, 2015). The literature provides evidence that there is a strong correlation between chronic illness and uncertainty, as presented earlier in this chapter. Through the use of the MUIS, researchers are able to measure the level and intensity of the uncertainty but little is known about the experiences of uncertainty. The literature does not provide evidence as to how individuals cope with uncertainty or manage the uncertainty of not knowing how the illness will impact daily activities.

To further expand on how individuals cope or manage with uncertainty in the next chapter I will discuss the research methodology I used to expand on the strategies used, as well as discuss the role of the researcher.

Chapter 3: Research Method

The purpose of this phenomenological qualitative study was to explore the lived experiences of those living with uncertainty in chronic illnesses. This chapter will describe the research design and rationale, the role of the researcher, the methodology used, and issues with the trustworthiness of the study.

Research Design and Rationale

The goal of this study was to gain a better understanding of how individuals living with chronic illness cope or manage uncertainty. Uncertainty, as defined by Mishel (2014), is the powerlessness to define the meaning behind an illness-related event and exists in chronic illness, further causing ambiguous, complex, and unpredictable situations. To further explore the lived experience and management of uncertainty in individuals with chronic illness I used a qualitative approach. According to Butina (2015) using open-ended questions utilized in qualitative methods, the researcher can gain an in-depth understanding of the study issues. The researcher is able to "understand and capture the points of view of other people without predetermining those points of view through a prior selection of questionnaire categories" (Butina, 2015 p. 190).

A phenomenological design was used for the study to answer the research question: What are the lived experiences of those living with uncertainty in chronic illnesses? I selected phenomenology, a qualitative method, because the design utilizes a small sample size allowing the researcher to gain an in-depth, detailed understanding of the experiences of the individuals who were selected (Butina, 2015). Dowling and Cooney (2012) also stated that the aim of nursing research often focuses on the

understanding of how clients experience the study issue, providing further rationale for the design selection. To interpret the findings, qualitative evidence synthesis (QES), the process of thoroughly reviewing and integrating the study's findings into a useful report, was used (Houghton et al., 2017; Sandelowski et al., 2007; Thorne et al, 2004).

Role of the Researcher

For my research study, my role was the data collector. I conducted all interviews, recorded, transcribed, and interpreted the findings. I have a personal connection with the topic of interest as I have been diagnosed with a chronic illness for almost 10 years. I have faced the uncertainty and discovered my own method for management, but remain passionate about exploring how others manage.

To avoid my own personal bias I did not share my personal experiences with uncertainty, I did not let the subjects know that I am chronically ill. The rationale for not sharing this information was because I did not want the interviews to focus on me or influence the subject's thoughts. I adhered to the questions (Appendix A) and allowed the subjects to share openly his/her experiences. I remained aware of personal experiences with the topic and did not allow myself to relate to the subjects. When interpreting and analyzing the findings I did not allow my personal bias to skew the results by providing a transparent display of the results. According to Malicki and Marusic (2014), the best method to ensure there is no bias is through transparency.

Ethical implications that were addressed were the subject selection. I posted a recruitment flyer (Appendix B) utilizing my personal social media accounts, Facebook and Instagram, along with recruiting from a local family practice. Subjects who I have a

close relationship with were not eligible and this was addressed upon subject response to the flyers and those participants were excluded. I maintained participants' privacy and confidentiality; no identifying factors were used, such as facilities or doctors providing treatment. All participants were provided a number for identification purposes.

Methodology

Participant Selection Logic

For this qualitative study, the lived experiences of managing uncertainty in chronic illness, subjects will be recruited who have been diagnosed with a chronic illness and express experiencing uncertainty. The population pool included all individuals who seek medical care from a local family medical group and individuals who utilize social media and have access to the public post. Inclusion criteria included all participants to be 18 years of age, English speaking, and diagnosed with a chronic illness. Exclusion criteria included close relationships to researcher and recent diagnosis or inability to verbalize understanding and experiences of uncertainty.

Criterion sampling was the strategy used in order to obtain a variety of experiences, as well as purposive sampling to ensure varieties of chronic illnesses were explored. The goal was to recruit participants with different ages along with different chronic illnesses. Phenomenologists typically utilize criterion sampling as a method to select a variety of subjects and explore a diversity of experiences based on the phenomena of interest (Polit & Beck, 2012).

I obtained approval through Walden's IRB, approval number 12-11-17-0155788, and after approval, I began to recruit participants by posting a flyer (see Appendix B) on

Facebook and Instagram. I also obtained permission from the medical center to post a flyer.

Phenomenologists typically select 10 or fewer participants who have experienced first-hand the phenomenon of interest (Polit & Beck, 2012). The goal was nine to 10 participants; however, data saturation is the sample size guiding principle (Polit & Beck, 2012). The process for phenomenological inquiring and analysis is through the process of reflective wondering, in-depth questioning, attentive reminiscing, and interpreting of the primary meaning of the individuals' lived experience (Van Manen, 2017). Phenomenological research is not a method selected to produce results that can be generalized but conducted to better understand the meaning behind an experience of the phenomenon, and therefore utilizes smaller sample sizes (Converse, 2012). Once I reached saturation and there was no longer new information being gained I stopped selecting participants and conducting interviews, with eight participants.

Instrumentation

In qualitative studies, data collection can evolve while in the field as the researcher may come across information that is worth pursuing (Polit & Beck, 2012). For this reason, semistructured interviews were used for data collection. This allowed the interviews to hit on the main topics to be addressed but also allowed the participants to feel comfortable to talk freely. This strategy allows the researcher to obtain all information necessary (Polit & Beck, 2012). I have created an interview guide (see Appendix A) that will be was used for all interviews. The first group of questions, one through three, readdressed the inclusion and exclusion criteria, I wanted to ensure all

participants have been diagnosed with a chronic illness and are able to state which

diagnosis and how long they have been diagnosed. I also wanted to make sure the

participant understands uncertainty and does in fact experience uncertainty. The

remaining questions, four through seven, will remain opened-ended and the participants

were able to take the question in the direction desired. According to Polit and Beck

(2012), it is important to use probes to elicit detail. The final question allowed the

participants to provide further information that they felt would be useful for the study. I

wanted to allow the participants enough time to open up and share his/her story and not

feel overwhelmed by too many questions, probing open-ended questions were asked as

well based on information provided by the participants. If the participant became

uncomfortable, s/he had the right to withdraw from the interview at any time and request

not to participate.

Procedures for Recruitment, Participation, and Data Collection

   I conducted interviews using FaceTime and if necessary telephone interviews

were conducted. The preferred method was to be able to view the participant to notice

nonverbal, visual cues. I did telephone interviews only if the participant was not local,

able to meet for a face-to-face, did not have FaceTime capabilities, or opted out of both

face-to-face and Facetime options.

   I sent a recruitment flyer to the family care medical group after receiving

permission from the facility and posted the same flyer on my Facebook and Instagram

page. The post was made public so everyone who has Facebook and Instagram were able

to view the flyer. The flyer provided instructions for those individuals with a chronic

illness who are interested in participating in a research study to contact me via email or telephone, both were provided. Once I was contacted by an individual that was interested I emailed the informed consent. Once the individual read the informed consent, he or she then emailed me back the signed consent form. If the individual did not have email or access to the internet, I would bring the consent if meeting in person for review prior to the interview, if not meeting in person I would read the consent to the participant prior to the interview and obtain verbal consent to continue. Once I received that the individual had consented to participate, I set up an interview at his/her convenience. A reminder email was sent out a day prior to confirm the appointment and offer a reminder. Polit and Beck (2012) suggested using an environment free from distractions, is quiet, and makes the participants feel comfortable. I was sure to be alone in my office during telephone interviews to secure privacy and provide a quiet environment for myself and participants to focus. If telephone calls are necessary I paid close attention to every word and tone expressed by the participant, as I did not have the visual cues to assess for any discomfort or emotion.

I began all interviews at the time scheduled. For telephone interviews, if the participant did not answer I called back in five minutes, left a voicemail, and sent an email requesting to reschedule. If the participant answered, I introduce myself and thanked the participants for taking the time to participate in my study. If the participant did not show up for a face-to-face interview I contacted the individual via phone or email, if I did not have contact information the participant was excluded. During telephone and live interviews, I made sure the participants were in a safe space where they could share

personal information and assure them that there were not others listening in from my end.

The length of time expected for the interview, 20-30 minutes, was addressed to make sure

he or she would not have to walk away in the middle of the interview. I reminded them of

the informed consent and that their participation was voluntary and that they have the

right to stop the interview at any point or request to not answer specific questions.

Permission to record the interview wsd also addressed at that time. When approved by

the participants all interviews were recorded and later transcribed verbatim for analysis.

Data Analysis Plan

Computer programs can offer many advantages to analyzing and interpreting data

(Polit & Beck, 2012). Qualitative analysis contains a large amount of data, requiring an

effective way to manage the results, for this reason, I will be using NVivo, computer-

assisted qualitative data analysis software (CAQDAS; Houghton et al., 2017). Once the

data is stored in NVivo I used a strategy called "fracturing," a strategy used to break

down the data and organize them into categories, to develop themes or categories across

all cases (Polit & Beck, 2012, p. 565). I then extracted main themes and subthemes, also

known as Nodes, as appropriate (Houghton et al., 2017). The data were coded, which

required me to review each interview several times, ensuring the meaning behind words

and statements were dissected and categorized properly, to determine relationships and

similar meanings. I pulled out key terms and patterns expressed by the participants. After

data analysis I presented the data based on the trends, themes, and categories discovered.

All data were backed up to my computer and a zip drive to ensure it is not lost.

Participant interviews and findings were secured with fingerprint access and password security. The data will be stored for five years and then deleted.

Issues of Trustworthiness

Trustworthiness is crucial for all research studies as it determines the rigor or validity of the study (Polit & Beck, 2012). In order to conduct a study that is credible and trustworthy strategies are necessary to determine if data collection and analysis is valid. Two strategies that I utilized are triangulation and member checks. Data triangulation included the use of multiple data sources, individuals with different chronic illnesses, and the use of different methods, such as observation during the interviews. Using participants with different chronic illnesses, I was able to have a variety of experiences, such as symptoms, treatments, and outcomes. The interviews were conducted face-to-face in order to observe visual cues from the participants to offer a different method of data collection. Member checks included me restating what the participant stated to confirm understanding if I did not feel I was understanding correctly (Polit & Beck, 2012). I also transcribed the data verbatim and did not alter the statements or change the information based what I interpret it as meaning.

Ethical Procedures

Ethical procedures addressed included obtaining IRB approval from Walden University prior to recruiting and collecting data. I also gain approval from the Family Care Medical Group to use their facility to post flyers for recruitment. All subjects were be 18 years or older and English speaking, ethical concerns consisted of ensuring their health status was such that he/she was able to consent and not on pain medications that

might prevent their abilities to provide consent to participate. To address this I included that all participants be able to consent and sent the individuals a consent form, as well as discussing the ability to provide consent prior to our interview. If individuals should exit the interview early or decline to continue, I gave them the option to finish another day or I would destroy the data collected. I interviewed individuals that were chronically ill and it was possible that symptoms could start and require the individual to withdraw or postpone the interview. I needed to be flexible given the population. Data collected is and will remain confidential; participants were given a number, names were not written down or recorded. I also sure not to document any other personal identifiers, such as health care facilities or doctor's names. I stored the data on my computer, NVivo, and backed it up on a zip drive. Each participant I interviewed was stored under the number assigned. Once the study was completed I saved the data with no individual identifiers to my computer. Participants names will only be provided to my committee chair and member if absolutely necessary. Another ethical issue is that I have a chronic illness, I needed to be cautious and aware, as to not let my own biases to alter or impact the participants during the interviews. I did not share my personal story with the participants, I was careful not to make faces or gestures suggesting that I agree or disagree with what was being said. My goal was to simply learn more about the lived experiences of those with chronic illnesses and the management of uncertainty. I do not feel that my personal history will impact the participants or skew the data.

Summary

The plan for my qualitative study was to use a phenomenological design to better understand the lived experiences of those with a chronic illness and the management of uncertainty. IRB approval was obtained prior to the start of any recruiting or data collection. Ethical issues related to recruiting and personal connection to the study were addressed.

 I conducted interviews via face-to-face or telephone to delve into the lives of 10 or fewer participants. The interviews were recorded and transcribed. I reviewed the data several times for coding and determined themes that developed.

The next chapter will provide a detailed explanation of the data collected, the analysis of the data, credibility, transferability, dependability, and confirmability. Also reviewed will be the results of the interviews with patterns and trends that resulted.

Chapter 4: Results

Purpose of Study

Living with and experiencing chronic illness, with physical impairments, lifestyle changes, new limitations, and for some hospitalizations, can be challenging to manage and even cause psychological distress (Valeria, Maria Daniela, & Lara, 2014). High levels of uncertainty or coping with the unknown can increase psychological distress (Iranmanesh et al., 2014; Livneh & Antonak, 2005). Understanding how individuals with chronic illness experience and cope with uncertainty is not clearly addressed and there is a gap in the literature addressing such awareness. The purpose of this study was to better understand uncertainty and chronic illness and how those living with chronic illness manage and cope with uncertainty.

Research Question

The research question selected for the qualitative research plan was: what are the lived experiences of those living with uncertainty in chronic illnesses?

This chapter includes a breakdown of the setting and demographics of the study along with data collection and data analysis processes. I will also address evidence of trustworthiness and the results of the study.

Research Setting

The recruiting process for the study occurred during the winter holiday season in late December early January. A recruitment flyer was posted on my Facebook and Instagram page, friends and family shared the flyer. Participants responded from different states within the United States. An unintentional limitation was the time of year the

interviews took place. Individuals who struggle with depression may see an increase in symptoms during the holiday season because of different factors such as a decrease in sunlight, shorter days, increase in financial stress, family, and lack of time (PR Newswire US, 2017) it is possible that increased depression could be reflective in the interviews.

Demographics

This qualitative phenomenological study included eight participants all living with and experiencing uncertainty and chronic illness or illnesses. Participants were recruited using social media. All had experience with uncertainty and were being treated for chronic illnesses for over one year. The chronic illnesses included arterial fibrillation, arterial sclerosis, interstitial cystitis, asthma, gastroparesis, and Ehlers-Dalos syndrome. The participants were all female ranging from the ages of 20 to 70 years old, English speaking, and from the United States (see Table 1).

Characteristics of Participants

Table 1 provides a summary of the characteristics of the study participants

Table 1

Characteristics of Participants

Characteristic		Number of individuals
		Sample ($n = 8$)
Gender		
	Female	8
	Male	0
Chronic illness type		
	Asthma	1
	Gastroparesis	5
	Ehlers-Dalos Syndrome	1
	Arterial Fibulation	1
	Sphincter of Oddi	1
	Arterial Sclerosis	1
	Interstitial cystitis	1
	Celiac disease	1
	Pancreatic Insufficiency	1
	New Daily Persistent headache	1
Age		
	21-30	3
	31-40	2
	41-50	1
	51-60	1
	61-70	1

Data Collection

Number of Participants

Fourteen people initially volunteered to participate in the study. Of the 14, 11 sent an email for communication and retrieval of the consent. Eight participants arranged an interview. Therefore, the study included eight volunteers who willingly participated in the interviews. All eight volunteers met the inclusion criteria specified, English speaking, 18 years of age, and diagnosed with a chronic illness and experienced uncertainty. Eleven sent back the consent to participate, eight responded to invitations to set up an interview. Four consenting participants were not included due to lack of response to set an interview date.

Location, Frequency, and Duration of Data Collection

To obtain the data for this study I conducted interviews with individuals who had one or more chronic illnesses and experience or have experienced uncertainty. Permission for human subject research was established through the Walden University IRB prior to recruitment efforts. Authorization was obtained December 11, 2017, approval number 12-11-17-0155788. After receiving approval from the IRB I posted my flyer (Appendix B) on my Facebook and Instagram pages. The recruitment flyer provided brief information about the study, who was qualified to participate, the purpose of the study, and my contact information.

Family and friends then shared my flyer and expanded the number of individuals who the flyer reached. Within hours I received individuals expressing interest in the comments on the posts from Facebook. I responded to all comments for the individuals to

email or text me and email address if available. Some individuals just emailed a desire to participate. Once I received an email from the willing participant I then emailed an electronic consent and requested that the participant print it, sign it, and scan it back to me. The first four individuals to send back the consent eagerly scheduled interviews. I then reposted the flyer stating that I was still recruiting for the study. This resulted in an increased interest, 10 or more with seven sending emails. Of the seven who sent back consents to participate only four responded back and confirmed interview days and times resulting in a total of eight participants. Interviews started December 14, 2017, and concluded on January 4, 2018. Several of the interviews were canceled and rescheduled because of the holiday season and last-minute conflicts for the potential participants.

The interview options were face to face, Facetime, or telephone. Three interviews were via facetime, one started out on facetime but because of poor connection, the interview concluded via telephone. Two participants stated they preferred to be interviewed via telephone and the remaining three did not have facetime capabilities and were not within the close vicinity for a face to face interview. During all interviews, privacy was ensured, as I wanted the participants to feel comfortable during the interview. Prior to all interviews, all participants were reminded that the interview was voluntary and they could stop the interview at any point or opt to not answer any questions that might make them uncomfortable. I assured them that their personal information would remain confidential, personal identifiers, names, treatment centers, or doctors would not be documented and each would be given a participation number for reference. I advised all participants that I was conducting this study for my dissertation as

a Walden University doctoral student. All participants agreed to participate and none voiced concerns.

The interviews lasted between 15 and 40 minutes. Prior to the interviews, each participant was provided a definition of uncertainty and chronic illness and each provided verbal assurance that they understood. Participants were encouraged to lead the discussion and tell as much of their stories as they felt comfortable with. I did use an interview guide (Appendix A) to start the conversations and ensure all participants were asked the same questions as they fit into the discussion. Many participants answered some of the questions while just telling their stories. At the conclusion of the interviews, all participants were informed that they would be receiving a summary of the results.

Data Recording

All participants were asked to be audio-recorded and all were agreeable. I recorded all eight interviews using a recording app on my password protected phone. The recordings started after participants consented to be recorded and we discussed not using any personal identifiers during the interview. During the first interview, the sound did not work and the participant's voice was not picked up. The remaining seven interviews were recorded without difficulties. During each interview, I also took hand-written notes and documented as much as I could of what the participants were saying. This was especially valuable for the first interview as no audio-recording was audible.

I started transcribing the interviews verbatim in notes on my password protected computer. After transcribing two interviews I realized I could import the audio recordings into NVivo. After the audio-recordings were imported I could then slow them down, time

stamp and transcribe the interviews. The interview that did not record I transcribed from my notes.

All participants received a participant number to ensure participant's privacy. No names, treatment facilities, doctors, or identifying factors were associated with the interviews. All recordings and emails remain stored on a password-protected computer and all paper files are stored in a locked file cabinet. The only individuals who have access to the data are myself, dissertation chair, and committee if necessary. I will keep all files secure for five years to remain in compliance. After the five year period all documents, files, and recordings will be destroyed.

Variations from Original Data Collection Plan

My original plan during the recruiting process was to post a flyer at a local medical center and to the Walden participation pool. I received such a quick response to my flyer via social media that I was able to recruit all necessary participants and reach saturation with the interviews. Therefore, it was not necessary to post the flyer elsewhere.

A second complication was the use of FaceTime. Many participants did not have FaceTime as their phones or computers were not compatible, and a couple of participants were not comfortable with FaceTime. My plan was to do all interviews, if possible, via FaceTime or face to face to observe the participant during the interview for body language. I did find that those who agreed to FaceTime appeared to be uncomfortable and quick to answer questions. Those who did the telephone calls went into detail about uncertainty and their lived experiences.

Data Analysis

Coding Process

I started the analysis stage by uploading all audio recordings into NVivo software. Once all recordings were uploaded, I then transcribed all interviews with time stamps. The software allowed me to code, categorize, and develop themes. I began by running a frequent word query but did not find that it produced useful results. I then moved on to developing nodes and common themes. The questions used for the interviews guided the participants in discussing six main themes. The participants described their chronic illness or illnesses including length of time diagnosed, experiences with uncertainty, and the impact of uncertainty on their daily lives, coping or managing strategies for uncertainty, communication from healthcare teams about uncertainty, and important information about uncertainty and chronic illness from their own experiences. Developing the nodes (See Table 2) enabled me to see all comments as they related to the theme.

Table 2

Nodes/Main Themes

Theme one: Chronic illness
    Diagnosis or diagnoses
    Length of time to diagnosis
    Length of time diagnosed
Theme Two: Uncertainty
    Experiences with uncertainty
    Uncertainty related to searching for diagnosis
    Uncertainty related to procedures for diagnosis
    Uncertainty related to treatments
    Uncertainty related to outcomes
    Uncertainty related to the future
Theme Three: Impact of uncertainty on daily life
    Psychological impact
    Planning daily activities
    Seclusion/fear of leaving the house
    Family impact
    Inability to work
Theme Four: Coping or managing uncertainty
    Finding routine
    Physical activity
    Spiritual rituals
    Researching
    Inability to manage
    Therapy
    Plan ahead
    Incorporate resting periods
Theme Five: Communication from healthcare team about uncertainty
    Trust in doctors
    Lack of information provided by healthcare team
    Unclear information provided by healthcare team
    Guidance from healthcare team
    Therapist referrals to assist in healthcare team communication
Theme Six: Important information from participants
    Have an advocate
    Treating each case differently
    Improve explanations of treatment plans
    Getting to know patients

NVivo tracked the data to the participant's data code, allowing me to see whichparticipant made the comment, making it easier to track back to the original participant interview. After the nodes were developed, I was able to run a query through NVivo and develop a node matrix, showing the data pulled from the participant's interviews (see table 3).

Table 3

Node Matrix

Participant	1	2	3	4	5	6	7	8
Node 1: Chronic Illness	2	2	2	3	2	2	2	2
Node 2: Uncertainty	4	1	2	1	1	1	1	2
Node 3: Impact of uncertainty	4	2	1	4	2	1	8	6
Node 4: Coping/Managing uncertainty	2	1	9	2	1	4	3	6
Node 5: Communication with healthcare team	1	1	0	0	2	4	1	1
Node 6: Additional information	0	1	0	1	1	1	1	2

The node matrix was useful in determining which node influenced each participant the most. The higher the number the greater the data pulled from the interview providing evidence that the participant had significant information to add as related to the node. For example, I can see that participant seven is considerably impacted by uncertainty given

that eight topics were pulled from the interview as related to node three, for example, "I had anxiety before I got sick with gastroparesis but it got severely worse where I was getting panic attacks that would send me into seizures" (P7) "The uncertainty impacts me so much I cannot work"(P7). "I just stay home because I never know if I will be sick"(P7). Participant 3 has developed strong coping and managing strategies, as shown by the statement, "I have learned what to avoid, I know what I need to do. I know I cannot have fruity drinks, or do certain exercises because I do not want to be in pain" (P3). In analyzing the data, I looked at the node matrix to locate any trends, for example, participant three provided a large number of coping strategies but also provided just one statement about the impact of the uncertainty, suggesting a possible correlation between the impact of uncertainty and coping strategies. However, I had to further investigate the nodes because the numerical data does not present positive and negative experiences. However, it did provide useful areas for comparison and correlation to further explore.

During the interviews I allowed the participants to tell their story. Some of the participants would go off topic and discuss more detail about the diagnosed chronic illness and not speak to the uncertainty. Open-ended questions were used to bring the participant back to uncertainty, so the data could be used for the analysis.

Observations were made during the interviews, as three of the interviews were done using Facetime. The participants that I was able to visualize moved their eyes a lot so as to not make eye contact during difficult topics, for example, when they discussed the doctors not believing them or healthcare team not taking them serioulsy, the particpant's eyes would go down toward the ground. I also noticed that during the

interviews via telephone the tone of the particpant's voices would change when talking about similar topics. The participants who I interviewed using Facetime also had shorter responses and would stop when they appeared to be uncomfortable rather than expanding on why they were uncomfortable as those that I could not see would discuss topics in detail.

<div align="center">**Evidence of Trustworthiness**</div>

Strategies to ensure trustworthiness included triangulation and member-checking. I was able to recruit participants with a wide variety of diagnosis and from different areas of the United States, keeping a small participant pool of eight as planned. My original plan was to use observation as an additional method. With technology complications and compatibility issues, I was not able to observe all participants during the interviews. I did audio record and hand write notes while the participant was speaking, I also wrote down if there were any changes in voice and if the participant laughed or got sad to strengthen my findings. All interviews were transcribed verbatim and I used member-checking to ensure I was understanding statements correctly. Miles, Huberman, and Saldana (2014) suggested member-checking, using active listen, and stating back to the participants to ensure understanding. This strategy offered the participants a chance to confirm or deny my understanding. During the interviews, I also remained mindful to not offer any of my own personal opinions or thoughts. I focused on asking the questions prepared and keeping the participant on the topic by asking open-ended questions to gain a better idea of the lived experience. All participants will receive a copy of the findings.

Study Results

I categorized nodes based on questions developed for the interview guide and common

themes brought up by the participants during the interviews to best explore the lived

experiences of individuals with chronic illness. The nodes offered a strategy to break

down the interviews for interpretation.

Node 1 : Chronic Illness

Participants shared chronic illnesses they were diagnosed with, the length of time

it took to get to a diagnosis, and how long they have been diagnosed. Examples include

all of the following: "Arterial fibrillation and arterial sclerosis, symptoms started two

years ago" (Participant 1). Participant 2 stated, "I have been diagnosed with asthma about

ten years ago; it took about five years to come to a diagnosis." According to Participant

3:

> Interstitial cystitis, symptoms started when I was 12 years old, for the longest time
>
> no one knew what was going on, I got sick of it and did research on my own, the
>
> first doctor did not listen and I finally found an NP that was open to listening and
>
> agreed that I had interstitial cystitis.

The first three participants struggled to get a diagnosis, Participant 1 and Participant 3

shared that they had to bring possible diagnoses to the doctors and do the research

themselves. Participant 2 continued to listen to the doctors and did not push for further

testing until an advocate stepped in and demanded further steps be taken. (Particpant 4) "I

have had NPDH since 2009 and I was diagnosed with gastroparesis, symptoms started at

the age of 16 and was just recently diagnosed at 22." This is a unique case in that the

individual has a psychiatric history and shared the delay in diagnosis was because the doctors brushed symptoms off as psychological and not physical. (Participant 5) "I have been diagnosed with gastroparesis and Ehlers-Dalos Syndrome." (Participant 6) "I am currently being treated for gastroparesis but I have never had any tests done, my doctor is just treating me off observation and seeing what works." Participant 7 received a quick diagnosis, "I was diagnosed with gastroparesis in two months in 2013" (Participant 7). Participant 7 shared that she had brought the tests she wanted to have done to the doctors and insisted on having them and that is how a diagnosis was determined so rapidly. Not the case for Participant 8, "I have been diagnosed with sphincter of Oddi dysfunction, severe gastroparesis, pancreatic insufficiency and celiac disease in 2012, with symptoms starting in 2008 after a gallbladder surgery" (Participant 8). Participant 8 shared the long journey from the start of symptoms to almost losing her life, she spent almost a year between the hospital and nursing home, had to travel to seek the best care and had to uproot her youngest child to get what was needed. After listening to the participant's diagnosis and the process each went through to get to a diagnosis it is clear that either having an advocate with you or being your own advocate is critical in obtaining a diagnosis.

Node Two: Uncertainty

Prior to the interviews uncertainty was defined and explained and all provided verbal assurance of understanding. Each participant was asked to share their experiences with uncertainty, examples include: Participant 1 shared;

I met with my cardiologist after having symptoms and my right leg gave out, things progressed slowly. I started treatment with my primary care doctor and was put in physical therapy, this did not work. I was very weak and very tired. With each treatment I thought I was going to be cured, the doctors still do not know what is happening to me. I fear that I may not ever be able to get out of the house. (Participant 3) For the longest time, no one was certain about what was going on, so I had to figure it out on my own, I remember dealing with a urologist and she did not believe me that I have interstitial cystitis and so she was kind of like insulting to me.

(Participant 5) "I experience a lot of uncertainty about what my quality of life will be like in the future."

Fear of the unknown was a common statement fearing the unknown, fearing if symptoms would worsen, fear of leaving the house, and fear of never go back to the life lived prior to chronic illness. All participants shared feelings of uncertainty during the diagnosis process and after being diagnosed. Participant 8 stated:

I was in constant fear that this was going to be my life and how am I going to go back to being a part of my children's lives and at the time my daughter was in sixth grade and I had two boys back here in high school, so it was very difficult not knowing what was going to happen to me, what was going to happen to them, not knowing if I was even going to live and that was even on the table as unknown.

Node Three: Impact of Uncertainty on Daily Activities

The impact that the uncertainty has on each of the participants provided insight into the fact that symptoms, fear, and the unknown can prevent individuals with chronic illness and uncertainty from even leaving the house or partaking in daily activities. Participant 1 stated that:

When not in A fib I have a very normal day but I never know if I am going to wake up and not be able to walk or get up and down my stairs, I am asleep by 3 pm, I miss out on family events because I am just too exhausted and I do not know if it will just come on, so then I have to cancel. Just walking becomes difficult so I do not want to venture off too far alone in case I just go into A fib.

Participant 2 shared a story about taking a chance and going hiking and not having access to necessary medication. "My husband and I went hiking and I had hiked down and I could not make it back up and I did not have my inhaler with me" (Participant 2). She also shared that when it is cold out it hurts to breathe so she does not leave the house if it too cold. Another participant shared that she just dealt with the pain; nobody knew what was causing it or how to control it. Participants also shared the inability to work because symptoms can become so severe at any time. Those who do work shared the need to wake up earlier in order to take medications, sit up ensuring the stomach is settled, and to schedule in rest time because it is too exhausting to put make up on and get dressed. Participants stated that: "It impacts me so much I cannot work because I do not know if I am going to wake up feeling ok and have the energy to get out of bed and go to a job and

do anything" (Participant 7). "My entire day is built around uncertainty and my symptoms because at any point I can become very very nauseous or I can become very very sick" (Participant 6). "I had to leave my job and my kid's lives were disruptive, I couldn't be left alone because I constantly was passing out" (Participant 8).

Participants also shared the inability to keep plans with friends and family. "I mostly stay at home, I can never say 100% I will be there, I am just too nervous about the consequences if I push the limit even just a little bit" (Participant 7). "I cannot make plans, I am always bailing" (Participant 4).

There are also psychological impacts from the uncertainty; participants shared increased levels of anxiety and depression. "I spent so much time in tears of frustration because there were no concrete answers for what was going on" (Participant 8). "My parents had to call an ambulance because my anxiety had gotten so bad after diagnosis that I had a panic attack so severe I could not breathe" (Participant 8).

Node 3 provided insight into the physical and psychological factors that result from uncertainty and chronic illness. Factors include the planning of daily activities, fear of leaving the house, how the chronic illness affects the family, and the inability to work or hold a job.

Node Four: Coping or Managing Uncertainty

After hearing about how the participants were impacted by uncertainty and chronic illness, I was looking forward to hearing about coping and management strategies used. The most common strategies shared was waking up early in the morning and planning ahead. Several of the participants shared that they have to make time to take

medications, including time to sit up to allow everything ingested digest to order to prevent symptoms. One participant has to wake up early to get ready, as frequent breaks are needed during the processes because of fatigue. Participant 2 stated:

> The first thing I do when I wake up is take my inhaler; if I do not do it right away when I get up I get busy doing other things, so I try to do it first thing when I wake up so that I am on the right path.

Other coping strategies included advocating for themselves and doing their own research and presenting it to the doctors. Some shared frustration in needing to do this information seeking, while some felt doctors just do not have time to do it. For example Participant 3 stated:

> It is kind of like my job, I have to figure out what is going on with the people and advocate for them so I am like well I have to do it for myself, I was looking up stuff on my symptoms and figured out this disorder is probably what I have so I brought it up to my OB GYN and she was like ok yeah, we were able to locate an NP familiar with the disorder and so I had to help myself.

One participant felt having to do this research on her own was not her responsibility and that is what the doctors were for and felt that she lost confidence in her doctor when she had to take these steps. "It is just a lot of googling and taking care of myself" (Participant 6).

Two participants shared that after diagnosis a team of doctors came together and they were started in therapy to address the psychological aspects of uncertainty and chronic illness. "It has been instrumental, I honestly do not know if I would be here today

if it was not for being in therapy and finding a good therapist that has experience with chronic illness" (Participant 7). Interestingly the two that participated in therapy shared that retraining their brains was key to being able to cope and manage uncertainty. "I had to retrain my brain to be accepting of the fact that I do not know what tomorrow will be like and do not know what later today will be like" (Participant 7). "Everyday I have to embrace it as my new normal so I get up and do what I have to" (Participant 8).

One participant shared that she rides horses, another tried to exercise every day to build muscle to help with recovery. Other participants discussed the need to avoid certain workouts and utilize the trial and error method to determine what work for them in order to cope and manage uncertainty.

Node Five: Communication with Healthcare Team about Uncertainty

The majority of participants were quick to answer the question whether the health care team discussed uncertainty with them or not. Most responded with "no." Participant 6 stated, "no, absolutely not, never, I mean in a sense of their own uncertainty about what is wrong with me or what is causing it but never in relation to me feeling uncertain." Several shared that the doctors would often give a flyer with information about the illness on it, but not go over any management strategies or give a medication, and ask the patient to return for a follow-up to see if symptoms improved. Participant 5 stated:

> The doctors they just give me a quick summary like yeah, we saw this on your last test and we are giving you this drug and I do not understand what it is. The test results came back showing and why they want to do what it is they are

suggesting, like not understanding the rationale behind my care creates greater

anxiety.

Those who were in therapy did have medical teams that discussed uncertainty

with them and that is how the psychological aspects were addressed, doctors worked with

the participants as a team approach to care. Participant 8 stated:

> Yes, there was the talk of uncertainty with the doctors; they were very clinical
>
> about it; when I was at the med center they set me up with a psychiatrist and a
>
> psychologist. Mostly because my stomach was not functioning and my brain was
>
> not getting the proper messages that I needed so they treated me for the
>
> depression and my dosage has since been going down as I am getting more
>
> nutrition.

Node Six: Additional Information

At the conclusion of all interviews, I asked each participant if there was anything

they would like to add or that they felt would be helpful for the study. A common

response was communication within the healthcare team and to not treat every case like

the other, be understanding that with a chronic illness not all cases present the same.

Participant 4 stated:

> If anything just like not treating every case like a textbook, not everything is the
>
> same from one patient to the other, I know that especially around me that is what
>
> a lot of the medical systems do, if you do not present with every single symptom
>
> or problem then they do not hear you out and if they hear anything about psych
>
> history they immediately dismiss you.

Other responses were for health care providers to explain using common terms and not medical jargon. "The patient will be able to understand what it is that is happening to them and what the proposed plan is" (Participant 5). Participants also shared it is important for individuals with chronic illnesses to learn that they do not have control over the sickness and that it is important to maintain a positive attitude.

Summary

During the interviews and analysis of audio-recordings, transcriptions, and handwritten notes, I was able to further explore the lived experiences of eight individuals living with chronic illness and uncertainty. Table 1 provides insight into the participant's characteristics, Table 2 provides the key themes from the interviews, and Table 3 provides a node matrix. The six themes that were identified were chronic illness, uncertainty, the impact of uncertainty on daily life, coping or managing uncertainty, communication from healthcare providers about uncertainty, and additions information from the participants.

I learned from the interviews that individuals living with uncertainty and chronic illness experience frustration from the start of symptoms. The participants shared not feeling well and dependent on their doctors to know what was wrong and how to fix it. Many experienced a trial and error process of medications in hopes one would work and fix the symptoms. In some cases, symptoms are controlled while others continue to struggle to find a treatment that will work. Even when symptoms have been controlled the fear of the treatment no longer working remains, as well as the fear that their illness could worsen. The participants shared that uncertainty is present every day in relation to

searching for a diagnosis; procedures that are necessary for diagnosis, treatments, outcomes; and what will happen to them in the future. All participants were impacted by uncertainty at different levels. They shared uncertainty having a psychological impact, it impacted their families, ability to work, and plan daily activities. Most experienced psychological impacts such as fear leading to seclusion and inability to work. Coping strategies were shared and included: finding a routine, staying physically active if possible, seeking information from the intranet, planning ahead to ensure time to complete medication regimes and daily routines, spiritual rituals, and participating in therapy and online support groups. One participant shared that she has not been able to cope with the uncertainty or find a strategy to manage it, she currently resides at home and is unable to work.

An interesting finding was that two participants stated their healthcare team used a team approach to care and offered guidance by psychiatrists. Other participants expressed a loss in trust of their doctors, as each procedure was to end the symptoms but did not work, while others did not receive any information at all from their healthcare team about uncertainty and chronic illness. Information the participants felt was important for others with chronic illness to know is to have an advocate at appointments who can help express that further care is necessary. Suggestions are for healthcare providers to treat each patient individually based on their needs, improve the explanation of treatment plans, and get to know each patient personally.

The information gained from the interviews has furthered the understanding of individuals with uncertainty and chronic illness and offered a greater insight into the

daily experiences of uncertainty, or not knowing, and how to manage uncertainty in chronic illness.

The next chapter will provide a brief introduction and summarize key findings, provide an interpretation of the findings, limitations of the study, recommendations, and implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to explore the lived experiences of those living with uncertainty in chronic illness. Literature shows that individuals with chronic illness experience uncertainty, it is possible that the patients do not understand the meaning of the events linked to the illness, and they are unable to predict when the events will occur (Valeria et al., 2014). The uncertainty can negatively impact the individual's quality of life. A qualitative methodology was used to better understand the experiences, more specifically a phenomenological approach with a small sample size and in-depth interviews were used to learn that participants do experience uncertainty, prior, during, and after diagnosis. Uncertainty is experienced as related to diagnosis, treatments, outcomes, and future health. All participants were impacted by uncertainty in some form either psychologically or physically. Examples include, the planning of daily activities, some mentioned families being impacted and uncertainty being so bad that they do not leave the house and experience fear. Strategies to cope with the uncertainty include participants finding a routine, researching symptoms on their own, exercising, planning ahead, and even looking to spiritual rituals and therapy.

Interpretation of Findings

The participants verbally expressed that they each experienced uncertainty after a small discussion about what uncertainty is as related to chronic illness. The findings from my qualitative study confirmed with those described in the literature review. Bennell and Taylor (2013) concluded after interviewing nine participants that chronic illness does

affect all aspects of the individual's life and that the uncertainty experienced can trigger psychological distress. Participants from my study also expressed feelings of fear, depression, anxiety, and that the stressors lead to seclusion and impacted their families as well. Participants from my study also shared that therapy and spiritual rituals were used to manage the psychological aspects but only reduced the uncertainty.

Many participants from my study expressed increased exhaustion and fatigue and needing to plan rest times during the day in order to complete daily tasks. Some are unable to work or make plans with friends and family because they are never certain how they will feel. Coventry, Dickens, and Todd (2014) found that individuals exhausted all their energy on coping with symptoms and therefore did not have energy left for daily activities.

Participants from my study also suggested that if doctors would use common language and clearly explain treatment plans and diagnosis patients would feel less uncertainty. This concept was supported by Suzuki (2012). Germino et al. (2013) concluded that individuals with breast cancer, who were in an intervention group, stated they experienced less uncertainty because they felt supported and educated. Information seeking was expressed as a strategy for coping with uncertainty by several of the participants from my study. Participants shared that if a doctor did not have answers or give clear answers, the participants would search for their own. After the participants collected information they would bring it to the doctors, which was not always accepted by the healthcare team. The need to information seek and not have it not be accepted caused a lack of trust in the doctor. For example, one participant shared that she stopped

contacting the doctor when she would have symptoms. She would receive feedback from the nurse that she should not worry about the symptom, without speaking with the doctor. The participant began to research her symptoms and not seek treatment.

An interesting key finding, as related to the theoretical framework, was that the participants who were treated by a team of healthcare providers and psychologists shared that a strategy utilized was to retrain their brain, through working with a psychologist on coping methods or readings, to learn to adapt to their new normal. This confirms with Mishel (2014) and the RUIT, the theory was developed to address those individuals with chronic or recurring illness that requires frequent treatment and has the possibility of reoccurrence. Mishel (2014) redeveloped the UIT because it only addressed acute treatment phases and did not take into account the changes that those with chronic illness experience and the need to adapt to a new norm. When individuals continue to feel uncertain they lose tolerance and disorganization begins to take over and it is this perspective that must change, individuals with chronic illness must change their perspective from what they used to have, predictability and control, to a new life with changes and unforeseen events (Mishel, 2014). This concept was clearly supported by the participants of my study and found to be a positive strategy for managing uncertainty.

Limitations of the Study

There were limitations to this study. I do have a chronic illness and therefore there are individuals who have access to my Facebook and Instagram page that share the illness. A large portion of the participants had a similar diagnosis, possibly from the sharing of my flyer by individuals with a similar diagnosis. Had I used different

recruiting strategies I might have been able to reach a different variety of diagnosis. Recruiting from the health care center might have allowed participants that do not have access to social media participate. I had to be careful of my own bias influencing the interviews. To avoid this I used the interview guide and did not offer opinions during the interviews. I also transcribed all interviews verbatim and did not summarize or put the responses into my own words. I also was not able to observe all of the participants as originally planned. However, those who I did interview via FaceTime were quick to answer and appeared uncomfortable. If I had conducted all interviews via telephone, the participants might have felt more comfortable and the interviews might have been longer and offered more detail. The last limitation was sample size. The goal was to obtain a diverse group of individuals with different demographics and backgrounds. I was able to recruit participants with a variety of chronic illnesses and from different locations. Many of the participants did share a similar chronic illness but had other illnesses as well creating variation in responses. Another limitation was the time of year the interviews were conducted. After receiving approval from the IRB and posting my flyer, it was mid-December and right in the middle of the holiday season. Responses could have been different, given the increase in depression that time of year, than if the participants were interviewed a different time of year.

Recommendations

The current literature, through the use of the MUIS, provides evidence that individuals with chronic illness do experience uncertainty (Mishel, 2014). This study provided information on the experiences of uncertainty in chronic illness as well as

strategies that worked for management of the uncertainty. Recommended areas for further research include: repeating the study with the use of males, more participants, and conducting interviews during different times of the year, as well as a study researching the use of a multidisciplinary team approach for chronic illness treatment. It was found by participants that when other individuals are pulled into the treatment process there is a reduction in uncertainty. According to Cheong, Bosnic-Anticevich, and Armour (2013) managing chronic illness is highly complex and the pathways are often unpredictable and unknown. Collaborative healthcare can close the gaps and improve patient outcomes (Cheong et al., 2013). During the interviews for my study, the participants suggested a gap in care increased the uncertainty. For example, a participant was told the office would call her to schedule her procedure, three weeks had gone by and she still did not hear from them, turns out the office does not do the procedure and she will have to go to a different facility to have it done. Per the interviews, participants often spent months to years without a diagnosis. Doctors treated symptoms and performed tests but did not always provided information in an easy to follow format. The participants suggested that it would be beneficial to have somebody explain the treatment plans, test results, and medications. A multidisciplinary approach that is patient-centered is an effective framework for chronic illness (Cheong, Bosnic-Anticevich, & Armour, 2013).

Implications

The results of my study are supported by the literature that individuals with chronic illness do experience uncertainty. Through in-depth interviews, I was able to

delve into the lived experiences of uncertainty and better understand what individuals with chronic illness experience from the beginning of symptoms to the management of their new normal. Self-care knowledge is important in managing uncertainty in chronic illness as confirmed by Hoth et al. (2015) who stated that self-care knowledge is a strategy to improve patient care and outcomes. My study has implications for social change by providing medical professionals a glimpse of what patients with chronic illness experience. My study also offers coping and management strategies that could potentially be implemented into treatment plans to help improve the quality of life for individuals with uncertainty in chronic illness.

Conclusions

Chronic illness is an increasing concern in the United States (Fleming et al., 2015). With increasing individuals seeking treatment for chronic illnesses, strategies for care need to be altered to fit the needs of the chronically ill. There will not always be a test for a diagnosis or definitive answer. This study provided the detailed experiences of eight individuals with chronic illness and uncertainty. The participants hoped to share their stories to improve future patient care and outcomes. As more healthcare providers become aware of how individuals with chronic illness perceive their care, they may adopt new strategies to improve the process.

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Appendix A: Interview Guide

Thank you (participant's name) for your willingness to participate in my research study. My name is Amanda Brown and I am a doctoral student in the nursing public health program at Walden University. I will be interviewing you as part of my dissertation research. The interview should take approximately 30 minutes.

I will be audio recording the interview, are you agreeable to this?

As reviewed in the Informed Consent, you can opt out at any point, as your participation is voluntary. You can also choose to not answer questions if you are uncomfortable. By choosing to answer the questions, you will be assisting in research to further explore the lived experiences of those with chronic illness and the management of uncertainty. Your responses will be confidential.

For the purposes of this interview, it is important to understand what uncertainty is, and uncertainty and chronic illness. Uncertainty is when you are not sure. Uncertainty and chronic illness is when you are not sure, when symptoms will occur, what will trigger symptoms to occur, and what medications will help symptoms.

Interview Questions

Q1. Do you currently have a chronic illness? Yes/No if no, participant is not eligible for the study.

Q2. What chronic illness have you been diagnosed with? If no chronic illness has been, diagnosed participant is not eligible to continue the study.

Q3. Are you familiar with uncertainty as defined above? If so, can you tell me about your experience with uncertainty?

Q4. How does uncertainty impact your daily routine and activities of daily living?

Q5. How much of your time is spent thinking about uncertainty or how much time would you say is spent living in an uncertain state?

Q6. Tell me about your interaction with the healthcare team during your diagnosis, was there talk about experiencing uncertainty?

Q7. What is a typical day like for you? How would you say you manage uncertainty, any daily rituals that improve symptoms or help you manage?

Q8. What are some activities, daily rituals or habits, if any, that you find help manage your uncertainty, or help improve the chances that you will have a good day?

Q9. Do you have any additional information that you would like to share?

I appreciate you taking the time to complete this interview and your input will contribute to learning more about uncertainty and chronic illness.

Appendix B: Recruitment Flyer

INVITATION

TO PARTICIPATE IN A RESEARCH STUDY

QUALIFIED PARTICIPANTS MUST:

- ✓ Be 18 years or older
- ✓ Be diagnosed with a chronic illness
- ✓ Experience uncertainty, or inability to fully understand your diagnosis, symptoms or treatment
- ✓ Participate in a 30 to 40-minute interview

Benefits of the Study:

- ✓ The results of the study will be used to increase nurses' understanding of how to better support you in managing uncertainty in chronic illness.

QUALIFIED PARTICIPANTS CONTACT:
- ✓ Amanda Brown
- ✓ Call or text: (385) 200-1595
- ✓ Email: Amanda.Brown@waldenu.edu

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