2017

Narratives of Men Living with Systemic Lupus Erythematosus

Kimberly Vandermark Lynch
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Kimberly Vandermark Lynch

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Nina Nabors, Committee Chairperson, Psychology Faculty
Dr. Susana Verdinelli, Committee Member, Psychology Faculty
Dr. Yoly Zentella, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2017

Abstract

Narratives of Men Living with Systemic Lupus Erythematosus

by

Kimberly Ann Vandermark Lynch

MA, Walden University, 2009

BS, Sam Houston State University, 1997

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

May 2017

Abstract

While systemic lupus erythematosus (SLE) has been traditionally viewed as a woman's disease, SLE impacts men as well. Although most research on SLE has concentrated on how it affected women, little is known about how it impacts men. The purpose of this phenomenological study was to examine how men who live with SLE perceive its psychological impact. Using the lens of the biopsychological theory, common themes were examined pertaining to how men with SLE perceive the impact that SLE has on their cognitive and emotional functioning. Data were collected via interviews with 9 men with SLE, and the data were analyzed using thematic analysis to determine common themes. The following common themes emerged: reflections on life before SLE, changes in interpersonal relationships, changes in intimate relationships, changes in self-concept, and changes in perspective about living with lupus. These themes suggest that, in order to improve the quality of life for patients living with SLE, it is not enough to address the physical symptoms; it is necessary to address the cognitive and emotional impacts of the disease process as well. Implications for positive social change of this research study include providing a greater level of understanding of the psychological impact of SLE on men as a resource for professional therapists and psychologists who are trying to find information that would be beneficial for their male SLE clients. Additional potential implications for positive social change include providing information for families and caregivers of those men with SLE, and how the disease impacts them from a psychological standpoint.

Narratives of Men Living with Systemic Lupus Erythematosus

by

Kimberly Ann Vandermark Lynch

MA, Walden University, 2009

BS, Sam Houston State University, 1997

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

May 2017

Dedication

This dissertation is dedicated to my late father, David Lloyd Vandermark, with all of my love and respect. He valued education and was notorious for telling me that he "worked hard with his back so I could work smart with my head." He really hoped that someday I would receive my doctoral degree. I hope that I have made him proud.

Acknowledgments

I would like to take this opportunity to thank all of those who made this dissertation possible. Dr. Nina Nabors, my dissertation chair, without you, I could never have made it through this long and arduous process. Thank you for pushing me and keeping me on track. Dr. Verdinelli, thank you for your wisdom and insight. Your expertise in methodology was invaluable.

To my best friends, Lori and James, thank you for believing in my when I stopped believing in myself, even if it meant that you had to show me some tough love. I could not ask for two more loyal and amazing friends.

To my loving aunt, Gail Pannell, thank you for being my rock. No matter what I needed you have been there to provide it, whether it was to help with babysitting, to loan me money when things got tight, or to just make me a Mississippi Mud Cake. Thank you for loving me like no one else.

Lastly, to my children, Cheyenne, Kaitlynn, Rhiannon, and Ayden, I could not have finished this without your support. Cheyenne and Kaitlynn, you helped with extra chores at home, cooked, did grocery shopping, and helped keep an eye on the little two for me when work and school pulled me in a million directions. Rhiannon and Ayden, you had to sacrifice fun time and tolerate a grumpy mom who did not always have the time and energy to do all of the things that I would have liked to have done with you. You are all amazing, and I love you with my entire heart. I hope that I have taught you the importance of education and that you can achieve any goal with faith and persistence, even if it sometimes takes longer than you planned.

Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Systemic lupus erythematosus (SLE) is a broad spectrum autoimmune disorder that involves numerous organs and tissues and produces a plethora of symptoms and manifestations that complicate diagnosis of the disease (Hawro et al., 2011). SLE is characterized by intermittent periods of high activity followed by remissions. Approximately 2 million people in the United States suffer from the disease, although it is widely believed that this estimate is low (Calvo-Alen et al., 2005). Typically, the rate of diagnosis in women and men is 9:1 (Schwartzman-Morris & Putterman, 2012). The disease can strike at any age, but typically occurs between the ages of 15 to 40, which coincides with a woman's childbearing years (Williams et al., 2009).

Ethnicity may play a role in the development of SLE. SLE is 2 to 3 times more common in Latino, Asian, and Native American women than it is in Caucasian women (Giffords, 2003). While there is no specific gene linked with the development of SLE, genetic factors may influence the frequency of occurrence of SLE, as Asian ethnicities are more commonly affected (Ebert, Chapman, & Shoenfeld, 2005). African American women are 3 times more likely to develop SLE than Caucasian women, and also suffer from significantly higher cause-specific mortality rates when compared with Whites (Alarcon et al., 2005). How SLE manifests may differ depending on the ethnicity of the patient. Patients with the same ethnicity may experience different clinical manifestations depending upon geography (Borchers, Naguwa, Shoenfeld, & Gershwin, 2010).

While there are no specific known causes of the disease, there are certain factors that seem to influence the development of the disease. Researchers have hypothesized

that environmental factors may be either a cause or a trigger for developing SLE, although ultraviolet light and certain drugs are the only proven environmental triggers (Williams et al., 2009). There are several toxic substances that have been possibly linked to the development of SLE. Scholars have suggested that mercury, radiation, the presence of particulates, infectious agents, metals, and other chemical factors may play a role in the development of SLE (Cooper & Parks, 2004). Long-term exposure to harmful environmental contaminants has also been linked to the development of SLE. Prolonged exposure to petroleum dumpsites has been linked with a significant increase in the number of SLE cases diagnosed (Smith, 2007). Similar increases have been found in areas with long-standing exposure to toxic waste sites and industrial emissions (Kardestuncer & Frumkin, 1997).

While environmental health hazards can impact anyone, differential exposure places certain portions of the population at greater risk of developing disease. Ethnic minorities and those with a lower socioeconomic status (SES) are far more likely to reside in areas that have greater exposure to social and environmental factors that negatively impact health (Williams et al.,2009). These risks are not limited solely to the environmental contaminants, but also include factors like poor quality housing, as well as limited financial resources and access to facilities that address health-related problems associated with such exposures (Williams et al., 2009). Furthermore, in the event that the disease is diagnosed, ethnic minorities and those with a lower SES tend to have lower quality of life (QoL) once diagnosed (Aberer, 2010).

In this chapter, several key issues will be discussed. The background of the disease will be explored. The problem statement, purpose statement, research question, and the theoretical framework will be identified. The nature of the study, definitions of key terminology, the assumptions of the study, and the limitations of the study will be emphasized. The significance of the study will also be analyzed.

Background

SLE involves the central nervous system and presents both neurological features and neuropsychological symptoms (Emori et al., 2005). Understanding the psychological impact of SLE can be explored through a variety of conceptual frameworks. Engel's (1977) biopsychosocial approach asserted that disease processes are best understood when examined through a combination of biological, psychological, and social influences rather than in strictly physical or biological terms. Researchers often refer to this as the "mind-body connection" or mindfulness-based interventions (Krasner, 2004). Sperry (2006) advocated the use of the biopsychosocial approach in treating chronic conditions, such as SLE. This approach to treatment challenged health providers to go beyond simply addressing the physical needs of the patient, but to see the patient as a whole person, and to address the various secondary psychological and social complications that are typical in chronic diseases.

Research has shown that SLE does present psychological challenges (Emori et al., 2005). Cognitive dysfunction including symptoms like decreased attention, lower verbal memory, and psychomotor speed are complications of the disease process (Emori et al., 2005). However, psychological complications are not limited to a decrease in mental

acuity. Olazaran, Lopez-Longo, Cruz, Bittini, and Carreno (2009) emphasized the prevalence of cognitive complaints in women such as mood disturbances, anxiety, depressive symptoms, and headaches, much of which was directly correlated to psychological distress, psychological reactions, or other psychosocial factors. As psychosocial factors and patients' reactions to the disease process exacerbate cognitive complaints, treating the psychological factors can serve to improve the overall QoL for patients (Sperry, 2006). Existing research has also proven that psychosocial factors, such as perceptions about illness, and behavioral interventions are fundamental to the management of the disease process and the care of patients with SLE (Philip, Lindner, & Lederman, 2009).

Problem Statement

People have traditionally viewed SLE as a woman's disease. Results have been able to support some generalizations, as researchers have studied the physical, psychological, and interpersonal impact of the disease in women. However, men are also diagnosed, and little is known about how they are psychologically impacted by the disease process, as the research has been limited primarily to women. Despite that, researchers have found gender-specific differences in coping with other chronic diseases (Steck, Amsler, Kappos, & Bürgin, 2000), which will be discussed further in Chapter 2. Therefore, it is possible to hypothesize that would be gender differences in the way that men are psychologically impacted by SLE.

Purpose Statement

The purpose of this qualitative phenomenological research was to broaden the scope of knowledge pertaining to the psychological impact of SLE on men by identifying the shared living experiences of men living with SLE and to examine common themes pertaining to how men living with SLE perceive the impact of the disease on their cognitive and emotional functioning.

Research Question

What is the shared lived experience of men diagnosed with SLE?

Theoretical Framework

The theoretical framework for this research design was the biopsychosocial theory. A biopsychosocial perspective addresses the physical, psychological, and interpersonal impacts of the disease on the participants in the study (Engel, 1977). As in many chronic illnesses, the impact of the SLE is not limited to its physical impact on the patient. There are issues with cognitive and emotional functioning, QoL, as well as stress on marriage and interpersonal relationships. Sperry (2011) conducted a case study of a woman suffering from SLE using the biopsychological approach. He showed how implementing this approach with patients and their spouses could increase the individual's acceptance of the illness, change how they perceived the illness, reduce marital strife, and improve the patient's overall health and well-being (Sperry, 2011). I discuss this in greater detail in Chapter 2. The research question addressed shared lived experience of men diagnosed with SLE. This theoretical framework does not focus on just the physical aspect of the disease process, but the psychological and interpersonal

impacts of the disease on the participants' lived experiences. By using this theoretical framework when conducting the research, it was possible to fully explore the psychological impact of SLE on patients.

Nature of the Study

The lack of existing research on the psychological impact of SLE on men's experiences justified the qualitative approach to the research, as there were no measures to create the foundations of a credible or significant theory. In this study, research was conducted on a population of nine men who suffer from SLE. Data were analyzed from a phenomenological perspective. Following Moustakas (1994), the goal of analysis was to identify shared experiences or recurring themes that related to the impact of the disease on both cognitive and emotional functioning of the participants. More specific details of the analysis are presented in Chapter 3.

Definitions

Biopsychosocial theory: A biopsychosocial theory acknowledges that disease processes impact the entire person, not just their physical being. It addresses the physical, psychological, and interpersonal impacts of the disease on the participants in the study (Engel, 1977).

Phenomenological approach: The description of human experiences as perceived by each individual (Moustakas, 1994).

Systemic lupus erythematosus (SLE): SLE is a broad spectrum autoimmune disorder. It is a chronic disease, with cycles of relapse and remission, in which the body

attacks its own organs and tissues. The symptoms and manifestations are vast and varied and make it a very difficult disease to diagnosis and treat (Hawro et al., 2011).

Assumptions

The primary assumptions in this study came from both the nature of the information being studied, as well as the method in which the information was gathered. First, I assumed that the participants in the study would share their experiences in a sincere and authentic way. Second, it was assumed that I as the researcher would act only as a facilitator for the research, allowing the participants to share their experiences without influencing or skewing the outcomes of the research.

Scope and Delimitations

One limitation of the study was that the nature of the population being studied. As cognitive dysfunction and emotional difficulties can cause individuals to have preconceived notions about being judged, especially men who are historically more reluctant to seek out mental health care, participants in the study may have been predisposed to altering their responses to questions in a manner that would portray them in, what they may have deemed to be, a more favorable light. Geographic limitations may have also been a factor in this study. Due to time and financial constraints, it was not feasible to conduct face-to-face interviews with all of the participants in the study. As such, the majority of the participants had to be interviewed via phone. While phone interviews are common, in this particular type of research, it may be viewed as a limitation because it did not allow me as the interviewer to make observations about the nonverbal cues participants gave during their responses.

Another geographic limitation was that the majority of the participants were from one geographic region of the country, the South, with only one being from the Northeast and another being from the West Coast. Having been selected from primarily one geographic location, the findings might not be transferable to men who were diagnosed with SLE in other regions of the United States, or it might even limit the transferability of the information to those who live outside of the country. A final limitation was that the majority of the participants were heterosexual. Only one participant was gay. This might mean that the data could not be transferred to all gay men who had been diagnosed with SLE.

Significance of the Study

Addressing a Need in the Literature

The research that has been conducted on the psychological impact of SLE has been focused on women. Existing research has shown how the disease process impacts not only the physical being, but the psychological and interpersonal aspect of a patient's life as well (Philip et al., 2009; Sperry, 2011).However, this left a gap in the research pertaining to men. The gap is worth filling, as research gathered about women does not necessarily apply to men. By conducting this research, I hoped to determine how SLE impacts the psychological functioning of men, thus eliminating a gap in the current research.

Professional Application and Social Change Implications

The shared experiences that I have discussed as part of this phenomenological research provide a wealth of information for physicians, psychologists, and other mental

health care professionals. With a greater understanding of the cognitive and emotional impact that SLE has on men, there is a greater level of understanding for addressing the biopsychosocial needs of the patients, thus improving their QoL and the quality of their interpersonal relationships. In an effort to fill in the gaps in the existing research, I intend to publish the results of my dissertation in a professional journal.

Summary

In Chapter 1, I discussed the background of the study, the problem statement, and the purpose of the study, which was to examine the psychological impact of SLE on men. The research question, theoretical framework, and the nature of the study were also addressed. Technical terms and special words were defined and clarified. The assumptions, scope and delimitations, significance of the study, as well as the professional application and social change implications were also clarified. In Chapter 2, I describe the theoretical foundations for this study, as well as the existing literature pertaining to the psychological impact of SLE on patients. The literature search strategy and literature review related to key variables and/or concepts are discussed. Risk factors for SLE, the psychological impact of the disease, the effects on cognition, possible causes of cognitive dysfunction, and effects on emotion are also analyzed. Gender differences in SLE are highlighted. Issues with caring for SLE patients and the outlook for SLE patients are also explored. The methodology in prior research is examined, and the gender gaps in the research are identified.

Chapter 2: Literature Review

Introduction

This literature review addresses the most current and existing literature on SLE. Furthermore, it identifies the need to continue research as it pertains to the psychological impact of the disease. This review has indicated a gap in the literature regarding the psychological impact of SLE on men and addresses why bridging the gap is significant.

In trying to determine the psychological impact of SLE on men, there were several important factors that impacted the strategy, content, and organization of the literature review. The first significant factor was to define what SLE is. The second factor was to provide the operational definition, for the purpose of this research, of what was meant by *psychological impact*. As this is a term that could have vast connotations and perceptions, it was necessary to provide clarification. The last significant factor to consider was the gap in the research. The majority of the research that had been done on SLE had been concentrated on women. As such, there was not significant information from which to conduct a thorough literature review strictly on the psychological impact of SLE on men. Therefore, the literature that was reviewed pertained to how SLE has impacted women psychologically.

Having knowledge of these factors helped to provide an obvious structure for the literature review, which included the literature search strategy, the theoretical framework, the conceptual framework, and the literature review related to key variables and/or concepts. The literature review began with a definition and characteristics of SLE, as well as the risk factors for developing the disease. This was followed by operational

definitions of psychological impact, as well as in-depth explanations of the impact of the disease process on a woman's psychological well-being. The complications involved in caring for a patient with SLE and the outlook for a patient were also discussed. Ultimately, the gap in the research was identified, the justification for the research was given, and the method of the research was presented, which then led into Chapter 3.

Literature Search Strategy

The strategy for searching through the literature began with searching multiple databases simultaneously for *the psychological impact of lupus*. This proved to be too specific and did not yield the required results. By broadening the topic search to *lupus*, there was a plethora of articles on all aspects of the disease, often focusing on what the disease is or how patients with the disease could be treated. To narrow the search to better fit the desired research question, the topics *lupus* and *cognition* were searched simultaneously, which provided research that was more specifically aligned to the topic, as well as information that would help to identify several gaps in the existing research. Keywords that were used in the various searches included *lupus and cognition, lupus and family,* and *lupus and daily life*.

During the literature search, the following databases were used: Academic Search Complete; PsychInfo; PsychArticles; PsychExtra; Medline Fulltext; Psychology: A SAGE Full Text Collection; Psychiatry Online; and SAGE Fulltext. Additional resources valuable in obtaining relevant information in researching the particular topic include the following: The National Institute of Mental Health; American Heart Association; Center for Disease Control and Prevention; Substance Abuse Mental Health Services

Administration; National Institute of Drug Abuse; National Institute of Alcohol Abuse and Alcoholism; National Alliance on Mental Illness; International Society of Psychiatric Genetics; United States Department of Health and Human Services; and Mental Health Foundation.

Theoretical Framework

The theoretical framework for this research design was biopsychosocial theory. A biopsychosocial perspective addresses the physical, psychological, and interpersonal impacts of the disease on the participants in the study (Engel, 1977). SLE does not merely impact a patient's physical being. While treatment of the physical complications of the disease process is essential, treating the patient as a whole being becomes especially important as psychological and social functioning are impacted by the disease process as well. Sperry (2006) advocated the biopsychosocial approach for the treatment of SLE and other chronic illnesses. He believed that self-management of the disease could greatly improve the QoL of those suffering from SLE. Relaxation techniques like deep breathing, progressive muscle relaxation, mental imagery, and biofeedback were encouraged to counter the negative impact of stress, which is both a trigger for and a response to SLE (Sperry, 2006). Sperry (2011) conducted a case study of a woman suffering from SLE using the biopsychological approach. He showed how implementing this approach with patients and their spouses could increase the individual's acceptance of the illness, change how they perceived the illness, reduce marital strife, and improve the patient's overall health and well-being (Sperry, 2011).

It is not enough, however, to identify the need for a biopsychological approach. Methods of addressing these needs must also be identified. Researchers have advocated the use of cognitive behavioral therapy as a way to help counteract the negative psychological impact of SLE in patients (Sperry, 2006). Using cognitive behavioral therapy to change negative thought processes about the disease and about what living with the disease has to mean can greatly improve the QoL for SLE patients. There is a direct correlation between the way patients with chronic illnesses think about their disease and how they physically respond to the disease, especially in areas like mood, activity level, and overall energy (Sperry, 2006). By using cognitive behavioral therapy to train SLE patients to think more positively about their physical condition, there can be an overall improvement in perceived health and ability to function physically.

Counseling and therapy can also be beneficial in addressing the social and interpersonal complications that can arise as the result of living with a chronic disease. Chronic diseases can take a heavy emotional toll of relationships, as expectations and reality begin to change because of the physical and psychological complications of the disease process (Sperry, 2011). Couples and family therapy can be useful in helping individuals to express concerns and to reassess practical expectations so that each member of the relationship feels that their needs are being heard and met to the greatest extent possible (Sperry, 2011).

Literature Review Related to Key Variables and/or Concepts

SLE is a systemic immunologic collagen disease (Breitbach et al., 1998) characterized by its impact on numerous organs and body systems, as well as a vast array

of immunological abnormalities (Omdai et al., 2005). One of the most difficult aspects of SLE is that the manifestations of the disease can vary from patient to patient. In essence, the body begins to attack itself, slowly damaging or destroying certain parts of the body or bodily functions.

Symptoms can vary from somewhat mild to extremely severe, and they include fever, headaches, nausea, dizziness, skin lesions, lupus nephritis, rashes, weight loss, anemia, fatigue, inflammation of the joints and glands (arthritis), reduced ability to fight infection, ulcers, cardiac difficulties, kidney complications, and pulmonary risks (Peralta-Ramirez et al. 2006). Patients may also suffer from sensitivity to the sun, hair loss, and Reynaud's phenomenon, which manifests as purple fingers and toes when the patients experience cold or stress. The most common symptoms, regardless of how mildly or severely SLE affects a patient, are typically arthritis, Reynaud's phenomenon, extreme fatigue, and the characteristic butterfly rash across the nose and cheeks (Sperry, 2011). This vast array of symptoms, which mimic so many other ailments and disease, can make it extremely difficult to make a diagnosis of the disease. Historically, an accurate diagnosis could take between 5 to 7 years. However, due to technological advances, diagnosis can now be made within 1 to 3 years (Giffords, 2003). Due to the serious impact the disease has on the body, as well as the patient's cognitive and emotional well-being, it becomes imperative to diagnosis the disease early.

Risk Factors for SLE

There are no definitive causes for developing SLE. It is not a contagious disease that can be passed from one person to the next (Schwartzman-Morris & Putterman,

2012). Despite the lack of definitive causes, it has been determined that specific factors can influence the development and the nature of the disease including genetics, hormones, and certain environmental factors (Schwartzman-Morris & Putterman, 2012). Sperry (2011) estimated that 9 out of 10 people who are diagnosed with SLE are women, and that the risk seems to increase exponentially during childbearing years, despite the fact that onset can begin at any time in the life cycle. Culture is a second risk factor for developing SLE. Minorities seem to be more greatly impacted by the disease. African Americans, Asians, Native Americans, and Latinos are 2 to 3 times more likely to develop SLE than are Caucasian individuals (Giffords, 2003). While there is no specific gene linked to the development of SLE, support for the theory that genetics may contribute to the development of the disease exists as Asian ethnicities have a higher frequency of occurrence of SLE (Ebert et al., 2005). It has also been suggested that SLE may be prevalent within families, but it is speculated that this risk is very low (Sperry, 2011).

Certain environmental and life factors have been proposed as possible risk factors for developing SLE. Researchers have suggested toxins to be one trigger for the onset of the disease. Cigarette smoke, which exposes an individual to several hundred toxins simultaneously, has been linked to the development of SLE (Costenbader et al., 2004). Exposure to toxins is further validated as a trigger as the use of certain drugs has also been linked to the development of SLE (Sperry, 2011). Environmental factors like stress, sunlight, and viruses have also been linked to the development of SLE (Sperry, 2011).

Psychological Impact

Having established the definitions and characteristics of SLE, it was imperative to provide an operational definition of psychological impact for the purpose of this research study. While the connotations and perceptions of this term can be vast, for the purpose of this research it was two-fold. The psychological impact of SLE focused on the impact on the patient's cognitive abilities as well as their emotional well-being.

Effects on Cognition

Considering the extreme physical complications that manifest as a result of this disease, a factor that makes the disease even more complicated is the wide array of cognitive impairments that a patient can suffer as a result of SLE. The initial cognitive impairments can affect a wide variety of abilities with the SLE patient, including memory, simple and complex attention, problem solving, reasoning, visual-spatial processing, sequencing, organizing, planning, and visual-spatial relations (Sweet, Doninger, Zee, & Wagner, 2004). This can affect the SLE patient's ability to maintain life as they knew it prior to the onset or diagnosis of the disease. Such major life changes, in conjunction with the very nature of SLE; can lead to an emotional upheaval in the patient. They can begin to feel as if they are losing themselves both physically and mentally, which further contributes to the risk of mood swings and depression. If the effects of the cognitive dysfunction become too severe, the individual may be unable to work, or possibly not be able to function without the assistance of a family member or caregiver.

Further neuropsychiatric manifestations can begin to show as the disease process progresses in SLE patients and can affect anywhere from 14% to 75% of lupus patients (Peralta-Ramirez et al. 2006). These manifestations can begin with symptoms as mild as headaches, mood swings, and anxiety (Denburg & Denburg, 2003). However, these symptoms can become extremely frightening and severe. SLE patients can begin to develop cognitive complications including migraines, seizures, and cerebral strokes (Glanz, Schur, Lew, & Khoshbin, 2005). They can also suffer from movement disorders, states of confusion, and psychosis (Peralta-Ramirez et al. 2006). Some patients even suffer from such severe neuropsychiatric manifestations as delusions, hallucinations, and schizophrenia (Emori et al. 2005). In the most extreme cases of patients with SLE, very rare cognitive dysfunctions such as echolalia, a condition in which the patient can only repeat meaningless words that they hear yet produce no independent sounds, have manifested as a result of the disease process (Zapoor, Murphy, & Enzenauer, 2001).

Hawro et al. (2011) conducted research on patients with SLE in an effort to determine the prevalence of neuropsychiatric disorders in SLE patients. The study consisted of 52 patients suffering from SLE. Participants were examined by a psychiatrist, and the disorders were according to a Clock Drawing Test, a Mini-Mental State Examination, and American College of Radiology criteria for neuropsychiatric SLE (Hawro et al., 2011). According to the results of the study, mental disorders were present in 30.77% of the participants; depressive disorders were present in 11.54%; cognitive dysfunction was present in 9.62% of the participants; anxiety disorder was present in 7.69%; and one participant manifested symptoms of psychosis.

Yu, Lee, Wang, Yang, and Chang (2006) conducted a study to determine the manifestations of neuropsychiatric complications in pediatric patients with SLE. The study tracked 185 participants over a 20-year period. According to the results of the study, 34.6% patients had neuropsychiatric manifestations, while 21.8% occurred at SLE onset. The most common neuropsychiatric manifestations were seizure disorder (84.4%), ischemic stroke (28.1%), and psychosis (21.9%). The strength of the research was that it tracked a large number of pediatric SLE patients over an extended period of time, which allowed for more conclusive findings over time. The weakness of the study was that it was a retrospective study, which could mean that the neuropsychiatric manifestations could have been underestimated in hindsight (Yu et al., 2006).

Nayak, Bhogale, Patil, and Chate (2012) reported on three different cases where women with SLE did not merely have neuropsychiatric manifestations, but in fact presented manifestations of psychosis, which is far less common. In the first case report, the subject was an unmarried, middle class, 20-year-old woman from an urban area. She had presented symptoms of poor self-care, third person auditory hallucinations, intermittent crying, suspiciousness, delusions of persecution and reference, and flat affect. It was determined that the individual suffered from organic delusional disorder, a schizophrenia like condition, which was secondary to SLE (Nayak et al., 2012). In the second case, a 17-year-old, low-income rural patient, who had no family history of mental illness and who had been psychologically well adjusted prior to the onset of the disease process, presented with symptoms of muttering, crying spells, smiling to herself, outbursts of anger, decreased sleep, irrelevant speech, and reduced range of mood. It was

determined that she also suffered from organic delusional disorder. The third case report was that of a 35-year-old woman with no family history of major mental illness. She presented symptoms that included decreased sleep, fearfulness, delusion of persecution, delusion of reference, irritability, and absence of insight. Like the first two case reports, this individual was diagnosed with organic delusional disorder (Nayak et al., 2012). With these extreme and rare cases of psychosis, there were no predictive factors like age, family history, or SES to determine which individuals would develop psychosis as a result of the disease process.

Possible Causes of Cognitive Dysfunction

There has been no definitive cause for the vast array of neuropsychiatric cognitive dysfunctions. Only the immune-mediated thromboembolism, which leads to a percentage of the cerebral strokes, has been consistently linked to the development of neuropsychiatric cognitive dysfunctions (Omdai et al., 2005). Despite this, researchers continue to search for causes and links or associations that seem to be predominant in patients with SLE. These neurological complications can be independent psychological disorders, may result from the drugs used to treat the disease, or they can manifest as a result of the brain involvement of the disease process itself (Nayak et al., 2012). According to Sweet et al. (2004), SLE patients demonstrate both neurocognitive dysfunction, as well emotional symptoms, but the level of cognitive impairment varies greatly with respect to the abilities that are affected, the severity of the impact, and course that the dysfunction will take.

Olzaran et al. (2009) conducted a study on the prevalence and correlates of cognitive dysfunction in SLE. In the study, 31 SLE female patients and 31 healthy women (to be used as the control group) were recruited. The areas assessed included: attention, memory, language, reasoning, visuospatial processing, and psychomotor speed. In the SLE patients, all cognitive domains were similarly affected, although every SLE patient presented a different pattern of dysfunction (Olzaran et al., 2009). Cognitive complaints seemed to be most strongly related to depressive symptoms, rather to the actual cognitive impairment, which suggests that cognitive complaints were most likely psychological reactions or that they were influenced by psychosocial factors. The strength of the research was that it demonstrated that cognitive dysfunction is frequent in SLE, and that it negatively impacted social functioning. The weakness of this research was that it did not identify any new specific causes of cognitive dysfunction in SLE, but that it reaffirmed that cognitive dysfunction was likely influenced by a variety of factors including SLE related factors, psychosocial factors, and medications (Olzaran et al., 2009).

Emori et al. (2005) conducted a study in an effort to determine the neuropsychiatric causes of patients with SLE. This study consisted of 21 patients with SLE and 17 healthy control subjects. Participants were assessed in the following areas of cognitive functioning: verbal memory, non-verbal memory, verbal reasoning, non-verbal reasoning, frontal lobe function, psychomotor speed, attention, and mental flexibility (Emori et al., 2005). SLE patients were also assessed for the presence of antiphospholipid antibodies. The SLE participants displayed poorer performance on paired associate tests

of the Wechsler Memory Scale, as well as on immediate, delayed, and interference of the Rey verbal test. The results were even more evident in the participants that had major neuropsychiatric symptoms. Despite this, there was no correlation between the cognitive deficits and the presence of antiphospholipid antibodies or the absence of the antiphospholipid antibodies (Emori, et al, 2005). The results of the research suggest that both verbal memory and psychomotor speed may be the underlying cause the neuropsychiatric symptoms found in patients with SLE. The strength of the research was that it offered some underlying factors for the neuropsychiatric symptoms. However, the weakness of the research was that it did not offer the causes of the actual cognitive deficits themselves.

Glanz et al. (2005) conducted a study in an effort to ascertain whether or not cognitive dysfunction presents in a lateralized pattern. There were 51 right-handed patients with SLE that participated in the study, who were matched for education and age against 30 healthy right-handed patients. Participants were assessed for psychomotor speed, motor function, verbal reasoning skills, visual spatial skills, memory, and attention as part of a 3-hour neuropsychological assessment (Glanz et al., 2005). The results of the assessment showed that 50% of the patients that suffered from SLE suffered from cognitive impairment that presented a pattern of performance that was evident in individuals with left hemisphere brain dysfunction. Results could not be linked to vascular lesions, but instead suggest that there were immune-mediated impacts on certain areas of the brain in this particular subgroup of individuals suffering from SLE (Glanz et al., 2005). The strength of this research was that it showed that there seemed to be a

lateralized pattern in cognitive dysfunction in SLE patients. The weakness of the research, however, is that it did not specify exactly what the immune-mediated causes were that impacted the brain in SLE patients.

Although not a direct cause of cognitive dysfunction, daily stress can directly impact the cognitive dysfunction in SLE patients. The greater the level of stress that is inflicted upon, or endured by, the SLE patient, the greater their level of risk becomes as a result. According to a study conducted by Peralta-Ramirez et al. (2006), stress not only complicates the conditions for SLE patients, but can worsen the health conditions and cognitive abilities of those under the most extreme stress. In this quantitative study, there were 21 participants, 20 women and one man who had participated in a previous study on stress. The daily stress of the participants was evaluated every day over a 6-month period of time. This was followed by a neuropsychological exam that included an evaluation of attention and memory. Results indicated that daily stress over a 6-month period greatly impacted scores on the participants recall visual memory, visual fluency, and attention speed (Peralta-Ramirez et al., 2006). The strengths of this study were that it took precautions to rule out the impact of emotional variables like depression and anxiety on cognitive functioning. However, the limitation of this study is that there is only one male participant, and his participation was based on archival data; he did not actively take place in the actual research study.

Effects on Emotion

Unfortunately, cognitive dysfunction is not the only complication that individuals suffering with SLE must face. Psychological distress is very common in patients with

SLE (Moses, Wiggers, Nicholas, & Cockburn, 2005). Depression is one of the most common types of psychological distress that patients with SLE develop. It is estimated that between 15 and 60 percent of patients with SLE will develop some form of depression in the course of their disease process (Sperry, 2011). One's emotions about the disease or perceptions about the disease process also impact their overall emotional health. Individuals with less understanding of the disease and greater consequences linked to their disease were far more likely to develop depressive symptoms (Philip et al., 2009).

Zakeri et al. (2012) conducted a study to assess the prevalence of depression in SLE patient. Eighty-five participants were assessed based on gender, age, disease duration, severity of disease, and use and duration of steroid treatments. Participants were given Beck's depression inventory, and clinical data on was gathered from patient files on disease progress and treatment (Zakeri et al., 2012). Sixty percent of the participants scored high in areas indicating depression; 88.2% of the participants had symptoms of fatigue and weakness; 82.3% displayed irritability; 77.6% manifested indicators of sadness; 76.4% manifested somatic preoccupation; 34.1% had symptoms of weight loss; 28.2% had low energy levels; and 10.5% manifested suicide ideation (Zakeri et al., 2012). The results of the study emphasized that the severity of depression increased significantly with the severity of the disease.

Carr et al. (2011) conducted a study to examine the relationship between psychological functioning and the disease activity in patients with SLE. 125 adult Hispanic and White participants were assessed based on sociodemographic information,

disease activity, and psychological functioning (Carr et al., 2011). According to the results of the study, depression was the only factor that predicted self-reported disease activity. The results of the study suggest that depression may prove to be an essential determinant in the health state of patients with SLE (Carr et al., 2011).

Depression in patients with chronic illnesses like SLE has also been linked increased morbidity (Moussavi et al., 2007). Schattner, Shahar, Lerman, and Shakra (2010) conducted a quantitative longitudinal study of 30 women suffering from SLE in an effort to differentiate between the broadly illness-related and personality-related aspects of SLE depression. What was discovered was that depression led to individuals trying to conceal symptoms of SLE, which in turn led to increase changes in illness intrusiveness (Schattner et al., 2010). In essence, it was the concealment and illness intrusiveness, not the actual physical symptoms, which had the higher correlation with morbidity in patients with SLE. These findings of this study illustrate the significance of the psychological impact of SLE on women. However, it did not address the psychological impact of SLE on men.

Gender Differences in the Impact of SLE

While gender differences have not been explored in reference to the psychological impact of SLE on men, gender differences have been explored in reference to how both men and women cope with other chronic illnesses. Gender differences in ineffective coping strategies have shown to negatively affect QoL for patients suffering from Parkinson's disease. There were 153 participants in the study, 79 were male and 74 were female (Dubayova et al., 2009). Multiple regression analysis were conducted to

determine whether it was the disease or the coping style that impacted factors including mobility, cognition, communication, stigma, social support, emotional well-being, activities of daily living and body discomfort. Personality traits appear as determinants of QoL in all areas except mobility, activities of daily living, and body discomfort (Dubayova et al., 2009). While poor coping styles can negatively impact emotional well-being in both men and women, it was statistically significant in men, in the areas of stigma, cognition, and communication only in men. The gender differences suggest that male and female patients suffering from chronic illnesses may require different types of coping strategies (Dubayova et al., 2009).

Gender differences have been discovered in the way that men and women cope with chronic somatic disease like Multiple Sclerosis (Steck et al., 2000). In this study, 48 participants and their spouses participated. The purpose of this particular study was to determine if variables such as gender, associated depression, or the level of disability impacted how the patient or their partner was able to cope (Steck et al., 2000). According to the results, a woman's ability to cope is directly correlated with her degree of physical impairment. However, physical impairment is not a significant factor in a man's coping index. A man's coping index was lowest in the dialogue dimension, which accounts for communication on a cognitive level, pertaining specifically to verbal expression, and an emotional level, which includes nonverbal expression (Steck et al., 2000). It was hypothesized in the research that this could reflect a gender pattern in which women are more communicative and men are more inclined to withdraw from sharing emotions and feelings. If this gender pattern is consistent, regardless of the type of chronic illness, it

can be hypothesized than men with SLE will cope differently both cognitively and emotionally than women. Furthermore, if the psychological impact of SLE on men is analyzed from a biopsychosocial perspective, whereby the cognitive, emotional, and interpersonal impacts of the disease process are as significant, if not more so, than just the physical impact of the disease, it can be hypothesized that men with SLE may face a greater struggle with the disease process than women.

Caring for SLE Patients

Caring for SLE patients can be an extremely difficult task for the caregiver and the physician. Care-givers and physicians must not only treat the physical symptoms of the disease, which can be a big adjustment physically and financially, but they must find ways to help the SLE patient cope with the loss of cognitive function that they experience as a result of the disease process. Patients can become unable to handle routine tasks such as paying bills, remember to turn off the stove, or even to close and lock the front door behind them. This creates external risks to the safety and well-being of the patient as a result of the cognitive dysfunction (Glanz et al., 2005).

As a result of the cognitive dysfunction, patients can become extremely emotional and difficult to handle. They may become depressed. SLE patients may also forget things as a result of the state of confusion that some patients experience (Glanz et al., 2005). They may forget people's names, places, their own identity, or may be prone to getting lost while driving. SLE patients may have a change in personality as a result of a cerebral stroke, which can contribute to stress within the household, further complicating the conditions mentally and physically for the SLE patient. They may no longer enjoy things

they once enjoyed, they may become hostile and aggressive, or they may lack a desire for physical intimacy and sexuality.

All of these factors place an enormous burden on family members and caregivers. They must make tremendous adjustments to their lifestyles in order to ensure that the SLE patient gets the best possible care. This may not always be easy, especially if the patient is in denial as to the level of care that they require. In many cases, it takes more than one care-giver or family member to guarantee that the SLE patient is safe and cared for at all times. In cases where cognitive dysfunction becomes extreme, like in the development of schizophrenia, decisions become even more difficult for care-givers. They must determine whether or not the patient can remain in the home and be safe, or if they need supervised care.

Due to the nature of caring for a patient with a chronic illness, social support is often something that is not given a real priority, although it is something that should be a priority when caring for a patient with SLE (Sperry, 2011). Studies have shown that social support from the family alone is typically not enough (Moses et al., 2005). Family relationships go through so much of a strain that outside social support is very significant. Unfortunately, relationships can take such a strain when caring for a patient with SLE that separations or divorce can result (Sperry, 2011).

Sperry (2011) conducted a case study using the biopsychological approach which illustrated how the disease process could drastically impact interpersonal harmony, personal expectations, and life satisfaction within a marriage due to the physical and psychological impact of the disease process. In the case study, a woman with SLE and

her husband sought couples' counseling for relationship problems that had coincided with the woman's being diagnosed with SLE. The couples' relationship problems, which had only been occasional ones previously, had significantly increased. The patient's health had required, per her doctor's instructions, that she give up her job. She was also no longer able to perform many of the household chores and activities that she had previously done. She was relegated to cooking meals and very light cleaning (Sperry, 2011). The patient was struggling with fully accepting the chronic nature of her illness, and she kept anticipating "getting better" on days when her symptoms were not as severe. The patient's husband had a better grip on accepting her diagnosis, but he did not grasp the practicality of what the diagnosis meant in relative terms to daily life. He expected his wife to be able to do many of the things for him that she had always done (Sperry, 2011). Both the patient and her spouse had given up their dreams and plans for having a family, and all of the factors had left them both feeling disempowered.

Through the use of both individual and couples' counseling sessions, the therapist was able to facilitate the couples' understanding of the chronic, progressive nature of SLE (Sperry, 2011). In addition, the couple was able to gain a better understanding of their interpersonal dynamics within the relationship, and how SLE was impacting their marriage. Lastly, the counselor was able to facilitate a change in the couple's relationship patterns and interpersonal dynamics in light of the chronic illness that they had to face together (Sperry, 2011).

The result of the study was that SLE not only impacted how the individual functioned, but how the couple functioned as well, and that it magnified existing personal

and relational dynamics. The strength of this study is it provided an in-depth look at the negative impact of the disease process on a specific marriage. The weaknesses of the study were that it only provided information on the experience of one couple and it focused on a patient that was a woman. There was no information provided on whether or not the results would be the same if the patient had been a man.

Outlook for SLE Patients

At the present time, there is no known cure for SLE. Life expectancy for the SLE patient is contingent on a variety of factors, including: severity of the disease, access to medical treatment, physical and emotional support, stress, and psychosocial factors (Breitbach et al., 1998). Thus, life expectancy varies from patient to patient, between 10 years to a normal life span. Treatment options are available for the care of SLE patients, in an effort to improve the overall QoL between periods of remission and relapse. Immunosuppressive therapies and the use of corticosteroid therapies have been long-term methods of treatment for patients with SLE (Emori et al. 2005). Intravenous infusions of Iloprost therapy have been successful for some patients in the improvement of cognitive function through creating a sustained cerebral blood-flow (Matthieu et al., 2002).

Methodology in Prior Research

Having reviewed the existing literature, it became necessary to choose a methodology for this particular research. The prior research conducted on SLE has focused on both quantitative studies and qualitative studies. Quantitative studies have been conducted on diagnostic tools. Adhikari, Piatti, and Luggen (2011) conducted a quantitative study to evaluate the Montreal Cognitive Assessment (MoCA) test as a

screening tool for detection of cognitive distortions in SLE. Studies have also been conducted on life stress and coping styles and the impact that these factors have on cognitive dysfunction in SLE (Kozora, Ellison, & West, 2009). Qualitative studies have been conducted on a variety of SLE topics as well. Feldman et al (2013) conducted a qualitative study aimed at designing interventions for patients with SLE in medically underserved areas. In this study, 29 women with SLE, 83% of whom were from medically underserved zip codes, participated in three focus groups that explored topics from healthcare barriers to isolation that was felt at the time of diagnosis. The majority of the participants favored peer support groups as a method of improving their quality of care. Qualitative studies have also been conducted to examine patients' perspectives on their QoL in living with SLE through the use of semi-structured interviews (McElhone, Abbott, Gray, Williams, & Teh, 2010). There does not seem to be a preponderance of evidence that there is a gap in either type of methodology in the prior research. However, as the focus of this research was on exploring the shared lived experiences of men who suffer from SLE, the research design required providing participants the opportunity to provide varied and in-depth descriptions of their day to day lived experiences with the disease, and to clarify their perspectives of these experiences. As answers were more varied and subjective, a qualitative approach was a more appropriate methodology for this particular study.

Gender Gap in the Research

One of the significant gaps in the research was that the majority of research that has been conducted on the psychological impact of SLE has been on women. Efforts to

identify a more readily available and less time consuming screening tool for cognitive dysfunction in SLE were part of a quantitative study conducted by Adhikari et al. (2011), which was funded by the Lupus Foundation of America. Of the 44 participants, the gender was primarily female. When examining the impact of life stress and coping styles and how the two factors related to cognition for patients with SLE, Kozora et al. (2009) created a quantitative study using 56 SLE patients (31 with overt neuropsychiatric symptoms and 22 that did not display those symptoms). Only three of the SLE participants in the study were men, one in the first category and two in the second (Kozora et al., 2009). In a 2011 study that examined the correlation between cognitive dysfunction and cognitive complaints in patients with SLE, not one of the 57 participants in this quantitative study were male (Vogel, Bhattachary, Larsen, & Jacobsen, 2011).

While the majority of those who suffer from SLE are female, research cannot be based solely upon women. Gender has been shown to be a significant factor in the physical aspects of SLE. Schwartzman-Morris and Putterman (2012) explored gender difference in the physical impact of SLE on patients using various archival data. Gender differences in SLE were explored in various sub-categories: in disease manifestations; in disease manifestations with a focus on renal disease; by geographic region; in pediatric lupus; and in pathogenesis. After comparing and contrasting archival data from these various sub-categories, it was determined that strong gender differences did exist when it came to the physical impact of SLE. What was determined as a result of the retrospective analysis of the data was that men are more severely impacted by the disease, regardless of age. This includes how rapidly the disease progresses, access to and effectiveness of

treatment, the severity of damage to internal organs, and morbidity related to organ failure (Schwartzman-Morris & Putterman, 2012).

However, while men have been included in the physical exploration of the disease process, they have largely been ignored or included in a very limited scope when it comes to the psychological aspect of the disease process Gender has been known to impact how individuals respond to a variety of psychological factors. In musculoskeletal disorders, gender differences have been identified in the way that men and women report pain, as well as the ability to predict mortality based on self-reported information (Khang & Kim, 2010). Gender has also been shown to be a factor in rates of chronic illnesses, the frequency with which these illnesses are reported, and the amount of social support those suffering from chronic illnesses receive (Green, Freeborn, & Polen, 2001).

To leave the psychological impact of SLE on one gender unexplored is to do a disservice to men who suffer from the disease, and it creates a significant gap in the research. Disparities between the genders have already been identified in research that targeted the physical impact of the disease. Therefore, it is logical to hypothesize that disparities between the genders may also exist when it comes to the psychological impact of SLE. Gender differences have also been identified as it pertains to treatment effectiveness and availability when treating the physical aspects of SLE (Schwartzman-Morris & Putterman, 2012). As such, it is possible that there would be gender disparities in the effectiveness of psychological and social interventions as they pertained to the participants lived experiences with SLE. Conducting research on the psychological impact of SLE on men is the only way to bridge the gap in the existing research.

Therefore, it was necessary to conduct a qualitative study on the psychological impact of SLE on men. Possible themes that would have emerged were the impact on the disease on cognitive functioning, emotional functioning, interpersonal relationships, and self-efficacy.

Summary

Chapter 2 described the theoretical foundations for this study, as well as the existing literature pertaining to the psychological impact of SLE on patients. The literature search strategy and literature review related to key variables and/or concepts was discussed. Risk factors for SLE, the psychological impact of the disease, the effects on cognition, possible causes of cognitive dysfunction, and effects on emotion were also analyzed. Gender differences in SLE were highlighted. The methodology in prior research was examined, and the gender gaps in the research were identified. Chapter 3 discusses the research design and rationale, the role of the researcher, methodology, and issues of trustworthiness.

Chapter 3: Research Method

Introduction

Chapters 1 and 2 included a specific analysis of the psychological impact of SLE, as well as the existing research on the psychological impact of SLE. However, as SLE is less frequent in men, researchers have focused their efforts on women. There has been no research that has focused on the psychological impact of the disease on men. The purpose of this qualitative phenomenological research was to broaden the scope of knowledge pertaining to the psychological impact of SLE on men by identifying the shared living experiences of men living with SLE and to examine common themes pertaining to the impact of the disease on the cognitive and emotional functioning of the participants. In Chapter 3, I discuss the methodology I used to analyze the psychological impact of SLE on men. As part of the discussion, I provide the research design and rationale, the role of the researcher, the methodology, and address issues of trustworthiness.

Research Design and Rationale

In conducting this research, I set forth to answer the following question:

What are the shared lived experiences of men diagnosed with SLE?

In an effort to answer the research question, there were several interview questions, including:

1. What was your QoL like before being diagnosed with SLE?
2. What were your thoughts, if any, about SLE prior to your diagnosis?
3. Tell me about your experiences living with SLE.
4. How do you live your daily life with SLE?

5. What changes did you notice in yourself since you were diagnosed with SLE?
6. What changes did you notice in your intimate relationship since your diagnosis?
7. How has SLE impacted your interpersonal relationships since your diagnosis?
8. How has SLE impacted your concept of whom you are as a man?

Justification for Qualitative Approach

The purpose of qualitative research is to provide an in-depth, detailed understanding of a given topic (Creswell, 2007). Qualitative research often answers the how and why of a given topic. However, it is due to the lack of existing research that a qualitative study was necessary for this project. Without existing research, it would be virtually impossible to establish research questions and measures that would create the foundations of a significant theory. As such, the use of a quantitative approach was not appropriate because a specific theory has not been proposed or tested, no experiment was conducted, and the establishment of patterns was not the primary focus of the research (Creswell et al., 2007). However, by conducting qualitative research on this subject, there will be a substantial basis for generating future theory, specifically those linked with gender-based comparisons.

Perhaps the most significant justification for implementing a phenomenological qualitative approach, as opposed to a quantitative approach, was what can be learned from shared experiences. It was the shared experiences of the participants that were so important in this particular research. It was not enough to have simple quantitative responses to questions, but it was observation of the individual that helped to fully

understand the meaning that was conveyed by the individual participants. Moustakas (1994) emphasized how much observation can add to the fullness of the responses, rather than relying just on written responses or text.

Philosophical Viewpoint

I examined the psychological impact of SLE on men from a postpositivist viewpoint (Creswell, 2007). The goal of my research was to create a valid, reliable, and objective description of the psychological impact of SLE on men. As such, focusing on a scientific approach to qualitative research, where the researcher systematically proceeds through a series of logically related steps, as is the nature of the postpositivist approach, was the most logical choice for my philosophical viewpoint.

Qualitative Tradition

The conceptual framework for this research design was a phenomenological study to determine the shared psychological experiences of men who suffer from SLE. I approached data analysis from a phenomenological perspective. Phenomenology was used in an effort to gain a better understanding of a shared experience of a given population. This type of qualitative study typically requires between five and 25 participants, and data are typically collected through interviews (Moustakas, 1994).

Other qualitative approaches considered for this project included case study and narrative analysis. A case study, while able to detail an individual's experience or even shared experiences of a small group like the phenomenological approach, was not the most appropriate choice for this research, as a case study is a type of qualitative research in which one or more individuals within a bound system is studied in-depth over an

extended period of time (Creswell, 2007). For example, a case study could follow a participant from the point at or closely following diagnosis, and then follow up with the participant at regular intervals over an extended period of time in an order to track and detail the changes that the participant had experienced, if any. Time constraints and expense made this type of study prohibitive for this particular research project.

Narrative research occurs when a researcher gathers and analyzes the information about the participants and then presents it in a narrative format (Creswell, 2007). The number of participants in this type of study is typically very small, or could even be a single individual. This type of research is used much like a biography, in an effort to convey the person or the group's particular life experiences. This type of research tends to be more informal and less structured. However, as I wanted to focus on the specific shared experiences of the participants in a manner in which the participants' voices where heard, a phenomenological study was the best option.

Role of the Researcher

In phenomenological research, the purpose of the research was to understand the subjective experiences of the participants (Van der Zalm & Bergum, 2000). However, the role of the researcher was to remain objective in the gathering and analysis of the data. This was best accomplished through bracketing (Dowling, 2004). Bracketing, which was originally a mathematical principle, is one of the primary concepts of Husserlian phenomenology. Within this method of phenomenology, the preconceived notions held by the researcher must be set aside, or bracketed, to ensure researchers do not allow their

personal expectations to influence the data collection or to shape their comprehension or analysis of the data (Polit & Beck, 2008).

Having personally known and had close interpersonal relationships with men who have suffered from SLE, it was imperative that I analyzed my own potential biases prior to conducting the research. For example, it would not be appropriate to anticipate the experiences and responses of the participants based on my prior knowledge of those who have experienced this disease. However, as accurately increasing the knowledge base about this particular topic is so significant to me, it was easy to set aside, or bracket, my previous experience in order to maintain objectivity during the research.

Methodology

Participant Selection Logic

Due to the decreased percentages of men who are diagnosed with SLE in comparison to women, the population was difficult to access. A qualitative study typically requires between five and 25 participants (Moustakas, 1994). There are a variety of factors that can influence sample size, but the most significant in qualitative research using interviews is saturation (Mason, 2010). The more limited the population sample is, the easier it is to reach saturation. The goal of the research project was to identify a sample of between seven and 10 men who suffer from SLE. I contacted online support groups in an effort to find participants. I posted flyers (Appendix A), as well as invited participants through support group leaders. I then solicited participation in the research study via letters, phone calls, and e-mails. Interviews took place via phone, due to the fact that participants in the study were located in many parts of the country. Participants were

interviewed once, and each interview took less than 2 hours. All interviews were recorded for transcription, analysis, and documentation. Participants received a $25 Visa gift card for participating in the survey. The only specifications for participation were gender and illness. Participants also filled out a demographic questionnaire (Appendix C). Race, national origin, culture, and religion did not impact the selection of participants in this particular research study.

Sampling and Data Collection

The research question guided the phenomenological research. Research that was collected focused on open-ended interviews with the research participants. The purpose of the interviews was to understand the psychological impact of SLE on men. Open-ended questions, followed by more in-depth, probing questions were used to encourage the participants to disclose their individual experience with the disease process (Creswell et al., 2007). By allowing flexibility in the questioning process, beginning with broad questions pertaining to the essential research question then narrowing to more probing questions based upon the individual responses, it was possible to gain more adequate details pertaining to each of the individual's experiences (Rubin & Rubin, 2005).

Data Analysis

The research was analyzed from a phenomenological perspective in the hopes of identifying patterns in the shared lived experience among participants. Data were transcribed using qualitative software Dragon Speak. This program provides auto transcription of the recorded interviews. Once this step of the data analysis was completed, transcripts were reviewed to identify emerging themes in the lived

experiences of participants (Hycner, 1985). In the last stage of analysis, themes were clustered according to specific concept similarities in an effort to find patterns. Any discrepant cases discovered during the analysis were described and analyzed separately, so as not to skew the data.

Issues of Trustworthiness

Trustworthiness was ensured through thick description, member checking, and an audit trail. Thick description is a process whereby the research information that is gathered, as well as the method by which it was gathered, is presented in such sufficient detail that not only are the results believable and dependable, it is possible for other researchers to ascertain the transferability of the study's results to other specific contexts. Member checking was done throughout the interview and analysis process. During the interview, I periodically summarized the information, and then I questioned the participant to determine accuracy. During the analysis, if questions arose, the research had been designed in a way that a follow-up interview could be conducted, and the participants could clarify information for accuracy and validity in the interpretation of responses. In addition, I had my dissertation chair peer review my findings to verify the validity of the results (LeCompte & Schensul, 1999). This was accomplished by paying great attention to the accuracy of my methodology, so that my research can be retested and verified for reliability and validity. Furthermore, I used members of my dissertation committee to ensure the veracity of my transcripts. Lastly, an audit trail will be available as my raw data, notes, and recordings will be kept for at least 5 years so that my research can be retested and verified.

Ensuring Data Quality

In an effort to guarantee quality and verification of my findings, I obtained informed consent. This ensured that I did not commit any ethical or legal violations (American Psychological Association, 2002). In addition, everything that I asked and reported hinged on my ability to accurately interpret and report the information that the participant had shared with me. I took great care with my transcription and coding. Transcription was a process in which I detailed the results of the interviews and responses word for word as relayed to me during the research process. Then I implemented qualitative data analysis software to code the results. It was then necessary to go through the information to verify that it had been transcribed and coded correctly, making sure to correct any misrepresentations. I also used specific quotes garnered from the participants' responses to questions to emphasize specific points and to make certain that the appropriate point of view were reflected (LeCompte & Schensul, 1999).

Ethical Procedures

Confidentiality and informed consent were two ethical considerations that had to be made when using human research participants. Confidentiality is a significant part of the therapeutic alliance as well as the research process. It is one of the fundamental reasons that clients or participants feel safe in divulging personal, and often painful, information with a therapist or researcher. According to the American Psychological Association (2002), researchers are obligated to take the necessary precautions to ensure that confidential information that is obtained from participants is protected, as well as

being stored in a secure location, acknowledging that there are limits to confidentiality that are controlled by the law.

Maintaining the confidentiality of the raw data was also imperative. Data were stored on paper, audio/visual recordings, and electronic media. Paper responses were stored in a locked and secured filing system in my personal office. Audio/visual recordings were stored there as well. All other files/data were stored on my laptop and jump drive. The jump drive, files, and audio/visual data were kept in a locked and secure location. Information on the laptop will be protected by multiple passwords. After 5 years, all paper documents will be thoroughly shredded before disposal. Audio/visual and electronic storage devices will be erased.

For legal and ethical reasons, informed consent is always a significant factor in research with human participants, and it should be obtained before the interviewing and observational process begins (American Psychological Association, 2002). Participants were required to sign a consent document prior to participating in the study. In order to give informed consent, the client must be at least 18 years of age, and they must also have the mental capacity to give informed consent. This would have been a concern for participants if their psychological functioning had been impacted.

In addition to the issues of privacy and informed consent, two other ethical considerations had to be taken into account. One ethical consideration was the amounts of psychological stress that participating in the research study could involve. It was a possibility that discussing thoughts and emotions related to the psychological impact of SLE could have been a sensitive topic for the participant, or that it could have brought

about unexpected psychological or emotional responses. The second ethical consideration was the disclosure of personal information that was irrelevant to the study. It was possible that the participant could reference one of these topics or disclose such information in the process of answering interview questions. While there was minimal risk to the participants' psychological well-being if the discussion of this topic proved to be an unexpectedly emotional experience, it was necessary to be aware of the issue so that a list of local free counseling resources could be provided to the participants in the event that psychological intervention was warranted.

Summary

In this chapter, I described the research design and rationale, the role of the researcher, and the method by which the data would be collected. First, data were collected using qualitative methodology, whereby research participants answered open-ended questions. Next, a justification for the choice of the methodology was provided. Then, I examined the qualitative tradition that informed my analysis. As the goal of the research was to examine the shared lived experiences of men with SLE, using phenomenological research was the most appropriate choice. Finally, I explained the strategies I used to address issues of trustworthiness. In Chapter 4 I discuss the setting of the research, demographics, data collection, data analysis, evidence of trustworthiness, and the results of the study.

Chapter 4: Results

Introduction

This phenomenological study presents the shared lived experiences of men with SLE and the psychological impact that the disease has had on their lives. This particular type of research allows for individuals to reveal their unique life experiences in an effort to provide clarity about a topic that has been unknown, minimized, or somewhat misunderstood. Directly quoting participants' responses has given the participants the chance to speak for themselves and to share their perspectives about how living with SLE has impacted and shaped their lives.

This chapter reveals the results and findings that were the result of nine in-depth interviews with men who had been diagnosed with SLE. The men who took part in this study represented diverse ethnicities, backgrounds, ages, sexual orientations, and life situations. The men reacted differently to living with SLE. While all participants were eager to improve the amount of information available on what it is like to live as a man with lupus, they shared their experiences with varying levels of openness and enthusiasm.

The primary research question was the following: What is the shared lived experience of men diagnosed with SLE?

The goal was to determine the shared lived experiences of men suffering from this particular disease and to try to uncover common themes in their experiences. The following interview questions guided the research study and allowed for open-ended responses from the participants, in an effort to allow them to share their experiences in their own ways:

1. What was your QoL like before being diagnosed with SLE?
2. What were your thoughts, if any, about SLE prior to your diagnosis?
3. Tell me about your experiences living with SLE.
4. How do you live your daily life with SLE?
5. What changes did you notice in yourself since you were diagnosed with SLE?
6. What changes did you notice in your intimate relationship since your diagnosis?
7. How has SLE impacted your interpersonal relationships since your diagnosis?
8. How has SLE impacted your concept of who you are as a man?

Demographic information such as age, sexual orientation, and relationship status was also collected. Those who participated in the research expressed being eager to take part in the study in order to provide information for men who would be diagnosed with SLE in the future.

Sample Setting

All of the participants had been diagnosed with SLE, which was their motivation for sharing their lived experiences. Some of the participants shared that they had been unable to find information about men living with SLE, and they wanted to change that for other men who were diagnosed. Others were encouraged to participate by members of their local support group who had already agreed to participate in the study.

Data Collection

In March of 2015, I began contacting lupus organizations in a large Southern state by phone and by e-mail in an effort to obtain permission to post recruitment flyers. Many

of the organizations did not respond to the voicemails or the e-mails. One leading lupus organization in a major metropolitan area in this state informed me that they would consider sharing the recruitment flyer, but that it first had to be approved by the national organization, the Lupus Foundation for America. As such, I contacted the Lupus Foundation for America by e-mail and inquired about how to get the study approved. I had to submit the Investigator Initiated Studies Posting Request along with study details and a signed copy of the IRB approval on institutional letterhead and wait for approval for the study to be posted to the national organization's website for recruitment.

While waiting for approval, I continued to contact other organizations around the country by phone and by e-mail, although most organizations provided a series of phone numbers that led to hours and hours of unreturned phone calls. I was able to reach a support group in an upper East Coast state who was willing to help. The organization allowed me to send the recruitment flyer so that members of the group could determine if they were interested in participating. Three men responded to the flyer. Of the three, two returned the informed consent documentation that I e-mailed and scheduled times to be interviewed. Of the two, however, only one completed the interview, Participant A, and he became the first participant in the study.

After receiving notification that the Lupus Organization for America had approved the study and posted the flyer on the national website, I contacted the organization who had originally refused my request. The organization then allowed me to bring flyers to post, and several of their smaller chapters posted the flyers as well.

Despite attending several functions and networking, the efforts proved futile. No participants were gained from this particular endeavor.

Upon becoming increasingly frustrated at the process, I was talking to an administrative assistant at my job about how increasingly frustrating the research process had become while trying to recruit participants. The administrative assistant informed me that she knew of an individual who had lupus and told me that she would inquire as to whether or not she could share his contact information. The individual agreed, and I contacted him. He became the second participant in the study, identified as Participant B.

I continued to call and e-mail support groups, rheumatologists, therapists, and hospitals in an effort to find places to recruit. Ultimately, a support group that had been reluctant upon initial contact agreed to assist in the process. This was the turning point in the research. The first person to respond was Participant C. Participant C was excited that someone was taking an interest in what it was like for men to live with lupus, as he had found it very difficult to find information about men with lupus upon receiving his diagnosis. Participant C was the catalyst for getting the other members of his local group to participate, as well as two men who he knew from other part of the country. Approximately 12 men, including Participant C, responded to the recruitment flyer. Out of 12, nine returned the informed consent. Out of nine, seven completed the interviews and became the remaining participants in the research study.

Each of the participants was interviewed by phone. I asked basic demographic information such as their age at diagnosis, their current age, and ethnicity. Although it was not a question that was specifically asked in the research, due to the nature of the

questions, participants also identified their sexual orientation. Participants then answered the specific interview questions, with varying levels of depth. Several participants gave extremely detailed and highly personal accounts about their experiences living with lupus. A few other participants responded thoroughly, yet they were somewhat more guarded about being vulnerable with me as the researcher. All of the participants, regardless of how they felt about sharing their personal information with a complete stranger, were adamant that the nature of the research was extremely important for others who might end up with the same diagnosis, so they willingly offered the information that they could share so that others might learn from their experiences.

Participant Profiles

The nine people interviewed each identified as being men who had been diagnosed with SLE. Participant demographics are summarized in Table 1.

Table 1

Participants

Participant	Ethnicity	Age	Sexual Orientation	Relationship Status	Age at Diagnosis
A	Caucasian	47	Homosexual	Committed Relationship	43
B	African American	34	Heterosexual	Married	27
C	African American	42	Heterosexual	Single	16
D	African American	38	Heterosexual	Single	37
E	African American	54	Heterosexual	Married	20
F	Caucasian	62	Heterosexual	Single	45
G	Caucasian	30	Heterosexual	Single	22
H	African American	60	Heterosexual	Married	59
I	Hispanic	32	Heterosexual	Single	17

Data Analysis Procedures

The interviews were recorded on a voice recorder. Each interview was then transcribed verbatim into a Word document. Any information that would identify the participant was removed and the documents were saved according to the participants' identifying alphabetical labels. The computer where the information is stored is password protected. If the information were to ever be accessed, the only information that could be gathered would be basic demographic information pertaining to location, age, ethnicity, sexual orientation, and current relationship status. All written and printed information

pertaining to the interviews were placed in a file and locked in a secure file cabinet in my home. All of the information will be stored for 5 years, at which time it will all be destroyed. The video recordings will be deleted, as will the electronic files stored on my computer.

The transcription process was arduous. I had to listen to each interview numerous times to ensure the accuracy of the transcription. I noticed often that while doing the initial transcriptions, I would leave out certain speech habits that the participant displayed. For example, one participant would say "ya know" quite often in the interview. During the initial transcriptions, I would leave such space fillers out. When I would subsequently go back and listen to the interviews, I found that I often had to add words or thoughts that I had omitted or filtered as being unnecessary to the overall concept during the initial transcriptions. Once the transcription process was complete, I had to read through each interview to ensure that there were no typos, misspelled words, or punctuation errors.

Data Analysis

The first step in identifying the commonalities in the research was in transcribing the interviews. Interviews were transcribed and then entered into software for coding. Data were coded using NVivo 11, a program designed to analyze qualitative data. I had to create nodes, which would scan the interviews searching for specific information. By coding the data using this program, it became possible to identify demographic information, frequency of words or ideas that were shared among the participants, as well as common themes that began to emerge in the research (Creswell et al., 2007). As

phenomenology is a study of people's experiences, there is the assumption that an underlying meaning or structure will be discovered based on these shared experiences (Patton, 1990). While reading the transcribed interviews, a thematic analysis was conducted by comparing and contrasting the interviews searching for meaningful similarities and differences. Themes were chosen based on the repetition of terms, phrases, and concepts that were shared amongst the participants' responses.

Table 2 shows a selection of interview excerpts regarding participants' thoughts about daily life with SLE, and focused coding.

Table 2

Interview Excerpts About Thoughts About Daily Life with Focused Coding

Interview Excerpts	Focused Coding
Participant B said:	Daily Life
"I went to see a holistic doctor to	anxiety, exercise, rest
find alternative measures for managing my SLE.	Daily maintenance
He suggested that I control my exposure to anxiety	Control stress
and stress, eat healthy, reduce/eliminate eating unnatural	Prevention
sugars, rest more, get ample sleep, exercise, and pray often.	
I do all of these things daily and repeatedly throughout the day.	Daily Life
When I am faltering on my preventative measures, I usually	Living with lupus
take a vacation to get away to restore balance."	
Participant I said:	
I start my day with no less than half-an-hour of simple stretches	Daily Life
to slowly wake my body up. Quiet meditations help when my mind	(exercise); Rest (naps)
is willing. Once I get the ball rolling, I can usually keep going.	
Midday naps are a requirement. It's like rolling a large stone boulder	Living with lupus
up a hill that is covered in a sticky tar. Each step is labored as not	
pushing forward would mean even greater pain.	
Participant G:	
Now I live my life as well as I can. I try to	Daily Life
live healthy by watching what I eat and drink, I	Living with lupus
spend a lot of time at the gym. And, fortunately I've	Gym (exercise)
been able to get myself off of all my medication	Living with lupus
except my lupus medication which I've gotten	
down to the lowest dose possible.	

Evidence of Trustworthiness

The evidence of trustworthiness was achieved through several credibility procedures including: thick description, member checking, an audit trail, and immersion in the data. I had not originally included immersion in the data in Chapter 3, but I determined that it was beneficial to include this step as the research continued to evolve. Thick description is a process whereby the research information that is gathered, as well as the methodology in which it was gathered, is presented in such sufficient detail that not only are the results believable and dependable, it is possible for other researchers to ascertain the transferability of the study's results to other specific contexts. This was achieved by incorporating direct quotes from each of the participants to the various themes that emerged in the research. As such, it is possible for other researchers to ascertain the transferability of the study's results to other specific contexts. Adequacy of the data was further demonstrated by having participants from every major ethnic group, as well as having participants whose age ranges spanned multiple decades, and whose relationship statuses included: single, married, divorced, and in a same-sex relationship.

Verbatim transcriptions of the interviews were made by listening to the recordings. This was done to ensure that the results remained objective and that the researcher's subjectivity did not intrude on the results. Throughout the interviews, I periodically summarized and checked for accuracy. When transcribing the interviews, I did have to contact one participant to verify the accuracy of information following the transcription. The participants were asked open-ended questions that allowed them to respond as they were comfortable, emphasizing the aspects of their experiences that they

felt were important to share. Dependability of the results was achieved through the repetition of shared experiences, which led to the emergent themes.

An audit trail of my raw data, notes, recordings, and transcriptions has been kept. Data was stored on paper, audio recordings, and electronic media. Paper responses have been stored in a locked and secured filing system in my personal office. Audio recordings have been stored there as well. All other files/data have been stored on my laptop. The files and audio data have been kept in a locked and secure location. Information on the laptop has been protected by multiple passwords. Having this information available for audit ensures the confirmability of the data.

My immersion in the data began with the initial stages of creating the participation flyer, recruiting and selecting the participants, conducting the interviews, listening to and transcribing the recordings, coding the transcriptions, verifying the accuracy of the transcription, organizing the codes, and identifying the emerging themes .I maintained my objectivity during the process by focusing on the goal of the research, in an effort to assure confirmability. I never found myself tempted to influence the results through my tone or responses. Maintaining my neutrality was achieved by a genuine, objective desire to share the truthful lived experiences of the participants.

Results of the Study

This study explored the lived experience of men who had been diagnosed with SLE and what the psychological impact of the disease was on these men. The lived experiences of the participants in this study were varied but similar, highlighting the changes of what life was like before SLE to what it was like to live life daily with SLE,

the significant impact that the disease had on relationships, and how the disease impacted each man's self-concept. The themes that were highlighted were derived from the participants' experiences. The interviews began with two interview questions, which provided the context and understanding of the participants' views on living life before SLE and living life with SLE. The participants discussed their daily life before the disease and then what it was like to live with the disease. The resulting themes for the research question were: life before SLE, changes in interpersonal relationships, changes in intimate relationships, changes in self-concept, and changes in perspective about living with lupus. Each theme with examples is described below.

Life Before SLE

The participants were asked what their lives were like before being diagnosed with SLE. They all had unique life experiences, physically and socially, before being diagnosed with SLE, which greatly impacted their view of the disease once they received the diagnosis. Due to the impact that their lived experience before being diagnosed has had on the participants, all of their responses are included, as this significantly impacts how their lived experiences contributed to their perceptions of living with SLE.

> Participant A: My quality of life was great. I had no restrictions and other the some minor symptoms that I have come to known as related to SLE, it did not affect my life in the slightest. I was able to work, socialize and have an active sex life with my partner.

Participant B: I was able to fully function without limitations. I enjoyed being outside during the summer months, staying up late, and taking on a lot of physical assignments.

Participant D: I was very athletic, active, went to gym four times a week, a workaholic, and maybe worked 60 hours or so per week. Prior to that, I had a career where I traveled quite a bit so I was an avid traveler, globally as well as in the U.S., um, yeah, so, so, basically, I lived a very active lifestyle.

Participant E: Superb. I was in perfect health.

Participant F: Just basically endless energy, activity, I could move around, do what I wanted to. I was very active, even though I did kinda slow down maybe 1 to 2 years prior to that. Up until then, I was really active.

Participant G: I was relatively healthy and very active. I worked on cars 40-50 hours a week at my job while going to college full-time, and still went out riding four wheelers almost every Sunday. It was my best way to relax and take a mental break from work and school. I also spent time running around having fun with friends on Friday and Saturday nights.

Participant H: It was very active, worked out a lot, my wife and I, I don't know if you know anything about Georgia, but my wife and I, we climbed Stone Mountain every weekend. Um, I would play ball. I would workout, lift weights…mentally strong and physically strong.

Participant I: Normal to great. I was active in gymnastics and sports.

Only one participant, who was diagnosed at a very young age, had a life before SLE that was not active or typical of the consensus of the rest of the participants.

> Participant C: I lived with chronic headaches for 6 years prior to my diagnosis with SLE. Therefore, had a limited social life and spent a lot of time absent from school. I did have friends and enjoyed normal childhood activities, but my illness limited by ability to be fully active.

Changes in Interpersonal Relationships

Participants were asked about the changes that they noticed in their interpersonal relationships after being diagnosed with SLE. All participants, except one who did not address the issue, noted change in their interpersonal relationships. However, participants noted varying levels of impact on the interpersonal relationships. About half of the participants articulated that SLE only slightly impacted their interpersonal relationships, and that what they had to focus on was educating their friends and families about the disease and its impact on their daily lives. These participants felt that communication was the key for minimizing the impact of the disease on their interpersonal relationships

> Participant H: I have great friends. They support me and they listen to me. Because in the beginning, my way of dealing with it was to talk about it. They would listen and they got a better understanding of what it was. A lot of folks knew people, in fact everyone I know knows someone with lupus, but they don't know exactly know what lupus is. So, I started explaining to my friends and my family how it affects me one way and how it can affect someone else a totally different way. That it is an autoimmune disease, because they didn't even know

> that. Then you have to explain the autoimmune disease to them and how it affects you. So being able to explain it to your friends and having them know exactly what you can deal with and how you want to be treated, I think that's another way, something else, having friends and family know how you want to be treated. I may not want someone to help be as much because I want to help myself, but that might not be the right thing for someone else with lupus. The thing about lupus is you have to find your way of dealing with it, but keeping it to yourself is not the way.

About half of the participants noticed a much more significant impact on their interpersonal relationships that education and communication alone did not remedy. While these participants articulated that education and understanding were important over the long haul, the disease impacted how they interacted with others and how they built relationships. This half of the participants talked about how there seemed to be a loss of privacy when it came to personal details about one's life and health, and that forming relationships was much more difficult than it had been previously. Participant G illustrated the shared experiences with the most clarity.

> At first it was difficult on my relationships. I distanced myself from everyone I knew and I didn't really care to build new relationships. This is what made things difficult on my family. They knew I had been diagnosed and they knew they saw a change in me. I went from very active, outgoing, and joking around to just quiet and distant. I wouldn't talk with them about the disease or anything else. They actually didn't even know what lupus was or what it does until I was in Piedmont

> Hospital and they met my Rheumatologist for the first time. Since my injury and seeing my psychiatrist things have changed. I am more like my old self; I still have some down moment from time to time but who wouldn't. The difference is now that I'll talk with my family about what's going on and I'll move past it instead of holding it in and becoming depressed. I've even grown closer to some of my family because of what I've been through. I can't really explain why, but I have.

Participant E focused more on his intimate relationship and his coping skills rather than specifically addressing this question, which led to the next emerging theme.

Changes in Intimate Relationships

Participants were asked to describe how being diagnosed with lupus impacted their intimate relationships. This was the area the participants were most hesitant to discuss, but where all but one of them asserted that the disease had a significant impact on how they functioned within intimate relationships. Some of the responses focused on the physical changes in intimate relationships due to fatigue, stress levels or medications that negatively impacted their libido.

> Participant E: My intimate relationship…I can say it like this…as I began to take all of this medicine…uh this toxic yet sometime helpful medicine, my intimate relationship began to diminish. My desire for intimacy diminished. I was wondering what was going on because I was addressing some other challenges as well, not associated with lupus, so I was dealing with a combination of things that

> kind of compromised my enthusiasm plus the medicine suppressed my libido so to speak.
>
> Participant A: Going from an active sex drive to having the SLE affect it has been the most difficult thing to accept as someone who has always had a high sex drive to not having one on most days can be disheartening.

Many of them began to doubt whether or not anyone else would see their value or their worth and even be willing to take a chance on a man that had been diagnosed with a chronic illness and an uncertain future. They expressed fears about loneliness, isolation, and whether or not they would be able to father children. While there was an overwhelming consensus that these intimate relationships were critical and desired, the uncertainty about whether or not they could be loved in spite of a chronic illness was overwhelming, especially for the single participants.

> Participant G: When I was diagnosed I had just received my Associates Degree and was headed for my Bachelors, but I gave up on school and relationships and just started floating through life. I didn't care anymore. What was the point? I felt that with this disease, who would want me? I was single at the time I was diagnosed and I just didn't think that trying to date was worth it after my diagnosis. I honestly felt that if I started to date someone and I told her I have lupus that she would just leave and I would never hear from her again. And, since talking with my psychiatrist I feel better about that but I've just been focusing on my recovery. As of right now, I'm not actively looking, but if an opportunity presents itself then I am comfortable enough with my situation that I will give

things a chance. I'm not scared to tell people about my disease anymore. Plus, it's not like I can hide it. The limp and the walking cane kind of send up a signal that something has happened.

Participant I: Well, prior to 17, my experience with intimacy was limited. One thing I can say is that for a time, I tried to ignore the fact that I was ill, and went about dating. And right on cue, a flare up would happen, and I would disappeared from the world. This put a damper on 2nd and 3rd dates. Too many questions and not enough fun I guess. It was difficult finding someone that was understanding. I dated for fun and made friends, but longed for something stable in my life. Unfortunately, no one lasted more than 2 years.

Participant F: You know, I don't know, there is certainly an impact. It impacted my relationship with my last girlfriend. And I don't think it is easy telling a woman I have lupus…In the past, I have been really sensitive to talking about it with women, but it didn't really change things if I get into an intimate relationship and the woman is okay with it. I think that there are a lot of women that wouldn't take a chance. I mean there are some women that would not take a chance.

There was one participant, however, who did not believe that lupus negatively impacted their intimate relationships. However, this participant was diagnosed at a very young age, so he had not experienced a sexual relationship prior to his diagnosis. His experiences were all after his diagnosis, so he could not detail a change in the nature of his intimate relationships.

> Participant C: I did not have intimate relationships prior to diagnosis. My current intimate relationships are healthy. My medications have not dampened my sexual desire. If I am in a lot of pain, I do limit my activity.

Despite the commonalities present as it pertained to the changes in intimate relationships, it was the last emerging theme, change in self-concept, where the opinions and emotions seemed to be the strongest.

Change in Self-Concept

Participants were asked to detail how lupus impacted their overall view of themselves as a man. All of the participants felt that SLE had impacted their concept of who they are as a man, whether the impact was slight or significant. Some patients expressed adverse impacts of the disease on their overall self-concept. They focused on their diminished physical appearance and capabilities, as well as the impact the disease has on their intimate relationships. Others focused on the inability to work and provide consistently, since that is traditionally viewed as a "man's job" within the family.

> Participant G: That whole misconception of it being a "woman's disease" never really bothered me. What did affect me was after my injury from lupus. Since I was 14 years old I've worked. I started by mowing lawns in the neighborhood and keeping the score board at the softball fields. I always liked earning my way, but once I suffered the brain injury from my lupus I wasn't able to work anymore. The idea of me not being able to earn a living can be a little depressing all on its own. It's also been difficult to watch my friends from when I was in school have their careers take off, get married, have kids, and buy homes. I have felt like

> despite how hard I worked and everything I've done I'll never be able to have those things all because of this disease. I now know that some of things are still possible, I'm just still not sure about having kids. There is a small chance that I could pass this disease along. Even though it's a small chance it is still a chance and I don't want to risk the possibility of having to see one of my children come even close to experiencing to pain and struggles that I have had to face.

Other participants, however, held a more positive concept of themselves as a result of their diagnosis with lupus. They acknowledged the changes, and even some of the limitations that they had experienced physically, but they embraced a more modern and inclusive concept of what it means to be a man. These participants felt that it had made them more emotionally responsive than they were, and acknowledged the positive benefits that had manifested as a result of their changed perspective. They focused on the parts of life that they cherished and appreciated life for what it is, rather than what they expected it to be.

> Participant B: I believe that it has made me a stronger and better man. I have been able to slow down and really appreciate life for what it is. I no longer believe that men have to take on and conquer everything. I cherish the little things in life which makes me more appreciative and understanding. My social, personal, business, and spiritual lives are all blooming in synch with one another.
>
> Participant I: Though I was diagnosed at 17, I was under doctor's care when I was about 14. Becoming ill so young, I feel as though I never reached my prime; it was all downhill from 14. True, there are a lot of things that I never got to do, and

> will likely never do, but being a man has so many definitions these days. I don't fit into the larger definition of societies "man", but I am comfortable with who I am. SLE has made me into a more determined man, as well as bestowed upon me wisdom, patience, and incredible problem solving skills. SLE has made me the man I am today, and I kinda like me.

One participant did not feel that lupus had impacted their self-concept either positively or negatively.

> Participant C: I can't really say that SLE has impacted my concept of being a man. I have lived with the disease so long and it developed during puberty it's difficult to say that it impacted my concept of being a man. I don't know anything different. I can say, however, that I do mow my own lawn, take care of housework, care for my car. I also know that I need to, my family, both male and female, will take on these tasks when I am sick.

Changes in Perspective About Living with Lupus

Participants were asked to describe their overall experience in living with lupus. The responses varied greatly, depending on how significant the diseased had impacted them both physically and psychologically. Participants detailed both the negative physical and psychological impacts of the disease. However, the changes in perspective about living with lupus really centered around two commonalities, or subthemes: learning to accommodate the physical symptoms and learning effective ways to cope with the disease. As this theme, and subthemes, most adequate reflects the shared lived

experiences over time; all participants' responses were included with as much detail as possible, without breeching confidentiality.

Learning to Accommodate the Physical and Psychological Symptoms

Participants suffered from a wide array of physical symptoms. Some suffered milder psychological symptoms of depression. Others were embarrassed and did not want to share their diagnosis or concerns with their family. Then there were those who suffered extreme cognitive impairment, where they had to learn to do things all over again.

> Participant A: I feel that as my SLE has progressed it's added to the interference of my daily routines, fatigue, and mood. I feel that I have increased anxiety because I am not sure of how the lupus might progress in the future. I try to live in the present. I have a sense of being dependent on others, and sometimes I feel overly analyzed my family and friends who sometimes chastise me if they feel I'm doing too much in a day. I usually have a good understanding of my fatigue but have to plan according to how I feel in a day as opposed to spontaneously making plans. I accepted my increased limitations and have embraced my new "normal".
>
> Participant B: I consider it a check and balance system inside of me. SLE is very prevalent when I am working extremely hard without much rest or sleep. I usually have very heavy breathing, heart palpitations, and almost complete loss of energy. My very worst episodes happen when I am awakened suddenly and have uncontrollable tremors.

Participant C: I've lived with SLE for 25 years. I have had long periods of remission and periods of disease activity or flares. During flares, I have lived with arthritis, anemia, and inflammation in my heart, lungs, kidneys, and brain. I have also lived with continued chronic headaches, but they are less frequent. I also have Sjogren's syndrome, Raynaud's phenomena and fibromyalgia which go hand in hand with some SLE patients. During flares, I live with random pains and have difficulty managing daily activities. I've always been able to work, but have had to take frequent breaks or schedule days of rest. I am currently in remission, and even in remission, I live with fatigue, muscle pain, and headaches.

Participant D: Um well you know, now it is just getting over the fatigue, not um feeling as up to doing social activities as I used to, or traveling, or socializing for now, because life has changed pretty radically. I have to find a balance between matching my pain and just being healthy because um I am on so many different medications, and at times, it is pretty toxic stuff.

Participant E: Ummm…It has been overwhelming, traumatizing, numbness. It has been depression. It has been emotional. It has been unbearable, unsettling. Now, I am at a place of acceptance. That would be over the course of the time till now.

Participant G: At first there wasn't much to talk about with it, I wouldn't even discuss it with my family. Then, about a year later, I started getting sick. At first I had a slight fever and was throwing up. I just figured I had the flu at first, but then my joints started hurting and swelling. At the time I was living in Alabama for work. My Grandmother came to check on me and found me on the couch. She

knew something was off because I was talking very strange, like I was hallucinating, because I was. She called my parents…and told them what was happening. My mom drove out there to check on me and by the time she got there I was not responding, I was barely breathing, and I had turned about three different colors. They tried to lift me to the car to go to the hospital but at 6'2 and around 200 lbs. they just couldn't lift me, I was dead weight. So, they called an ambulance. When the ambulance got there I was put on a stretcher and put in the ambulance to go the hospital. Since I was considered stable at first they didn't turn on the lights and sirens. My mom followed the ambulance to the hospital but on the way there she saw the lights come on and the ambulance pick up speed. At the hospital one paramedic Jumped out and told my mom to follow her. On the way inside the hospital my mom asked what was going on and the paramedic told her they lost me on the way, but they were able to bring me back. During the next 2 weeks they thought that I had pancreatic cancer which scared my entire family. After they eventually ruled that out they released me and I was brought back…after I began falling down and having slurred speech…Over the next few weeks I had several blood transfusions, I wasn't bleeding I was just losing blood. They took lymph node biopsies, did a spinal tap, took bone marrow, and blood test trying to figure out what was happening. I had my rheumatologist, a neurologist, a hematologist, and an infectious disease doctor all working together to figure out what was happening. My neurologist and my rheumatologist came up with an idea, they did and MRI and sure enough they were correct. My

immune system was attacking the cerebrum of my brain causing it to swell and press against my skull, this is what was causing my head to feel like it was splitting in two and causing all the other problems. They also determined that it was my white blood cells attacking my red bloods cells causing me to need the blood transfusions. Now that they knew what was going on they started treatment. I was put on a once a month dose of Cytoxan (a form of chemotherapy) to wipe out my immune system. At this time, I was down to 160 lbs., I couldn't speak, I couldn't remember anything, I could barely breathe on my own, and I couldn't move anything from the neck down other that my left arm. I had feeling, I just couldn't move. My family was told that they should prepare for when I come home to take care of me. They said that I wouldn't walk again and that at best I would have about 75% cognitive recovery….My family fought to get me in (to rehabilitation) as did my rheumatologist who told them to treat me as if I had a stroke. From what I was told I was also the first patient to arrive there still in a bed not in a wheel chair. I had to relearn almost everything. How to breathe, eat, drink, work on my memory and cognitive abilities, and learn to do things left handed. All this and we couldn't even think about walking yet. Six months of chemotherapy, two rehab facilities, and 9 months later I had the use of my right arm again (its limited use but it's there), I was cleared 100% cognitive recovery, and I was walking on a walker…I was told my recovery is unheard of. I don't know why I have had such a remarkable recovery, but I thank God for it.

Participant H: It was finding out the right combination of meds that made my daily life much easier.

Participant I: The first 5 years was full of muscle and stomach cramps. Partly this was due to SLE, partly due to the numerous trial drugs. Once I was on a working drug cocktail, the rollercoaster began. Almost like clockwork, barring any unforeseen stresses, I would feel alright for about 2 to 3 months, but I would have a full week of hell. My body would feel like it was tearing itself apart. I would call in sick to work and school, and cancel any plans with friends and family. Then after a week, I'd go back to my life. Now, for the last 5 years, I've been in a steady state of fatigue and soreness. No dips, and no highs. Just blah.

Learning Effective Ways to Cope With Disease

Participants expressed a variety of ways that they had learned to effectively cope with the disease, which changed their perspective about what it meant to live with SLE. Some participants relied on support from their family, friends or support groups.

Participant A: When I receive emotional and physical support from my family, I feel more in control of my life and my future. Knowing that I have sought out the best care in doctors also reinforces these feelings. Being involved in support groups and having an understanding and empathy with others is empowering for me. Responding positively to the medication prescribed for my treatment is reassuring as well but it's frustrating when I feel I am doing well and receive negative blood results and when I feel terrible and receive normal blood work. The uncertainty of lupus is perhaps one of the most frustrating things I have ever

experienced in my lifetime. I feel that I am trying to utilize all my coping mechanisms and support to live life to the fullest with my SLE. I realize I have my good days and bad days. And I'm grateful for the good days, and sometimes disappointed with the bad ones, but I am learning to embrace all the good and bad experiences.

Participant F: I have been fine, but still, what basically happened is lupus is not cured, but I got active again….I got interested in being more proactive in learning more about lupus. I got involved in the lupus organization here.

Participant H: So the combination of going to the doctor, listening to him, listening to my body, going to support groups and understanding how other folk, how other people with lupus were dealing with it, so that's been a great help. Then also I have a team from Aetna Insurance that I go through. So those are things that are able to help me, and then I have to pace myself throughout the day. The better I pace myself, the more I can do. I will tell anyone with lupus to listen to your doctors but not working out, you actually feel much weaker.

Other participants found that physical exercise and being active actually helped them

Participant D: For me, it is just a matter of regrouping and getting back to living you know an active lifestyle because it is necessary. Whereas before I did it for recreation or just for fun, but no it's like, I am on all of these meds and I am living a more sedentary life, so I need to I definitely need to be active, ya know?

Participant F: I have been able to do what I wanted to do. Hike. Hike. I have hiked 10, 11, 12 miles a day on the Appalachian Trail. I have been in really great shape

Participant H: When I was first diagnosed, I worked out a lot. They, the doctors, they didn't want me to lift weights or anything because my muscle enzymes were so elevated they thought I would burn out my muscles. However, I was actually getting weaker by not working out. Since then, I have started working out. My wife and I have been working out. She could push me a little bit. That made a difference. Little by little, I was able to focus on lifting 10 pounds, but I couldn't hardly lift anything else, I was so weak. Before I was lifting up to 100 pounds and working out with 100 pounds. There were so many things I used to do that I couldn't do. But I started building up my resistance, and I started gaining my weight back from when I worked out. I feel pretty strong. I feel like I felt before. It's a day to day challenge but I'm feeling much better.

Summary

The chapter depicted the shared lived experiences of nine men and the psychological impact that SLE had on their lives. Allowing the participants words to be used directly provided a more authentic view of what it is like for these men to live their daily lives, to interact with others, and to cope not just with the physical strain of the disease, but with the psychological impact of the disease as well. The majority of the participants had little or no knowledge about SLE prior to their diagnosis, and most of them acknowledged leading vibrant, very active lives prior to their diagnosis. Participants acknowledged various levels of changes to their daily lives, but they did acknowledge the importance of resting often and being aware of what was happening with their bodies on a daily basis, and making the necessary accommodations. Participants acknowledged

various levels of changes in their interpersonal and intimate relationships, but the majority of them acknowledged that the deep and meaningful relationships were still strong. Participants acknowledged a vast array of responses when it came to how SLE impacted their concept of who they were as a man. While In chapter 5, I will provide connections between these findings and relevant literature, discuss how this work can be used for practical applications, and generate ideas for future research as it pertains to the study of men with SLE.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This study addressed a research gap concerning the psychological impact of SLE on men. The primary purpose of this phenomenological research study was to gain a better understanding of the shared lived experiences of men who had been diagnosed with SLE, as well as the various ways that the disease impacted their psychological well-being. The results of this research study detailed the lived experiences of nine men who had been diagnosed with SLE and how the disease had impacted how they saw themselves as men, as well as how they dealt with interpersonal and intimate relationships. It highlighted how the participants reconciled their preconceived notions of what a man should be with what they were physically capable of doing after being diagnosed with the disease. The sharing of the lived experiences of the psychological impact of SLE on the lives of these nine participants was earnest, filled with emotion and truth, and heightened with a sense of urgency to ensure that this information be available to any and all who might seek it.

There were specific themes that emerged from the analysis of the participants' interviews. The themes that emerged were as follows: life before SLE, changes in interpersonal relationships, changes in intimate relationships, changes in self-concept, and changes in perspective about living with lupus.

Interpretation of the Findings

The goal of this research study was to determine the shared lived experiences of men suffering from this particular disease and to try to uncover common themes in their

experiences. The results of this study broadened the understanding of the psychological impact of SLE on men. This increase in knowledge was achieved through the thick, rich descriptions provided by the participants. The primary research question that guided this research study was this: What is the shared lived experience of men diagnosed with SLE?

The result of this research study was that SLE can have a significant impact on men who have been diagnosed with the disease. Participants noted change in their interpersonal relationships. Furthermore, participants in the research study asserted that the disease had a significant impact on how they functioned within intimate relationships. All of the participants felt that SLE had impacted their concept of who they are as a man, whether the impact was slight or significant. Existing research had shown how the disease process impacted not only the physical being, but the psychological and interpersonal aspect of a patient's life as well, but that research had focused on women (Philip et al., 2009; Sperry, 2011). The results of this research showed that SLE impacted the psychological and interpersonal aspect of the lives of men who lived with the disease.

The theme of life before SLE emphasized how the majority of the participants felt that their lives had changed significantly since their diagnosis. Many expressed a decrease in energy and physical ability, while others detailed changes in relationships. Schwartzman-Morris and Putterman (2012) provided evidence that men are more severely impacted by the disease, regardless of age. This includes how rapidly the disease progresses, access to treatment, effectiveness of the treatment received, the severity of damage to internal organs, and morbidity related to organ failure. The current research showed that at least two of the participants were diagnosed in adolescence and might

have had the disease for an indeterminate time prior to that, while two other participants suffered from significant and life-threatening health complications such as strokes.

The theme of changes in interpersonal relationships was significant as participants noted change in their interpersonal relationships. Some patients felt a heavy burden to explain their disease and educate their friends and family about SLE and how the disease impacted their lives. Others felt like they had lost their privacy and that it had become more difficult to form relationships while living with SLE. Sperry's (2011) research supported the results of the study by emphasizing that social and interpersonal complications can arise as the result of living with a chronic disease. It detailed how chronic diseases can take a heavy emotional toll of relationships, as expectations and reality begin to change because of the physical and psychological complications of the disease process. SLE affected how the men in the current study interacted in various interpersonal relationships such as the work place, as well as how they interacted with friends and family.

The theme of changes in intimate relationships was very significant for the participants in this research study. The participants asserted that the disease had a significant impact on how they functioned within intimate relationships. Patients experienced changes in libido and sexual ability due to fatigue or changes in medications. Others worried about the changes in their ability, with some even questioning whether or not they should engage in intimate relationships due to the fear of being abandoned, not being able to father children, or not being truly loved unconditionally. Sperry's (2011) research using the biopsychological approach, which was the theoretical framework for

this research design, supported this theme by illustrating how the disease process could drastically impact interpersonal harmony, personal expectations, and life satisfaction within a marriage due to the physical and psychological impact of the disease process. Some of the men were hesitant to engage in intimate relationships, while others struggled with changes in sexuality and stamina.

The theme of changes in self-concept described how lupus impacted the participants' overall view of themselves as men. All of the participants felt that SLE had impacted their concept of who they are as a man, whether the impact was slight or significant. McElhone et al. (2010) related that a patient's perspective of SLE had a serious relation to QoL. The participants who held a more positive self-concept of who they were as men seemed to cope better with the disease overall. The men who seemed to feel the least psychological impact seemed to report an overall higher satisfaction with their own lives, while those who had struggled more physically and psychologically seemed to have less overall life satisfaction and questioned whether they could be loved or viewed as valuable, whether in the traditional sense of manhood or in relationships.

The theme of changes in perspective about living with lupus focused primarily around two basic commonalities, or subthemes: learning to accommodate the physical symptoms and psychological symptoms and learning effective ways to cope with the disease. Learning to accommodate the psychological symptoms meant learning to cope with things like depression, changes in cognitive abilities, and focusing on living in the moment rather than worrying about what might or might not happen at some time in the future. Research from Sweet et al. (2004) emphasized that the initial cognitive

impairments can affect a wide variety of abilities with the SLE patient including memory, simple and complex attention, problem solving, reasoning, visual-spatial processing, sequencing, organizing, planning, and visual-spatial relations. Sweet et al. emphasized that the changes could significantly impact the SLE patient's ability to maintain life as they knew it prior to the onset or diagnosis of the disease. Such major life changes, in conjunction with the very nature of SLE, often lead to an emotional upheaval in the patient. They would begin to feel as if they are losing themselves both physically and mentally, which further contributes to the risk of mood swings and depression. Therefore, those who were able to change their perspective about the impact of the disease on their lives tended to have less psychological complications as a result of the disease. Philip et al.'s (2009) research supported the fact that one's emotions about the disease or perceptions about the disease process also impact their overall emotional health. Individuals with less understanding of the disease and greater consequences linked to their disease were far more likely to develop depressive symptoms. Participants who appeared to be less depressed seemed to have fewer physical symptoms than those who were struggling more emotionally.

For a large percentage of the participants, learning to cope with the disease meant relying on family and social support to get through the difficult periods of time. Due to the nature of caring for a patient with a chronic illness, social support is often something that is not given a real priority, although it is something that should be a priority when caring for a patient with SLE (Sperry, 2011). For others, learning to cope with the disease meant doing their best to maximize their physical health, which tended to minimize their

depression and give them a greater feeling of control over an uncontrollable situation. Sperry's (2006) research supported the results of this study. He believed that self-management of the disease could greatly improve the QoL of those suffering from SLE. Relaxation techniques such as deep breathing, progressive muscle relaxation, mental imagery, and biofeedback were encouraged to counter the negative impact of stress, which is both a trigger for and a response to SLE (Sperry, 2006). Each of the participants found their own unique way of coping with the disease, either by relying on social support or by changing their perceptions about what it meant to live with SLE.

Limitations

As this study was phenomenological in nature, its purpose was to describe the shared lived experiences of this particular group of men who had been diagnosed with SLE. One limitation was that the majority of the participants were heterosexual. Only one participant was gay. This might mean that the data could not be transferred to all gay men who had been diagnosed with SLE. A second limitation is that the majority of the participants were from one geographic region of the country, the South, with only one being from the Northeast and another being from the West Coast. Having being selected from primarily one geographic location, the findings might not be transferable to men who were diagnosed with SLE in other regions of the United States, or it might even limit the transferability of the information to those who live outside of the country. A third limitation of this particular research study is that, due to geographical restrictions, the participants had to be interviewed via phone. While phone interviews are common in this

particular type of research, it may be viewed as a limitation because it did not allow me as the interviewer to make observations about the nonverbal cues given during responses.

Implications for Social Change

Implications for positive social change of this research study include providing a greater level of understanding of the psychological impact of SLE on men. It will serve as a resource for professional therapists and psychologists who are trying to find information that would be beneficial for their male SLE clients. Additional potential implications for positive social change include providing information for families and caregivers of those men with SLE, and how the disease impacts them from a psychological standpoint. This may include providing them with SLE patients' perspectives on interpersonal and intimate relationships that they had not previously considered as a factor when considering the impact of the disease.

Another social change implication that should be considered is the overall significance of understanding gender as it applies to other chronic illnesses that typically impact women. Are there gender differences in the way that men and women deal with those chronic illnesses? It would also be significant to address the impact that other diseases that are traditionally considered a "woman's disease," such as breast cancer, have on men that are diagnosed with those diseases.

Recommendations for Action

Presenting this information in various forums would help circulate this research data. Sharing this information with SLE support groups or psychological organizations can assist men who have been diagnosed with SLE to learn more about the lived

experiences of others who have been diagnosed with the disease. Removing some of the fear of the unknown by sharing the lived experiences of the participants may minimize the psychological impact of those who have been recently diagnosed.

Recommendations for the communities, clinicians, family caregivers, and support organizations would be to educate themselves on helping individuals who had been diagnosed with SLE overcome the stereotypical expectations of what a man should be and to help them accept what life will be like living with this chronic illness. Helping men diagnosed with SLE to maintain a strong sense of self can help mitigate the psychological impact that SLE has on their daily lives.

Recommendations for Further Study

Through a phenomenological lens, this study sought to answer questions, but knowing that new questions would be created. These recommendations are relevant for men who have been diagnosed with SLE. The following are questions that still exist:

- Is there a significant difference between the psychological impact of SLE on men and the psychological impact of SLE on women?
- Does a positive self-concept improve physical health and minimize the impact of the disease process for men living with SLE?
- Does marital/relationship status have an impact on the psychological impact of SLE on men?
- Is there a difference in the psychological impact of SLE on men when compared with the psychological impact of other chronic illnesses that typically impact women more often than men?

My recommendations would be for more research studies that were inclusive of men with SLE, rather than focusing predominately on women. I would also suggest determining if gender was a deciding factor in the ways individuals cope with SLE, and if so, identifying what the precipitating factors were that made gender so significant in the differences in coping with the disease. I would also suggest researching if being in an existing intimate relationship had an impact on the psychological impact of the disease when compared with those who were not in a committed intimate relationship. Lastly, I would suggest trying to compare the psychological impact of SLE on men to the psychological impact of other chronic illnesses that typically impact women on men to determine if common themes emerged.

Researcher's Experience

I have taken precautions throughout this research process to ensure that my biases were not incorporated into or affect this process. I was candid with the participants concerning my personal experiences of having two men in my life that had been diagnosed with SLE, and assured them that my goal was to honor their lived experiences and not my own.

I developed open-ended questions for the interviews in order for the participants to be able to describe their experience. The participants were allowed to describe their experiences and their emotions without any interruption, except for needed clarification. All of the interviews were recorded with the same voice recorder. I actively listened as the participants shared their experiences, being aware of their emotions and the need that many of them had not to feel overly vulnerable, especially to a stranger.

Transcribing the interviews was an arduous and extremely tedious process. It took me much more time to complete the process that I initially anticipated that it would take. I would begin the transcription and realize that I was missing words or that I could not keep up with the speed of the recorder, and I would have to begin listening to the interview again to ensure that I had adequately transcribed each part. It took multiple times of listening to and transcribing each interview before they were accurate and complete. I gave each participant the opportunity to correct any mistakes in the transcription. None of the participants requested any changes. That completed the member checking portion of the process.

I have not had the experience of living with a chronic and, often terminal, disease. I have, however, experienced what it was like to be a caregiver for someone who had been diagnosed with SLE. I have seen the devastating impact that it took on him, not just physically, but psychologically. I watched him berate himself for not being able to do things that he had once been able to do, and I saw how negatively it impacted his view of who he was as a man. There were days when love and support were enough to help him refocus on who he was in spite of the disease, and there were days that no amount of encouragement, or even professional psychological help, was enough to fight off the overwhelming depression and self-loathing that he felt. My experiences in no way compare to what it is actually like to live with the disease. This research has given me an opportunity to better understand the depths of the shared lived experience of men with SLE and the psychological impact that the disease has on their lives. I will forever hold

these participants in a place of honor, respect, gratitude and awe, as they opened themselves up so willing to me so that others might learn from their experiences.

Conclusion

This research study contributes to the gap in the literature with respect to the psychological impact of SLE on men. This study provides valuable information for men diagnosed with SLE, clinicians, families, and caregivers for individuals who have been diagnosed with SLE to better understand this phenomenon. The research study documents the participants' reports of their lived experiences with the disease, and how it impacted their relationships with others and their relationships with themselves. Each of the participants shared their experiences because they acknowledged how little information had been available to them when they were diagnosed, and with the hope that doing so will benefit other individuals who receive a similar diagnosis. They shared their experiences so that other men would know that being diagnosed with SLE does not automatically mean that life is over, or that their worth or value as a man is diminished in any way. Men living with SLE would know and understand that it is possible to be diagnosed with SLE and still maintain friendships, maintain intimate relationships, and to maintain one's self-worth, even if it meant viewing life from a new perspective. All of the participants discussed how their experience made them feel. They shared the uncertainty and confusion that accompanied the initial diagnosis, as well as the feelings of powerlessness and worthlessness that initially accompanied the physical changes that their bodies were experiencing. They also shared how they were able to make adjustments to not only how they lived physically, but how they viewed living with a

chronic illness. They shared how they were able to reconcile life before SLE with living with SLE, to learn to cope, and then to learn to face the challenge of living with SLE with a strong sense of self, even if it was a challenge at times. These findings remind us how significant the psychological impact of SLE can be, and how important dealing with the psychological impact of the disease can be for those living with a chronic illness.

References

Aberer, E. E. (2010). Epidemiologic, socioeconomic and psychosocial aspects in lupus erythematosus. *Lupus, 19*(9), 1118-1124. doi:10.1177/0961203310370348

Adhikari, T., Piatti, A., & Luggen, M. (2011). Cognitive dysfunction in SLE: Development of a screening tool. *Lupus, 20,* 1142-1146. doi:10.1177/0961203311405374

Alarcon, G. S., Beasley, T. M. Roseman, J. M., McGwin, G., Jr., Fessler, B. J., Bastian¸ H. M., . . . LUMINA Study Group. (2005). Ethnic disparities in health and disease: the need to account for ancestral admixture when estimating the genetic contribution to both (LUMINA XXVI). *Lupus, 14*, 867-868. doi:10.1191/0961203305lu2184xx

American Psychological Association. (2002). Ethical standards and code of conduct. Retrieved from http://www.apa.org/ethics/code2002.html

Ashton, E., Vosvick, M., Chesney, M., Gore-Felton, C., Koopman, C., O'Shea, K., . . . Spiegel, D. (2005). Social support and maladaptive coping as predictors of the change in physical health symptoms among persons living with HIV/AIDS. *AIDS Patient Care &Stds, 19*(9), 587-598. doi:10.1089/apc.2005.19.587

Borchers, A. T., Naguwa, S. M., Shoenfeld, Y., & Gershwin, M. (2010). The geoepidemiology of systemic lupus erythematosus. *Autoimmunology Review, 9*, A277–87. doi:10.1016/j.autrev.2009.12.008

Breitbach, S. A., Alexander, R. W., Doltroy, L. H., Liang, M. H., Boll, T. J., Karlson, E. W., Partridge, A. J., . . . Straaton, K. V. (1998). Determinants of cognitive

performance in systemic lupus erythematosus. *Journal of Clinical and Experimental Psychology*, *20*(2), 157-166. doi:1380-3395/98/2002-157

Calvo-Alen, J., Alarcon, G. S., Campbell, R., Jr., Fernandez, M., Reveille, J. D., & Cooper, G. S. (2005). Lack of recording of systemic lupus erythematosus in the death certificates of lupus patients. *Rheumatology, 44,* 1186-1189. doi:10.1093/rheumatology/keh717

Carr, F. N., Nicassio, P. M., Ishimori, M. L., Moldovan, I. I., Katsaros, E. E., Torralba, K. K., . . . Weisman, M. H. (2011). Depression predicts self-reported disease activity in systemic lupus erythematosus. *Lupus*, *20*(1), 80-84. doi:10.1177/0961203310378672

Cooper, G.S., & C.G. Parks. (2004). Occupational and environmental exposures as risk factors for systemic lupus erythematosus. *Current Rheumatology Reports, 6*, 367-374. doi:10.1007/s11926-004-0011-6

Costenbader, K., Kim, D., Peerzada, J., Lockman, S., Nobles-Knight, D., Petri, M., & Karlson, E. (2004). Cigarette smoking and the risk of systemic lupus erythematosus: A meta-analysis. *Arthritis & Rheumatism, 50,* 849-857. doi:10.1002/art.20049

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Creswell, J. W., Hanson, W. E., Clark, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist, 35*(2), 236-264. doi:10.1177/0011000006287390

Denburg, S.D., & Denburg, J.A. (2003). Cognitive dysfunction and antiphospholipid antibodies in systemic lupus erythematosus. *Lupus*, *12*(12), 883-890. doi:10.1191/0961203303lu497oa

Dowling, M. (2004). Hermeneutics: An exploration. *Nurse Researcher*, *11*, 4, 30-39. doi:10.7748/nr2004.07.11.4.30.c6213

Dubayova, T., Nagyova, I., Havlikova, E., Rosenberger, J., Gdovinova, Z., Middel, B., . . . Groothoff, J. W. (2009). The association of Type D personality with quality of life in patients with Parkinson's disease. *Aging & Mental Health*, *13*(6), 905-912. doi:10.1080/13607860903046529

Ebert, T., Chapman, J., & Shoenfeld, Y. (2005). Anti-ribosomal P-protein and its role in psychiatric manifestations of systemic lupus erythematosus: Myth or reality? *Lupus*, *14*, 571-575. doi:10.1191/0961203305lu2150rr

Emori, A., Matsushima, E., Aihara, O., Ohta, K., Koike,R., Miyasaka, N., & Katu, M. (2005). Cognitive dysfunction in systemic lupus erythematosus. *Psychiatry and Clinical Neurosciences, 59*(5), 584-589.

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*, 129– 136.

Feldman, C., Bermas, B., Zibit, M., Fraser, P., Todd, D., Fortin, P., . . . Costenbader, K. (2013). Designing an intervention for women with systemic lupus erythematosus from medically underserved areas to improve care: a qualitative study. *Lupus*, *22*(1), 52-56. doi:10.1177/0961203312463979

Garcia, M. A., Marcos, J. C., Marcos, A. I., Pons-Estel, B. A., Wojdyla, D. D., Arturi, A.

A., . . . Alarcon-Segovia, D. D. (2005). Male systemic lupus erythematosus in a Latin-American inception cohort of 1,214 patients. *Lupus, 14*(12), 938-946. doi:10.1191/0961203305lu2245oa

Giffords, E. (2003). Understanding and managing systemic lupus erythematosus (SLE). *Journal of Social Work in Health Care, 37,* 57-72. doi:10.1300/J010v37n04_04 ·

Glanz, B. I., Schur, P. H., Lew, R. A., & Khoshbin, S. (2005). Lateralized cognitive dysfunction in patients with systemic lupus erythematosus. *Lupus, 14*(11), 896-902. doi:10.1191/0961203305lu2244oa

Green, C. A., Freeborn, D. K., & Polen, M. R. (2001). Gender and alcohol use: The roles of social support, chronic illness, and psychological well-being. *Journal Of Behavioral Medicine, 24*(4), 383-399. doi:10.1023/A:1010686919336

Hawro, T., Krupinska-Kun, M., Rabe-Jablonska, J., Sysa-Jedrzejowska, A., Robak, E., Bogaczewicz, J., & Wozniacka, A. (2011). Psychiatric disorders in patients with systemic lupus erythematosus: Association of anxiety disorder with shorter disease duration. *Rheumatology International, 31,* 1387–1391. doi:10.1007/s00296-010-1689-6

Hycner, R. H. (1985). Some guidelines for the phenomenological analysis of interview data. *Human Studies, 8,* 279-303. doi:10.1007/BF00142995

Kardestuncer, T., & Frumkin, H. (1997). Systemic lupus erythematosus in relation to environmental pollution: An investigation in an African-American community in North Georgia. *Archives of Environmental Health, 52,* 85-90. doi:10.1080/00039899709602869

Khang, Y. & Kim, H. R. (2010). Gender differences in self-rated health and mortality association: Role of pain-inducing musculoskeletal disorders. *Journal Of Women's Health (15409996), 19*(1), 109-116. doi:10.1089/jwh.2009.1413

Kozora, E., Ellison, M. C., & West, S. (2009). Life stress and coping styles related to cognition in systemic lupus erythematosus. *Stress and Health,. 25*, 413-422. doi:10.1002/smi.1253

Krasner, M. (2004). Mindfulness-based interventions: A coming of age?. *Families, Systems, & Health, 22*(2), 207-212. doi:10.1037/1091-7527.22.2.207

LeCompte, M.D., & Schensul, J.J. (1999). *Analyzing & interpreting ethnographic data* (Vol. 5). Walnut Creek, CA: AltaMira Press.

Mason, Mark (2010). Sample Size and Saturation in PhD Studies Using Qualitative Interviews [63 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 11*(3), Art. 8, http://nbn-resolving.de/urn:nbn:de:0114-fqs100387.

Matthieu, A., Sanna, G., Mamel, A., Pinna, C., Vacca, A., Cauli, A., Passiu, G., & Piga, M. (2002). Sustained normalization of cerebral blood-flow after iloprost therapy in patient with neuropsychiatric systemic lupus erythematosus. *Lupus, 11*(1), 52-56. doi:10.1191/0961203302lu137cr

McElhone, K. K., Abbott, J. J., Gray, J. J., Williams, A. A., & Teh, L. S. (2010). Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus, 19*(14), 1640-1647. doi:10.1177/0961203310378668

Moore, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum for Qualitative Social Research, 11*(3),Art. 8. Retrieved from http://nbn-resolving.de/urn:nbn:de:0114-fqs100387

Moses, N., Wiggers, J., Nicholas, C., & Cockburn, J. (2005). Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. *Patient Education and Counseling, 57,* 30-38. doi:10.1016/j.pec.2004.03.015

Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: Results from the World Health Surveys. *The Lancet, 370,* 851-858. doi:10.1016/S0140-6736(07)61415-9

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

Nayak, R. B., Bhogale, G. S., Patil, N. M., & Chate, S. S. (2012). Psychosis in patients with systemic lupus erythematosus. *Indian Journal of Psychological Medicine, 34*(1), 90-93. doi:10.4103/0253-7176.96170

Olazaran, J., Lopez-Longo, J., Cruz, I., Bittini, A., & Carreno, L. (2009). Cognitive dysfunction in systemic lupus erythemastosus: Prevalence and correlates. *European Neurology, 62,* 49–55. doi:10.1159/000215879

Omdai, R., Brokstad, K., Waterloo, K., Koldingsnes, W., Jonsson, R., & Mellgren, S.I. (2005). Neuropsychiatric disturbances in SLE are associated with antibodies against NMDA receptors. *European Journal of Neurology*, *12*(*5*), 392-398. doi.10.1111/j.1468-1331.2004.00976.x

Patton, M.Q. (1990). *Qualitative research and evaluation methods* (2nd ed.). Newbury Park, CA: Sage.

Peralta-Ramirez, M.I., Coin-Mejias, M.A., Jimenez-Alonso, J., Ortego-Centeno, N., Callejas-Rubio, J.L., Caracuel-Romero, A., & Perez-Garcia, M. (2006). Stress as a predictor of cognitive functioning in lupus. *Lupus, 15*(12), 858-864. doi:10.1177/0961203306071404

Philip, E., Lindner, H., & Lederman, L. (2009). Relationship of illness perceptions with depression among individuals with lupus. *Depression & Anxiety (1091-4269), 26*(6), 575-582. doi:10.1002/da.20451

Polit, D., & Beck, T. C. (2008) *Nursing research: Generating and assessing evidence for nursing practice* (8th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.

Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data.* Thousand Oaks, CA: Sage Publications.

Schattner, E., Shahar, G., Lerman, S., & Shakra, M. (2010). Depression in systemic lupus erythematosus: The key role of illness intrusiveness and concealment of symptoms. *Psychiatry: Interpersonal & Biological Processes, 73*(4), 329-340. doi:10.1521/psyc.2010.73.4.329

Schwartzman-Morris, J., & Putterman, C. (2012). Gender differences in the pathogenesis and outcome of lupus and lupus nephritis. *Clinical and Developmental Immunology, 2012,* 1-9. doi.10.1155/2012/604892

Seawell, A. H. & Danoff-Burg, S. (2004). Psychosocial research on systemic lupus erythematosus: a literature review. *Lupus, 13,* 891–899. doi:10.1191/0961203304lu1083rr

Smith, S. (2007, May 18). Study finds Boston lupus rates highest in Roxbury, Mattapan.

Boston Globe.

Sperry, L. (2006). Psychological treatment of chronic illness: A biopsychosocial therapy approach. Washington D.C.::American Psychological Association.

Sperry, L. (2011). Systemic lupus erythematosus: The impact of individual, couple, and family dynamics. *Family Journal: Counseling and Therapy for Couples and Family, 19*(3), 328-332. doi:10.1177/1066480711407476

Steck, B., Amsler, F. F., Kappos, L. L., & Bürgin, D. D. (2000). Gender-specific differences coping with chronic somatic disease (e.g. multiple sclerosis). *Archives Of Women's Mental Health, 3*(1), 15-21.doi:10.1007/PL00010324

Sule, S., & Petri, M. (2006). Socioeconomic status in systemic lupus erythematosus. *Lupus, 15*(11), 720-723. doi:10.1177/0961203306070008

Sweet, J. J., Doninger, N. A., Zee, P. C., & Wagner, L. I. (2004). Factors influencing cognitive function, sleep, and quality of life in individuals with systemic lupus erythematosus: A review of the literature. *The Clinical Neuropsychologist, 18*(1), 132-147. doi:10.1080/13854040490507244

Van der Zalm, J. E., & Bergum, V. (2000). Hermeneutic-phenomenology: Providing living knowledge for nursing practice. *Journal of Advanced Nursing, 31*, 1, 211-218. doi:10.1046/j.1365-2648.2000.01244.x

Vogel, A., Bhattachary, S., Larsen, J. L., & Jacobsen, S. (2011). Do subjective cognitive complaints correlate with cognitive impairments in systemic lupus erythematosus? A Danish outpatient study. *Lupus, 20,* 35-43. doi:10.1177/0961203310382430

Williams, E. M., Zayas, L. E., Anderson, J., Ransom, A., & Tumiel-Berhalther, L. (2009). Reflections on lupus and the environment in an urban African American community. *Humanity & Society, 33*, 5-17. doi:10.1177/016059760903300102

Yu, H. H., Lee, J. H., Wang, L. C., Yang, Y. H., & Chang, B. L. (2006). Neuropsychiatric manifestations in pediatric systemic lupus erythematosus: A 20-year study. *Lupus, 15*, 651-657. doi:10.1177/0961203306070990

Zakeri, Z., Shakiba, M., Narouie, B., Mladkova, N., Ghasemi-Rad, M., & Khosravi, A. (2012). Prevalence of depression and depressive symptoms in patients with systemic lupus erythematosus: Iranian experience. *Rheumatology International*, *32*(5), 1179-1187. doi:10.1007/s00296-010-1791-9

Zapoor, M., Murphy, F. T., & Enzenauer, R. (2001). Echolalia as a novel manifestation of neuropsychiatric systemic lupus erythematosus. *Southern Medical Journal, 94*(1), 70-72. doi:10.1038/nrneurol.2014.148

Appendix A: Participation Flyer

Researcher at Walden University wants to learn about the psychological impact of Systemic Lupus Erythematosus (SLE), or Lupus, on men.

Participating in research is always voluntary!

Would the study be a good fit for me?

This study might be a good fit for you if:

- You are male
- You have been diagnosed with SLE
- You would like to share how SLE has impacted your mental and emotional functioning
- You would like to share how SLE has impacted your interpersonal relationships.

What would happen if I took part in the study?

If you decide to take part in the study, you would:

- Agree to be interviewed
- Agree to answer questions to the best of your ability

Men who agree to participate in the study will receive a $25 Visa gift card to thank them for their time.

There may be possible benefits if you take part in the study.

- You get a chance to explore or reflect on how SLE has truly impacted you.
- You get to be a part of expanding the knowledge base of how SLE impacts the psychological functioning of men.

Appendix B - IRB Approval

March 3, 2015
Dear Ms. Lynch,

This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, "Psychological Impact of Systemic Lupus Erythematosus on Men."

Your approval # is 03-03-15-0132267. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail is the IRB approved consent form. Please note, if this is already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date.

Your IRB approval expires on March 2, 2016. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date.

Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application document that has been submitted as of this date. This includes maintaining your current status with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 1 week of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you made a commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

Both the Adverse Event Reporting form and Request for Change in Procedures form can be obtained at the IRB section of the Walden website:
http://academicguides.waldenu.edu/researchcenter/orec
Researchers are expected to keep detailed records of their research activities (i.e., participant log sheets, completed consent forms, etc.) for the same period of time they retain the original data. If, in the future, you require copies of the originally submitted IRB materials, you may request them from Institutional Review Board.

Please note that this letter indicates that the IRB has approved your research. You may not begin the research phase of your dissertation, however, until you have received the **Notification of Approval to Conduct Research** e-mail. Once you have received this notification by email, you may begin your data collection.

Both students and faculty are invited to provide feedback on this IRB experience at the link below:
http://www.surveymonkey.com/s.aspx?sm=qHBJzkJMUx43pZegKlmdiQ_3d_3d

Sincerely,
Libby Munson
Research Ethics Support Specialist
Office of Research Ethics and Compliance
Email: irb@waldenu.edu
Fax: 626-605-0472
Phone: 612-312-1283
Office address for Walden University:
100 Washington Avenue South, Suite 900
Minneapolis, MN 55401

Information about the Walden University Institutional Review Board, including instructions for application, may be found at this link:
http://academicguides.waldenu.edu/researchcenter/orec

Appendix C: Demographic Questionnaire

1. Are you male?
2. How old are you?
3. Where do you reside?
4. Are you married or single?
5. What is your sexual orientation?
6. How long have you had Systemic Lupus Erythematosus?