EXAMINING THE IMPACT OF SELF-EFFICACY, POSITIVE SOCIAL SUPPORT, PROBLEMATIC SOCIAL SUPPORT AND RACE ON QUALITY OF LIFE IN SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS

by

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ABSTRACT

STACIE CAMP BENNETT. Examining the Impact of Self-Efficacy, Positive Social Support, Problematic Social Support, Self-Efficacy and Race on Quality of Life in Systemic Lupus Erythematosus Patients. (Under the direction of DR. SUSAN FURR).

Systemic Lupus Erythematosus patients are living longer with an unpredictable and incurable chronic condition (Dua, Touma, Toloze, & Jolly, 2013). Quality of life research allows insight into the impact of SLE and SLE treatments on different life domains from the patients' perspective. Despite knowing that quality of life in SLE patients is significantly lower than the general population, the relationships and roles of variables such as self-efficacy, social support, and race on quality of life in SLE patients are not well understood (Chaigne et al., 2017; Jolly, 2005; & Kuriya et al; 2008). The purpose of this study was to examine the impact of self-efficacy (SEMCD), positive social support (ISEL-12), problematic social support (Problematic Support Scale), and race on Health-Related and Non-Health-Related Quality of Life utilizing a lupus specific quality of life instrument (LupusPro). For this study, 344 participants were recruited from SLE support sites on Facebook and through Rheumatologist offices throughout the country. The majority of participants were White (72%), females (97%) with an average age of 45 years old. Results of multiple regressions indicate self-efficacy, problematic social support and positive social support accounted for 38% of the variance in Health-Related Quality of Life. Positive social support, self-efficacy, and problematic social support accounted for 25% of the variance in Non-Health-Related Quality of Life. Race did not demonstrate a significant impact on Health-Related or Non-Health-Related Quality of Life.

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CHAPTER 1: INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic, inflammatory, multi-system autoimmune disease that impacts up to 500,000 Americans (Lupus Foundation of America, 2017). Ninety percent of all SLE patients are women. The progression of SLE is characterized by unpredictable patterns of relapsing and remitting symptoms. SLE symptoms include but are not limited to fatigue, joint pain, hair loss, skin rashes, headaches, breathlessness, seizures, memory loss and confusion. More than half of all SLE patients will eventually develop functional or structural damage to one or more organs (Swaak, et al., 1999).

Survival rates for SLE have increased significantly in the past 40 years in response to medication and treatment advancements (Kuriya, Gladman, Ibenez, & Urowitz, 2008; Urowitz, Gladman, Abu-Shakra, & Farewell, 1997). However, living longer and managing an incurable and unpredictable disease comes at a significant psychosocial cost to the patient (Beckerman, Auerbach, & Blanco, 2011; Carr et al., 2011; Campbell, Cooper, & Gilkenson, 2008). Research indicates up to 65% of SLE patients meet the criteria for a psychiatric disorder, most commonly mood and anxiety disorders (Bachen, Chesney, & Criswell, 2009; Zhang, Fu, Yin, Zhang, & Shen, 2017). Depression and anxiety are associated with disease activity, pain, extreme fatigue, and side effects of toxic medications (Carr et al., 2011; Daleboudt, Berger, Broadbent, & Kaptein, 2011; Karlson et al., 2003; Moses, Wiggers, & Nicholas, 2008; O'Neill, & Cervera, 2010). In addition to depression, anxiety, pain, and fatigue, many SLE patients report feeling invisible and misunderstood by friends, family and medical professionals (Moses et al., 2008).

Statement of the Problem

Researchers, medical professionals, and counselors are being called to develop effective interventions to improve quality of life in SLE patients who are living longer with an unpredictable and incurable chronic condition (Dua, Touma, Toloze, & Jolly, 2013). Quality of life research allows insight into the impact of SLE and SLE treatments on different life domains from the patients' perspective. In turn, this information can be utilized by counselors through health promotion theories like Social Cognitive Learning Theory (SCLT) to develop and provide effective interventions for improving SLE patients' quality of life (Bandura, 1997 McCarley, 2009).

Despite knowing that quality of life in SLE patients is significantly lower than the general population, the relationships and roles of variables such as self-efficacy, social support, and race on quality of life in SLE patients are not well understood (Benitha & Tikly, 2007; Chaigne et al., 2017a; Daleboudt et al., 2011; Jolly, 2005; Kuriya et al; 2008; Wolfe, Michaud, Li, & Katz, 2010). A large amount of existing SLE quality of life research has utilized quality of life instruments that are not specific to SLE. In addition, limited research has addressed self-efficacy and problematic social support specifically in SLE patient quality of life (Mazzoni, Cicognani, & Petri, 2017). However, there is a paucity of research that addresses the combined influence of these variables in SLE patients' quality of life. In addition, there is no clear understanding of how race relates to SLE patients' quality of life when also considering self-efficacy and social supports. Without a true understanding of the relationships and roles of these variables, counselors cannot accurately assess

SLE patient needs nor can they formulate effective interventions for improving SLE patients' quality of life.

Quality of Life and Systemic Lupus Erythematosus Patients

The concept and definition of quality of life has been difficult for researchers to operationalize. According to The World Health Organization (1958), quality of life is an "individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p. 1). Quality of life generally includes an individual's perception of life satisfaction in their biological, psychological, and social wellbeing (Megari, 2014; Post, 2014). Health-related quality of life refers to the impact of an illness or the treatment of that illness on an individuals' physical, psychological, and social functioning (Megari, 2014; Shofany, 2017). Quality of life has been widely studied in chronic illness populations over the past twenty years and has been found to be predictive for mortality in several chronic diseases including rheumatoid arthritis (Dua et al., 2013; Michaud, Vera-Llonch, & Oster, 2012; Shofany, 2017). However, quality of life as specifically related to SLE is still emerging.

Existing research demonstrates significantly lower quality of life in SLE patients versus the general population (Benitha & Tikly, 2007; Chaigne et al., 2017b; Daleboudt et al., 2011; Jolly, 2005; Kuriya et al; 2008; Wolfe et al., 2010). Some studies have shown significant quality of life differences between SLE patients and other chronic illness populations including other rheumatic disease patients (Chaigne et al., 2017a; Daleboudt et al., 2011; Jolly, 2005). These differences include mental health, vitality, body image, feelings of isolation, lack of validation through family

and feeling misunderstood, concerns about fertility, and having to wait to have a family (Moses et al., 2008; Sutanto et al. 2013).

Non-disease specific quality of life instruments have been widely used when measuring SLE quality of life. As a result, many researchers question if the true impact of SLE on quality of life is being explored (Dua et al., 2013). In response, some researchers have begun to identify symptoms and domains that are specific to SLE quality of life by creating SLE-specific quality of life instruments (Grootscholten et al., 2003; Jolly et al., 2012; Leong et al., 2005; McElhone et al., 2007; Teh, McElhone, & Abbott 2010). For example, Jolly et al. (2012) utilized data from qualitative studies to create the Lupus Pro, a SLE-specific quality of life instrument. This study found areas of importance for SLE patients' health-related quality of life that include: (a) medications, (b) vitality, (c) sexual health, (d) physical functionality, (e) self-image, (f) emotional health, and (g) pain. Important non-health-related quality of life domains include: (a) desires and goals, (b) coping, (c) relationships and social support, and (d) satisfaction with care.

SLE quality of life research has demonstrated the importance of psychosocial factors (Mazzoni & Cicagnoni, 2011; McElhone et al., 2007; Moses et al., 2008; Rinaldi et al., 2006; Sutanto et al., 2013). For example, SLE patients with higher self-efficacy reported less pain, fatigue, and stiffness (Somers, Kurakula, Criscione-Scheiber, Keefe, & Clowse, 2012). Karlson et al. (1997, 2004) found that self-efficacy and social support were significantly related to mental health, disease activity, and fatigue levels. Once counselors understand the importance of self-

efficacy and social support in the treatment of SLE, counselors can intervene utilizing health promotion theories like (SCLT) to improve quality of life in SLE patients.

Self-Efficacy and Systemic Lupus Erythematosus Patients

Self-efficacy and social support are modifiable variables and are especially important for counselors when assisting individuals with a chronic illness like SLE (Bandura, 1997; Karlson et al., 2004; Mazzoni et al., 2017). Self-efficacy is defined as an individual's belief about personal competence to produce designated levels of performance, which influence events that affect living (Bandura, 1986). In terms of chronic illness, self-efficacy is patients' belief that they are capable of working with professionals and caregivers to manage their illness and treatments (McCarley, 2009). Self-efficacy influences how individuals think, feel, motivate self, and perform health behaviors (Bandura, 1997). For example, self-efficacy is associated with better treatment compliance, behavior changes, and quality of life in chronic illness populations (Marks, Allegrante, & Lorig, 2005; Mazzoni & Cicagnoni, 2014; Tsay & Healstead, 2002).

According to Bandura (1997), individuals with high self-efficacy will attempt more difficult tasks and will persist longer and with more effort than those with low self-efficacy. Individuals with high self-efficacy will also recover more quickly and continue to persevere with their goals when challenged with a setback. SLE is an unpredictable disease of flares and remission. Therefore, the ability to focus through setbacks could be especially useful for SLE patients. Thombs, Kwakkenbos, Riehm, Saadat and Fedoruk (2016) reported self-efficacy in SLE patients was lower than other similar chronic conditions. Existing SLE quality of life research supports the

positive relationship between self-efficacy and quality of life (Karlson et al., 1997; Karlson et al., 2004; Thumboo & Strand, 2007). However, the majority of SLE research on self-efficacy has focused on the effectiveness of SCLT interventions rather than the relationship between self-efficacy and quality of life (Marks et al., 2005; Mazzoni et al., 2017; Reblin & Uchino, 2008; Thombs et al., 2016).

Social Support and Systemic Lupus Erythematosus

Social support has been an intense area of research for health psychologists focused on improving quality of life in chronic illness patients (Symister & Friend, 2003). Social support can be provided by friends, family, social relationships, support groups, and medical professionals (Mazzoni & Cicagnoni, 2014; Reblin & Uchino, 2008). Social support has demonstrated significant relationships to mortality, functionality, pain, and general wellbeing in chronic illness populations (Reblin & Uchino, 2008. However, researchers and treating physicians do not have a well-developed understanding of the relationships and roles of social support in chronic illness management.

Positive Social Support and Systemic Lupus Erythematosus

Positive social support is defined as "the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us" (Mazzoni & Cicognani, 2011, p. 1118). Strong positive social support has been found to be one of the most important components for a high quality of life in SLE patients even if disease activity is high (Bae, Hashimoto, Karlson, Liang, & Daltroy, 2001; Daleboudt, et al., 2011; Meacock, Dale, & Harrison, 2013; Moses et al., 2008). SLE patients with positive social support demonstrated decreased stress levels

(Mazzoni & Cicognani, 2016), increased physical and mental functioning (Karlson et al., 1997; Zheng et al., 2009), decreased fatigue (Jump et al., 2007), and higher general wellbeing (Brooks, Andrade, Middleton, & Wallen, 2014). Yet many SLE patients expressed a lack of understanding and empathy by family, friends, employers and the public (Brennan & Creaven, 2016; Sutanto et al., 2013). However, researchers are increasingly exploring the fact that social support in SLE patients is not always perceived as desirable and may be negative in its outcomes (Mazzoni & Cicagnoni, 2016).

Problematic Social Support and Systemic Lupus Erythematosus

Problematic Social Support is defined as social support perceived by the recipient to be unneeded, unsolicited, or unhelpful (Boutin-Foster, 2005; Lehman & Hemphill, 1990; Riemsma et al., 2000; Revenson et al., 1991; Smyster & Friend 2003). The majority of problematic social support research has been performed on rheumatoid arthritis patients. Problematic social support for rheumatoid arthritis patients has been related to a decrease in life satisfaction (Coty & Wallston, 2010), increased depression (Coty & Wallston, 2010; Revenson et al., 1991; Riemsma et al., 2000), and increased fatigue (Riemsma et al., 1998). There is a paucity of research for problematic social support in other chronic illness populations including SLE.

Seminal research by Archenholtz, Burckhardt, and Segeston (1999) found that social support was the second highest area of dissatisfaction for both SLE and rheumatoid arthritis patients. Mazzoni and Cicognani (2016) found negative correlations between problematic social support and levels of stress, health-related quality of life, and non-health-related quality of life in SLE patients. A longitudinal

study by Mazzoni et al. (2017) found that problematic social support significantly influenced health-related quality of life in SLE patients. SLE quality of life researchers need to examine the impact of problematic social support on SLE patients in order to gain a better understanding of the impact of this phenomenon on SLE patients.

Race and Systemic Lupus Erythematosus Patients

SLE affects minority females more than any other population. SLE is diagnosed most frequently in women of African American, Indian, Asian, and Hispanic descent (Borcher, Naguwa, Shoenfield, & Gershwin, 2010; National Institute of Health, 2007). . Within SLE patient populations, African Americans have the highest mortality rates of all races or ethnicities (Alarcon et al., 1999; Alarcon et al., 2004; Cooper et al., 2002). The mortality for African Americans with SLE is significantly higher than that of white Americans (Alacron, 2006; Cooper et al., 2002; Hendricks; 2012; Krishnan & Hubert, 2006; Reveille, Bartolucci, & Alacron, 1990). Results from the on-going LUMINA (LUpus in Minorities: Nature versus Nurture) cohort indicate that individuals who are African American and Hispanic from Texas have higher levels of disease activity (Alacron et al., 2006). This same study has shown that African American women develop SLE earlier than other populations and accumulate disease damage more quickly (Alacron et al., 1999; Alacron et al., 2004; Cooper et al., 2002).

Despite the prevalence of SLE in African American, Hispanic, Native American, and Asian American women, the study of race specific quality of life in SLE patients is limited (Alacron et al., 1999; Alacron et al., 2004; Barnado, Wheless,

Meyer, Gilkeson, & Kamen, 2012).). Much of the existing SLE quality of life literature that addresses race and ethnicity has been plagued with possible cofounding variables of low SES, low education levels, or inconsistent results (Alacron et al., 2004; Karlson et al., 1997; Kiani, Strand, Fang, Jaranilla, & Petri, 2013). Kiani et al. (2013) found lower physical function scores in health-related quality of life for African American SLE patients.

Intervention programs to improve quality of life in SLE patients have not been widely validated for minority SLE patients (Williams et al., 2016). The impact of social support in minority SLE patients is not well understood. A study by Bloor et al. (2006) found a positive association between emotional support and health-related quality of life in all Caucasian SLE participants and in African Americans SLE participants with higher levels of education. Bloor et al. (2006) found that greater levels of emotional support were related to poorer self-perceptions of physical health in all African Americans SLE participants. In contrast, Williams et al. (2015) found no significant differences in social support levels between African American SLE patients with high levels of stress versus African American SLE patients with low levels of stress.

Research has shown low health-related quality of life in Mexican rheumatologic disease patients (Garcia-Carrasco et al., 2012). In addition, Mexican SLE patients reported feeling that their family and friends underestimated the impact of SLE on the patient's quality of life (Ramos-Remus et al., 2014). Some researchers believe that the cost of social support in some cultures exceeds the benefits (Etchegaray-Morales et al., 2017; Williams et al., 2015).

Purpose of the Study

The purpose of this study was to examine how health-related quality of life and non-health-related quality of life in Systemic Lupus Erythematosus patients were influenced by self-efficacy, positive social support, problematic social support, and race.

Significance of the Study

The significance of this study was to assist medical professionals, counselors, and SLE patients in better understanding the impact of self-efficacy, positive social support, problematic social support, and race on quality of life in SLE patients. Mental health and medical professionals are tasked with improving quality of life in culturally diverse SLE patients who are living longer with an unpredictable and incurable disease (Williams et al., 2016). Through health promotion theories like SCLT, counselors can utilize interventions to modify theory specific variables like self-efficacy and social support to increase quality of life in SLE patients.

However, knowledge has been limited regarding the relationships and roles of self-efficacy and social support on quality of life in SLE patients. Even less is known about the impact of problematic social support on quality of life in SLE patients. To date, no previous study has examined the impact of self-efficacy, positive social support, problematic social support, and race on SLE patients' quality of life. Researchers, medical professionals, and counselors must have a more thorough understanding of these variables if they hope to develop effective interventions to enhance quality of life in SLE patients.

Research Questions

The following research questions were addressed in this study:

1. How is health-related quality of life in adult Systemic Lupus Erythematous patients related to self-efficacy, positive social support, problematic social support, and race?
2. How is non-health-related quality of life in adult Systemic Lupus Erythematosus patients related to self-efficacy, positive social support, problematic social support, and race?

Research Design

This study was a correlational non-experimental survey design. Participants were a convenience sample of adult (18 or older) systemic lupus erythematosus patients. Participants were recruited from systemic lupus erythematosus Facebook support sites. No variables were manipulated in this study. This study did not produce causality for any of the variables involved. Participants voluntarily completed a web-based survey after they self-reported eligibility for age (18 or over) and diagnosis (SLE). Participants agreed to an informed consent before beginning the survey.

The survey obtained demographic information such as age, race, educational status, and length of time since SLE diagnosis. This demographic information allows the researcher to describe the group of participants. This survey utilized validated instruments to measure health-related quality of life, non-health-related quality of life, self-efficacy, positive social support, and problematic social support. A hierarchical multiple regression was utilized to examine the relationships between positive social support, problematic social support, self-efficacy, and race on health-related quality

of life and non-health-related quality of life in adult Systemic Lupus Erythematosus patients.

Assumptions

The following assumptions have been made in performing this study:

1. Participants were able comprehend and respond to each survey item.
2. Participants responded honestly to the self-report survey.
3. The intended respondent was the person that completes the survey.
4. Participants accurately comprehended and responded to the survey items to the best of their ability.

Delimitations

The researcher has identified the following delimitations:

1. Only participants over the age of eighteen were included in this study.
2. Only participants who have a diagnosis of Systemic Lupus Erythematosus were included in this study.
3. Participants were limited to individuals who are able to read and respond in English.

Limitations

The following limitations are true of this study:

1. The participants of this study were limited to adults who have a diagnosis of Systemic Lupus Erythematous; therefore the results cannot be generalized to other populations with chronic illness.
2. Social desirability bias is the tendency of participants to answer survey questions in a way they think might be favorable viewed by others. Due to the

wording of some of the survey questions, social desirability responses could limit the results of the study.

3. The sample was not randomly selected. It was a convenience sample. SLE patients were recruited from the Lupus Foundation of America, various rheumatologist offices, and Facebook SLE support sites.
4. The study was a correlational study; therefore, the researcher cannot make causal inference.

Threats to Internal Validity

Internal validity is associated with the extent to which the results of the study can be accurately interpreted (Johnson & Christensen, 2004). Surveys have the potential to compromise internal validity. To minimize threats to internal validity in this study, the instruments used to measure positive social support, problematic social support, perceived stress, self-efficacy, and quality of life both health-related and non-health-related have been evaluated for validity and reliability in previous studies. Another threat to internal validity might be the accuracy of self-report measures (Donaldson & Grant-Vallone, 2002).

Threats to External Validity

External validity is associated to the extent to which the results of the study can be generalized (Johnson & Christensen, 2004). This study utilized a convenience sample of respondents who respond to recruitment attempts through Facebook Lupus support groups. These participants may not be a complete sample of the entire population of SLE patients in the United States.

Operational Definitions

The operational definitions for the variables included in this research are as follows:

Health-related quality of life is defined as the impact of an illness or the treatment of that illness on an individuals' physical, psychological and social functioning (Megari, 2014; Shofany, 2017).

Non-health-related quality of life is defined as features of the natural and created environment, and personal resources that impact the individual's health perceptions, functioning and wellbeing (Jolly et al., 2007).

Self-efficacy is defined as an individual's belief about their competence to produce designated levels of performance which influences events that affect their lives (Bandura, 1986).

Positive social support is defined as "information leading the subject to believe that he/she is care for and loved, esteemed, and a member of a network of mutual obligations" (Cobb, 1976, p. 301).

Problematic Social Support is defined as social support that is not perceived by the recipient to be unneeded, unsolicited or unhelpful (Revenson et al., 1991).

Summary

This Chapter of the proposal is an introduction to quality of life in SLE patients and the variables of self-efficacy, positive social support, problematic social support and race. As SLE patients live longer with an unpredictable and incurable disease, modifiable factors that can increase quality of life are of vital importance. However, information regarding the impact of self-efficacy, positive

social support, problematic social support, and race on SLE quality of life is limited. In summary, the purpose of this study was to examine the impact of self-efficacy, positive social support, problematic social support, and race on health-related quality of life and non-health-related quality of life in SLE patients.

Organization of the Study

This dissertation is presented in three chapters. Chapter One, Introduction, provides the reader with information on the variables SLE patient quality of life, self-efficacy, positive social support, problematic social support, and race. Additionally, Chapter One defines the statement of problem, significance of this proposed study, research questions, research design, delimitations, limitations, assumptions, threats to external and internal validity, operational definitions, summary, and organization of this proposed study. Chapter Two, Literature Review, is a review of the relevant literature regarding the variables of this proposed study. Specifically, an in depth exploration of the previous research in this area was examined. Chapter Three, Methodology, is an outline of the methodology of this study, including, participants, procedures, instruments, data analysis, and summary.

CHAPTER 2: REVIEW OF THE LITERATURE

Introduction

Systemic lupus erythematosus (SLE) is a chronic, incurable, and unpredictable disease that takes a tremendous physical, psychological, and social toll. The quality of life for SLE patients has been shown to be lower than the general population and in some studies, lower than other rheumatic disease sufferers (Jolly, 2005). As SLE patients live longer, it is becoming increasingly relevant to medical and counseling professionals to determine factors that improve or decrease quality of life. Health promotion theories such as Social Cognitive Learning Theory (SCLT) seek to inform professionals on the relationships of modifiable factors such as positive social support, problematic social support, self-efficacy, and cultural factors such as race on individuals with chronic illness quality of life (Bandura, 1997). As medical professionals and counselors develop a better understanding of how these factors interact, we as a profession can begin to translate these findings into intervention strategies for SLE patients to improve their quality of life.

However, the literature concerning the interaction between positive social support, problematic social support, self-efficacy, and race with health-related quality of life in SLE patients is limited. To date, there is one study that addressed positive social support, problematic social support, and self-efficacy in Italian SLE patients' health-related quality of life (Mazzoni & Cicognani, 2016). There have been no comparable studies in the U.S and none that have also examined how race relates to self-efficacy, positive social support, and problematic social support in SLE patients' health-related quality of life.

This literature review will define and discuss systemic lupus erythematosus, quality of life, and social cognitive learning theory followed by a review of the literature on the constructs of this study: self-efficacy, positive social support, and problematic social support as related to quality of life in SLE patients. Each section includes relevant research as well as gaps that exist in the current literature. Each section will also include relevant literature available on race. The literature review concludes with a discussion of the lack of research studies relating self-efficacy, positive social support, and problematic social support in SLE patients.

Systemic Lupus Erythematosus

The term Lupus applies to three different autoimmune diseases: discoid lupus, systemic lupus erythematosus, and drug-induced lupus. Of these three different diseases, systemic lupus erythematosus or SLE is the most serious. Discoid lupus is usually contained to the skin and does not impact internal organs. Drug-induced lupus is typically triggered by a medication and then abates when the medication is discontinued. SLE presents with multiple symptoms in multiple systems that may initially mimic other diseases. These symptoms include rashes, fatigue, swelling of joints, arthritis, and pain. SLE inflammation can occur in the skin as well as in the nephrological, pulmonary, neurological, and cardiovascular systems. SLE patients often go undiagnosed or misdiagnosed for some time before receiving the correct diagnosis (Pons-Estel et al., 2010). SLE mimics bone, blood, lung, heart, muscle, and kidney diseases as well as diabetes, thyroid diseases, Lymes disease, fibromyalgia, and rheumatoid arthritis. Initial symptoms may also be unpredictable and mild, which makes individuals hesitant to seek medical treatment. SLE may lead to

disfigurement, disability, severe pain, organ damage, and depletion of the patient's financial, emotional, and support resources (Campbell et al., 2008).

Prevalence

SLE once was thought to be rare. However, changes in medical professional awareness and diagnostic criteria have led to a much different understanding of SLE. An estimated 500,000 Americans have been diagnosed with SLE with 1,600 patients newly diagnosed annually (Helmick, Felson & Lawarence, 2008). SLE occurs more often in women than men, with a ratio of 9:1. SLE is diagnosed most frequently in women of African, American, Indian, and Asian descent (National Institute of Health, 2013) during the ages of 15-40 (Sutanto et al., 2013). Hispanic women also demonstrate a higher prevalence than white women, but research is limited (Borchers et al., 2010). Before the 1950s, SLE patients had a lifespan of less than five years. According to Stoller, Michota, and Mandell in The Cleveland Clinic Institute of Intensive Review of Internal Medicine (2012) now indicates that 80% of SLE patients will live more than 15 years.

Definition

According to the Lupus Foundation of America website (2017), SLE is "a chronic, autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body)" (p.1). A chronic disease generally refers to one that lasts at least 12 months, requires on-going medical monitoring and interventions, and is not curable (Meacock et al., 2012). An autoimmune disorder occurs when an individual's immune cells no longer recognize other cells in the individual as belonging. When this occurs, the immune cells no longer produce antibodies to

protect the body's tissues and cells. The immune cells instead begin to produce autoantibodies against the body's own tissues. The immune system reaction creates inflammation and damage to these tissues (Mendelson, 2006; Pons-Estel et al., 2010). For SLE there is no known cause, although genetics, environment, and viral infection are all suspect (Borchers et al., 2010).

Symptoms and Diagnosis

SLE symptoms include: debilitating pain, debilitating fatigue, joint pain, fevers, breathlessness, musculoskeletal pain, hair loss, headaches, seizures, oral ulcers, malar rash, photosensitivity, pain in the chest, thrombocytopenia, leukopenia, Raynaud's phenomenon, memory loss, and confusion (Helmick et al., 2008; Simard & Costenbader, 2007). More than half of all SLE patients will eventually develop functional or structural damage to one or more organs (Swaak et al., 1999). SLE can impact the heart, kidneys, lungs, and brain (D'Cruz, Khamashta, & Hughes, 2007). According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (2013), there is no definitive test used to diagnose SLE. It is diagnosed through a process of medical examinations, symptom history and monitoring, blood analysis, and biopsies. Blood analysis of anti-DNA, anti-Sm, anti-RNP, anti-Ro (SSA), and anti-La (SSB) look for antibodies often present when an individual has SLE. These tests are not conclusive, however. An individual may test positive for antibodies for different reasons such as infection, another autoimmune disorder, or other unknown factors.

SLE patients often suffer for long lengths of time before being diagnosed. It can take years of going to multiple doctors for multiple tests before being definitively

diagnosed (Wallace, 2002). Often SLE patients feel as though their doctors and family believe they are malingering or hypochondriacs (Hale et al., 2006). As a result, many SLE patients feel isolated, misunderstood, and depressed (Brennan, 2016). In seven studies reviewed by Sutanto et al. (2013), subjects reported going to the doctor multiple times for symptoms that were misdiagnosed or ignored. (Chute, 1998; Goodman, Morrisey, Graham, & Bossingham, 2005; Hatfield-Timajchy, 2007; Mendelson, 2006; Miles, 2009; Porter, 2000; Zeddies, 2002). Many SLE participants report being diagnosed with depression when they presented with initial symptoms. After diagnosis most of these subjects reported feeling validated, relieved, and "not crazy". They felt as though their doctors, families and friends would finally believe their struggle.

Flare and Remission Patterns

SLE patients generally experience symptoms in a flare/remission pattern that is difficult to predict. A flare occurs when disease activity increases, new symptoms occur, new organ systems become involved, or there is a worsening of existing symptoms or organ involvement (Moses et al., 2008). When a flare occurs, the SLE patient requires more medical examination and monitoring, medical tests, increases or changes in medications, and possible hospitalization while experiencing crippling fatigue and pain. During a flare, it is often difficult or impossible for the patient to participate in work, family, or social roles due to symptoms of SLE or side effects of the medications used to treat SLE (Beckerman & Sarracco, 2012; Sutanto, et al., 2013). The SLE patient's needs for psychosocial resources such as social support

increase during a flare, with their quality of life, and mental and physical health decreasing (Beckerman & Sarracco, 2012; Meacock et al., 2013).

Three patterns of SLE disease activity have been defined (Petri, Buyon, & Kim, 1999). One pattern is known as relapsing remitting. This pattern occurs when symptoms present after a period of being in remission or symptom free. As stated previously, these symptoms can be pre-existing or can be new symptoms with new system involvements. The second pattern is chronic activity. This pattern is characterized by continuous disease activity. In chronic activity, there is no return to a normal, symptom-free state. The third pattern is quiescence. This pattern indicates long periods of the individual being symptom free with no disease activity interspersed with unpredictable periods of increased disease activity and symptoms (Moses et al., 2008). From day to day, individuals living with SLE cannot predict their energy, pain, or disease activity levels (Moses, Wiggers, Nicholas, & Cockburn, 2005). This uncertainty stresses their ability to participate in family, work and social roles.

Quality of Life

Research in the areas of pharmacology, medicine, and lifestyle has increased the lifespan of humans in general, and individuals with chronic illness specifically. Yet living longer with an invisible disease with unpredictable symptoms, unpredictable flares, and remissions produces significant issues in SLE patients' physical, psychological, and social wellbeing (Tamayo, Fischer-Betz, Beer, Winkler-Rohlfing, & Schneider, 2010). For SLE patients, the unpredictable and chronic nature of SLE decreases physical and emotional quality of life (Kulczycka, Sysa-

Jedrejowska, & Roback, 2010). Disease activity and symptoms do not necessarily predict the emotional wellbeing of SLE individuals. As a result, the Systemic Lupus International Collaborating Clinics recommended that in addition to SLE diagnostic criteria and disease activity, quality of life should also be taken into account by helping professionals when considering the impact of SLE and SLE treatments on patients (Gladman et al., 1996).

The World Health Organization (1958) defined quality of life as "individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p. 3). Quality of life generally includes an individual's self-reported life satisfaction on their biological, psychological, social, and spiritual well being (Meagari, 2014; Post, 2014). As early as 1947, the WHO viewed health as "not just the absence of disease or infirmity" but rather as a biopsychosocial state of well being (Meagari, 2014).

Quality of life is a term that has been increasingly utilized in research on chronic illness over the past twenty years (Shofany, 2017). Quality of life research offers helping professionals a quantitative, patient-specific perspective on how a specific chronic illness impacts physical, psychological, and social areas of the patient's life in contrast to a healthy general population or to patients suffering from another chronic illness. It also allows practitioners to examine the cost versus detriment of treatment interventions, outcome measures for interventions, and the ability for treatment modifications. Insurers, physicians, and patients are now

utilizing quality of life to justify benefits and treatment decisions (Barnado et al., 2012; Doward et al., 2011; Dua et al., 2013; Strand et al., 2000; Zhu et al., 2010).

While widely used in health research and literature, the meaning of quality of life is often vague and study dependent. To further confuse meaning, the term health-related quality of life is often used interchangeably with quality of life in the literature. Shofany (2017), Meagari (2013), and Post (2014) reviewed available research on quality of life and health-related quality of life for chronic illness patients in an effort to explore the various meanings and measures utilized by different studies. These reviews agreed that while the definitions of quality of life and health-related quality of life vary by researcher, theory, and measurement instrument, there tends to be a shared concept of a multidimensional approach. This multidimensional approach includes biological, psychological, and social domains.

Health-related quality of life as a term manifested itself in the 1980s (Post, 2014). It refers to the impact of an illness or the treatment of that illness on the individuals' physical, psychological, and social functioning (Megari, 2014; Shofany, 2017). However, measures of illness impact on an individual's life pre-existed the terminology of quality of life. These measures included The Nottingham Health Profile, the Sickness Impact Profile, and the SF-36 (Bergner, Bobbitt, Pollard, & Martin, 1976; Hunt et al., 1980; Ware & Sherbourne, 1992). These generic measures of health-related quality of life, specifically the SF-36, have been greatly utilized in chronic illness quality of life research and will be discussed further later in this review.

The complicated nature of defining and measuring quality of life is not lost on SLE quality of life literature. When examining the research literature, it becomes evident that the factors that influence the biopsychosocial lives of SLE patients are not neatly contained within one area of research. There tends to be three prominent means of defining and collecting quality of life in SLE data. These data collections means include qualitative research, non-disease specific quality of life measures like the SF-36, and SLE- specific quality of life measures like LupusPRO. All methods of measurement have offered valuable insights into the field, but all have limitations as well**.**

Qualitative Research

Qualitative research on SLE patients' quality of life has been valuable in allowing researchers, clinicians, and family members to better understand the internal experience of SLE patients. Although qualitative studies on the topic of SLE and quality of life tend not to use the term quality of life per se, the domains of biological, psychological, and social functioning tend to be similar (Beckerman & Sarracco; 2012; Brennan & Creaven, 2016; Cleanthous et al., 2014; Mendelson, 2006; Sutanto et al., 2013). Qualitative data have been able to capture the experience of SLE patients that may be lost in non-disease-specific quality of life measures. For example, postponing parenthood, body image, and fatigue are not addressed in the SF-36 (Sutanto et al., 2013). The limitations of qualitative studies tend to be convenience samples that have small sample sizes, and therefore leads to a lack of generalizability.

Sutanto et al. (2013) reviewed 46 qualitative studies that had studied adult, SLE patients and their experiences of living with SLE. The analysis of these qualitative studies revealed five themes that followed the biological, psychological, and social domains associated with quality of life. These themes were: (a) Restricted lifestyles (pervasive pain, debilitating fatigue, mental deterioration, disruptive episodic symptoms, and postponing parenthood); (b) Disrupted identity (gaining diagnostic closure, prognostic uncertainty, being a burden, hopelessness, fear of rejection, guilt, and punishment); (c) Societal stigma and indifference (illness trivialization, socially ostracized, and averse to differential treatment; (d) Gaining resilience (optimism, control and empowerment, being informed and involved, and mutual understanding, and (e) Treatment adherence (preserving health, rapport with clinicians, negotiating medication regimens, and financial burdens).

Other qualitative studies have identified themes of loss of physical ability, independence, family balance, identity, coping with uncertainty related to disease activity and symptoms, feeling invisible, and lack of validation through family, friends and medical professionals (Beckerman & Sarracco; 2012; Brennan & Creaven, 2016; Mendelson, 2006; Rutter & Kiemle, 2015). The available qualitative data on SLE patients definitively outlines the need for further research in how feelings of stress, sense of self, feelings of control, and social support impact quality of life. Brennan and Creaven's (2016) qualitative study and Sutanto et al.'s (2013) literature review bring to the light the concepts of self-efficacy, positive social support and problematic social support.

Gallop et al. (2012) suggested a conceptual model of health-related quality of life for SLE patients. This cross-sectional, qualitative study employed a purposeful sample of twenty-two U.S. SLE patients. This study utilized a literature review of SLE symptoms and health-related quality of life variables to create semi-structured interview questions to focus on quality of life specific for SLE patients. The model developed by Gallop et al. (2012) focuses on the interconnectedness of all aspects of the SLE patients' life.

The first level of the Gallup et al. (2012) conceptual model is made up of the physical activities, stress and environmental factors that influence the second level of the model, SLE symptoms. In turn, SLE symptoms influence the domains of: cognitive abilities, social/family/leisure, employment, emotional impact, impact on appearance, and impact on daily living, All of these domain are also multidirectional in that they influence one another in addition to being influenced by SLE symptoms. This conceptual model demonstrates the complexity and interconnectedness of all levels of an individual's SLE experience that create health-related quality of life.

Non-disease specific Quality of Life Measures

The Medical Outcomes Study Short Form-36 has demonstrated reliability and validity for measuring quality of life in SLE patients as well the general population and other illness populations (Gladman et al., 1996; Urowitz et al., 2012; Ware & Sherbourne, 1992;Yazdany, 2011). The SF-36 is the most used instrument for SLE quality of life studies. The Systemic Lupus International Collaborating Clinics recommended the use of the SF-36 in examining quality of life for SLE patients (Gladman et al., 1996). The SF-36 looks at the impact of illness on biological,

psychological, and social domains with eight subscales that include: Physical Function, Role Physical, Bodily Pain, Global Health, Vitality, Social Function, Role Emotional, and Mental Health. The benefit of the SF-36 is that it allows for the comparison of SLE against the general population as well as against other illness populations (McElhone et al., 2006; Ware & Sherbourne, 1992). Yet some studies have suggested that the SF-36 may not be sensitive to differences in quality of life over time in SLE patients and may be missing dimensions specific to SLE like fatigue, sleep, and body issues (Kuriya et al., 2008; Leong et al., 2005). The SF-36 only measures health-related quality of life and does not account for non-health-related quality of life domains. Often in SLE quality of life research, the SF-36 is paired with SLE-specific instruments to measure variables such as body image, fatigue, and sexual wellbeing (Devillieres et al., 2012).

Some researchers conducting studies using non-disease specific quality of life measures have suggested that SLE patients may have lower quality of life in certain domains than other chronic illnesses (Benitha & Tikly, 2007; Chaigne et al., 2017a; Jolly; 2005; Wolfe et al., 2010). Jolly (2005) utilized the SF-36 to compare 90 SLE patients to patients with diabetes, depression, congestive heart failure, hypertension, and myocardial infarction. Results indicated that not only were SLE patients significantly lower in quality of life than age-matched women in the general U.S. population, but they were also significantly worse in all domains than individuals with hypertension, diabetes, and myocardial infarction. Congestive heart failure clients were comparable to SLE patients in physical function, role-physical, role emotional, and vitality. SLE depressive patients had lower quality of life in emotional

and mental health domains. This study was limited by a small sample size and the fact that to date, these results have not been replicated successfully for a significant difference on all domains of quality of life.

Even within rheumatoid illnesses, SLE patients can present with different quality of life issues. Chaigne et al. (2017a) utilized the SF-36 to compare quality of life in 267 Swiss SLE patients versus 267 Swiss rheumatoid arthritis patients. These results indicated that while both are rheumatoid diseases, when participants were matched by age, sex, and duration of illness. SLE and rheumatoid arthritis affected quality of life differently. SLE patients demonstrated greater disturbance in mental health than rheumatoid arthritis, whereas rheumatoid arthritis patients were impacted more in physical health. These results support data by Benitha and Tikly (2007) for 50 South African SLE versus RA patients. This study found that rheumatoid arthritis participants had greater physical dysfunction and bodily pain. SLE patients had a significant relationship between disease activity and physical health, mental health, and vitality scores. Greenfield et al. (2017) compared four groups of systemic autoimmune rheumatic diseases and found that SLE patients had lower mental component summary scores than RA patients. SLE patients scored higher on mental component scores than participants with idiopathic inflammatory myopathies or systemic sclerosis. These studies bring to focus the fact that although general quality of life measures assist researchers in comparing different populations, these scores may not always be useful in viewing the nuances of a specific disease.

Studies using the SF-36 have demonstrated a lack of sensitivity in change of quality of life in SLE patients over time. Kuriya et al. (2008) and Panopalis et al.

(2005) both utilized the SF-36 to evaluate quality of life in SLE patients over time. At baseline, participants had significantly lower quality of life in all domains than the general population. Kuriya et al. (2008) found no significant change in quality of life in Canadian SLE patients over an eight-year period even when accounting for disease activity, damage accumulation, or steroid use. There was a significant difference in nonwhite participants' physical function as compared to white participants with SLE over the eight-year period. Panopalis et al. (2005) reviewed quality of life in 715 Canadian, U.S., and U.K. SLE patients over the course of four years. They also found that quality of life remained stable in SLE patients in all three countries over time.

The relationship between disease activity and quality of life in SLE patients is varied in the literature. Several studies such as Chaigne et al. (2017b), Jolly (2005), Kulczycka et al. (2010), and Urowitz et al., (2014) have reported a relationship between an increase in SLE disease activity and a decrease in quality of life areas such as role physical and role emotional domains. However, these relationships were weak, and these studies were cross-sectional in nature. The nature of the disease activity such as musculoskeletal, renal involvement, and photosensitivity may also be impactful to understanding the relationship between SLE disease activity and quality of life. Often a physician's report of disease activity is different from a patient's self reported outcomes (McElhone et al., 2007). McElhone et al. (2007) suggested that disease activity, damage accumulation, and health-related quality of life are three different independent domains that should be viewed through variance by researchers.

Disease Specific Quality of Life Measures

It is important to note when reviewing quality of life and SLE research, there has been a call to develop and utilize SLE-specific quality of life measures for the purpose of content validity (Jolly et al., 2012; McElhone, Abbott, Gray, Williams, & Teh, (2010). The U.S. Food and Drug Administration has highlighted the need to look at SLE-specific issues like fatigue as a component of both SLE symptoms and treatment (Holloway et al., 2014). Lupus-specific measures like LupusQoL, L-QoL, SLEQoL, SLE Symptom Checklist, and LupusPro are being investigated in an effort to better measure change over time, assess SLE- specific domains, and evaluate specific therapeutic interventions in SLE patients' quality of life data (Jolly et al., 2012; Touma & Gladman, 2017). Some disease-specific quality of life measures like the LupusPro differentiate between health-related quality of life and non-health-related quality of life in SLE patients (Dua, et al., 2013; Jolly et al., 2012; Yazdany, 2011). Health-related quality of life domains for SLE-specific quality of life include: SLE symptoms, cognition, medication side effects, fertility, body image, fatigue, and intimate relationships (Harrison et al., 2012; Jolly et al., 2012). Non-health-related quality of life allows researchers to look at the relationship between SLE and SLE treatment on coping, social support desires-goals, and satisfaction (Jolly et al., 2012).

SLE-specific quality of life instruments attempt to combine results from both qualitative studies and SF-36 or other general quality of life measured studies. Many of the SLE-specific quality of life measures are normed against the SF-36 and have proven validity and reliability (Jolly et al., 2012). The limitations of SLE-specific quality of life instruments lie in limited generalizability in minority populations as

well as in certain nationalities (Dua et al., 2013; Jolly et al., 2012; McElhone et al., 2010; Yazdany, 2011).

Moses et al. (2008) developed a Needs Assessment Questionnaire specifically for SLE patients. Their six-month study of Australian SLE participants suggested that the stability of quality of life might be a result of SLE patients having significant unmet needs that remained unmet over time. They found no significant difference in quality of life over time by age, ethnicity, medication use, marital status, or time since diagnosis. Moses et al. (2008) also found that SLE patients had more unmet needs than other patient populations. These findings are supported by Danoff-Burg and Friedburg (2009) who performed a similar study on New York SLE patients. For this population, the greatest unmet needs were related to fatigue, pain, and sleep issues followed by needs related to fear of disease progression, anxiety, and depression. Unmet needs on the social domain included anxiety and stress around maintaining relationships with family and friends as well as changing sexual relationships.

Cultural Considerations of Quality of Life

As reported, SLE impacts minority females more than any other population. Within the SLE patient population, African Americans have the highest mortality rates of all race or ethnicity. The mortality for African Americans with SLE is three times higher than that of white Americans (Alacron, 2006; Cooper et al., 2002; Hendricks, 2011; Krishnan & Hubert, 2006; Reveille et al.,1990). Research indicates that African American women develop SLE earlier than other populations and accumulate disease damage more quickly (Alacron et al., 1999; Alacron et al., 2004; Cooper et al., 2002).

One of the most notable studies on ethnicity and SLE disease activity is the ongoing Lupus in Minorities: Nature vs. Nurture or LUMINA study (Alacron et al., 2006). This study has been ongoing since 1994. The LUMINA study published results in 1999 that examined factors related to disease activity in a diverse sample that included 100 Hispanics from Texas, 94 Hispanics from Puerto Rico, 199 African-Americans, and 161 whites. Ninety percent of these participants were women. This study used a descriptive, univariate and multivariate analysis to identify the impact of age, ethnicity, education, occupation, marital status, health insurance, income, social support coping behaviors, and helplessness on disease activity over the course of an average of 3.5 years.

Results from the LUMINA cohort indicated that individuals who are African American and Hispanic from Texas had higher levels of disease activity (Alacron et al., 2006). This study found that psychosocial and socioeconomic factors such as health insurance, poor social support, poor coping skills, and poverty were significantly related to higher levels of disease activity (Alacron et al., 1999; Alacron et al., 2001; Alacron et al., 2004; Alarcon et al., 2006). African American female SLE patients demonstrated the most difficulty in maintaining follow-up appointments. The LUMINA study as well as a study by Petri et al. (1999) indicated that individuals with lower income, higher unemployment, lower educational levels, no insurance, and less access to health care had higher morbidity, more severe symptoms, and lower QoL. In these studies, African American SLE patients had the highest prevalence of these socioeconomic factors.

The Einstein Lupus Cohort in New York demonstrated similar findings to the LUMINA study (Blanco, 2017). The Einstein Lupus Cohort consisted of 300 SLE participants, which included a sample of individuals who were African American (57%) and Hispanic (37%). This study found that racial and ethnic minority participants had higher rates of permanent damage, lupus nephritis, and other severe health issues like stroke, anemia, and infections. African Americans were more likely to be working while disabled. This cohort demonstrated greater anxiety for participants who had to live with someone other than their spouse. These individuals reported struggling with feelings of being a burden and isolation.

SLE-specific quality of life instruments have been used internationally. Studies using LupusQoL have been performed in the U.S., China, France, Germany, Iran, Italy, Mexico, Spain, Turkey and the U.K (McElhone et al., 2007). Out of fourteen studies utilizing the LupusQoL, performed in nine different countries, the most commonly affected domains were being a burden to others and fatigue (Delis;, 2016; Devilliers et al., 2012; Devilliers et al., 2015; Etchegaray-Morales et al., 2017; Garcia-Carrasco et al., 2012; Gordon et al., 2013; Mirbagher, Gholamrezaei, Hosseini, & Bonakdar, 2016; Pamuck et al., 2013; Yilmaz-Oner et al., 2015). Significant relationships were found between quality of life and disease activity, accumulated damage fibromyalgia, depression and anxiety (Dua et al., 2013; Garcia-Carrasco et al., 2012; Kulczycha et al., 2010; Kuriya et al.,2008; McElhone et al., 2007; Touma et al., 2017; Zhu et al., 2010).

All studies performed in Mexico, Turkey and Italy ranked feeling like a burden as the most affected domain. Body image was not as important to quality of

life in Turkish studies (Pamuk et al., 2013; Yilmaz-Oner et al., 2015), and planning was not as important to quality of life in Mexican studies (Etchegaray-Morales, 2017; Garcia-Carrasco et al., 2012). European studies did not rank intimate relations as an important domain to quality of life (Gordon et al., 2013). Studies examined were both cross-sectional and longitudinal.

Despite the instrument utilized to measure quality of life, research has clearly indicated a complex and interactional system of biological, psychological, and social domains that are affected by SLE. Conversely, SLE symptoms appear to be influenced by biological, psychological, social domains, and interventions. As age, disease activity, fatigue, comorbid conditions, pain levels, and sleep difficulties increase, quality of life decreases (McElhone et al., 2007; Stoll et al., 1997; Karlson et al., 1997; Seawell & Danoff-Burg, 2004; Strand et al., 2000; Zheng et al., 2009). Depression, anxiety lack of coping, and social support correlate with a decrease in SLE patient quality of life and an increase in disease activity and pain. As educational status, disease duration, social support, self-efficacy, and knowledge of lupus increase, quality of life tends to increase. As quality of life increases, pain levels, fatigue and disease activity decrease (Karlson et al., 2004; Zeng et al., 2009).

Positive social support and self-efficacy remain consistent variables in chronic illness research. These variables both have demonstrated positive relationships with treatment adherence, satisfaction with medical care, and quality of life in SLE patients (Mazzoni & Cicognani, 2011). Both have demonstrated a negative correlation to pain, disease activity, and fatigue. Positive social support and self-efficacy are extremely important concepts for the management of chronic illness

because they are considered to be factors that are modifiable through education and therapeutic interventions (Karlson et al., 2004). Social cognitive learning theory assists researchers in gaining a better understanding of social support and self-efficacy as modifiable variables.

Social Cognitive Learning Theory

Social cognitive learning theory was derived from behavioral theories but sought to include the internal process of individuals as well. SCLT is one of the most utilized health behavior change theories in the area of management of chronic illness (Painter et al., 2008). SCLT frames the concept of health behavior through the interaction of five internal and external variables. These variables are: (a). self-efficacy, (b). perceived barriers and aids to change (social, environmental, and individual self-efficacy), (c). outcome expectations (social models and support), (d). knowledge of risks and benefits, and (e). goals (social support through medical professionals, social models, and self-efficacy) (Westmaas, Gil-Rivas, & Silver, 2007). Because of the relationship that occurs among these variables, Bandura (2005) believed that "human functioning is rooted in social systems" (p. 10).

The five variables of health behavior determine an individual's habits, meanings, purpose, routines, patterns, and health behavior skills. Health behaviors are achieved through the vicarious experiences of people seen as similar to one's self. Individuals determine their capabilities by comparing themselves to social models. Social models can demonstrate effective or ineffective coping skills and strategies for dealing with environmental factors. When an individual sees positive coping or behavior change occurring, they can in turn develop a greater sense of confidence in

succeeding at the behaviors themselves. When individuals are given social messages of support and confidence in their ability, they in turn develop a greater sense of confidence at succeeding (Bandura, 1997). This internal confidence is called self-efficacy and is considered the most important component of SCLT.

Although, Bandura does include social factors into reciprocal determinism, these forces have largely taken the background in research to psychological influences in the determination of self-efficacy. As a result, self-efficacy is not well understood through the lens of social context, which includes "historical, political, and legal structures and processes (e.g., colonialism and migration), organizations and institutions (e.g., schools and health care clinics), and individual and personal trajectories (e.g., family, interpersonal relationships" (Burke et al., 2016, p. 111S). This is an important consideration for the purpose of this study, which seeks to examine the relationships between self-efficacy, positive social support, problematic social support, race, and quality of life in adults with SLE.

Self-Efficacy

Self-efficacy is defined as an individual's belief about their competence to produce designated levels of performance, which influences events that affect their lives (Bandura, 1986). In terms of chronic illness, self-efficacy is patients' belief that they are capable of working with professionals and caregivers to manage their illness and treatments (McCarley, 2009). Self-efficacy influences how individuals think, feel, motivate self, and perform (Bandura, 1997). Self-efficacy may be especially important when assisting individuals in long-term maintenance of a chronic illness. According to Bandura (1997), individuals with high self-efficacy will attempt more

difficult tasks and will persist longer and with more effort than those with low self-efficacy. Individuals with high self-efficacy also will recover more quickly and continue to persevere with their goals when challenged with a setback. As SLE is an unpredictable disease of flares and remission, this ability to focus through setbacks may assist the individual in coping and persisting.

There are four different sources of information that form an individual's perceived self-efficacy (Bandura, 1997). These sources are mastery experiences, vicarious experiences, verbal/social persuasion, and physiological state. Mastery experiences are the most powerful source of self-efficacy information. Mastery experiences involve the individual attempting behaviors, persisting through obstacles, and rebound from setbacks. Mastery experiences can be developed early in a patient's diagnosis by having written goals and processing how realistic these goals are for the patient. Clinicians can also assist by processing obstacles and failures in a meaningful effort to persist and move forward. Once attempts have succeeded through obstacles, self-efficacy can then be generalized to other situations

Vicarious experiences or modeling refers to the patient being able to observe other individuals' efforts and experiences in succeeding at a desirable behavior (Bandura, 1997). Vicarious experiences can take place in support groups or psychoeducation groups for individuals with the same chronic illness. Verbal persuasion refers to the message individuals receive from meaningful individuals regarding their capability to be successful. Verbal persuasion can be a coachable behavior for family members, caregivers, and physicians of SLE patients. Finally, patients must be able to identify physiological and emotional states in order to

identify strengths and weaknesses that may affect their ability to meet their goals. These informational domains are successful avenues for increasing self-efficacy in the chronic illness patient (Cramm Strating, & Nieboer , 2013).

Self-Efficacy and Chronic Illness

Self-efficacy has demonstrated positive correlations to medication adherence (Es et al., 2002), health behaviors (Bar-Mor, Bar-Tal, Krulik, & Zeevi, 2000), pain management (Somers et al., 2012), and disease management (Lorig & Holman, 2003) in chronic illnesses. Self-efficacy has demonstrated a consistent positive correlation with quality of life across most chronic illnesses (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002; Lorig & Holman, 2003). Higher levels of general self-efficacy are associated with higher levels of global quality of life (Scholtz et al.2002).

Rutten et al., (2016) performed a cross-sectional study with data from the Health Information National Trends Survey of U.S. adults collected in 2012-2013. The sample size of this study was 3,630. Researchers analyzed this data for the prevalence of six chronic conditions, depression and anxiety, patient-centered communication, and health-related self-efficacy. All results were self-report, and self-efficacy was measured utilizing one question. Participants were asked to rate their confidence in their ability to take care of their health. Self-efficacy was measured using a Likert 5-point scale with completely competent, very competent, somewhat competent, a little competent, and not competent at all as answer choices. Multiple linear regressions were utilized to analyze the relationship between predictors and outcome variables, adjusting for sociodemographic and healthcare characteristic.

Results of Rutten et al. (2016) indicated that individuals with greater chronic illness burden (more than one chronic condition) had less health self-efficacy. Individuals who reported depression or anxiety had significantly lower health self-efficacy. Higher levels of patient-centered communication demonstrated higher levels of self-efficacy. This association was even more pronounced when participants had more than one chronic illness and had depression or anxiety. Chronic conditions of high blood pressure, arthritis, depression/anxiety, lung disease, and diabetes were present at higher rates in individuals who were older, divorced, separated, or widowed. Higher education and income were associated with fewer chronic conditions. These findings support the current trend toward interventions to assist chronic illness patients in developing self-management skills.

Self-efficacy is a crucial component of self-management and symptom management (Marks et al., 2005; Ritter, Lee, & Lorig, 2011). Interventions that enhance perceived self-efficacy seek to change health behaviors by altering cognitive processes (Bandura, 1997). Marks et al. (2005) suggested that higher self-efficacy in performing symptom controlling behavior may be symptom management and self-management enhancing in its own right. Self-management programs should attempt to enhance an individual's self-efficacy by:(a) identifying and reinforcing the patient's past and present successful accomplishments; (b) directing the patient to observe successful behaviors of others;(c) providing positive feedback for the patient's efforts and encourage others in the patient's social network to do so; and (d) trying to ensure that patients interpret their feelings correctly. (Hoffman, 2013;

Mazzoni, Cicognani, & Petri, 2017). Many self-efficacy enhancing interventions come in the form of positive social supports.

Robbins, Allegrante, and Paget (1993) reported that many interventions studied are not successful for minority groups due to their use of majority group values, symbols, and practices. This is an important consideration when considering SLE is predominantly a minority female disease. Ethnic minority patients also have more severe symptoms and worse prognosis than white patients (Mosley-Williams et al., 2002). SCLT and other social theories have fallen short in finding how theoretical constructs apply to different culture as well as interventions that address ethnic minority group's social norms and beliefs. They have also failed to address cultural distrust of medical systems and socio-economic disparities (Assaari & Lankarani, 2016; Burke et al. 2009). Rutten et al. (2016) found that individuals who received positive clinician-patient communication had higher degrees of self-efficacy. This relationship was even more important when accounting for multiple chronic illnesses and depression.

Self-Efficacy and Rheumatoid Arthritis

SCLT constructs have been more widely researched in rheumatoid arthritis than in SLE (Knittle, Maies & de Gucht, 2010). Indeed, some of the earliest research applying SCLT to self-management was conducted in the field of arthritis. Lorig at al. (1986) are credited with applying SCLT to facilitate arthritis patients in developing disease self-management skills. Lorig et al. (1985) also developed the Arthritis Self-Management Program based upon self-efficacy theory. This program reported significant early and long term improved arthritis self-efficacy, pain management,

depression management, increased exercise, relaxation, and self-management activities without added cost to the patient. In addition, the program demonstrated improved health status, increased feelings of control, and reduced medical service usage (Barlow et al., 2002).

High self-efficacy in arthritis patients has been correlated with better pain management (Arnstein, Caudill, & Mandle, 1999), controlling of stress and decreased fatigue (Riesma, et al., 1998), better psychological functioning (Schiaffino & Revenson, 1995), and increased quality of life (Lorig et al., 2001). A more recent study by Hammond and Freeman (2001) demonstrated significant improvement in hand pain, general pain, early morning stiffness, self-reported number of flares, and visits to the doctor for arthritis symptoms as a result of increasing arthritis self-efficacy through a joint protection program.

Gong and Mao (2016) studied the impact of self-efficacy on 207 Chinese rheumatoid arthritis patients utilizing the SF-36, the eight-item, Arthritis Self-Efficacy Scale and the MOS Social Support Survey utilizing structural equation modeling. This study found a significant direct positive effect of self-efficacy on the psychological well being of Chinese patients with rheumatoid arthritis. Individuals with lower self-efficacy reported more intense depression and anxiety. Low self-efficacy was significantly, directly and indirectly, negatively correlated with mental and physical health-related quality of life. Health-related quality of life was negatively correlated with participants with lower self-efficacy, greater fatigue, lower social support, being employed, higher disease activity, lower income, being female, being older, and living in a rural setting.

Lorig et al. (2001) performed a randomized, controlled study to examine the impact of a self-management intervention based on self-efficacy theory on health status and health service utilization in 489 participants with various chronic illnesses. After one year, participants of the seven-week, small-group intervention demonstrated statistically significant increases in self-efficacy, health behaviors (exercise, cognitive symptom management, and communication with physician), health status (fatigue, shortness of breathe, pain, role function, depression, and health distress) and decreased visits to the emergency department than those who were not in the program. At a two-year follow up, participants had significantly higher self-efficacy and significantly lower health distress (Lorig et al., 2001).

Self-efficacy and Systemic Lupus Erythematosus

There is a paucity of research for SCLT and SLE, especially concerning self-efficacy. Much of the SLE self-efficacy research was conducted as part of intervention studies (Drenkard et al., 2012). SCLT based interventions have been found to be successful in pain prediction, symptom management, disease activity, treatment adherence, and depression and anxiety in rheumatoid arthritis and SLE patients (DiMatteo, 2004; Resnick, Orwig, Magaziner, & Wynne, 2002). There are only a few studies that have examined self-efficacy as related to health-related quality of life in SLE patients.

It is important to note that many SLE self-management programs have not been validated on African American SLE patients. Drenkard et al. (2012) pilot tested the Chronic Disease Self-Management Program (CDSMP) on forty-nine, African American SLE patients in Georgia. The key principle of the CDSMP is that self-

efficacy is the key mechanism to change for chronic illness patients. The CDSMP is the only evidence-based generic self-management program. Researchers utilized the SF-36 and the Self-Efficacy for Managing Chronic Disease Scale. After the four-month intervention, individuals had significantly higher self-efficacy scores, higher physical component summary scores on the SF-36, and better communications with physicians, cognitive symptom management, and treatment adherence. There was limited generalizability due to lack of a control group, low sample size, and utilization of a general QoL measure.

In a review of qualitative literature, Sutanto et al. (2013) identified several themes among SLE patients that contribute to self-efficacy. The theme of gaining resilience included the desire to have greater feelings of control and empowerment. In addition, individuals reported wanting to be better informed. Twenty-two studies identified SLE patients as having a desire to learn to control their bodies in order to cope better with fatigue and pain. These are arguably individuals attempting to gain self-efficacy in fatigue and pain control. Participants also identified making positive health behavior changes and practical lifestyle adjustments as important themes. Ten studies identified SLE patients in support groups as feeling understood and valued. These individuals also reported sharing feelings, experiences and coping strategies. Support groups offered these individuals the opportunity for vicarious learning to occur.

Thombs et al. (2016) performed a literature review of studies utilizing the Self-Efficacy for Managing Chronic Disease Scale. This study sought to compare self-efficacy levels among several chronic illness populations. This review revealed

that SLE patients demonstrated lower self-efficacy scores than all other disease populations. A study by Siu, Spector, Cooper, and Chang-qin (2013) was part of the literature reviewed by Thombs et al. (2017). This study found that SLE patients, along with cardiovascular disease, diabetes, rheumatoid arthritis, and chronic pain patients had higher levels of job satisfaction when their self-efficacy for managing their disease was higher. Individuals with more support in the workplace were also more satisfied with their jobs.

Self-efficacy as a modifiable variable creates knowledge for counselors on strategies and techniques that can be utilized to assist SLE patients in coping with depression, anxiety, and pain for SLE patients. Beckerman et al. (2011) found that SLE patients who felt a higher sense of control over their illness (as measured by locus of control) and had higher education had lower rates of depression and anxiety. A study by Reeves et al. (2008) found that individuals with the lowest self-efficacy and health-related quality of life at baseline had the most significant response to CDSMP. Control group participants who had low-moderate self-efficacy and health-related quality of life at baseline had significant decline in health-related quality of life at the six-month mark.

Somers et al. (2012) examined the relationship between self-efficacy for pain control and pain catastrophizing in relation to pain, stiffness, fatigue, and psychological distress among 74 SLE (60% African American) patients at the Duke Lupus Clinic. Self-efficacy for pain control and pain catastrophizing accounted for 36% of the variance for pain. Only self-efficacy for pain control was a significant predictor for pain severity, stiffness, and fatigue. Pain catastrophizing was the only

significant predictor of positive mood. Participants with lower self-efficacy for pain control reported more pain, morning stiffness, and fatigue. A regression analysis determined that self-efficacy accounted for more variance than pain catastrophizing in stiffness, pain, and fatigue. Disease activity was not associated with pain, morning stiffness, or fatigue. Self-efficacy for pain control and pain catastrophizing was considered a pain coping cognition that can be manipulated through intervention. However, this study was cross-sectional and only included 5% males and therefore, generalizability is limited.

Karlson et al. (1997) in a study of 53 women with SLE and of whom the majority was black (93%) found a significant relationship between disease activity and self-efficacy. This study found that greater disease activity was correlated with poorer self-efficacy, low levels of social support, and low income. This study also found that lower self-efficacy and low levels of social support were related to poorer mental health as measured by the SF-36. Hierarchical models found that low self-efficacy, low social support, and younger age at diagnosis were the best predictors of disease activity. Low self-efficacy and social support were also predictors of poorer physical and mental health. Self-efficacy and social support were stronger predictors of disease activity than baseline disease activity or sociodemographic variables. This study was cross-sectional, and while the correlations for self-efficacy and social support with disease activity, mental health, and physical health were significant, they could not determine causality. Researchers reported that social support and self-efficacy are modifiable variables that could greatly affect quality of life for SLE patients.

Karlson et al. (2004) later performed a randomized control trial to measure the effect of a self-efficacy and social support enhancing intervention on 122 SLE patients and their partners. Information was collected at baseline, six-months, and twelve-months. At the twelve-month point, self-efficacy, couples' communication, and social support were significantly higher and fatigue was significantly lower for the experimental group than the control group. Mental health scores were significantly higher at the twelve-month point for the experimental group. Emotional coping and self-efficacy were significant predictors of mental health at twelve months. This study sought to build both self-efficacy and social support for participants. It is difficult to determine how these variables interact with one another. This study utilized a convenience sample from two hospitals and lacks generalizability. Participants were predominantly white and college educated.

Social Support

Social support is considered a powerful and modifiable variable in the field of health psychology. For example, legislation has been passed to assist older adults in the U.S with on-going social support efforts like in-home services and group meals (Woodruff, Talavera, & Elder, 2002). For example, community health workers, called promotores, assist Latino communities with diabetes education and smoking cessation (Ingram, Gallegos, & Elenes, 2005; Woodruff, Talavera, & Elder, 2002). Strine Chapman, Balluz, and Mokdad, (2007) examined health-related quality of life and health behaviors by level of social support in community based adults in the U.S. This study utilized a random, state-based digital telephone survey to obtain health-related

quality of life, life satisfaction, health behaviors, and social support in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

Results indicated that 18 million U. S. adults reported that they rarely or never received social support. The lack of social support was related to impaired health-related quality of life, disability, adverse help behaviors, and dissatisfaction with life. Poor social support was significantly related to poor sleep, mental health and depressive symptoms, somatic complaints, and pain. Older participants, males, and Latinos were most likely to report never receiving emotional support. Limitations of this study included the fact that it was a telephone survey, so participants had to be economically advantaged enough to have a phone. Limitations also include emotional support and social support both being measured by one question.

Like the concept of quality of life, the definition of social support can be varied. Mazzoni and Cicognani (2011) reviewed the literature available on social support and health-related quality of life in SLE patients. These reviewers reported a consensus in the literature that define positive social support as "the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us"(2011, p. 1118). Social support can be received from a partner, family, friends, coworkers, or relationships within the community. Social support can be an actual emotional, physical, or financial transaction from supporter to the supported. Social support can also be the supported individual's perception that resources are available if needed (Bandura, 1997). Social support is measured through structure of support versus function of support (Taylor, 2011).

Structural social support focuses on the number of social connections, the frequencies of contacts, and the structure of those relationships. Functional social support examines the specific function that the social support has provided and the effect on coping. Functional social support can be informational, instrumental, or emotional (Taylor, 2011). Informational support occurs when someone assists the individual in gaining a greater understanding of a stressor and also includes available resources and possible coping strategies. Instrumental support includes provision of services such as transportation, financial assistance, or food. Emotional support involves efforts to make someone feel loved, valued, and validated.

According to Taylor (2011) in The Oxford Handbook of Health Psychology, research supports that individuals with positive social support demonstrate better coping, emotional wellbeing, less depression, and fewer risk behaviors. Social support is linked to positive adaptation and adjustment to chronic illnesses (Revenson & DeLongis, 2011; Uchino, 2004) and has been linked to positive psychological adjustment to coronary artery disease (Holahan, Moos, Holahan, Carole, & Brennan,1997), diabetes, HIV (Turner-Cobb, Gore-Felton, & Marouf, 2002), cancer (Pennix et al., 1998), and rheumatoid arthritis (Revenson & DeLongis, 2011). Although most of this research is cross-sectional, available research supports the benefits of positive social support across chronic illness populations.

Positive Social Support and Systemic Lupus Erythematosus

Instructional, instrumental, and emotional social supports are all positively associated with quality of life in SLE patients. However, emotional social support has been the most widely used in SLE research (Brooks et al., 2014; Lincoln & Chae,

2012; Mazzoni & Cicognani, 2011). Emotional social support has been correlated with higher self-efficacy, lower depression, and lower levels of stress hormones in SLE patients (Bloor et al., 2006).

Positive social support is defined as "information leading the subject to believe that he/she is care for and loved, esteemed, and a member of a network of mutual obligations" (Mazzoni & Cicognani, 2011, p. 1118). Positive social support from family and friends helps individuals cope with the unpredictable nature of SLE, the possible loss of support from work, and the possible loss of financial independence (Campbell et al., 2008). Mazzoni and Cicogani (2011) reviewed 20 research articles on social support and health-related quality of life in SLE patients. Their findings indicated that social support is vital for SLE patients in both health-related and not-health-related quality of life.

In this review, all articles demonstrated a positive influence of positive social support on physical and mental health domains on quality of life in SLE patients. Bae et al. (2001) reported higher positive social support levels demonstrated a significant impact on mental and physical health in SLE patients. Karlson et al. (1997) reported a significant association between lower social support and higher disease activity. Alarcon et al. (1999) found that the negative relationship between social support and disease activity was significant only in White participants. Alarcon et al. (2006) in a later study added poor social support as the final variable in a multivariable model.

Alarcon et al. (2006) analyzed predictors for renal involvement for SLE patients in an ethnically diverse population by utilizing socio-economic demographic variables, psychosocial variables, disease activity measures, and DNA and

immunologic variables. This study found that 54% of the variance in SLE renal involvement was explained by a combination of socioeconomic variables like poverty, education and insurance as well as the DNA analysis for Amerindian, Caucasian, and African. When input separately, age, gender and disease duration only explained 4.6% of variance in renal involvement and ethnicity only accounted for 7.27%. This study highlights the highly interactive nature of biological, psychological and social elements in SLE symptom manifestations and quality of life.

An often-cited qualitative study by Archenholtz et al. (1999) found that among women with Rheumatoid Arthritis and SLE, social support was a consistent domain of importance. Both RA and SLE patients reported the need for good, loyal, and understanding family and friends. Both groups also reported the need for family and friends to be willing to help and to have awareness of needs. SLE patients more often reported the need for continuity of medical care, being in a good mood, and having self-esteem. SLE patients reported feeling misunderstood by doctors, family, and friends.

Social support has also demonstrated as a component of levels of fatigue reported by SLE patients (Jump et al., 2006; McElhone et al., 2010). Jump et al. (2006) performed a study of 127 SLE patients and factors that affected fatigue levels. The outcomes indicated that neither disease activity or medication usage significantly impacted fatigue levels. Positive social support was correlated negatively ($p<.05$) with fatigue levels. Social support accounted for 42% of variance in fatigue scores. Depression and pain positively predicted fatigue. Fatigue has been demonstrated to have a significant impact on health-related QoL in SLE patients (McElhone et al.,

2010). Researchers postulate that social support may have a buffering effect for pain and stress levels on fatigue.

SLE patients who perceive their spouse to be supportive have fewer depressive symptoms, higher marital satisfaction, better psychological adjustment, and a higher sense of well being (Beckerman et al., 2011; Feke, Stephens, Michelson, & Druley, 2007; Moses et al., 2008; Tamayo, 2010). Yet other findings have shown that family relationships can be a contributor to anxiety and depression (Danoff-Burg & Friedberg, 2005). These findings are mirrored by results demonstrating perceived social support can either increase or decrease quality of life in SLE patients (Reis & Pereira da Costa, 2010). While models of interaction, causality, and mediation are still widely debated, the concept of positive versus problematic support has become a focus for the new generation of social support research (Mazzoni & Cicognani, 2016).

Williams et al. (2015) analyzed the quality of life of 41, SLE patients whom were predominately African American in the Buffalo, New York area. This study utilized the SF-36 to examine the effect of social support and perceived stress on quality of life. The authors had hoped to determine if social support could produce a buffer for higher perceived stress. This study looked at both structural and functional social support but did not observe a significant relationship between social support and level of perceived stress. However, researchers indicated that the majority of their participants had strong social support in place at the time of the study. The sample size also was small and not conducive to statistical analysis. Researchers recommended this study be reproduced with a larger sample size.

Zheng et al. (2009) performed a case controlled study of 202 Chinese SLE patients' QoL versus a healthy control group of individuals from the same communities as the SLE patients. Control group participants were matched by age, gender, education, and marital status. This study found that SLE patients had significantly lower social support scores than the control group. A study by Kozora, Ellison, Waxmonsky, Wamboldt, and Patterson, (2003) study was smaller in sample size. This study found no significant social support between their control group and SLE patients. The Zheng et al. (2009) speculated that poor social support for Chinese SLE patients may result from fear of SLE being contagious and a fear of abandonment that made patients isolate themselves.

These studies demonstrate the multiple factors that influence how SLE patients attempt to utilize or isolate from social support systems. Social support can come from family, friends, support groups, or even from cultural influences (Gallant, 2003). SLE patients in seven studies reported hiding their diagnosis from friends and family because they feared abandonment or rejection (Jolly et al., 2012; Karlen, 2002; Robbins et al., 1993; Schattner, Shahar, & Abu-Shakra, 2008; Waldron, et al., 2011; Zeddies, 2002).

Problematic Social Support and Systemic Lupus Erythematosus

Revensen et al. (1991) defined problematic social support as situations of helping behaviors that are well intended by the provider but are perceived as non-supportive by the patient. Social support can be perceived as problematic when it is ill timed, feels oppressive, or when the supporter does not have accurate information. The invisibility, flare and remission patterns, and lack of general knowledge about

SLE can lead to problematic social support for SLE patients. However, research is extremely limited for this population. In rheumatoid arthritis research, problematic social support has been positively correlated to fatigue (Riemmsa et al., 1998) and depression (Coty & Wallston, 2010; Revenson et al., 1991; Riemsma et al., 2000). Problematic social support was inversely related to life satisfaction and functioning in family roles (Coty & Wallson, 2010).

Mazzoni and Cicognani (2016) studied the effect of positive social support and problematic social support on the quality of life in 480 Italian SLE patients. Positive social support was positively correlated with both health-related quality of life and non-health-related quality of life while being negatively correlated with perceived stress. Problematic social support was found to be negatively correlated with quality of life and positively correlated with perceived stress. This study also tested the moderation effects of positive and problematic social support and stress. Health-related quality of life as a dependent variable was significantly affected by all three predictors. Therefore, both social and problematic social support had a significant effect on health-related quality of life. Their findings supported the idea that problematic social support and lack of positive social support significantly affect QoL in SLE patients. These results support the previous work by Revensen et al. (1991) on positive and problematic social support on rheumatoid arthritis patients' quality of life.

In quantitative studies using the Systemic Lupus Erythematosus Needs Questionnaire, Moses et al. (2005) and Danoff-Burg and Friedman (2009) both found that roughly 78% of SLE patients had unmet social needs. In the Moses et al. (2005)

study, the unmet social needs included sexual information for partner and explaining the unpredictability of SLE symptoms. The unmet social needs identified in the Danoff-Burg and Friedman study were the ability to function in social situations, the ability of people close to them to help them cope, maintaining relationships, and changes in sexual relationships. Similarly, Sutanto et al. (2013) found that in 24 qualitative studies, SLE participants reported a lack of empathy and understanding from their friends, family, and physicians. Participants in 14 studies valued informational and instrumental social support.

Several older studies have demonstrated a relationship between social support and disease activity in SLE patients (Alarcon et al., 2004; Karlson, Dalhoy & Lew; 1997). Karlson, Dalhoy and Lew (1997) found that poor social support was related to increased disease activity despite race, socioeconomic status, or clinical factors. However Alacron et al. (1999) found that only white participants' disease activity was significantly related to social supports.

Medical Professionals as Problematic Social Support

Most SLE patients require a team of medical professionals that can include rheumatologist, internal medicine, hematologist, cardiologist, nephrologist, endocrinologists, neurologists, social workers, psychologists, and counselors ((Lupus Foundation of America, 2017). SLE patients experience difficulty and frustration in communicating with their medical professionals, feeling heard by their medical professionals, and feeling as though no one professional is taking the lead on their treatment (Brennan & Creaven, 2016; Hale et al., 2006; Tamayo et al., 2010). Hale et al. (2006) found in a qualitative study that SLE patients often perceived they were being treated as "malingering" by different doctors as well as feeling a lack of

communication with their doctors regarding information about their disease. This study also demonstrated that SLE patients perceived a lack of integration of their healthcare by their different doctors. These feelings of frustration and helplessness were linked to a lack of treatment adherence and not seeking medical help when flaring by study participants in multiple studies (Brennan & Creaven, 2016).

In a qualitative study by Brennan (2016), SLE individuals did not feel they were treated as individuals versus a disease, felt that medical professionals ignored their most significant symptoms, such as fatigue, and perceived that treatment was disjointed, with no communication between the doctors and the patient or between medical professionals. Berrios-Rivera et al. (2006) found that increased trust in one's doctor was correlated with fewer side effects and better overall health. This study also found that Latino and African American SLE patients had lower levels of trust in doctors that remained significant after controlling for the doctor-patient communication styles. These findings are important when considering the fact that SLE is predominantly a minority female disease (O'Neil & Cervera, 2010).

Sutanto et al. (2013) reviewed 16 studies and found that trust and communication levels were identified as significant factors in treatment, appointment, and medication adherence. Trust and communication also impacted how forthcoming patients are with symptoms (Berrios-Rivera et al., 2006). It is also important to note that some SLE patients found appointments with their doctors to be a source of information and support when good communication existed (Brennan, 2016). Medical professionals can be viewed as a source of positive social support or problematic social support by SLE patients. As a result, medical professional

involvement has the potential to be a significant support or barrier to the SLE patient's quality of life.

Self-Efficacy and Social Support

The relationship between self-efficacy and social support is complex and not well understood. To date, there have been no studies examining the moderating or mediating role of self-efficacy on social support in SLE patients. However, there have been studies that examined self-efficacy as a moderating influence on social support in rheumatoid arthritis patients, results that provide promise for SLE patients (Liu, Xu, & Wang, 2017).

Liu, Xu and Wang (2017) examined the role of self-efficacy as a moderator for social support with depression and anxiety symptoms in 297 Chinese rheumatoid arthritis patients. Valid instruments were utilized to examine depressive symptoms, anxiety symptoms, perceived social support, and general self-efficacy. Within this sample, over half of all participants suffered from depression and anxiety symptoms. This study reported higher depression rates than other studies within or outside of China. Anxiety symptoms were reported at a higher rate than previous studies performed in China. Age, marital status, household income, and chronic comorbidity were associated with depressive and anxiety symptoms.

Social support was found to be a positive source of coping for depression and anxiety in the Liu, Xu, and Wang (2017) study. Self-efficacy also was found to have an inverse relationship with anxiety and depression but once other factors were controlled for, it was found to have a significant negative relationship with anxiety. This study found that self-efficacy and social support interact with one another in

their associations with depression and anxiety. It also found that self-efficacy did act as a moderator for social support. Simple slope analysis revealed that when self-efficacy is higher, the relationships between social support and depressive and anxiety symptoms were weakened. One conclusion was that rheumatoid arthritis patients who operated at higher levels of self-efficacy may be able to cope with depression and anxiety, even if they are operating at a lower social support level.

Mazzoni, Cicagnoni, and Petri (2017) performed a longitudinal study of 162 Italian SLE patients' health-related quality of life as related to self-efficacy, positive social support, and problematic social support. This study found that problematic social support in the form of denying or uninformed support when measured at the baseline, negatively correlated with health-related quality of life at the second measurement date. High levels of self-efficacy at the baseline positively predicted higher health-related quality of life at the second measurement date. The amount of self-efficacy and problematic social support at the baseline, accounted for 28% of the variance in health-related quality of life at the second measurement date (R^2= .28). Self-efficacy and problematic social support were significantly negatively correlated (r=-.20). This study has not been replicated in a U.S. population of SLE patients and did not consider race as a variable in quality of life.

Summary

This chapter provided a comprehensive review of literature regarding factors that impact quality of life in SLE patients. The findings of this literature review indicated that quality of life is an important tool for measuring the impact of SLE on individual's physical, psychological, and social wellbeing.

Existing research has found significant relationships to modifiable variables like self-efficacy and social support. However, research is limited for the relationships between self-efficacy and problematic social support on SLE patients' quality of life. To date, with the exception of this study, no studies have examined the impact of self-efficacy, positive social support, problematic social support and race on quality of life in adult SLE patients.

This research project was needed to add to the literature by identifying the relationships between self-efficacy, positive social support, problematic social support, and race on quality of lie in SLE patients. Additionally, this study will assist counselors in understanding how these factors influence quality of life so that effective interventions can be developed and utilized in assisting this population in living longer with an incurable and unpredictable disease. This study can help to inform counselors, medical professionals, SLE patients, and families about factors that play a role in higher quality of life for SLE patients.

CHAPTER 3: METHODOLOGY

Introduction

This chapter provides a description of the methodology used to complete this study, including a description of participants and procedures related to data collection. This chapter will discuss instrumentation, study design, research questions, and data analysis. The purpose of this study was to examine the impact of self-efficacy, positive social support, problematic social support, and race on health-related quality of life in adult Americans with SLE.

Participants

Participants in this proposed study were a purposive sample of adults, ages 18 and over, who self-reported having been diagnosed with Systemic Lupus Erythematosus by a rheumatologist. Participants were recruited within the United States, nationally via posted information regarding the purpose of the study and a link to the survey in posts on Face Book SLE support sites. An invitation to participate was extended to at least 1,000 adult patients with SLE through Facebook SLE support sites in various states including but not limited to: Nevada, California, Texas, North Carolina, South Carolina, New Mexico, New York, New Mexico, Maine, Kansas and Oklahoma. A power analysis using G*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009) to estimate samples size indicated that a sample of 326 would detect a multiple regression with a medium effect size and a power of .95. A total of 448 participants responded to the web-based study with a total of 344 completed surveys that were used for this study.

Procedures

This researcher applied for and was granted approval through the Institutional Review Board for Research with Human Subjects through the University of North Carolina Charlotte to conduct this study. Once IRB approval was obtained, data were collected utilizing a web-based survey. Research has supported web-based surveys as efficient, fast, and inexpensive ways to collect data. In an effort to increase response rates, all communications with participants addressed how this study will be useful to individuals with SLE and the professionals assisting them (Dillman, Smyth, & Christian, 2014).

The first recruitment method utilized in this study was the researcher mailing and emailing rheumatologists across the country requesting the posting of this study information in their offices. After email and phone consultations with differing rheumatologists across the country, emails were sent to five rheumatologists that included an introductory explanation of the purpose of this study, age and diagnostic qualifications, informed consent, and a link to the survey on surveymonkey.com. These rheumatologists agreed to post a notice of this study. Many rheumatologists contacted by this researcher reported that they would require IRB approval through their governing agencies as well. Other rheumatologists contacted responded only through administrative staff and refused participation in this study.

The second recruitment method approved was an investigator-initiated study through the Lupus Foundation of America's Center for Clinical Trials Education. The application for submission was sent to the Lupus Foundation of America's Center for Clinical Trials Education in June 2018. The application process took approximately

four weeks to be accepted. Once approved, this researcher was informed that that there would be a substantial fee per hour for the clerical work associated with emailing the study to Lupus Registry participants and that a four-hour commitment was required. At this point in time, the researcher had already obtained over 300 participants for this study and declined Lupus Foundation of America participation due to financial constraints.

The researcher posted an introduction and invitation for this study with a link to the informed consent and survey on 98 Facebook SLE support sites. Facebook is becoming an increasingly popular and inexpensive way for researchers to recruit participants (Baltar & Brunet, 2012). These sites included: Lupus Awareness Support Group, Lupus Lovelies, Lupus Warriors, Lupus Has an Impact on My Life, Lupus Support Group of Charleston, Lupus Support Group of Highlands Ranch Colorado, Colors of Lupus Nevada, Defying Lupus, The Wolf in My House, Lighthouse for Lupus, New Life Outlooks, Purple Wings, Houston Lupus Support Group, Oklahoma Lupus Support Group, Gaston/Lincoln County Lupus Support Group, Durham Support Group, Lupus of Nevada, and Lupus of Seattle. Efforts were made by the researcher to include male specific lupus support sites as well as minority specific lupus supports sites including LGBT, African American, and Latino specific sites. Efforts were made by the researcher to include support sites specific to all regions of the U.S. including the Northeast, Southern, Midwest, Northwest and Southwest regions.

Two weeks from the initial post date, the researcher reposted the notice and invitation for this study with a link for the web-based survey. In addition, because this

is not a randomized sample, this researcher asked viewers to share this study information with other individuals in an attempt for snowball sampling (Kurant, Markopoulou, & Thiran, 2010). The size and diversity of the Facebook population help to limit the disadvantages of snowball sampling and are reported to be no more biased than traditional paper and pencil populations (Baltar & Brunet, 2012).

Introductory Letter

An introductory letter, which included vital information regarding this study, was sent to rheumatologists (See Appendix A). The physician version of the letter included the introductory notice for participants to be posted in their offices. The purpose of this study was included as well as the qualifications for participants. Physicians were encouraged to email the researcher with questions regarding this study. This letter was accompanied by a copy of the IRB approval letter, introductory notices for participants, and information regarding the informed consent for participants of this study.

An introductory letter for participants was posted on Lupus Facebook support sites (See Appendix B). The purpose of the study was discussed as well as the fact that this study was voluntary and all participants would remain anonymous. The age and diagnostic qualifications of being over the age of 18 and having a SLE diagnosis were included in the introductory post. This introductory post contained a link to the survey on surveymonkey.com. This post also requested participants to share this study information with other individuals**,** who have been diagnosed with lupus.

Informed Consent Form

When participant clicked on the suverymonkey.com link included in the introductory post, an Informed Consent Form (see Appendix C) immediately appeared on the site stating that participation in the study was completely voluntary, anonymous, and confidential. Further, participants were informed that they could stop taking part in the study at any time without penalty. Participants were asked to acknowledge that they met the criteria to participate in this study and their election to take part in the study was indicated by clicking on Accept at the end of the Informed Consent. Clicking on Accept was required in order to move forward.

Instrumentation

For the purpose of this study, the web-based survey was comprised of two qualifying questions regarding age and diagnosis, demographic questions, and several instruments utilized to measure the independent and dependent variables (See Appendix D)**.** These instruments included: LupusPro, Problematic Social Support Survey, The Interpersonal Support Evaluation List 12, and The Self-Efficacy for Managing Chronic Disease 6 Item Scale.

Survey

Section I: Qualifying Questions

After accepting the terms of the informed consent, participants were asked if they were 18 years of age or older. An answer of yes was required an answer to move forward. Participants were then asked if a doctor had diagnosed them with SLE. An answer of yes was required to move forward.

Section II: Demographics

The second section of this survey addressed demographic information. Demographic information requested included participants' age, race, gender, marital status, educational level, employment status, and the age at which the participant was diagnosed with lupus. This section also requested information on the last time the participant went to the doctor or hospital for lupus related symptoms. In addition, participants were asked to identify if they see a rheumatologist, cardiologist, nephrologist, neurologist, hematologist, dermatologist or other type of doctor for lupus related symptoms.

Section III: Lupus Patient Reported Outcome (PRO)

For the purpose of this study, health-related and non-health-related quality of life was measured by the total score of the Lupus PRO questionnaire, English version (Jolly et al., 2012). Health-related quality of life is defined as the mental, physical, emotional, and social domains of an individual's life that are impacted by changes in the individual's health or disease status (Spilker & Revicki, 1999). The Lupus PRO was chosen for this study because it is one of the few quality of life instruments that is SLE specific and looks at both health-related quality of life and non-health-related quality of life. These two dimensions give a more comprehensive assessment of the individual's with SLE life. The Lupus PRO also was developed utilizing feedback from both male and female SLE patients. This is in contrast to most QoL SLE instruments, which are normed only on women. The Lupus Pro is normed in the United States on an ethnically diverse population. The Lupus PRO is a 5-scale

questionnaire that measures the following ten domains for the past four weeks of the participant's life.

Health-related Quality of Life is defined as the mental, physical, emotional, and social domains of an individual's life that are impacted by changes in the individual's health or disease status (Spilker & Revicki, 1999). Health-related quality of life is measured by the Lupus Pro v. 1 in the following eight domains: (1) lupus symptoms, (2) lupus medications, (3) physical health [themes: physical function and role physical], (4) emotional health [themes: emotional function and role emotional], (5) pain vitality [themes: fatigue, sleep], (6) procreation [themes: sexual health and reproduction], (7) cognition, and (8) body image.

Non-health-related quality of life was defined as natural, environmental, and personal domains that are not related to the individual's health or disease status. Non-health-related quality of life is scored by adding the scores from the LupusPro non-health-related quality of life section of the questionnaire, English version (Jolly et al., 2012). NHRQoL contain four domains: (1) desires/goals, (2) coping, (3) relationship/social support, and (4) satisfaction with care.

The LupusPro is estimated to take approximately 7-10 minutes to complete by researchers who have utilized this tool (Jolly et al., 2012). Ethnically diverse U.S. populations were utilized when developing this tool. This measurement tool has been validated for use in the United States. The Lupus Pro was developed with qualitative input from individuals with SLE (Holloway et al., 2014). Jolly et al. (2016) demonstrated validity and reliability of this measurement tool by comparing the LupusPro to instruments measuring disease activity (SELENA-SLEDAI (SS),

BILAG and SLICC-SDI/ACR (SDI)), fatigue, (MOS SF36, FACIT-Fatigue), insomnia (Insomnia Severity Index for sleep), perceived stress (Perceived Stress Scale (PSS)-4), and depression (Patient Health Questionnaire-9 (PHQ-9) (Jolly et al., 2016). Cronbach alpha was utilized to determine internal consistency reliability (ICR) for each domain. The Cronbach alpha for health-related quality of life was 0.96. The Cronbach alpha for non-health-related quality of life was 0.81. The Spearman Coefficient Correlation was utilized to measure convergent construct validity against domain measurement tools such as the SF 36. The Lupus Pro had strong correlations in the domains of sleep, fatigue, pain, physical health, and emotional health in relation to Insomnia Severity Index scores, Facit-fatigue scores, and SF 36 scores (Jolly et al., 2016).

Section IV: Self-Efficacy

Self-efficacy is defined as "one's perceived ability to the action necessary to achieve the desired effects or outcomes" (Westmaas, Gil-Rivas, & Cohen Silver, 2011, p.76). Self-efficacy was measured by the English version, Self-Efficacy for Managing Chronic Illness 6 Item Scale (SEMCD), which was developed using social cognitive learning theory (Lorig & Chae, 2001). The SEMCD is a six-item questionnaire that measures self-efficacy on a scale of 1 "not at all confident" to 10 "totally confident". The SEMCD has been utilized to measure self-efficacy in several different chronic illness populations including COPD (Stellefson Tennant & Chaney, 2012), heart disease, lung disease, stroke, arthritis (Lorig et al. 2001), and SLE (Mazzoni & Cicognani, 2014).

Ritter and Lorig (2014) reviewed six studies, in different locations, that utilized the SEMCD to measure self-efficacy in order to determine psychometric properties. The findings of this analysis demonstrated internal consistency reliability (Chronbach alpha) at a range of 0.88 to 0.91 in these studies. Cronbach alpha for internal consistency reliability was acceptable when measuring self-efficacy in SLE patients (*a*=.89) (Mazzoni & Cicognani, 2014). Freund, Gensichen, Goetz, Szecsenyi, & Mahler, (2013). found that the SEMCD was valid and reliable for measuring self-efficacy in chronically ill German patients. Convergent validity for the SEMCD has been demonstrated by comparing the scale to other self-efficacy scales such as the German General Self-Efficacy Scale (Freund et al., 2011). Construct validity for the SEMCD has been demonstrated by Amtmann et al. (2012) who compared seventeen and six item self-efficacy scales for individuals with disabilities with the SEMCD. They obtained correlation coefficients of 0.83 and 0.81 respectively.

Section V: Positive Social Support

Positive Social Support was measured by the total score of the Interpersonal Support Evaluation List 12 (ISEL 12) with higher scores indicating higher perceived levels of social support (Mertz et al., 2014). Positive social support is defined as "information leading the subject to believe that he/she is care for and loved, esteemed, and a member of a network of mutual obligations" (Cobb, 1976, p. 300). The traditional ISEL was developed to assess how individuals perceive the availability of social support in the general population (Brookings & Bolton, 1988). The traditional ISEL is a 40-item questionnaire that has demonstrated good internal consistency reliability, test-retest reliability, convergent validity, and structural

validity (Brookings & Bolton, 1988; Cohen, 2008; Cohen & Hoberman, 1983; Cohen & Willis, 1985). It utilizes a 4-point scale that ranges from Definitely False to Definitely True.

The modified and shorter ISEL 12 was utilized for this study. Although the ISEL 12 has less research than the traditional ISEL, the ISEL 12 utilizes the four highest correlated questions for each domain of the original ISEL (Cohen, Janicki & Deverts, 2012). The ISEL 12 is scored by totaling all of the scores for an overall social support score. Within this overall score there are three domains measured: (a) appraisal items, (b) belonging, and (c) tangible support (Cohen et al., 1985).

Mazzoni and Cicognani (2016) reported the internal reliability of the ISEL 12 as high across all items (a=.82). Mertz et al. (2014) sought to determine reliability and validity for the ISEL 12 among Latino/Hispanic populations due to the fact that the majority of research had been performed on white populations. The Cronbach alpha for ISEL 12 total scores was above .70 but reliability did not hold for the three domains sub scores. For this study, only the total ISEL 12 scores will be utilized.

Section VI: Problematic Social Support

Problematic Social Support (PSS) is defined as social support that is perceived by the recipient to be unneeded, unsolicited, or unhelpful (Revenson et al., 1991). This construct was measured using the total score on the Problematic Support Scale, which is a ten-item scale (Mazzoni & Cicognani, 2016). The PSS was developed by Mazzoni and Cicognani (2016) to specifically measure problematic social support in SLE patients. The authors utilized findings from their own qualitative study (2014) as well as a review of the literature on problematic social support in rheumatoid arthritis

to determine three main domains of problematic social support. These domain are: (a) oppressive support, (b) support denying the illness, and (c) support based on divergent illness representations (Coty & Wallston, 2010; Revenson et al., 1991; Riemmsa et al., 1998; Riemmsa et al., 2000).

The PSS was developed and normed on 344 Italian SLE patients and utilizes a seven-point scale from 1 “complete disagreement” to 7 “complete agreement”. The PSS has demonstrated acceptable reliability (*a*=.76) (Mazzoni & Cicagnoni, 2016). Cranach’s alpha for denying/uninformed support was 0.81, oppressive support 0.76, and total scale 0.76. The PSS correlated well with Revenson et al. (1991) problematic support scale with r=.48 (p<.001) for denying/uninformed support, r=.23 (p<.001) for oppressive support, and r=.52 (p<.001) for total scores. These correlational results confirm good concurrent validity (Mazzoni & Cicognani, 2016)

Research Design

The research design for this study was a non-experimental descriptive design. A cross-sectional survey design was utilized. This survey was web-based. In order to answer the below research questions, this study utilized data collected to analyze the relationships of the independent variables self-efficacy, positive social support, problematic social support, and race on the dependent variable, health-related quality of life in adult SLE patients. Health-related quality of life was analyzed by determining the frequencies, averages, and percentages of scores. These independent variables were examined to determine if there are significant relationships with health-related quality of life in adult SLE patients. The amount of variance in health-related quality of life was also analyzed by each independent variable and the totality

of all variables. The independent variables self-efficacy, positive social support, problematic social support, and race were examined to determine significant relationships among one another.

Research Questions

The following research questions were addressed in this study:

1. How is health-related quality of life in adult SLE patients related to self-efficacy, positive social support, problematic social support, and race?
2. How is non health-related quality of life in adult SLE patients related to self-efficacy, positive social support, problematic social support, and race?

Data Analysis

This study was submitted for IRB approval through the University of North Carolina Charlotte before any data was collected. Upon IRB approval, data was collected from a web-based survey and downloaded into The Statistical Package for the Social Sciences (SPSS) data analysis software. SPSS was utilized to screen the data, gather descriptive data, and analyze the data.

Screening Data

A careful examination of all data for accuracy of data entry and missing values was performed by the researcher before any statistical analyses were performed. The researcher ensured that all statistical assumptions were met before data analysis began. The researcher screened data to detect outliers and missing data and addressed issues of normality including multivariate normality and multicollinearity. Out of 448 total surveys, any surveys that were missing values were removed before the data was analyzed resulting in 344 analyzed surveys. The

majority of these omitted surveys fell into one of two groups. One groups of omitted surveys had been opened and only two or three answers were given and then never completed. The second set of omitted surveys had not answered any of or completed the last page of the survey.

Descriptive Statistics

Descriptive statistics were used to describe the participants who took part in the study. Specifically, data from the demographic section of the survey were processed through SPSS to analyze age, gender, race, education level, marital status, time since diagnosis, and work status. Tables were created using SPSS to determine frequencies and percentages for each demographic variable.

To determine scores for self-efficacy, positive social support, problematic social support, and health-related quality of life, the items of for each instrument were computed for each individual and added to the spreadsheet. Race was gathered from the demographic section of the survey. Descriptive statistics include the range of scores, coefficient alphas, mean scores, and standard deviation for all the variables in the study.

Data Analysis for Questions One

SPSS was utilized to perform a multiple regression analysis. Correlation coefficients can assist the researcher in determining if there is a linear relationship between the dependent variable and the independent variables and to determine multicollinearity (Tabachnick & Fidell, 2013). Once full correlations and the unique contribution of each independent variable to the dependent were considered, hierarchical multiple regression was utilized to determine how the independent

variables self-efficacy, positive social support, problematic social support, and race were related to health-related quality of life scores.

Data Analysis for Question Two

SPSS was utilized to perform a multiple regression analysis. Correlation coefficients can assist the researcher in determining if there is a linear relationship between the dependent variable and the independent variables and to determine multicollinearity (Tabachnick & Fidell, 2013). Once full correlations and the unique contribution of each independent variable to the dependent were considered, hierarchical multiple regression was utilized to determine how the independent variables self-efficacy, positive social support, problematic social support, and race related to non-health-related quality of life scores.

Summary

This chapter presented the methodology of this proposed descriptive study. The participants and the method for obtaining the sample were first described. Second, the procedures for gathering the data were identified. The third section explained the three instruments that were utilized for the study.

CHAPTER 4: RESULTS

Introduction

The purpose of this study was to examine how the variables of disease self-efficacy, types of social support, and race influence health-related quality of life and non-health-related quality of life in Systemic Lupus Erythematosus patients. Demographic information including age, gender, marital status, educational status, employment status, types of doctors, and time since being seen by a doctor or hospital for lupus-related symptoms were collected. The following research questions were addressed in this study:

1. How is health-related quality of life in adult SLE patients related to self-efficacy, positive social support, problematic social support, and race?
2. How is non health-related quality of life in adult SLE patients related to self-efficacy, positive social support, problematic social support, and race?

This chapter presents the results of this study. The first section will provide a description of the participants in this study. The following sections of this chapter will address the two questions as listed above. The final section of this chapter will provide an overall summary.

Description of Participants

The population of this study consisted of adult (18 years old and over) SLE patients in the United States. This study sought to invite at least 1,000 SLE sufferers to participate. This goal was met by posting invitations and links to the web survey on multiple SLE support sites. A total of 448 participants responded to this study. After eliminating respondents with missing or invalid data in the

demographic section (*n=10*) or in the other variable sections (*n=94*), a total number of 344 participants were included in this study. Therefore, the sample size needed for statistical significance was met.

Gender and age.

The demographic information for this study is presented in Table 1. The majority of participants were Caucasian (72.1%, *n* =248) and female (97.1%, *n=334*). The mean age of participants for this study was 45 years old with a range from 21 years old to 75 years old (SD=12.09). Despite efforts to collect data from male only support groups, only 2.0% (*n=7*) of participants were male and .9% (*n=3*) non-binary. No participants responded as transgender male or transgender female. The gender data does reflect the fact that SLE is a predominantly female disease with a ratio of nine women for every one male diagnosed with SLE (National Institute of Health, 2013).

Table 1

Gender and Age of Participants

Demographic	*n*	%
Gender		
Female	334	97.10
Male	7	2.00
Non-Binary	3	.09
Age		
20-29	30	8.70

30-39	86	25.0.
40-49	97	28.2
50-59	76	22.1
60-69	52	15.1
79-79	3	.9

Race.

The race demographic data for this study indicates that while the majority of participants were Caucasian (72.1%, n=*248*), 27.9% reported themselves to be of different races. Thirty-three participants (9.6%) identified themselves as African American, 30 participants as Hispanic/Latino (8.7%), 5 participants as Asian/Pacific Islander (1.5%), 6 participants as Native American (1.7%), 17 participants (4.9%) identified themselves as Other race, and 5 participants (1.5%) identified themselves as multiracial.

Table 2

Race of Participants

Race	*n*	%
Caucasian	248	72.10
African-American	33	9.60
Hispanic/Latino	30	8.70
Other	17	4.90
Native American	6	1.70

Asian/Pacific	5	1.50
Multi-Racial	5	1.50

Relationship status.

As stated previously, the majority of participants reported being married (57.8%, n=199) while 13.1% (n=45) reported being divorced. Forty-six participants (13.4%) reported being single, and 11 (3.2%) reported being widowed. Fourteen participants (4.1%) reported being separated, and 29 (8.4%) reported being in a committed relationship with a life partner.

Table 3

Relationship Status of Participants

Relationship Status	*n*	%
Married	199	57.80
Single	46	13.40
Divorced	45	13.10
Committed Relation	29	8.40
Separated	14	4.10
Widowed	11	3.20

Employment status.

The largest group of participants (32.3%, n=111) reported being employed full-time. The second largest group of participants (27.3%%, n=96) reported being disabled and receiving disability benefits. Just over 11% (n=39) reported being

employed part-time, 8.1% (n=28) retired, 5.8% (n=20) disabled and have been denied disability benefits, 4.4% (n=15*)* disabled and have applied for Disability benefits, 2.6% (n=9) unemployed and looking for work, and 8.1% (n=28*)* categorizing their work status as other.

Table 4

Employment Status of Participants

Employment Status	*n*	%
Full-time	111	32.30
Disabled and Receiving Disability	94	27.30
Part-time	39	11.30
Retired	28	8.10
Other	28	8.10
Disabled and Denied Disability	20	5.80
Disabled and Applied for Disability	15	4.40
Unemployed Looking for Work	9	2.60

Education status.

The participants in this study had a range of educational experiences. The majority of participants had attended college with 34.0% (n=117) having a college degree, 31.1% (n=107) having some college education, and 18% of participants (n=62) having a Master's degree or higher. Of the remaining participants, 11.3% (n=39) reported being high school graduates, 3.2% of participants (n=11) reported having a GED, and 2.3% (n=8) of participants reported having less than a high school education.

Table 5

Educational Status of Participants

Educational Status	*n*	%
Master's Degree or +	62	18.0
College Graduate	117	34.0
Some College	107	31.10
High School Graduate	39	11.30
GED	11	3.20
Less than High School	8	2.30

Lupus Demographic Information

Age at time of diagnosis.

The mean age of participants at the time of lupus diagnosis was 34.8 (*SD*=12.50). There was a wide range of ages at the time of SLE diagnosis, with the

youngest reported being 3 years of age and the oldest being 72 years of age. The majority of participants (74.3%) were diagnosed with SLE between the ages of 20-49.

Table 6

Age at Time of SLE Diagnosis

Age	*n*	%
0-19	38	11.00
20-29	86	25.00
30-39	111	32.27
40-49	57	16.57
50-59	41	11.90
60 +	11	3.20

Types of doctors seen by participants.

Participants were asked to check from a list the type of doctors that they see for lupus-related symptoms. The most frequently reported doctor was a Rheumatologist (95.1%, n=327). Participants reported seeing several other types of doctors for their lupus-related symptoms. The second most seen doctor was a Dermatologist, with 39% of participants, while 38.1% reported seeing another type of doctor not listed. The fewest amount of participants reported seeing a Nephrologist (18.3%).

Table 7

Types of Doctors Seen By Participants

Doctor	*n*	%
Rheumatologist	327	95.1
Dermatologist	134	39.0
Other Type Dr.	131	38.1
Cardiologist	109	31.7
Neurologist	106	30.8
Hematologist	68	19.8
Nephrologist	63	18.3

Time last seen by doctor for SLE-related symptoms.

To determine severity of symptoms at the time of the survey, this study gathered information on the last time participants went to the doctor, emergency room, or hospital for lupus-related symptoms. As reported previously, the majority of participants had sought medical treatment for lupus-related symptoms in the last three months. Just over 24% of participants (n=83) reported seeking medical treatment in the last week, 31.4% in the last month, and 16.9% (n=58) in the last three months. For the remaining participants, 7.6% of participants (n=26) reported seeking medical treatment in the last six months, 8.4% (n=29) of participants reported seeking medical

treatment in the last year, and 11.6% reported that they not sought treatment in over a year.

Table 8

Last Time Seen at Doctor/Hospital for SLE-Related Symptoms

Last Time Seen at Dr. or Hospital	*n*	%
In the Last Week	83	24.10
In the Last Month	108	31.40
In the Last 3 Months	58	16.90
In the Last 6 Months	26	7.60
In the Last Year	29	8.40
Longer than 1 Year	40	11.60

Health-Related Quality of Life

The Health-Related Quality of Life score is a continuous variable obtained from the LupusPro instrument which measures responses on a five-point Likert scale from 0=None of the time, 1= A little of the time, 2= Some of the time, 3= Most of the time and 4= All of the time. Transformed scores range from 0 (worst quality of life) to 100 (best quality of life) (Jolly et al. 2008). There are eight observed domains within Health-Related Quality of Life which include: Lupus Symptoms, Cognition, Lupus Medications, Procreation, Physical Health, Pain Vitality, Emotional Health, and Body Image. The mean raw score for these categories was obtained by totaling the scores for each domain and then dividing by the number of items in that domain.

The mean raw score is transformed to scores (TM) by dividing the number of Likert responses -1) by 4 and then multiplying by 100. After reverse coding, items 1-34 as directed by the authors, domain scores were obtained as follows in Table 9. The transformed Mean for Health-Related Quality of Life was 51.97 (*SD*=16.63), on a scale of 0 (Worst Quality of Life) and 100 (Best Quality of Life).

The highest Health-Related Quality of Life scores for participants in this study were found in the domain of Procreation (*M*=90.55, *SD*=20.93). However, this domain was rated as Not Applicable by 82% of respondents for question 1: Concern that lupus medication(s) will make it difficult to have a baby. Eighty-nine percent of participants answered Not Applicable for question 2 on Procreation: Worry about the ability to prevent unplanned pregnancy. Not Applicable responses were coded 0 when transforming scores. Most other domains yielded scores that were in the middle of the range such as Physical Health (*M*=58.85, *SD*=23.19), Lupus Medications (*M*= 55.25, *SD*=31.62), and Lupus Symptoms (*M*=51.13, S*D*=23.58), which fell toward the middle of the 0 (Worst Quality of Life) to 100 (Best Quality of Life) range. The lowest Health-Related Quality of Life scores for participants of this study were in the domains of Pain Vitality (*M*= 34.18 *SD*=22.09), Cognition (*M*=37.90, *SD*=26.86), and Emotional Health *(M*=39.21, *SD*=23.26).

Table 9

Health-Related Quality of Life Means and Standard Deviations

Domain	Raw *M*	*SD*	Transformed *M*	*SD*
Lupus Symptoms	2.05	.94	51.13	23.58
Cognition	1.52	1.07	37.90	26.86
Lupus Medication	2.22	1.27	55.25	31.62
Procreation	3.62	.84	90.55	20.93
Physical Health	2.36	.93	58.85	23.19
Pain Vitality	1.37	.88	34.18	22.09
Emotional Health	1.57	.94	39.21	23.26
Body Image	1.84	1.12	45.98	28.09
Health-Related Quality of Life Total	2.08	.67	51.56	16.63

Note. Raw mean domains are averaged on a 0 (worst quality of life) to 4 (best quality of life) scale.

Non-Health-Related Quality of Life

Similarly, Non-Health-Related Quality of Life is derived from four domains found within the LupusPro. These domains include Desire and Goals, Coping, Social Support, and Satisfaction with Care. The raw mean scores and transformed scores are found the same way as Health-Related Quality of Life. The transformed mean for Non-Health-Related Quality of Life was 46.91 *(SD*=14.85) , on a scale of 0 (Worst Quality of Life) and 100 (Best Quality of Life). For Non-Health-Related Quality of

Life, Coping (*M*=59.79, *SD*=22.14) and Satisfaction with Care (*M*=57.96, *SD*=30.19) were the domains with the highest Non-Health-Related Quality of life scores. The domains of Desire & Goals (*M*= 31.21, *SD*=19.54) and Social Support (*M* =51.16, *SD*=27.66) had the least amount of Non-Health-Related Quality of Life.

These scores are listed below in Table 10.

Table 10

Non-Health-Related Quality of Life Means and Standard Deviations

Domain	Raw *M*	*SD*	Transformed *M*	*SD*
Desire/Goals	1.25	.78	31.21	19.54
Social Support	2.05	1.11	51.16	27.66
Coping	2.39	.88	59.79	27.66
Satisfaction with Care	2.32	1.21	57.96	30.19
Non-Health-Related Quality of Life Total	2.06	.62	46.91	14.85

Note. Raw mean domains are averaged on a 0 (worst quality of life) to 4 (best quality of life) scale.

Self-Efficacy

Self-efficacy was measured utilizing the Self-Efficacy for Managing Chronic Disease 6-Item Scale (Lorig & Chae, 2001). These questions were answered by the participant indicating on a scale of 1 (Not Confident at All) to 10 (Totally Confident) in their degree of confidence in preventing interference in things that they want to do

in the six areas of chronic disease. The overall Self-Efficacy Score for this study was low at (*M*=3.60 *SD*=1.78). These scores are presented below in Table 1.

Areas of highest confidence were Ability to do Things Other Than Medication to Reduce Illness Impact (*M*=4.33, *SD*=2.56) and Ability to Perform Tasks to Manage Health (*M*=4.06 *SD*=2.34). In all six areas of confidence, participants were less than confident as indicated by scores of less than five, which is the middle of the scale. The lowest areas of confidence were Managing Fatigue (*M*=3.10,*SD*=2.01), Physical Discomfort and Pain (*M*=3.16,*SD*=2.04), Symptoms and Health Problems (*M*=3.06,*SD*=2.11), and Emotional Distress (*M*=3.86, *SD*= 2.41).

Table 11

Self-Efficacy Domain Means and Standard Deviations

Domain	*M*	*SD*
Fatigue	3.10	2.01
Physical Discomfort	3.16	2.04
Emotional Distress	3.86	2.41
Symptoms	3.06	2.11
Tasks	4.06	2.34
Other than Meds	4.33	2.56
Self-Efficacy Score	3.60	1.78

Note. Scores are averaged on a 1 (not confident at all) to 10 (totally confident).

Positive Social Support

Positive social support was measured by using the Interpersonal Support

Evaluation List 12 item scale or ISEL 12 (Cohen, 1988). The ISEL 12 contains 12 questions that ask the participant to score their answers on a scale of 0 (Definitely False), 1 (Probably False), 2 (Probably True) and 3 (Definitely True) in different scenarios where they may need assistance. The ISEL 12 is scored by reverse coding items 1, 2, 7, 8, 11, and 12 and sum total of scores with scores ranging from 0 to 36 with higher scores indicating higher levels of social support. In addition to a total social support score, the ISEL 12 measures social support in the three areas of Appraisal, Belonging, and Tangible Social Support. The sub scores for Appraisal, Belonging, and Tangible were scored by adding the scores for the four questions in each domain with a range of 0 (least amount of social support) to 12 (most amount of social support). Total social support scores (M=22.05, *SD*=7.80) indicate moderate levels of perceived social support on the scale of 0 (Least amount of support) to 36 (Most amount of support). The means for these scores are shown in Table 12.

Table 12

Positive Social Support Domain Means and Standard Deviations

Domain	*M*	*SD*
Appraisal	6.71	2.89
Belonging	7.04	3.02
Tangible	8.24	3.13
Positive Social Support Total Score	22.05	7.80

Note. Scores are averages on a 1(low social support) to 12 (high social support) scale.

Problematic Social Support

Problematic social support was measured by utilizing the Problematic Support Scale (Mazzoni & Cicognani, 2016). The PSS is a 10-item scale that measures areas of problematic social support by having participants answer question on a scale from 1 (Complete Disagreement) to 7 (Complete Agreement). This instrument measures two areas of problematic social support, both Denying/Uninformed social support and Oppressive social support as well as providing a total score for Problematic Social Support. Denying social support consists of four items that measure how individuals in the SLE patient's support system avoid discussing the illness or reject the idea of them having an illness. Oppressive social support consists of four items that measure overprotectiveness and excessive concern by individuals in the SLE patient's support network. Participants in this study reported higher levels of Denying/Uninformed problematic social support than Oppressive Support.

Table 13

Problematic Social Support Domain Means and Standard Deviations

Domain	*M*	*SD*
Denying/Uninformed	3.96	1.59
Oppressive	2.54	1.37
PSS Total Score	3.39	1.01

Note. Scores are averages on a 1 (low levels of problematic social support) to 7 (high levels of problematic social support) scale.

Analysis for Research Question 1

Part One.

To determine the relationship between positive social support, problematic social support, self-efficacy, and race on Health-Related Quality of Life, a linear multiple regression was performed utilizing SPSS. Health-Related Quality of Life is the transformed total score that consists of the eight domains including: lupus symptoms, cognition, procreation, medications, physical health, pain vitality, emotional health, and body image from LupusPro. For the independent variable race, a categorical variable was created that was composed of Caucasian and Non-Caucasian with Caucasian coded 0 and Non-Caucasian coded 1. The Non-Caucasian variable collapsed the categories of African-American, Asian/Pacific Islander, Native American, Hispanic/Latino, Multi-racial, and Other into one category. Positive Social Support is the total score of the domains: Appraisal, Belonging and Tangible from the ISEL 12. Problematic Social Support is the total score of the two domains: Denying/Uninformed and Oppressive from the Problematic Support Scale. Self-Efficacy is the total score from the six items in the Chronic Disease Self-Efficacy Scale.

To examine multicollinearity, the correlations between the independent variables of Race, Positive Social Support, Problematic Social Support, and Self-Efficacy were computed. No independent variables were correlated to one another at a .7 or greater. Collinearity statistics for both Tolerance and VIF indicate no multicollinearity occurring.

Table 14

Summary of Intercorrelations for Scores on Health-Related Quality of Life, Positive Social Support, Problematic Social Support, Race and Self-Efficacy

Variable	1	2	3	4
1. H-R QoL				
2. Positive Social	.38			
3. Problematic Social	-.44	-.39		
4. Race	-.03	-.04	.01	
5. Self-Efficacy	.53	.42	-.23	-.01

The data was checked for outliers utilizing Mahalanobis distances which indicate a maximum critical value of 18.47 for 4 independent variables. The maximum Mahalanobis distance in Residual Statistics was 16.98. A scatterplot for Health-Related Quality of Life also was analyzed. There were no indications of significant outliers skewing the data that needed to be removed.

To evaluate the appropriateness of this model, the model summary was examined to determine the amount of variance in Health-Related Quality of Life that is explained by Positive Social Support, Problematic Social Support, Self-Efficacy, and Race. A significant regression equation was found [F (4, 339) = 53.65, p<.001], with an R^2= .38. According to this analysis, 38% of the variance in Health-Related Quality of Life is explained by Positive Social Support, Problematic Social Support, and Self-Efficacy.

The standardized beta coefficients indicate that Self-Efficacy (β=.42, p<.0005) has the most influence on Health-Related Quality of Life. Problematic Social Support (β = -.31, p<.0005) was the second strongest influence on Health-Related Quality of Life and was inversely related. Positive Social Support (β=.10, *p*=.06) and Race (β=.04, *p*=.31) were not statistically significant. By utilizing the partial correlation coefficient squared, it was determined that Self-Efficacy accounted for 19 % of the variance in Health-Related Quality of Life after controlling for all other variables while Problematic Social Support accounted for just over 10 % of the variance.

Table 15

Regression Analysis Evaluating Predictors of Health-Related Quality of Life

Variable	B	SE	β	*P*	Partial R	Partial R^2
Self-Efficacy	3.90	.44	.42	.0005	.44	.19
Problematic Support	-4.50	.71	-.30	.0005	-.33	.10
Positive Support	.21	.11	.09	. 06	.10	.01
Race	1.59	1.59	-.04	.31	.05	.002

Note. Race was coded 0=Caucasian and 1=Non-Caucasian.

Part Two.

Research suggests that certain variables contained in the demographic portion of the survey may be confounding variables that also play a role in Health-Related Quality of Life. To determine if these factors were impacting Health-Related Quality of Life in this study, a separate hierarchical multiple regression was calculated

controlling for the following variables; age at time of participation, marital status, educational status, employment status, age at time of diagnosis, and the last time seen by a doctor for lupus symptoms. Employment status was collapsed into two categories, employed (*n* = 150, 43.6%) and not employed (n= 194, 56.4%). Relationship status was collapsed into two categories, in a committed relationship (n=228, 66.3%) and not in a committed relationship (n=116, 33.7%). Educational status is on an ordinal scale with the higher the score the higher the educational status. Time last seen by a doctor is also on an ordinal scale, with the higher the score, the longer it has been since the participant has been seen by the doctor for lupus related symptoms. Age at time of participation and age at time of diagnosis are continuous variables.

Prior to the hierarchical regression analyses, the independent variables were examined for collinearity. Results of the variance inflation factor (all less than 2.0) suggest that the estimated *b*s are well established in the following regression models. The results of the hierarchical regression predicting Health-related quality of life from demographic characteristics, positive social support, problematic social support, self-efficacy and race are reported on Table 16. The results of step one indicated that the variance accounted for (R^2) with the first six predictors (age at time of participation, relationship status, educational status, employment status, age at time of diagnosis and the last time seen by a doctor for lupus-related symptoms) equaled and R^2 of .22 (adjusted R^2=.21), which was significantly different from zero ($F_{(6, 335)}$ = 15.89, p<.001). Three of the demographic variables (the last time seen by

a doctor for lupus symptoms (β = .388, p = .0005), age at participation (β = .19, p = .002) and employment status (β = -.16, p =.001) were statistically significant. Next scores for positive social support, problematic social support, self-efficacy and the demographic race variable were entered into the regression equation. The change in variance (ΔR^2) was equal to .24., which was a statistically significant increase in variance over the step one model ($F_{(4, 331)}$= 36.77, p<.001).

Positive social support, problematic social support, and self-efficacy accounted for 24% of variance in Health-Related Quality of Life when controlling for age at participation, employment status, marital status, educational status, age at diagnosis, and last time seen by doctor for lupus symptoms. Self-efficacy (β = .35, p = .0005) and problematic social support (β = -.23, p = .0005) were the most significant predictors of Health-Related Quality of Life. When considering partial correlation coefficients squared, self-efficacy demonstrated 14% of variance when accounting for all variables including demographic variables, and problematic social support accounted for 7.3% of variance in Health-Related Quality of Life. Positive social support accounted for 1% of variance (β= .10, p = .03). Race (β = .04, p =.33) was still not a significant factor in Health-Related Quality of Life.

Table 16

Hierarchical Regression Analyses Evaluating Predictors of Health-Related Quality of Life

Measures	R	R^2	ΔR^2	ΔF	*df*	β
Demographic	.47	.25	.23	15.89	6, 335	

Age at Participation						.18	***
Education						.06	
Relationship						.02	
Employment						.16	***
Age at Diagnosis						.02	
Time Last Seen by Dr.						.39	***
Variables	.68	.47	.25	36.77	4, 331		
Positive Support.						.10	*
Problematic Support						-.23	***
Self-Efficacy						.35	***
Race						.04	

Note. Betas reported are those from the step at which the variable was entered into the equation.

*p< .05. ***p < .001.

Analysis for Research Question 2

Part One.

A linear multiple regression was calculated to determine the influence of positive social support, problematic social support, self-efficacy, and race on Non-Health-Related Quality of Life. Non-Health-Related Quality of Life consists of the total transformed score from the Desire/Goals, Social Support, Coping, and Satisfaction with Care domains on the LupusPro. The independent variables of positive social support, problematic social support, self-efficacy, and race are defined

as stated previously in the analysis of Research Question 1. A significant regression was found [F (4, 339) = 28.08, p =.0005], with an R^2 of .25.

To satisfy multicollinearity, the correlations between all independent variables of race, positive social support, problematic social support, and self-efficacy were evaluated to determine significant strength at .7 or higher. No independent variables were correlated to one another at a .7 or greater. Collinearity statistics for both Tolerance and VIF indicate no multicollinearity occurring. The data were checked for outliers utilizing Mahalanobis distances, which indicated a maximum critical value of 18.47 for 4 independent variables. The maximum Mahalanobis distance in Residual Statistics was 16.95. A scatterplot for Health-Related Quality of Life was also analyzed. There are no indications of significant outliers skewing the data that need to be removed.

Table 17

Summary of Intercorrelations for Non-Health-Related Quality of Life

Variable	1	2	3	4
1. N-H-R QoL				
2. Positive Social	.44			
3. Problematic Social	-.30	-.40		
4. Race	.06	.04	.01	
5. Self-Efficacy	.36	.42	-.23	.01

To evaluate the appropriateness of this model, the Model Summary was examined to determine the amount of variance in Non-Health-Related Quality of Life explained by positive social support, problematic social support, self-efficacy, and race, (R^2= .25, p=.0005). This indicates that 25% of the variance in Non-Health-Related Quality of Life is explained by positive social support, problematic social support, and self-efficacy.

The standardized beta coefficients indicated that Positive Social Support (β = .29, p=.0005) had the most independent influence on Non-Health-Related Quality of Life. Self-efficacy (β = .21, p=.0005) was the second strongest influence on Non-Health-Related Quality of Life. Problematic social support (β = -.14, p = .007) demonstrated a small but significant influence on Non-Health-Related Quality of Life. Race (β =-.05, p=.25) exerted little to no influence on Non-Health-Related Quality of Life.

By utilizing the partial correlation coefficient squared, it was determined that positive social support accounted for 8% of the variance in Non-Health-Related Quality of Life scores after controlling for all other variables. Self-Efficacy accounted for 4% of the variance, and problematic social support accounted for 2%. Race had no discernible effect on Non-Health-Related Quality of Life.

Table 18

Regression Analysis Evaluating Predictors of Non-Health-Related Quality of Life

Variable	B	SE	β	*P*	Partial R	Partial R^2
Positive Support	.57	.11	.30	.0005	.28	.08
Self-						

Efficacy	1.75	.44	.21	.0005	.21	.04
Problem Support	-1.88	.69	-.14	.007	-.15	.02
Race	1.77	1.55	.05	.255	.06	.003

Part Two

With the same reasoning, this researcher sought to control for age at time of participation, relationship status, educational status, employment status, age at time of diagnosis, and the last time seen by a doctor for SLE-related symptoms when examining how positive social support, problematic social support, self-efficacy and race impact Non-Health-Related Quality of Life. To determine if these factors were impacting Non-Health-Related Quality of Life in this study, a separate hierarchical multiple regression was calculated controlling for the following variables; age at time of participation, marital status, educational status, employment status, age at time of diagnosis, and the last time seen by a doctor for lupus symptoms. Age at time of participation and age at diagnosis were separated into categories as seen in Tables 1 and 6.

Prior to the hierarchical regression analyses, the independent variables were examined for collinearity. Results of the variance inflation factor (all less than 2.0) suggest that the estimated *b*s are well established in the following regression models. The results of the hierarchical regression predicting Non-Health-related Quality of Life from demographic characteristics, positive social support, problematic social

support, self-efficacy and race are reported on Table 19. The results of step one indicate that the variance accounted for (R^2) with the first six predictors (age at time of participation, relationship status, educational status, employment status, age at time of diagnosis and the last time seen by a doctor for lupus-related symptoms) equaled .05 (adjusted R^2=.04), which was significantly different from zero ($F_{(6, 335)} = 3.45$, $p<.001$). For step two, scores for positive social support, problematic social support, self-efficacy and the demographic race variable were entered into the regression equation. The change in variance (ΔR^2) was equal to .25 which was a statistically significant increase in variance over the step one model ($F_{(4, 331)}= 22.12$, $p<.001$). Two of the demographic variables (the last time seen by a doctor for lupus symptoms (β = .15, p = .005), and employment status (β = -.11, p =.03) were statistically significant. Positive social support, problematic social support, and self-efficacy accounted for 25% of variance in Non-Health-Related Quality of Life when controlling for age at participation, employment status, marital status, educational status, age at diagnosis, and last time seen by doctor for lupus symptoms. Positive social support (β = .29, p = .000), self-efficacy (β = .18, p = .001) and problematic social support (β = -.11, p = .03) were significant predictors of Health-Related Quality of Life. When considering partial correlation coefficients squared, positive social support accounted for 8% of variance when accounting for all variables including demographic variables. Self-efficacy accounted for 4% and problematic social support accounted for 1% of variance in Non-Non-Health-Related Quality of Life. Race (β = .04, p =.33) was still not a significant factor in Health-Related Quality of Life.

Table 19

Hierarchical Regression Analyses Evaluating Predictors of Non-Health-Related Quality of Life

Measures	R	R^2	ΔR^2	ΔF	*df*	β	
Demographic	.24	.05	.07	3.45	6, 335		
Age at Participation						.09	
Education						.09	
Relationship						.03	
Employment						.11	*
Age at Diagnosis						.05	
Time Last Seen by Dr.						.15	*
Positive Support.	.51	.26	.18	12.95	4, 331	.29	***
Problematic Support						-.11	*
Self-Efficacy						.19	*
Race						.06	

Note. Betas reported are those from the step at which the variable was entered into the equation.

*p< .05. ***p < .001.

CHAPTER 5: DISCUSSION

The purpose of this quantitative web-based research study was to examine the impact of social and psychological factors on both Health-Related and Non-Health-Related Quality of Life in SLE patients. Specifically, this study sought to examine the impact of self-efficacy, positive social support, problematic social support and race on both Health-Related Quality of Life and Non-Health-Related Quality of Life in adult Systemic Lupus Erythematosus patients in the U.S.

The following chapter concludes this research study. The sections for this chapter include an interpretation and discussion of the results of this study, contributions and limitations in this research study, implications of the findings, recommendations for future research, and concluding remarks.

Overview

Systemic Lupus Erythematosus is a chronic multisystem disease that requires those afflicted to constantly adjust to changing life conditions. SLE patients cope with not only the biological aspects of flares and remission of symptoms, development of new symptoms, damage accumulation and medications with extreme side effects but also psychological factors such as feelings of anxiety, depression, feelings of isolation and body image issues (Pons-Estel, Alarcon, Scofield, Reinlib, & Cooper, 2010). As Gallup et al. (2012) suggests, SLE symptoms are highly impacted by psychosocial and biological factors that are interconnected and in turn impact SLE symptoms. With an estimated 500,000 Americans having been diagnosed with SLE and 1,600 more newly diagnosed annually, it is crucial for researchers and helping professionals

to gain a better understanding of the roles and directionality of all factors that impact quality of life for SLE patients (Helmick et al., 2008; Pons-Estel et al., 2010; Trager & Ward, 2001).

The improvement of coping strategies and modifiable factors such as social support and self-efficacy are linked to increased health-related quality of life in SLE patients (Burckhardt et al., 1993; Haupt et al., 2005; Karlson et al., 1997; Mazzoni & Cicagnoni, 2017). This study sought to add to the knowledge about factors that influence quality of life that can be addressed by counselors who work with SLE patients.

Discussion of Results

The sample for this study consisted of 344 participants who completed this web-based survey, with no missing data. These participants were predominately female, White, college educated, married, and working full-time. The age of participants ranged from 21-75 with a mean of 45.77. The mean age at Diagnosis was 34.77 with a range from 3-72. Research shows that SLE is diagnosed mostly in women and can be diagnosed from age 2 to 80 years of age or older (Danchenko, Satia, & Anthony, 2006). SLE is diagnosed most often between 15-44 years of ages. Most participants saw a Rheumatologist for lupus-related symptoms, and 31% had been seen by a doctor, hospital, or emergency room within the last month. All participants had been diagnosed with SLE by a doctor, and six participants indicated they had also been diagnosed with Discoid Lupus.

Health-Related Quality of Life has been related to better management of the disease and can be categorized into different components (Nicassio, Carr &

Moldovan, 2011). Participants in this study demonstrated highest Health-Related Quality of Life scores for the Procreation domain. It is important to note that the Procreation domain was rated as Not Applicable by 82% of respondents for question 1: Concern that lupus medication(s) will make it difficult to have a baby. Eighty-nine percent of participants answered Not Applicable for question 2 on Procreation: Worry about the ability to prevent unplanned pregnancy. Physical Health, Lupus Symptoms and Lupus Medication domains were more moderate and tended to be closer to the middle of the scale of 1 (lowest health-related quality of life) -100 (highest health-related quality of life). The lowest Health-Related Quality of Life scores were in the domains of Pain Vitality, Emotional Health, and Cognition. Non-Health-Related Quality of Life scores were highest in the domains of Coping and Satisfaction with Care but were lowest in Desire/Goals. Overall, both health-related quality of life and non-health-related quality of life scores were comparable with other studies utilizing the LupusPro (Mazzoni & Cicagnoni, 2016; Mazzoni, Cicagnoni, & Prati, 2017).

Self-efficacy is a key component of how patients manage disease (Marks & Allegrante, 2005) and therefore is a key concept in this study. Participants demonstrated higher scores in self-efficacy for managing chronic disease in two domains, their ability to do Things Other than Medications and in Managing Health Tasks. Self-efficacy scores were lower in participants' confidence in handling Fatigue, Symptoms, and Physical Health. Overall, the self-efficacy scores for this study were lower than the mean scores for other studies analyzed by Thombs et al.

(2017) that utilized the same self-efficacy instrument that were including chronic illness, cancer, heart disease, heart failure, COPD and SLE.

Social support was examined from both the perspective of positive social support and negative social support. Previous research has shown that positive social support increased health-related quality of life and decreased feelings of anxiety and depression (Mazzoni & Cicognani, 2016). However, problematic social support decreases health-related quality of life and increases feelings of stress. In this current study, participants scored highest in the category Tangible forms of positive social support, which is defined as the provision of money, goods, and services (Cohen, 1988). Participants scored lowest in Appraisal, which is viewed as being valued and held in esteem. Problematic social support scores were higher for the category of Denying/Uninformed social support than for the category of Oppressive social support. These score mean that participants for this study felt that support-giving individuals did not want to discuss participants' symptoms and did not educate themselves about SLE (Mazzoni & Cicagnoni, 2016).

Results from the Pearson Correlation Coefficient in this study indicate that positive social support and self-efficacy were strongly positively correlated. Problematic social support was moderately negatively correlated to self-efficacy. Positive social support and problematic social support were strongly negatively correlated. These correlations are comparable to results found in Mazzoni, Cicognani, and Prati (2017).

Discussion of Research Questions.

Two research questions were identified for this study. Question 1: How is health-related quality of life in adult SLE patients related to self-efficacy, positive social support, problematic social support, and race? Question 2: How is health-related quality of life in adult SLE patients related to self-efficacy, positive social support, problematic social support, and race?

Question 1.

Results of this study indicated that before controlling for demographic information, self-efficacy, positive social support and problematic social support accounted for 38% of the variance in health-related quality of life. Self-efficacy (19%) had the highest amount of influence on health-related quality of life. As self-efficacy increases, health-related quality of life also increases. Problematic social support (10%) had the second highest amount of influence on health-related quality of life. However, Problematic social support negatively correlated to health-related quality of life meaning that as problematic social support increases, health-related quality of Life decreases. Positive social support (1%) had a small positive amount of influence while race did not have any significant impact on health-related quality of life.

Due to this researchers concern regarding confounding variables, the demographic variables of age at time of participation, employment status, marital status, educational status, age at time of diagnosis, and the last time seen by a doctor for SLE-related symptoms were included into an addendum to Question 1. At step one, the demographic variables accounted for 21% of the variance in health-related

quality of life. The date last seen by a doctor for SLE-related symptoms accounted for 8% of variance in this model. The more recently the participants were seen by a doctor for SLE-related symptoms, the lower their health-related quality of life. Employment status accounted for 2% and age at the time of participation in this study accounted for 1% of variance in health-related quality of life.

At step two, positive social support, problematic social support and self-efficacy accounted for 45% of the variance when controlling for demographic variables. Self-efficacy (14%) continued to account for the most variance in health-related quality of life. Problematic social support accounted for 7.3% of the variance, and positive social support accounted for 1% of the variance in health-related quality of life. Race continued to demonstrate no statistical significance for health-related quality of life.

Both analyses for Question 1 demonstrate the importance of self-efficacy and problematic social support to health-related quality of life. To a lesser degree, positive social support accounted for a small but significant variance. Race did not demonstrate statistical significance for health-related quality of life for either analyses. The date since last seen by a doctor accounted for significant variance and may be an indicator of SLE disease activity or severity. Disease activity or damage accumulation could result in symptoms that would result in a doctor's appointment or a visit to the emergency room. Research supports disease activity and damage accumulation as a possible predictor of health-related quality of life in SLE patients (Monov, Monova, & Ivanova, 2017; Panopalis et al., 2005). As supported by multiple

studies, employment status also played a role in health-related quality of life (McElhone et al., 2010; Meacock et al., 2013; Meagari, 2014).

Question 2.

Positive social support, problematic social support and self-efficacy accounted for 25% of the variance in non-health-related quality of life. Before controlling for demographic variables, non-health-related quality of life was most significantly influenced by positive social support (8%) and self-efficacy (4%). Problematic social support (2%) played a small but significant role in non-health-related Quality of life. Race played no significant role in non-health-Related Quality of life.

At step one of the hierarchical regression, only 4% of the variance in non-health-related quality of life was accounted for by demographic variables. Date last seen by a doctor for SLE-related symptoms and employment status played small but statistically significant roles in non-health-related quality of life. At step two, after controlling for demographic variables, positive social support, self-efficacy and problematic social support accounted for 25% of the variance in non-health-related quality of life. After controlling for demographic variables, positive social support and self-efficacy remained the most significant influencers of non-health-related quality of life. None of the demographic variables were significant influencers of non-health-related quality of life after positive social support, self-efficacy, problematic social support, and race were added into the regression equation. None of the variables changed in their impact on non-health-related quality of life, with positive social support (8%) and self-efficacy (4%) accounting for the most variance. Problematic social support remained a small (1%) but significant influencer of non-

health-related quality of life. Race continued to have no impact on the amount of variance accounted for by the independent variables. As positive social support and self-efficacy increase, Non-Health-Related Quality of Life increases as well. As problematic social support increases, Non-Health-Related Quality of Life decreases.

Discussion of Results

In this study, self-efficacy remained a consistent strong influence on both health-related and non-health-related quality of life in SLE patients. Self-efficacy had the strongest impact on health-related quality of life. These results are consistent with Mazzoni et al. (2017) who found that as self-efficacy increased, both health-related quality of life and non-health-related quality of life increased. This study furthers knowledge by demonstrating the importance of self-efficacy in both health-related and non-health-related quality of life despite that self-efficacy and positive social support share a strong positive correlation while self-efficacy and problematic social support share a moderate negative correlation. Self-efficacy for chronic illness patients "implies the perceived capacity of working in partnership with carers and health professionals to manage their diseases and related treatment" (Mazzoni et al., 2017, p. 126). Therefore, self-efficacy is inherently impactful of and impacted by social support.

The importance of self-efficacy as such a strong predictor of health-related and non-health-related quality of life comes from the theory that self-efficacy is one of the most modifiable factors through counseling and educational interventions. Self-efficacy interventions for SLE patients have been shown to increase mental health status (Karlson et al., 2004). Conversely low self-efficacy has been related to higher

levels of pain, stiffness, and fatigue (Somers et al., 2012). According to Bandura (1997) self-efficacy is formed through mastery, vicarious experiences and verbal persuasion. All of these self-efficacy skills are influenced and informed by positive and problematic social support.

In this study, employment status contributed significantly to both health-related and non-health-related quality of life. There is a possibility of some type of relationship between self-efficacy and work that contribute to quality of life. Bandua (1979) postulated that mastery experiences of overcoming obstacles increases self-efficacy; thus being able to work would demonstrate a sense of mastery of the effects of the disease. It is also possible that feeling more empowered in one's life through having a job and earning money decreases a sense of feeling like a burden or other feelings of helplessness. This concept is supported by Moses et al. (2005) who reported that SLE patients feel as though they are a burden to others and do not feel a sense of power and control in their lives. Working may counterbalance this sense of being powerless. Another source of self-efficacy is verbal persuasion, which is facilitated by having others strengthen our beliefs that we can accomplish our goals. The work setting provides opportunities for others to support personal accomplishments and provide encouragement when things are difficult. The relationship between self-efficacy and work as these factors influence quality of life need further exploration.

Consistent with several research findings, social support played a strong role in both health-related quality of life and non-health-related quality of life for SLE patients in this study (Cohen 1988; Mazzoni & Cicognani, 2016; Mazzoni &

Cicognani, 2011; & Mazzoni et al., 2017). However, the findings of this study also demonstrate that not all types of social support are beneficial to health-related and non-health-related quality of life in SLE patients. In this study, positive social support only contributed to non-health-related quality of life while problematic social support contributed to changes in both health-related and non-health-related quality of life.

Problematic social support made a significant negative contribution to health-related quality of life, while positive social support was not significant. Conversely, positive social support made a significant contribution to non-health-related quality of life while problematic social support was significant but smaller. These findings may indicate the differences between health-related quality of life and non-health-related quality of life. Health-related quality of life focuses more on the physical and mental symptoms and concerns regarding symptoms, medications, procreation and body image as related to SLE. Problematic social support may be more damaging when symptoms and side effects are being ignored or minimized, whereas, non-health-related quality of life focuses on social supports, hopes and dreams, and satisfaction with care. Positive social support from medical professionals may be significantly more meaningful than from family members or friends.

This concept is supported by research findings that SLE patients do not feel heard or understood by their physicians and do not feel that they are being provided adequate information and resources for coping with their disease (Brennan & Creaven, 2016; Hale et al., 2006; Taymayo et al., 2010).) While both

quality of life domains are impacted by SLE, there appears to be a difference in the types of social support needed for each domain. Hale et al. (2006) found that many SLE patients felt that their doctors thought they were malingering or over exaggerating symptoms. Positive social support from medical professionals in terms of information and resources could in fact increase a sense of self-efficacy over SLE symptoms.

The majority of problematic social support research has been performed on Rheumatoid Arthritis patients (Mazzoni, Cicognani, & Prati, 2017; Revensen et al., 1991; Riemsma et al., 2000). There is a paucity of research concerning SLE and problematic social support. This study demonstrates the importance of problematic social support on health-related quality of life in SLE patients. Providing too much support or providing it at the wrong time may actually be damaging to the SLE patients' health-related quality of life even when it is well meant (Mazzoni & Cicognani, 2016). Additionally, family members, friends and caretakers who refuse to discuss SLE symptoms and how these symptoms are impacting the individual, are also damaging health-related quality of life.

Non-health related quality of life appears to focus on a different concept for SLE patients. Existing research has suggested that SLE patients have feelings of isolation and feel misunderstood by family, friends, and physicians and that many SLE patients have unmet social needs (Moses et al., 2005; Sutanto et al., 2013). Getting these social needs met may be the reason that Positive Social Support is strongly aligned with overall quality of life. The strong contribution that positive social support makes to SLE patients in terms of overall quality of

life appears to be related to the patient perceiving that others are available to talk to about their problems as well as having someone to do things with who may provide material aid.

The findings of this study are consistent with Mazzoni and Cicognani's (2016) findings where problematic social support had a significant effect on health-related quality of life and positive social support had a significant effect on non-health-related quality of life. The Mazzoni and Cicognani study found that stress from problematic social support and lack of positive social support significantly impacted SLE patients' quality of life. The importance of understanding the roles and directionality of positive social support and problematic social support lies in the understanding that social support is a variable that helping professionals can modify through psycho-educational interventions to increase quality of life in SLE patients.

Amir, Roziner, Knoll and Neufeld (2005) performed a study examining self-efficacy and social support as mediators between disease severity and quality of life in epilepsy patients. This study found that self-efficacy mediated the relationship between disease severity and quality of life while social support was a mediator between disease severity and self-efficacy. These finding are supported by Mazzoni et al. (2017) who examined social support as a possible mediator and/or moderator between perceived stress in SLE patients and quality of life. This study found that positive and problematic social support both had a significant impact on stress, which in turn had a significant impact on both health-related and non-health-related quality of life.

There is a strong negative correlation between positive social support and problematic social support both in this study and in other studies by Mazzoni and Cicognani (2016) and Mazzoni et al. (2017). These findings indicate that these support scales represent different concepts that play different roles in quality of life. When examining quality of life related to managing one's disease, there is a strong negative impact when the support provided is excessive or neglects the impact of the disease. The fact that in this study, problematic social support played a more significant role in health-related quality of life than positive social support supports this claim. As these negative forms of support increase, health-related quality of life decreases and appears to negate the impact of positive social support.

Race did not have a significant impact on health-related or non-health-related quality of life in this study. Race and cultural factors that impact quality of life in SLE patients has not been well conceptualized or researched (Barnardo et al., 2012; Jolly & Utset, 2004). The findings of Alarcon et al. (2006) demonstrate the importance of considering genetics, psychosocial factors, and disease activity when considering health-related and non-health-related quality of life. Existing research has been conflicted with possible confounding variables and opposing findings (Kuriya et al., 2008). Kuriya et al. (2008) found that ethnicity made a significant impact on the physical function domain of the SF-36 at the second assessment of quality of life but that ethnicity did not significantly predict health-related quality of life. The LUMINA and Einstein cohort studies demonstrated that minority SLE patients had higher levels of anxiety,

depression, disease activity, and accumulated damage and to be at risk for demographic variables such as poverty and lack of insurance that decrease treatment attendance and availability. Race and ethnicity are more than categorical constructs. They encompass genetics, perceptions of self and others, socialization of how to be sick and the impact of oppression and prejudice on the biopsychosocial wellbeing of the individual. For all of these reasons, it remains difficult to determine the impact of race and ethnicity on health-related and non-health-related quality of life in SLE patients.

Significance of the Study

To date, this is the first study assessing the impact of self-efficacy, positive social support, problematic social support, and race on both Health-Related and Non-Health-Related Quality of Life in SLE patients. First, this study furthers the knowledge of quality of life in SLE patients by utilizing a SLE-specific quality of life instrument. Many of the existing SLE patient quality of life studies have been performed utilizing disease general quality of life instruments (Gladman et al., 1996; McElhone, Abbott & Teh; 2006; Ware & Sherbourne, 1992). The findings of this study indicate that there are different contributing factors to health-related quality of life and non-health-related quality of life. These finding illustrate the importance of exploring multiple concepts of quality of life in SLE patients and the needs that are specific to the different domains of quality of life.

Additionally, this study furthers the knowledge of how social support specifically for SLE patients must be addressed from both a positive and problematic point of view. The majority of problematic social support research

has been in the field of rheumatoid arthritis patients and other chronic illness patients (Mazzoni, Cicognani, & Prati, 2017; Revensen et al., 1991; Riemsma et al., 2000). There is a paucity of research regarding problematic social support specifically to SLE patients. With flare and remission patterns, difficulty of diagnosis and lack of public knowledge of SLE, SLE patients may experience problematic social support in differing ways than other chronic illness populations. With a better understanding of problematic social support in SLE patients, counselors can create and provide better interventions to both SLE patients and their families.

The majority of self-efficacy studies for SLE patients have examined the ability of various interventions to enhance self-esteem versus the direct impact of self-esteem on health-related or non-health-related quality of life. (Drenkard et al., 2012). This study provides an analysis of the ways in which self-efficacy interacts with other factors to affect health-related quality of life specifically in SLE patients, using a SLE- specific quality of life instrument. The hope is that as researchers and clinicians gain a stronger understanding of how self-efficacy influences SLE patient quality of life, then more effective interventions can be created to increase self-efficacy in culturally diverse populations. In addition, there has been little understanding of the roles and directionality of positive social support, problematic social support and self-efficacy. Because counselors have an understanding of how clients can increase self-efficacy, interventions can be implemented along with social support changes to improve quality of life in SLE patients.

Limitations of the Study

This study has several limitations that should be considered. First, this study utilized an on-line purposive sample for a cross-sectional, web-based survey. The completion rate for this study was 80% and yielded 344 completed surveys. However, because this was an on-line survey, some limitations are inherent. First, participants had to have access and at least limited knowledge of how to use a computer. This requirement may have limited participation of individuals without the means or accessibility to a computer, phone with data, and the Internet. Therefore, the results cannot be considered to be representative of all SLE patients. While Query and Wright (2003) did not find a significant difference among on-line surveys and paper and pencil surveys, it is not possible to determine if any of the differences in this survey are attributed to participants being on-line participants.

The study was a cross-sectional study. Therefore, it is not possible to make inferences regarding the causality of self-efficacy, positive social support, problematic social support, and race on quality of life in SLE patients. It is also not possible to determine if results would have changed as a result of time, disease status, or other life changes that might occur in the participants' life. Future longitudinal research is recommended.

The majority of this sample was obtained utilizing Facebook, SLE-specific support sites. This approach omitted participants who were not already members of a Facebook SLE support site, who did not have computer access, or were not computer literate. Therefore, generalizability of the results is limited and does not necessarily encompass the entire U.S. SLE population. This study relied on participants to self-

report their age, race, diagnosis, and other demographic information as well as instrumental results. With this purposive sample, there may be selection bias and recall accuracy may be uncertain (Chen et al., 2005). However, any surveys that were not completed were eliminated from the data analysis sample. This can help to diminish response and non-response bias (Helms, Gardner & McInnes, 2017). Most of the Facebook SLE sites utilized in this survey were closed sites and required participants to apply for permission to become a member. This means that all discussions within that site are private and participants have been screened through the site administrators.

Another limitation of this study is the use of self-reported SLE diagnose rather than rheumatologic assessment. Additionally, there was no measure of disease activity other than the length of time since they were last seen for SLE-related symptoms. As stated, self-report measures run the risk of participants being deceptive or inaccurate in their responses.

All participation for this study was voluntary. It must be considered that the response of those who voluntarily participated in this study may be different from those who chose not to participate. There is a risk that participants provided answers that they considered to be socially desirable. Even though the participants were informed in advance that their answers would be kept anonymous and confidential, they may still have responded in a manner that would not be representative of their true feelings or knowledge.

Another limitation of this study is related to the demographic characteristics of the participants. The majority of the respondents in this study were female (97%)

despite the researcher's efforts to recruit male participants. However, this researcher believes that this reflects the fact that SLE is predominantly a female disease with a ratio of 9:1 (National Institute of Health, 2013). In addition, the majority of participants were Caucasian (72%) despite the researcher's effort to recruit more diverse populations through minority specific Facebook SLE sites. Because, SLE is more predominant in African-American, Native American, Asian American and Hispanic populations, the lack of a larger sample size for non-Caucasian participants does not reflect the SLE population (Borchers et al., 2010; National Institute of Health, 2013). Although 28% of participants were not Caucasian, it is not possible to generalize results to the diverse populations. Because the categorical groups of race were collapsed for data analysis due to small sample sizes for each race, there is no way to determine the unique contribution that each cultural or racial group could have added to health-related and non-health-related quality of life. Therefore, it is not possible to definitively determine the role that race may play in Quality of Life in SLE patients.

Recommendation for Future Research

There are several recommendations for future research in the field of SLE specific quality of life research as a result of this study. As stated previously, there is a paucity of research for SLE specific studies regarding problematic social support and self-efficacy. Future research should concentrate on the roles and directionality of positive social support, problematic social support and self-efficacy. Liu, Xu, and Wang (2017) found that self-efficacy acted as a moderator for social support in Rheumatoid Arthritis patients. When self-efficacy was higher in

participants, the relationship between depression and anxiety and social support was weakened. Because self-efficacy played such an important role in this study in both health-related quality of life and non-health-related quality of life, further research should analyze the role of self-efficacy as a possible moderator/mediator for problematic social support and positive social support in relation to SLE health-related and non-health-related quality of life by utilizing a structural equation modeling.

The next recommendation for future research is further analysis of different roles and importance of both positive social support and problematic social support on SLE patients' health-related and non-health-related quality of life. Future research should focus on determining the most influential forms of positive social support and the most detrimental forms of problematic social support. This knowledge would allow counselors and health psychologists to focus more effectively on interventions to increase positive social support and decrease problematic social support provided by family members, friends, caregivers and medical professionals. If problematic social support is more detrimental from medical professionals then a change in educating medical professionals could produce increased quality of life in SLE and other chronic illness patients.

As stated in the limitations section, because this study was cross-sectional, future longitudinal research would bring a fuller understanding of the long-term impact of positive social support, problematic social support and self-efficacy on health-related and non-health-related quality of life in SLE patients. Longitudinal studies would also allow for tracking how changes in positive social support and

problematic social support impact quality of life in both health-related and non-health-related domains.

Because there was no measure of disease activity or damage accumulation, future research should also include instruments that provide greater understanding of how these factors interact with positive social support, problematic social support and self-efficacy when predicting health-related and non-health-related quality of life. Additionally, researchers need to gain a better understanding of how employment status plays a role in this process. Does positive social support and problematic social support impact how the SLE patient copes with financial problems, employment issues, and SLE symptoms? Does positive social support and problematic social support impact how SLE patients internalize SLE symptoms, financial problems, and employment issues? Do SLE symptoms, financial problems and employment issues decrease a sense of self-efficacy? Future research can assist in a better understanding of this process.

Lastly, future research in the area of SLE quality of life should address race and ethnicity as biological, psychological and sociological components. The concept of race is difficult to operationalize and control for all possible confounding variables (Toloza, Jolly, & Alarcon, 2010; Touma & Gladman, 2010). SLE is a predominantly minority female disease, yet much of the studies on SLE and quality of life have been performed on white women. Research focusing on the cultural, psychological, sociological and biological components can help medical and counseling professionals to gain a better understanding of the unique perspective of minority

SLE patients. This in turn could assist in the development of educational, counseling and medical interventions that address the needs of this population.

Concluding Remarks

SLE mortality is decreasing but the reality of living longer with a chronic, unpredictable illness while be treated with medications that produce extreme side effects impacts the SLE patients, family, friends, caregivers, the medical profession, and the economy. As research provides better diagnostic criteria and pharmacological treatment, we must also consider the benefits of non-pharmacological treatments. The value of counseling and health psychology interventions on quality of life in chronic illness populations is only just being understood. The value of these interventions for SLE patients is even less well known (Sprangers & Schwartz, 2017; Touma & Gladman, 2010).

The results of the study suggest that positive social support, problematic social support and self-efficacy have an independent impact on health-related quality of life and non-health related quality of life. There are multiple implications for the counseling and health psychology professions. In addition to understanding more about positive social support, problematic social support, self-efficacy and race in SLE patients, we should also begin to analyze the relationships and directionality of positive social support, problematic social support and self-efficacy. Counselors, health psychologists, and researchers can provide positive social support through helping relationships in a manner that stimulates self-efficacy growth. Helping professionals can assist clients in gaining knowledge about their disease and developing symptom management techniques. According to Fu, LeMone, and

McDaniel (2004), this process should include "a dynamic and multidimensional process" in which the chronic illness patient "intentionally and purposefully acts on the perception of the symptoms to initiate activities or direct other to perform activities to relieve or decrease distress" (p. 66). Part of this support may come from counselors, health psychologists, and physicians conveying that they believe their clients and patients when these individuals share the difficulties they are experiencing with their health.

In addition, helping professionals can educate not only clients but also caregivers, medical professionals, and one another in gaining a better understanding of symptoms and symptoms management. Finding ways to provide positive social support and ways to increase self-efficacy in SLE patients may help increase health-related and non-health-related quality of life. Communication of healthy helping behavior and unhealthy helping behavior can assist SLE patients in communicating effectively with family and caregivers. This in turn increases self-efficacy in the SLE patient's ability to manage symptoms, while also increasing positive social support and minimizing problematic social support (Mazzoni et al., 2017). By increasing the ability of the patient's entire system of care to provide positive and encouraging support, SLE patients may be better equipped to manage this challenging illness.

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Appendix A

Introductory Letter

Dear Medical Professional:

My name is Stacie Camp Bennett and I am inviting you to assist me in finding participants in an online survey as part of my dissertation requirements for a Doctor of Philosophy Degree in counseling at the University of North Carolina at Charlotte. The purpose of this proposed study is to examine the relationships between and among self-efficacy, positive social support, problematic social support, race, and health-related quality of life in adult SLE patients.

The hope is that this research will assist medical and counseling professionals, families and lupus patients in having a better understanding of how positive social support, problematic social support and self-efficacy impact health-related quality of life. This study requires that participants are 18 years of age or older and have been diagnosed by a medical professional with Systemic Lupus Erythemathsus.

The survey will take approximately 15-20 minutes to complete. Your participation in carrying out this research will add valuable information to the understanding of factors that impact SLE patients. In turn, this knowledge can impact how medical and helping professionals as well as caregivers, family members, and lupus patients themselves, attempt to provide support and treatment for lupus. If your patients choose to participate in this study, their information will be kept both anonymous and confidential, as no names or email addresses will be identified with their responses. Participants may withdraw or decline without penalty at any time.

I am attaching copies of the informed consent, IRB approval form, and an introductory letter that you can provide to your patients or post in your waiting room. The introductory letter for patients has a copy of the hyperlink for the study.

Thank you very much for helping with this study. If you have any questions or concerns regarding this study, please feel free to contact me by email.

Stacie Camp Bennett MA, LPCS, LCAS
Doctoral Candidate
Department of Counseling
University of NC Charlotte
sdcamp@uncc.edu

Susan Furr, PhD
Dissertation Chair
Department of Counseling
University of NC Charlotte
srfurr@uncc.edu

Appendix B

Introductory Post

Dear Lupus Thriver:

My name is Stacie Camp Bennett and I am inviting you to participate in an online survey as part of my dissertation requirements for a Doctor of Philosophy Degree in counseling at the University of North Carolina at Charlotte. The purpose of this proposed study is to examine the relationships between and among self-efficacy, positive social support, problematic social support, and health-related quality of life in adult SLE patients.

The hope is that this research will assist medical and counseling professionals, families and lupus patients in having a better understanding of how positive social support, problematic social support and self-efficacy impact health-related quality of life. This study requires that you are 18 years of age or older and have been diagnosed by a medical professional with Systemic Lupus Erythemathsus.

The survey will take approximately 15-20 minutes to complete. Your participation in carrying out this research will add valuable contribution to the understanding of factors that impact SLE patients. In turn, this knowledge can impact how medical and helping professionals as well as caregivers, family members and lupus patients themselves, attempt to provide support and treatment for lupus. If you choose to participate in this study, your information will be kept both anonymous and confidential, as no names or email addresses will be identified with your responses. You may withdraw or decline without penalty at any time.

If this study is of interest to you, or if you want to review the informed consent form, click your unique URL address or copy and paste the URL address into your web browser:

<hyperlink>

Thank you very much for helping with this study.

Stacie Camp Bennett MA, LPCS, LCAS
Doctoral Candidate
Department of Counseling
University of NC Charlotte
sdcamp@uncc.edu

Susan Furr, PhD
Dissertation Chair
Department of Counseling
University of NC Charlotte
srfurr@uncc.edu

Appendix C

Participant Consent Form

Department of Counseling
College of Education Building Suite 241
9201 University City Blvd.
Charlotte, NC 28223

Informed Consent for

Examining the Relationships Among and Between Self-Efficacy, Positive Social Support, Problematic Social Support, Race and Health-Related Quality of Life of Adult Systemic Lupus Erythematosus Patients

Project Title and Purpose:

You are invited to participate in a research study entitled, Examining Self-Efficacy, Positive Social Support, Problematic Social Support, Race and Quality of Life in Adult Systemic Lupus Erythematosus Patients. The purpose of this study is to examine the relationships between and among self-efficacy, positive social support, problematic social support, health-related quality of life and race in adult Systemic Lupus Erythematosus patients.

Investigator(s):

This study is being conducted by Doctorial Candidate, Stacie Camp Bennett MA, LPCS, LCAS, University of North Carolina Charlotte (UNCC) and the Dissertation Chair, Dr. Susan Furr, University of North Carolina Charlotte (UNCC).

Description of Participation:

Your participation in this study will assist researchers, counselors, medical doctors, and SLE patients in better understanding factors that impact the lives of adults living with Systemic Lupus Erythematosus. This information in turn, can assist professionals, patients, and caretakers of patients in better understanding how to increase the level of quality of life in Systemic Lupus Erythematosus patients. If you are currently over the age of 18 and have been diagnosed with Systemic Lupus Erythematosus, you are eligible to participate in this study. You will be asked to complete an online survey inquiring about your demographic information, your feelings and thoughts regarding your health, how your health effects your life, feelings of control over your disease and amounts and types of social supports.

By clicking on the Accept button at the bottom of this page I am providing that I am 18 years of age or older and I have been diagnosed with Systemic Lupus Erythematosus by a medical doctor.

Length of Participation

Your participation in this project will take about 15 to 20 minutes to complete.

Risks and Benefits of Participation:

There are no known risks to participation in this study. However, there may be risks which are currently unforeseeable. You will receive no paid compensation for your participation in this research project.

Volunteer Statement:

You are a volunteer. The decision to participate in this study is completely up to you. If you decide to be in the study, you may stop at any time.

You will not be treated any differently if you decide not to participate or if you stop once you have started.

Confidentiality:

If you choose to participate, please note the confidential nature of this study.

The

hyperlink contained within this email is authentic and unique to you. Upon submission of the survey your contact information will be deleted.

Fair Treatment and Respect:

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704-687-3309) if you have any questions about how you are treated as a study participant.

If you have any questions about the project, please contact me, Stacie Camp Bennett MA, LPCS, LCAS, at 704-301-8093 or my Dissertation Chair, Dr. Susan Furr, PhD, 704-687-8967.

Participant Consent:

I have read the information and by clicking on the Accept button at the bottom of this page I am giving consent to participate in this study. Thank you for taking the time to participate.

Sincerely,

Stacie Camp Bennett MA, LPCS, LCAS
Doctoral Candidate
Department of Counseling
Counseling
UNCC

Susan Furr, PhD
Dissertation Chair
Department of

UNCC

Appendix D

Quality of Life Survey

Section I: Participant Eligibility

Instructions: Please check the appropriate box

1. I am 18 years of age or older?

☐ Yes

☐ No

2. I have been diagnosis with Systemic Lupus Erythematosus by a medical doctor?

☐ Yes

☐ No

Section II: Demographic Information

Instructions: Please check the appropriate box

1. Indicate your current age?

(Age is a Continuous Variable That the Participant Enters)

2. Which of the following best identifies your race?

☐African American

☐Asian/Pacific Islander

☐ Caucasian

☐ Hispanic/Latino

☐ Native American

☐ Multi-Racial

3. Indicate your gender?

□ Female

□ Male

□ Transgender

4. What is your current marital status?

□ Single

□ Married

□ Divorced

□ Separated

□ Widowed

□ Committed Relationship with Life Partner

5. What is your current education level?

□ Less Than High School

□ High School Graduate

□ GED

□ Some College

□ Graduated College

□ Master's Degree or Higher

6. What is your current work status?

□ Full-time

□ Part-time

□ Retired

□ Disabled and unable to work but receive Disability Benefits.

□ Disabled and unable to work but do not receive Disability Benefits.

□ Disable and unable to work and have applied for Disability Benefits.

□ Unemployed but looking for work.

7. How many years has it been since you were diagnosed with SLE?

(A Continuous Variable that the Participant Enters)

Section III: Lupus Patient Report Outcomes (v 1.7)

This questionnaire asks for your views about the effect of lupus or its treatment on your health, quality of life, and the medical care you receive related to your lupus. Answer each question by placing a cross mark (x) in the response box that best describes you. If you are unsure about how to answer a question, please answer as best you can. There is no right or wrong answer. Please select only one response to each question. You may choose the "Not Applicable" option for a question only if a box is provided in that column for that particular question.

A. In the past 4 weeks, how often did you experience the following due to your lupus?

1. Loss of hair

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

2. New or flare of previous lupus-related skin rashes

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

3. Lupus flare

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

4. Poor memory

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

5. Lack of Concentration

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

6. Lupus medication(s) related bothersome side effects.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time □N/A

7. Concern about the number of medications being received for lupus.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time □N/A

8. Concern that lupus medication(s) will make it difficult to have a baby.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time □N/A

9. Worry about ability to prevent unplanned pregnancy.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time □ N/A

B. How often were you limited in performing the following daily activities because of your physical health due to your lupus over the **past 4 weeks?**

10. Taking care of your personal needs (dress, comb hair, toilet, eat, bathe)

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

11. Getting in and out of a bed or chair

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

12. Fulfilling family responsibilities

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

13. Taking care of those who directly depend on me (family, pet).

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

14. A burden to family or friends due to your physical disabilities.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

C. How often did you feel the following due to your lupus in the **past 4 weeks?**

15. I woke up feeling worn out

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

16. I felt pain and aching in my body

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

17. I was unable to do my usual activities due to bodily pain

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

18. I was unable to perform usual activities for long periods of time (e.g. around home or at work) because of pain or fatigue

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

19. I was limited in the kind of tasks or activities I could perform because of pain or fatigue

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

D. During the **past 4 weeks,** how often did you feel because of your lupus that you were**…**

20. Worried about lupus' impact on my future

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

21. Worried about losing income

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

23. Anxious

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

22. Depressed

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

23. Concerned that lupus (or its treatment) may lead to more health problems

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

24. Concerned that lupus related health problems will last a long time

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

E. During the **past 4 weeks,** how often did you feel the following due to lupus?

25. I disliked my appearance

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

26. I thought less of myself

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

27. I lack control over my appearance

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

28. I was self conscious about my appearance

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

29. I was embarrassed about how others perceived me

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

F. During **the past 4 weeks**, how often did lupus interfere with your:

30. Ability to plan activities and schedule events

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

31. Overall life satisfaction

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

32. Enjoyment of life

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

33. Fulfillment of career goals

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

G. During the **past 4 weeks,** how <u>often</u> would you say in <u>regards to your lupus?</u>

35. I received support from my friends.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

36. I received support from my family.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

37. I focused on making my situation better.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

38. I learned to live with my lupus.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

39. I received comfort/strength from my religious or spiritual beliefs.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

H. During the **past 3 months**, how often did you feel the following about the medical care <u>for lupus</u> you received?

40. My doctor was accessible when I had a question regarding my lupus.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

41. My doctor understood the impact of lupus on my life.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

42. My doctor provided me with the information I need to understand my lupus.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

43. My doctors discussed/monitored the side of effects of lupus medicine/s.

□ None of the time □ A little of the time □ Some of the time □ Most of the Time □ All of the Time

Section IV: Self-Efficacy for Managing Chronic Illness

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident do you feel that you can keep the fatigue caused by your disease from Interfering with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not confident at all				Confident					Very Confident

2. . How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not confident at all				Confident					Very Confident

3. How confident do you feel that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not confident at all				Confident					Very Confident

4. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things that you want to do?

1	2	3	4	5	6	7	8	9	10
Not confident at all				Confident					Very Confident

5. How confident do you feel that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

1	2	3	4	5	6	7	8	9	10
Not confident at all				Confident					Very Confident

6. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

1	2	3	4	5	6	7	8	9	10
Not confident				Confident					Very

at all Confident

Section V: Interpersonal Evaluation of Support List

This scale is made up of a list of statements each of which may or may not be true about you. For each statement check "definitely true" if you are sure it is true about you and "probably true" if you think it is true but are not absolutely certain. Similarly, you should check "definitely false" if you are sure the statement is false and "probably false" is you think it is false but are not absolutely certain.

1. If I wanted to go on a trip for a day (for example to the beach, the country or the mountains), I would have a hard time finding someone to go with me.

___definitely true ____definitely false ____probably true ____probably false.

2. I feel that there is no one I can share my most private worries and fears with.

___definitely true ____definitely false ____probably true ____probably false

3. If I were sick, I could easily find someone to help me with my daily chores.

___definitely true ____definitely false ____probably true ____probably false.

4. There is someone I can turn to for advice about handling problems with my family.

___definitely true ____definitely false ____probably true ____probably false.

5. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me..

___definitely true ____definitely false ____probably true ____probably false.

6. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

___definitely true ____definitely false ____probably true ____probably false.

7. I don't often get invited to do things with others.

_definitely true ____definitely false ____probably true ____probably false.

8. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc).

___definitely true ____definitely false ____probably true ____probably false.

9. If I wanted to have lunch with someone, I could easily find someone to joint me.

___definitely true ____definitely false ____probably true ____probably false.

10. If I was stranded 10 miles from home, there is someone I could call who would come and get me.

___definitely true ____definitely false ____probably true ____probably false.

11. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.

___definitely true ____definitely false ____probably true ____probably false.

12. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.

___definitely true ____definitely false ____probably true ____probably false.

Section VI: Problematic Social Support
Instructions: *Please read each statement below and circle the number that best corresponds with your feelings.*

1.Some people, who are close to you, find it hard to listen to you when you talk about your illness**.**

1 2 3 4 5 6 7

Complete Disagreement — Agreement — Complete Agreement

2. Some people who can support you in case of need, avoid speaking with you about your illness.

1 2 3 4 5 6 7

Complete Disagreement — Agreement — Complete Agreement

3. Some people who are available to you in case of need, reject the idea that you have a serious illness.

1 2 3 4 5 6 7

Complete Disagreement — Agreement — Complete Agreement

4. Some people who are close to you, do not believe that you are really ill.

1 2 3 4 5 6 7

Complete Disagreement — Agreement — Complete Agreement

5. Other people do not realize by themselves when it is the right time to give you support.

1 2 3 4 5 6 7

Complete Disagreement — Agreement — Complete Agreement

6. Many people give you wrong advice about your illness management.

1	2	3	4	5	6	7
Complete Disagreement			Agreement			Complete Agreement

7. Some people are excessively worried about your physical health.

1	2	3	4	5	6	7
Complete Disagreement			Agreement			Complete Agreement

8. Some people want to check too often your physical condition.

1	2	3	4	5	6	7
Complete Disagreement			Agreement			Complete Agreement

9. Your relatives are too present and overprotective of you.

1	2	3	4	5	6	7
Complete Disagreement			Agreement			Complete Agreement

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10. Other people's excessive concern is a source of stress for you.

1	2	3	4	5	6	7
Complete Disagreement			Agreement			Complete Agreement