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Lupus-Related Damage, Social Support, and Depression: An Exploratory Study

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By

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Bachelor of Science
University of Michigan
2013

Thesis Committee Chair: Nancy Thompson, PhD

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

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African American women are disproportionately diagnosed with Systemic Lupus Erythematosus (SLE); however, very few studies focus specifically on this population. The purpose of this study is to understand the relationship between lupus-related organ damage and depression in African American women and to understand how emotional support influences this relationship. For this mixed-methods study, 437 participants from Year 3 of the Georgians Organized Against Lupus (GOAL) cohort study were analyzed using correlations, linear regressions, and ANOVAs. Qualitative interviews were also conducted with 15 GOAL participants to further explore the role of emotional support for lupus patients. The results of this study demonstrated that there is a significant, positive association between lupus-related organ damage and depression ($r=0.163$, $p=0.001$). Furthermore, the results demonstrated that emotional support does not serve as a mediating or moderating variable but depression is significantly associated with level of emotional support ($F=17.574$, $p<0.001$). Also, the relationship between lupus-related organ damage and depression gets weaker with more support, except in those who always receive the support they need. The results of the qualitative interviews identified some emotional challenges of lupus being relying on other people, not being able to do "normal things", and changes in abilities since pre-lupus diagnosis. Participants also mentioned their family and friends' understanding of lupus being an important factor in their level of support and also how having lupus affects their level of emotional support. The results of the qualitative interviews help to understand the results of the quantitative survey data. Those with the most serious health problems have the greatest visible need for support and assistance and may receive more support as a result. However, their need may be so great that it is not possible for them to always receive the support they need or, perhaps, those who always receive the support they need are protected from high levels of damage. Overall, these findings highlight the importance of monitoring depressive symptoms in lupus patients and developing interventions aiming to increase emotional support available to lupus patients.

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Julia Jordan, MPH

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Chapter 1: Introduction

Epidemiology

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease that affects a variety of organ systems in the human body. SLE is most prevalent in women and strongly affects the central nervous system. Health problems stemming from SLE include arthritis, vasculitis, and fibromyalgia, as well as a variety of mental illnesses (Palagini et al., 2013). The overall age-adjusted incidence rate is approximately 5.5 per 100,000 individuals per year, and the age-adjusted prevalence is 72.8 per 100,000. SLE is much more common in women than it is in men; in women, the incidence rate is estimated to be 9.3 per 100, 000 women per year, with an age-adjusted prevalence of 128.7 per 100,000 (Somers et al., 2014). Specifically, in the Georgia Lupus Registry, the age-adjusted incidence rate is 5.6 per 100,000. The incidence rate in women in the Georgia Lupus Registry is 9.2 per 100,000 and the incidence rate in men is 1.8 per 100,000 (Lim et al., 2014). Along with the difference between men and women, there is also a difference between African Americans and Caucasians. African Americans are 2.3 times more likely to have SLE, and African Americans diagnosed with SLE are also more likely to develop renal disease (Somers et al., 2014). However, even though African American women have much higher rates of SLE than the rest of the population, very few studies have focused solely on this population.

Disease Activity and Disease Damage

When discussing SLE disease status, the disease can be discussed in terms of disease activity or disease damage. Disease activity is the consequence of inflammatory processes that cause a variety of clinical manifestations, which are potentially reversible with adequate treatment. Organ damage is any permanent, irreversible change in organs or systems as a result of disease activity over time or from treatment of the disease. Lupus patients with longer disease duration and higher disease activity show greater accrual organ damage (Anic, Zuvic-Butorac, Stimac, & Novak, 2014).

Factors Associated with SLE

Due to the challenging nature of the disease, diagnosis, and treatment, patients with SLE may be more likely to have depression, anxiety, or other mental illnesses. Estimated comorbid rates range from 17-75%, depending on the population and the mental illness. It is important to note that these rates may be lower than the actual rates because health providers have many other physical symptoms to focus on in SLE patients and may fail to note mental distress. The most common psychiatric symptoms in SLE patients are fatigue, weakness, somatic disorders, and sleep disorders (Palagini et al., 2013)

SLE and Social Support

A limited number of studies have been done to look at the effect of emotional and social support for lupus patients. One qualitative study found that women with SLE thought their family and friends were a very important aspect in maintaining a high quality of life. These women highlighted that being a part of a family and being able to socialize helped them. They also discussed that having family and friends who understood their situation was important (Archenholtz, Burckhardt, & Segesten, 1999). Another study of 44 SLE patients found that pain and helplessness contributed to depression, but that family support was not significant as it pertains to depression (Tayer, Nicassio, Weisman, Schuman, & Daly, 2001).

Theoretical Framework: Diffusion of Innovations

The Theory of Diffusion of Innovations provides a helpful model to understand how the quality of life among patients diagnosed with SLE is related to both the physical and mental components of the disease. According to Rogers (2002), innovation development to address a problem begins with identification of the problem or need. Once the problem or need is identified, basic and applied research must take place before developing an innovation. Although there has been research done on a variety of different ethnic groups and populations, there has been minimal work done looking specifically at African American women on the topic of SLE-related organ damage, depression, and emotional support, even though African Americans are more likely to be diagnosed with SLE than other groups. Thus, this study aims to determine whether there is a relationship between lupus-related organ damage and depression. It also aims to research the role of emotional support in managing lupus and depression, with an eye toward developing an innovation to improve lupus patients' quality of life.

Study Purpose

In summary, SLE occurs with the greatest frequency among African American women, but research targeting this population is limited. Mental illnesses in general, and depression in particular, occur with increased frequency among people with SLE. While depression has been linked with disease activity among people with SLE, there is a lack of research assessing the relationship between lupus-related damage and depression. Furthermore, while emotional support has been linked with reduced depression among people with other chronic diseases, whether this is true among people with SLE and the role of emotional support in the relationship between SLE-related damage and depression has not been studied. Thus, this study will focus on the following research questions:

1. Is there a relationship between SLE-related organ damage and depressive symptoms in African American women?
2. What role does emotional support play in this relationship?

Chapter 2: Literature Review

SLE Background

The Centers for Disease Control and Prevention (2014) define SLE as "an autoimmune disease in which the immune system produces antibodies to cells within the body, leading to widespread inflammation and tissue damage." The causes of SLE are unknown and may be linked to genetic, environmental, and hormonal factors. There are two different types of lupus, discoid (skin only) and SLE, with SLE being the most serious. People with SLE may display a variety of symptoms, including fatigue, pain, swelling in joints, skin rashes, and fevers, and SLE affects a variety of different organ systems (CDC, 2014). CDC reports the prevalence of SLE to be as high as 1,500,000 people in the United States, but also states that prevalence estimates vary due to the challenging and unknown nature of the disease. Incidence rates vary from 1.8 to 7.6 cases per 100,000 people per year. Congress has funded two population-based SLE registries with the purposes of providing better prevalence and incidence rates for Caucasians and African Americans. These registries are based in Michigan and in Georgia (CDC, 2014). Specifically, in the Georgia Lupus Registry, the age-adjusted incidence rate is 5.6 per 100,000. The incidence rate in women in the Georgia Lupus Registry is 9.2 per 100,000 and the incidence rate in men is 1.8 per 100,000 (Lim et al., 2014).

Similar to the prevalence and incidence rates, the mortality due to SLE is also hard to estimate because, many times, the cause of death is an outcome of lupus. From 1979 to 1998, the annual deaths with lupus as an underlying cause rose from 879 to

1,406. Mortality from SLE is higher as the patient ages. Women are also about five times more likely to die from SLE than men, and African Americans are about three times more likely to die from SLE than Caucasians. The death rates are highest among African American women aged 45-64 (CDC, 2014). In addition to the active SLE disease, causes of death as a result of lupus can be kidney failure, infection, or cardiovascular disease from accelerated atherosclerosis (CDC, 2014). Among rheumatic conditions, lupus has a high mortality rate but the survival has been improving. This may be due to an improvement in treatment and because more and milder SLE cases are being identified (CDC, 2014).

SLE is very challenging for doctors to diagnose. The American College of Rheumatology (2013) requires that patients show four of the following symptoms: rashes, mouth sores, arthritis, lung or heart inflammation, kidney problems, neurologic problems, or abnormal blood tests. However, SLE still presents diagnostic challenges since these signs and symptoms are not specific and abnormal blood tests are frequent in the general population (CDC, 2014).

Treatment of SLE consists of immunosuppressive drugs and corticosteroids; however, medication compliance is an issue. Many medications used to treat lupus have adverse side effects and, since SLE is most common in women of childbearing age, patients may not want to take their medication if they are trying to become pregnant (CDC, 2014).

SLE and Mental Illness

Mental illnesses are very common among individuals diagnosed with SLE, with estimated comorbidity rates ranging from 17-75%, depending on the population and the mental illness. However, many times mental illnesses go undiagnosed in individuals with SLE since providers are focusing on the multiple other health concerns in these patients. The most common psychiatric symptoms among those with SLE are fatigue, weakness, somatic disorders, and sleep disorders. Suicide ideation is also much more common among those diagnosed with SLE than among individuals in the general population (Palagini et al., 2013). Anxiety, too, is present in approximately 20% of individuals with SLE, due to limited physical functioning and decreased energy (Shen et al., 2013). Depression is estimated to be present in approximately 39% of patients with SLE, and general cognitive dysfunction is present in up to 80% of SLE patients. The disease itself, along with environmental factors such as retroviruses and medications, may influence the onset of mental illnesses (Meszaros, Perl, & Faraone, 2012).

Various studies have looked at the relationship between SLE and various mental illnesses. One study, specifically focusing on children with SLE, found that out of 50 pediatric patients with SLE, 10 demonstrated depressive symptoms compared to 4 out of 50 healthy patients. Suicidal ideation was also present in 7 of the SLE patients, compared to 2 of the healthy patients. The study also found that those with depressive symptoms utilized healthcare significantly less than those without depressive symptoms. Finally, being of a non-white race was shown to be an independent risk factor for depression (Knight et al., 2014).

Tayer, Nicassio, Weisman, Schuman, and Daly (2001) conducted a study to determine the effect of disease status, hopelessness, and depression on fatigue in patients diagnosed with SLE. Participants in this study included 81 patients with SLE. The participants were asked to report psychosocial data, depression, helplessness, and fatigue.

In addition, rheumatologists completed the Systemic Lupus Activity Measure. Results showed that SLE disease status directly predicts fatigue, while helplessness and depression indirectly predict fatigue in SLE patients through a measure of disease status (Tayer et al., 2001). Fatigue is a symptom of SLE that relates to both physical and mental well-being. This study demonstrated that disease status influences fatigue but depression influences disease status.

Importance of diagnosing and treating mental illnesses in conjunction with SLE

Because of the many physical symptoms resulting from SLE, physicians may focus on these issues, rather than diagnosing depression when necessary. One study of 80 female SLE patients found that almost 19% of the patients had depression. This study also evaluated the relationship between patients' perceived illness stigma and depression. Illness stigma looked at patients' perceived social rejection, financial insecurity, internalized shame, and social rejection. The study found that depressed SLE patients had a significantly higher level of perceived stigma than those without depression. These results highlight the need to diagnose depression in patients with SLE and also promote coping skills in these patients (Sehlo & Bahlas, 2013).

Macejova, Zarikova, and Oetterova (2013) evaluated patients with SLE and factors that reduce their social activities. A sample of 120 individuals, 60 individuals diagnosed with SLE, 30 in a healthy control group, and 30 individuals diagnosed with other autoimmune diseases, were chosen for this study. Participants were asked to complete an activity index, a self-rating depression scale, and a morale scale, and the scores were compared between the groups. Within the group diagnosed with SLE, the relationships among activity, age, disease duration, medication dose, depression score, and morale were also evaluated. There was a significant difference between the SLE group and the healthy control group in their activity score, showing that something relating to SLE limits activity. The study found that there are significant relationships among activity levels, well-being, and depression (Macejova, Zarikova, & Oetterova, 2013). This, again, highlights the importance of diagnosing and treating mental illnesses in conjunction with treating SLE. To help individuals maintain their ability to continue normal life-style activities, this study demonstrates that control of depression is vital.

Health Related Quality of Life

Due to the physical and emotional limitations coinciding with SLE, patients report consistently lower health-related quality of life (HRQOL) than that of the general population. HRQOL has both a physical health component and a mental health component. Within these two components, the scale looks at eight domains: physical function, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. African Americans with SLE demonstrate lower scores in physical functioning compared to Caucasians (Kiani, Strand, Fang, Jaranilla, & Petri, 2013).

Kiani and Petri (2010) used a variety of valid quality of life instruments to determine what contributes to poor quality of life in patients diagnosed with SLE. Tools used included the SF-36, SF-20, Euro QoL, Lupus QoL, and the SLE Symptom Checklist, with the SF-36 being the most commonly used tool to measure quality of life. These tools include a variety of content to determine quality of life such as physical and mental health, social functioning, patient satisfaction, and fatigue. This study determined that fatigue, fibromyalgia, depression, and cognitive dysfunction are strong contributors to the poor quality of life that stems from SLE. Fibromyalgia specifically impacts physical function, bodily pain, and vitality, and even those SLE patients without active fibromyalgia or associated damage show poorer quality of life than SLE patients without fibromyalgia. It was also determined that poor functioning may be related to fatigue, rather than to the active disease; however, fatigue is not correlated with SLE severity. SLE activity and organ damage were not highly correlated with quality of life. Finally, this study also determined that adequate social support, good coping mechanisms, and higher income increased quality of life (Kiani & Petri, 2010). As demonstrated by this study, quality of life in patients diagnosed with SLE is dependent on a variety of factors, not just those that can be classified into the physical health or mental health realms.

Similarly, Pettersson et al. (2012) used the SF-36, with a variety of other tools, to determine the most distressing symptoms of SLE and to determine how those symptoms relate to quality of life, anxiety and depression, patient demographics, and disease characteristics. This cross-sectional study consisted of 324 patients diagnosed with SLE between the ages of 18 and 84. These patients self-reported the SLE symptoms they felt were the most difficult to experience, and their responses were categorized into 23 symptom categories. For example, these categories included those labeled as pain, musculoskeletal, skin, kidney function, cognitive distress, infection, and discomfort. Fatigue, pain, and musculoskeletal distress were found to be the most common responses to what symptoms are the most difficult to experience; however, only patients reporting fatigue showed statistically lower scores on both the mental and physical components of the health-related quality of life. It was also shown that SLE patients who did not have present symptoms had a higher quality of life and lower levels of depression and anxiety than those patients with present SLE symptoms (Pettersson et al., 2012).

SLE and Mental Health

Lupus-related disease activity and organ damage are both outcomes of SLE. Disease activity is classified as any SLE outcome that has been present in the past 3 months, whereas organ damage is any permanent, irreversible change in organs or systems as a result of disease activity over time or from treatment of the disease. (Anic et al., 2014). Little research has evaluated the relationship between SLE-related damage and depression. In contrast, various studies have evaluated the relationship between SLE-related disease activity and depression, yielding varying results. One study found that patients with major depression had higher levels of disease activity than patients without major depression. The study also found the same relationship when controlling for major life events (Nery et al., 2007). Another study, primarily determining that the rate of depression in patients with SLE is higher than the rate of depression in the general population, found that there was no relationship between SLE disease activity and depression or between organ damage and depression (van Exel et al., 2013). A separate study of 127 participants found that having moderate or severe depression is associated with higher pain levels and participants with moderate or severe depression were 49% more likely to have lupus-related arthritis (Karol, Criscione-Schreiber, Lin, & Clowse, 2013).

Some studies have been done to determine the effect of lupus-related damage and lupus activity on patients' health-related quality of life. One study, with a sample of 297 pediatric lupus patients, compared patients' damage scores and patients' activity scores to their health-related quality of life scores. The study found that both lupus-related damage and lupus activity are associated with a decreased health-related quality of life score in the physical domain and disease activity was also associated with a decreased health-related quality of life score in the mental health domain (Ruperto et al., 2004). Another study evaluated the relationship between disease activity and organ damage in SLE patients and health-related quality of life. This cross-sectional study found that damage and activity are both associated with a decrease in quality of life scores. The study also found an association between patients' perceived health status and damage, activity, bodily pain, capacity, usual activity, and mobility (Wang, Mayo, & Fortin, 2001).

SLE and Activity Level

Individuals with SLE who are unable to participate in normal social activities due to lupus-related damage or depression may also show a decrease in quality of life. Schmeding and Schneider (2013) examined what is known about the burden of SLE on individual patients, focusing specifically on health-related quality of life and individual symptoms. A literature review was performed focusing on this topic and a qualitative analysis was performed looking at function, disability, patient perceptions and expectations of their illness, unmet needs, and work disability and employment status. Primarily, it was found that SLE significantly lowered quality of life of people with SLE compared to healthy individuals. This may be because SLE patients have a decreased ability to participate in and successfully carry out normal daily activities, leading to a high level of disability among those diagnosed with SLE. This team also found that disease activity and organ damage are poor predictors of quality of life, but older age, fatigue, and co-morbid mental illnesses are strong predictors of decreased quality of life (Schmeding & Schneider, 2013).

A cross-sectional qualitative study explored how fatigue as a result of SLE impacts SLE patients' lives. Results of the study demonstrated that 21 of the 22 participants had experienced fatigue as a result of SLE. These participants also said that their fatigue impacted their emotion, cognition, work, activities of daily living, leisure activities, social activities, and family activities. These participants discussed how fatigue significantly impacted their daily lives and prevented them from participating in many normal, social activities (Sterling et al., 2014).

Social support as a protective factor among African Americans

Various studies have looked specifically at African Americans and how social and emotional support affects their depressive outcomes. One study focused on African American women and possible psychosocial factors that may influence depression. This study had a sample comprised of a diverse group of 63 African American women and data was self-reported. The study found that 65% of the women had mild depressive symptoms. Depressive symptoms were positively and significantly associated with low self-esteem, low social support, and depressive stigma. Depressive symptoms were also negatively associated with spiritual well being (Holden et al., 2012). A separate study surveyed 100 African American women between the ages of 20 and 35 and found a positive association between depression and stressful life events and a negative association between depression and social support (Warren, 1997). Hamilton et al. (2013) looked at African American cancer patients and aimed to determine how psychosocial factors predict depressive outcomes. They found that emotional support and religiosity may serve as protective factors against depression in this population, however, stigma was not a significant predictor of depression.

Another study researched how social support from church and family members impacts depressive symptoms in African American adults. The study of 686 African Americans looked at adults who attended church at least a few times a year. Among those adults, the study found that social support from church members was inversely associated with depressive symptoms. The study also found the negative interactions with church members was positively associated with depressive symptoms. Furthermore, among churchgoers, emotional support from family members was also inversely associated with depressive symptoms (Chatters, Taylor, Woodward, & Nicklett, 2014).

Additionally, religiosity was evaluated as a type of social support that may be a protective factor against depression. A prospective study of 1,992 depressed adults and 5,740 non-depressed adults looked at organizational (attending services), non-organizational (private prayer), and intrinsic measures of religiosity and depression onset (in the baseline non-depressed group) and depression recovery (in the baseline depressed group). The study found that religiosity was a protective factor of depression onset and depression recovery. Organizational and non-organizational religiosity impacted the two groups differently. In the non-depressed group at baseline, individuals remained non-depressed at follow-up if they frequently attended church services, whereas those who were depressed at baseline were less likely to be depressed at follow-up if they frequently engaged in private prayer (Ronneberg, Miller, Dugan, & Porell, 2014).

Social support and depression among people with lupus

Social support has been shown to be a protective factor in decreasing the severity of depression in individuals with chronic diseases, but only in a limited number of studies have explored this in people with lupus. These studies have had varying results about the importance of emotional and social support in lupus patients. One dissertation used semi-structured interviews with ten African American women to understand the relationship between social support and depression in people with SLE. This study found that African American women with SLE report many challenges while dealing with SLE and they have developed varying coping strategies to manage these challenges. One of the most important coping strategies found was the role of social support (Howe, 2009).

Another study focused on emotional and problematic support exchanges between women experiencing lupus flares and their husbands. The participants in this study were asked to report the amount of support they provided to their partner and whether the support they received from their partner was emotionally validating. The study found that more spousal emotional support was interpreted to be more emotionally validating, which then was associated with an increase in well being. The study also found that problematic support was interpreted as being less emotionally validating, which led to a decrease in well being. This demonstrated that couples who were able to meet their partner's emotional and social needs had greater well being (Fekete, Stephens, Mickelson, & Druley, 2007).

Archenholtz et al. (1999) found that women with SLE valued their family and friends for the social support they provided. In this qualitative study, the women highlighted that being a part of a family and being able to socialize helped them. They also discussed that having family and friends who understood their situation was important. One study did find an inconclusive relationship between social support and depression. This study of 44 SLE patients found that pain and helplessness contributed to depression but that family support was not significant as it pertains to depression (Tayer et al., 2001).

Chapter 3: Methods

Participants and Procedures

Quantitative. A secondary data analysis was performed on data collected in the population-based cohort study, "Georgians Organized Against Lupus," or GOAL. To be eligible for the GOAL cohort study, participants must have had a validated SLE diagnosis, been a part of the Georgia Lupus Registry (a population-based SLE registry used to estimate the prevalence and incidence rates of lupus in Atlanta, GA) or been referred by a physician, and been willing to provide informed consent. Eligible participants for the GOAL study were identified through the SLE registry or referred to the study by physicians from community-based practices or local private practices. Participants were recruited into the GOAL cohort study through the mail, phone, or in person, using the Georgia Lupus Registry as a sampling frame (Drenkard, Rask, Easley, Bao, & Lim, 2013). For this study, eligible participants must have completed only Year 3 of the GOAL study and must have completed all portions of the survey necessary to answer the research questions for this study. Participants must also have self-identified as African American and female. A total of 437 participants were included in the analyses.

Qualitative. 15 participants were also recruited from the Grady lupus clinic to participate in interviews to further examine the role emotional support plays for an SLE diagnosis. To be eligible to participate in the interviews, participants had to be at least 18 years of age, self-identify as an African American woman, and have participated in the GOAL cohort study. Participants were not chosen based on their levels of lupus-related organ damage. Participants were asked to provide verbal consent prior to the start of the interview. Participants were recruited at normally scheduled lupus appointments and were asked if they were interested in participating in an interview.

Measures

Quantitative. The first research question uses the quantitative constructs of depression and lupus-related damage. To assess *depression*, the PHQ-9 was used (Kroenke & Spitzer, 2002). The PHQ-9 is a nine-item scale to measure the severity of depressive symptoms. The internal reliability alpha for the PHQ-9 in the general population is 0.83 to 0.92, showing that the PHQ-9 is an acceptable measure of depression (Cameron, Crawford, Lawton, & Reid, 2008). The PHQ-9 has also been shown to detect both major depression and sub-threshold depressive symptoms (Martin, Rief, Klaiberg, & Braehler, 2006). For this study, depression will be measured as a continuous variable, with possible scores ranging from 0 to 27.

To assess *lupus-related damage*, the Brief Index of Lupus Damage (BILD) was used. This is a 28-item scale that is a patient-reported measure of organ damage relating to lupus. These items ask whether a doctor has ever told the participant that she has certain conditions or diseases relating to lupus. For example, one question asks: “Has a doctor ever told you that you had any of the following conditions: pulmonary hypertension, which is high blood pressure in the lungs?” This scale has been validated for use in the primarily African American cohort of participants used for the original GOAL study and was shown to have an item-by-item agreement with the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI) of over 80%. The SDI is the most commonly used measure to assess damage in lupus patients (Drenkard et al., 2014). The lupus-related damage construct was measured as a continuous variable, with possible scores ranging from 0 to 28.

The second research question used the above two constructs, as well as the construct of emotional support. *Emotional support* was assessed using the question "How often do you get the social and emotional support you need?" Response choices include: "always, usually, sometimes, rarely, or never."

Qualitative. 15 in-depth interviews were conducted to further determine the importance of *emotional and social support* for SLE patients. The aim of the interviews was to supplement the quantitative findings by exploring the perceived importance of emotional support and how lupus-related damage impacts individual's ability to receive and seek out emotional support. Example questions for the focus groups included: "Where do you seek emotional social support for your lupus diagnosis?"; "If you are part of a support group, how does this affect your feelings of support?"; and "How confident are you that you can manage your lupus diagnosis with the support you have?"

Procedure

Quantitative. Details of the quantitative data collection are described elsewhere (Drenkard et al., 2013).

Qualitative. When possible, the interviews took place immediately prior to or after a normally scheduled physician appointment. These interviews were audio recorded and later transcribed; the participant's name was not recorded, to preserve confidentiality, and each participant was assigned a participant ID number instead. The interviews took place in a quiet and private area of the physician's office, either an empty office area or empty exam room, and lasted no more than 30 minutes.

Analysis

Quantitative. Prior to answering the research questions, descriptive statistics including frequencies and means/standard deviations were run to determine characteristics of the sample. For the first research question, a correlation was used, since both the independent variable (lupus-related damage score) and dependent variable (depression) are continuous. Analysis of the second research question employed a multiple linear regression with the above independent and dependent variables, but also adding in emotional support as a possible mediating or moderating variable and exploring the interaction between emotional support and lupus-related damage.

Qualitative. Following the completion of all interviews, the recordings were transcribed verbatim by one of two transcribers and two readers developed a codebook based on common themes in the transcripts. Two coders used MAXQDA to assist in coding the transcripts. If any discrepancies arose between the two coders, they were discussed to achieve consensus. All audio recordings were destroyed following completion of the analyses.

Chapter 4: Results

Quantitative

A total of 437 participants fit the eligibility criteria for this study (Table 1). These African American women ranged in age from 21 to 87 with a mean age of 48.28 (sd= 12.645). Of these 437 women, 318 (72.8%) reported having an immediate family member with lupus. Prior to their lupus diagnosis, 312 (72.1%) reported working full-time and 23 (5.3%) were unemployed or unemployed due to disability. Comparatively, at the time of the survey, 112 (26.7%) reported working full-time and 171 (40.7%) reported being unemployed or unemployed due to disability. When asked about receiving disability payments or support in the past 12 months, 211 (50.4%) reported receiving payments from social security and 29 (7.9%%) reported receiving private disability benefits. Participants were also asked about their current relationship status and 118 (27.3%) reported being married, 147 (34.0%) reported never being married, and 84 (19.4%) reported being divorced.

Participants were asked to complete the PHQ-9 and the BILD scales. The PHQ-9 scores of the participants ranged from 0 to 27 with a mean of 8.26 (sd=6.408). When dichotomized, the PHQ-9 scores indicate that 273 participants (62.5%) reported minimal or mild depression with 164 (37.5%) reporting moderate, moderately severe, or severe depression. The BILD scores ranged from 0 to 16 with a mean of 2.49 (sd=2.456). Finally, participants were asked how often they received the social and emotional support that they needed and the majority reported that they always or usually did; 145 (33.2%) reported always, 104 (23.8%) reported usually, 97 (22.2%) reported sometimes, 53

(12.1%) reported rarely, and 38 (8.7%) reported never receiving the social and emotional support they needed.

Table 1: Characteristics of the Sample

		N	%
Total		437	
Age (mean, sd)		48.28	12.645
Family Members with lupus			
	Yes	108	25.40%
	No	318	74.60%
Job Status Before Diagnosis			
	Working Full-Time	312	72.10%
	Working Part-Time	28	6.50%
	Retired	5	1.20%
	Homemaker	8	1.80%
	Student	57	13.20%
	Unemployed (Includes disabled)	23	5.30%
Job Status After Diagnosis			
	Working Full-Time	112	26.70%
	Working Part-Time	32	7.60%
	Retired	59	14.00%
	Homemaker	28	6.70%
	Student	18	4.30%
	Unemployed (Includes disabled)	171	40.70%
Social Security Disability Payments in last 12 months			
	Yes	211	50.40%
	No	208	49.50%
Private Disability Benefits in last 12 months			
	Yes	29	7.90%
	No	336	92.10%
Relationship Status			
	Never Married	147	34.00%
	Married	118	27.30%
	Separated	28	6.50%
	Divorced	84	19.40%
	Widowed	28	6.50%
	Living with partner (not married)	27	6.30%

To answer the first research question, a correlation was used, since both the independent variable (lupus-related damage score) and dependent variable (depression) are continuous. A Pearson correlation test was performed to examine the association between lupus-related damage and depression. Results indicated that there is a statistically significant, positive association (r=0.163, p=0.001), suggesting that as lupus-related damage increases, depression also increases.

Analysis of the second research question employed a multiple linear regression with the above independent and dependent variables, but also adding in emotional support as a possible mediating or moderating variable and exploring the interaction between emotional support and lupus-related damage. To examine whether emotional support mediated the association between lupus-related damage and depression, three correlations were conducted. The first research question shows a significant association between lupus-related damage and depression. Second, a Pearson correlation was conducted to examine the relationship between emotional support and depression. The results of this correlation suggest a statistically significant, negative association (r= -0.317, p<0.001), demonstrating that as emotional support decreased, depressive symptoms increased. Finally, a Pearson correlation was conducted to examine the relationship between lupus-related damage and emotional support. The results demonstrate that the relationship between lupus-related damage and emotional support was not statistically significant (r= -0.035, p=0.468). Therefore, emotional support does not act as mediating variable between lupus-related damage and depression.

To examine whether emotional support moderated the association between lupus-related damage and depression, two multiple linear regressions were performed (Table 2).

First, lupus-related damage and emotional support were included in the model. Results show that the main predictor of depression, i.e., lupus-related damage, was a statistically significant predictor in the model (β = 0.152, p=0.001). Additionally, emotional support was a statistically significant predictor of depression (β = -0.311, p<0.001). However, when a multiple linear regression was conducted with lupus-related damage, emotional support, and an interaction term of lupus-related damage and emotional support, lupus-related damage remained a significant predictor of depression (β = 0.319, p=0.018). Emotional support also remained a statistically significant predictor of depression (β = -0.254, p<0.001). The interaction term was not significant (β = -0.184, p=0.189). Thus, the two regression models demonstrated that even though emotional support did not serve as a moderating variable, it did have a direct, protective relationship to depression.

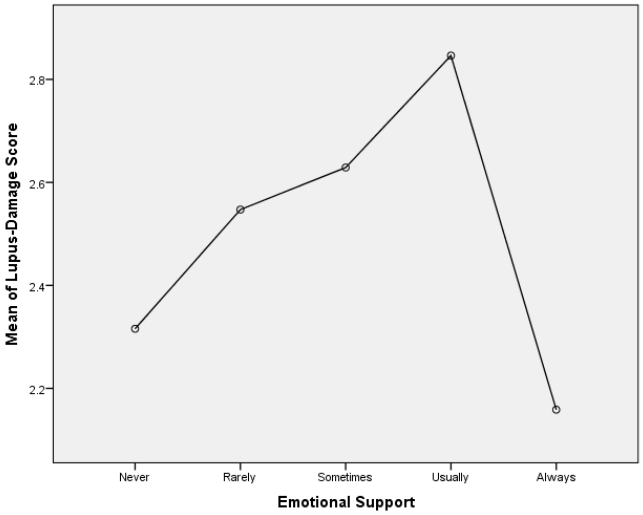
Table 2: Multiple Linear Regression Models for Predicting Depression

	Model 1 (without interaction term)		Model 2 (with interaction term)	
Predictor Variable	β	p-value	β	p-value
Lupus-related Damage	0.152	0.001*	0.319	0.018*
Emotional Support	-0.311	<0.001*	-0.254	<0.001*
Lupus-related Damage, Emotional Support Interaction			-0.184	0.189

*Indicates p-value of <0.05

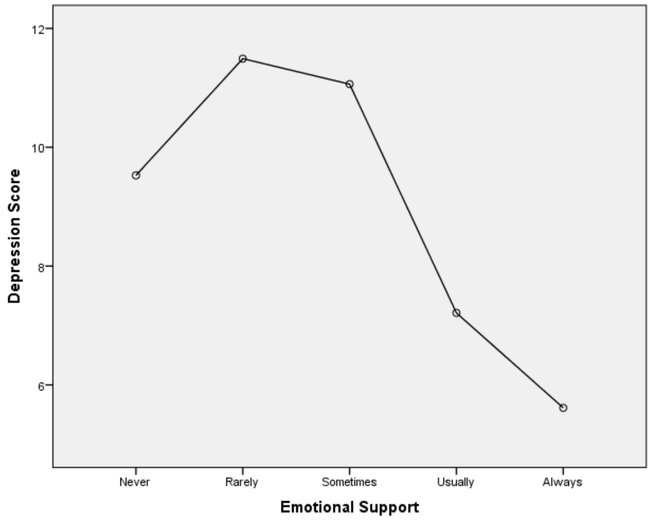
Although emotional support did not serve as a mediator or a moderator, additional statistical tests were done to further explore the nature of the effect of emotional support on the association between lupus-related damage and depression. First, an ANOVA was performed to assess whether between lupus-related damage was associated with level of emotional support. The results were not significant (F=1.344, p=0.253) but the graph of the results shows a clear increase in the damage score across increased levels of emotional support until we come to those who always received the emotional support they needed (See Figure 1). In other words, the people with higher emotional support are those with higher lupus-related damage scores, but those who always received the support they need did not follow this pattern.

Figure 1: Emotional Support and Lupus-Related Damage



Another ANOVA was also performed to assess whether emotional support was associated with depression. This ANOVA was significant (F=17.574, p<0.001). Figure 2 shows that as the level of support increases, depression score increases. Those who never received the support that they needed followed a slightly different pattern, showing a lower level of depression.

Figure 2: Emotional Support and Depression



Finally, correlations between lupus-related damage and depression were performed for each category of emotional support (see Table 3). The results of these analyses demonstrate that the relationship between lupus-related damage and depression gets weaker with more support, until the category of those who always get the support they need. The results range from r=0.321 (p=0.05) for those who never have support, to r=0.04 (p=0.684) for those who usually get the support they need. However, those who always receive the support they need have a strong correlation between damage and depression (r=0.174, p=0.036).

Table 3: Correlation between Lupus-Related Damage and Depression by Support

Level of Support	r	p-value
1 Always	0.174	0.036*
2 Usually	0.04	0.684
3 Sometimes	0.16	0.118
4 Rarely	0.195	0.162
5 Never	0.321	0.050*

*Indicates p-value of <0.05

Qualitative

To further examine how lupus patients perceive emotional support and how emotional support serves as a protective factor against depression, fifteen qualitative interviews were conducted with patients from the lupus clinic at Grady Memorial Hospital. Participants ranged in age from 35 to 64, had been diagnosed with lupus at various ages, and had known about their lupus diagnosis for varying amounts of time. Participants reported a variety of health problems relating to their lupus diagnoses including arthritis, kidney problems, hair loss, rashes, a weakened immune system, fatigue, diabetes, chronic pain, and osteoporosis. Almost every participant reported having felt depressed at some point since being diagnosed with lupus.

Emotional Challenges of Lupus

Participants were asked to describe how lupus could be difficult emotionally and any emotional struggles they may have because of their lupus. Three prominent themes were identified: 1) relying on other people; 2) not being able to do normal things; and 3) a change in abilities since before their lupus diagnosis (including job-loss).

Many participants noted that having to rely on other people was emotionally challenging. Participants who were unable to drive often had to rely on family members or friends for transportation and, to avoid further burdening these people, the participants noted they would try to get in and out of their doctor’s appointments as quickly as possible and would avoid scheduling other types of appointments. These participants also seemed to avoid seeking out further support so as not to further burden these people. One participant noted,

> "…that's one thing that's been a big issue for me, to feel dependent on someone else. So that makes me feel like, almost, inadequate if I could say, because I mean I still go to work every day but I'm not able to do everything I should do every time."

Another participant stated,

> "I have to depend on other people to take me wherever I have to go because when I was working I had my own transportation but I lost all that so it's kind of hard for me to just depend on somebody else all the time to take me places."

Almost all of the participants noted that not being able to do normal, everyday activities was also an emotional challenge they experienced because of lupus. Participants noted that they sometimes felt isolated or excluded from their family and friends because they could not participate in some of the physical activities with other people. One participant gave the following example:

> "…like go to the movies or go out to eat. You can't do that because I'm always hurting or either tired or just…to see whoever you went with, they're enjoying themselves and you can't enjoy yourself because of what's going on and how you feel so that that's kind of hard."

A final emotional challenge of lupus that many participants mentioned was a change in abilities since before their lupus diagnosis. Participants noted that they had to change their activity level significantly since being diagnosed. Participants who were mothers noted struggling with not being able to attend as many of their children's activities and feeling like they were not capable of completing all of their responsibilities around the house. Many participants also discussed the struggles associated with a change in job status and the challenges faced with no longer being able to work because of lupus. One participant associated her job loss to her depression, saying,

> “Because I worked with special needs children in a classroom and you’re in the classroom and you get attached. It had been over 25 years and so it was really hard that now you don’t have anything to do when you’re used to working from the time you walked in the classroom door. You know so it was very, very, very depressing.”

This ties in with the theme of relying on other people and those participants who no longer worked and had to live with others, either for financial or physical reasons, described how challenging it was to see a dramatic change due to lupus.

Family and Friend Understanding of Lupus

Another theme that participants discussed was what their family and friends understand about lupus. Participants explained whether their family and friends were aware of their lupus diagnosis, whether they understood what lupus is, and whether they had made an effort to learn about lupus. The families and friends of participants seemed to either know a lot about lupus and seemed to have made a significant effort to understand the disease or they seemed to be unaware of the significance of the disease. One participant stated, “my oldest daughter, she went online when I was in and out of the hospital to learn what lupus [is]… she found out there was three types of lupus and I didn’t even know that at the time.” Some participants also noted that they had chosen not to talk to their families and friends about their diagnosis because of a fear of being judged or stigmatized. Some participants said their families didn’t understand because the only people who understand lupus are the people who have it. One participant stated:

> "when I was working, the people were saying there wasn't anything wrong with me. I was just trying to get out of work. But all of that changed when I was uh admitted into the hospital."

She then went on to say that she stopped talking to people about her diagnosis because she didn't think anyone would understand or listen to her.

Who Provides Support to Patients

Participants were asked to describe what individuals provide them with support. This was not specifically emotional support and included things such as helping out around the house, helping afford medication for lupus, providing transportation when needed, and providing childcare. In general, participants mentioned their families, partners, children, and friends. Participants who lived with other individuals reported their roommates or others living in their household as a source of emotional support.

Participants also discussed where they receive their emotional support, with themes being from family or friends, from their doctors, from religion, or from a lupus support group. Many participants reported their families or friends as sources of emotional support, and some discussed just talking about how they are feeling as the best way their receive emotional support. Other participants noted that just knowing that they had someone they could call if they were to need help was the most useful form of emotional support.

Many of the participants reported that their doctor provided good emotional support and took the time to answer any questions they had or made sure to fully explain what was happening with each individual's lupus diagnosis. One participant stated that her doctor is always available and

> "He's great at listening to anything you say, no matter how crazy you think it sounds to you, he's heard it before and he won't make fun of you. He won't put you down; he doesn't say oh that's your mind telling you that. He's not that kind of doctor, he's very supportive."

However, some participants did note that they wished their doctors were better at providing test results between appointments.

Almost all of the participants stated that religion was a source of emotional support and many stated that they felt like they had a church family they could rely on for emotional support. Participants also noted that they felt their faith was one thing they could rely on and they felt it was one of the most prominent things helping them cope with their disease. One participant said, "That's what really keeps me going, knowing that the One knows how I feel and understands how I feel. That's what really matters. No one else really understands." Many other participants echoed these thoughts.

Participants were also asked if they had ever attended a lupus support group and if they had, how this affected their feelings of emotional support. Of the participants who attended the group, many mentioned that the group was a good place to discuss their experiences with other people who understood the challenges of lupus. Participants also stated that they saw people with much more severe symptoms of lupus, and this helped them realize what they had to be grateful for. One participant mentioned,

> "It's nice to see other people with problems like me so, some people are worse off than I am so we look to each other for support and we understand each other and what we're going through. And they can always call me if they want to talk."

One participant did however note that she felt that the support group led her to feel concerned about how her lupus could become more severe.

How Having Lupus Affects Patients' Support Levels

Participants were also asked to describe how they felt having lupus influenced the amount of emotional support available to them. Many participants said they felt like they had more emotional support after being diagnosed with lupus because people were available to help out with whatever was needed. However, some participants mentioned that because they are physically limited, they feel isolated and excluded. One participant stated,

> "sometimes when we go on like family reunions and stuff and you know it will be three days or something, I'll be like I have to sit out of an event. Or if it's in like the summer and I have to tell them you know, I can't stay outside in the sun like that all the time and they don't understand."

Another participant said that she was unable to participate in activities, such as going out to eat and going to the movies. She went on to say,

> "You can't do that because I'm always hurting or either tired or just uh to see whoever you went with, they're enjoying themselves and you can't enjoy yourself because of what's going on and how you feel so that that's kind of hard."

Confidence Managing Lupus

Finally, participants were also asked to describe how confident they are managing their lupus with the emotional support they have available to them. All of the participants said that regardless of their support level, they are confident they can manage their lupus. Participants who did not have a lot of emotional support available to them stated that they have found ways to manage their lupus on their own, while participants with a lot of emotional support stated that they have a strong support system that allows them to feel confident. Some participants also described their faith as what keeps them feeling confident in being able to manage their lupus. One participant stated, “That’s just me trying to live with lupus and trying to be godly and trying to live my life the best and trying to be happy.”

Relation of Quantitative and Qualitative Results

The survey data showed that emotional support does not serve as a mediating or moderating factor but that it does have a direct, protective effect on the relationship between lupus-related damage and depression. The results of the qualitative interviews provided further information on how lupus patients value emotional support and where they seek out emotional support. The participants interviewed had varying levels of emotional support available to them and described different experiences in dealing with lupus with the support available to them. The interviews demonstrated that there are a multitude of emotional challenges that lupus patients face but that people cope with these challenges differently. For some of these African American women, having to rely on others seemed to inhibit their desire to seek out further emotional support. Others felt that they had to rely on the emotional support available to them to manage their lupus. Lupus patients seek out emotional support in a variety of ways and when emotional support is not available to participants, they find other ways to cope with their diagnosis. However, some participants did not discuss their diagnosis with their family or friends because of the fear of not being accepted or understood. These individuals did not have the support they would have liked and had to seek out other types of emotional support.

The role of emotional support for lupus patients is a very complex issue that is dependent on many other factors.

Chapter 5: Discussion

Summary of Findings

Up to this point, little research has been done examining the relationship between lupus-related damage and depression. Similarly, little research has been done on African Americans with lupus or examining how emotional support affects lupus patients. This study helps to provide a starting point for research in the field. Results of the qualitative study show that there is a significant correlation between lupus-related damage and depression. Results also indicate that emotional support has a direct, protective relationship to depression, but it does not serve as a mediating variable or a moderating variable in the relationship between lupus-related damage and depression. The study also suggested that emotional support may have an impact on the relationship between damage and depression that is complex, perhaps non-linear. The regression results showed a clear protective association between emotional support and depression. The ANOVA results showed that this pattern excluded the people who never get enough emotional support. The qualitative results provide some possible explanations. Perhaps individuals who never receive enough emotional support may not find that emotional support influences their mood, or they may choose not to utilize emotional support as a coping mechanism.

The relationship between lupus-related damage and emotional support was not linear and not significant. This may be due to a bi-directional association between damage and support; in some cases, emotional support may inhibit the progression of their disease while in others, the progression of their disease may lead to receiving increased emotional support. Previous studies have shown that those with more support may experience a degree of protection, or buffering, from developing the most serious health problems (Cohen & Wills, 1985; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). In contrast, this study demonstrated that, in general, the people with more emotional support had higher lupus-related damage scores (i.e., the most serious health problems), with the exception of those who always receive the support they need. Those with the most serious health problems have the greatest visible need for support and assistance and may receive more support as a result. But their need may be so great that it is not possible for them to always receive the support they need or, perhaps, those who always receive the support they need are protected from high levels of damage. As the qualitative data suggest, it is also possible that, for some of these African American women, having to rely on others inhibited their desire to seek out further emotional support, while others felt that they had to rely on their emotional support to manage their lupus. Perhaps the "strong black woman" role makes it difficult to seek support until one's need is advanced (Abrams, Maxwell, Pope, & Belgrave, 2014). All of these reasons are possible explanations for the lack of a significant association between damage and support in this population, and worthy of further exploration.

When looking at the correlation between damage and depression stratified across the different levels of support, the relationship got weaker and weaker with more support (except for people who always get the support they need). This suggests that emotional support may serve as a protective factor against depression in people with lupus-related damage. People who reported that they "always" received the social and emotional support they "needed" may be a mixture of those who receive a great deal of support, and those who do not “need” much support. Furthermore, this response suggests a more positive perspective, and a lower level of depression.

The results of the qualitative study help to further explain these results. In the relationship between emotional support and depression, the quantitative results demonstrated an association between emotional support and depression, except in people who never get the support they need. The results of the qualitative study suggest that these people might include those who never ask or seek out emotional support. These people may not need the support of others to prevent depressive symptoms and may feel they can manage without the support of others.

Furthermore, participants described how having lupus can either increase or decrease the amount of emotional support they received. Some participants said they have added emotional support because they need family or friends to help out because of limitations related to lupus. Others reported feeling isolated or excluded because they are not able to participate in activities with others. Participants also described the emotional challenges due to a change in abilities since before being diagnosed with lupus and how this can lead to feeling depressed. Participants who had to stop working described how challenging this was emotionally for a variety of reasons. Participants said they felt they had a purpose when they were working and once they had to stop, this was taken away. They also stopped receiving an income and many had to rely on others because of this. Finally, some participants also described that their family and friends had a strong understanding of lupus while others said their family and friends did not know much about lupus or did not try to learn about lupus. Some participants whose family and friends did not understand much about lupus felt frustrated that they were battling the disease on their own without the support of their families. Those who had families and friends who had spent the time learning about lupus and the challenges of lupus seemed to appreciate this and seemed to feel their support levels were higher.

Strengths and Limitations

There are some strengths and limitations of this study. A primary strength is that it is a mixed methods study that uses multiple sources of information to draw conclusions. Without the qualitative portion of the study, it would have been difficult to fully understand the complex effect of emotional support for lupus patients. The mix of methods helped to begin to understand a previously understudied topic. Another strength is the large sample size for the quantitative portion of the study. A total of 437 participants were analyzed for this study. Also, the interviews in the qualitative portion of the study took place in a convenient, comfortable location. This encouraged participants to provide honest information and be open about their feelings regarding emotional support and their lupus.

One of the main limitations of the study is that this is a cross-sectional study so it is not possible to determine the direction of the association between emotional support and depression and lupus-related damage and depression. Another limitation is that those who chose to participate in interviews seemed to either want to talk about their emotional support because they had a lot of support or because they had very little support. Furthermore, the results of the quantitative study are generalizable to the female, African American lupus population in Atlanta but may not be generalizable to other populations of lupus patients. The qualitative interviews are not generalizable to African American women outside of the group interviewed. Finally, the quantitative study measured depressive symptoms, not depression diagnosis. Many of those who reported depressive symptoms may not be diagnosed with depression and may be hard to monitor in the future.

Public Health Implications

Primarily, the results of this study demonstrate that lupus-related damage and depression have a significant, positive, linear relationship. Healthcare providers need to be aware of this relationship and recognize that depression is common among lupus patients, especially those with multiple permanent negative health outcomes as a result of lupus. It will be important to track depressive symptoms in these individuals to diagnose depression when necessary and to link these individuals to depressive care. The results of this study also demonstrated a strong, protective relationship between emotional support and depressive symptoms. This indicates the importance of utilizing emotional support to limit depressive symptoms in lupus patients. Healthcare providers of lupus patients should help to provide resources to SLE patients to assist people in asking for support. While the exact nature of how emotional support influences depression in people with lupus-related damage is still unknown, public health practitioners should stress the importance of a support system for lupus patients, and possibly even encourage friends and family to offer support without making the person with lupus ask. The challenging nature of lupus makes a support system very helpful for lupus patients, since many physical activities become challenging due to joint pain. This support can come from family and friends, religion/faith, or support groups and some forms of support will work better for some individuals than others.

If possible, teaching sessions should be designed to educate the family and friends of lupus patients on what lupus is and the challenges of living with lupus. Many lupus patients who felt their family and friends did not understand their disease also seemed not to have much emotional support. By educating those surrounding individuals with lupus about the health outcomes caused by lupus, it may be possible to naturally encourage an increase of support for lupus patients.

Future Research

Future research should be done to continue to explore how emotional support influences depression in lupus patients, especially those with lupus-related damage since it correlates strongly with depression. Because of the complex nature of emotional support, future research should aim to understand whether lupus patients seek out emotional support because of necessity and/or whether emotional support prevents damage and depression from developing. Further answering this question can help to understand the most effective ways of working with lupus patients. While this study demonstrated that emotional support is important, it is also necessary to understand exactly when and how it is most useful to lupus patients. A longitudinal study would be the best way to determine when emotional support is most important and most needed.

Furthermore, research should also be conducted to understand the other needs of lupus patients outside of emotional support. This study demonstrated that emotional support may impact the association between lupus-related damage and depression, but there are undoubtedly other factors that influence these outcomes. It is important to recognize these factors and target them among lupus patients in order to encourage effective lupus management.

Using the Theory of Diffusion of Innovations as a lens for this study also helps to determine the best course of action for future research. Because this study demonstrates that lupus-related damage and depression are related, and that emotional support is an important factor that influences lupus patients, it is important to conduct further research to work to improve the quality of life for lupus patients. By further understanding these issues, and translating research findings into innovative intervention practices, the goal can be to improve the physical and emotional outcomes for lupus patients.

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Appendix A: Interview Guide

To get started, I have a couple questions about you.

1. How old are you?
2. How old were you when you were diagnosed with lupus?
3. Tell me a little bit about your lupus.
4. What are some of the health problems you have because of lupus?
5. Have you ever felt depressed?
6. What do you think your family understands about your lupus diagnosis?
7. What do you think your friends understand about your lupus diagnosis?
8. How do your family and friends support you?
9. What are some of the things about having lupus that are difficult emotionally?
10. In general, who are the people in your life who support you emotionally?
11. How does your health, especially your lupus, affect your emotional support?
    a. Are there ways you feel you have more support due to having people around to help you with any physical limitations?

   b. Are there ways you feel isolated or excluded because you may not be as active as your friends and family?

12. What types of emotional support do you find most useful?

13. What types of emotional support do you wish you had?

14. How does your doctor provide you with any emotional support?
    a. How could your doctor provide you with better emotional support?

15. How does your faith impact your feelings of emotional support?

16. If you are part of a lupus support group, how does this affect your feelings of emotional support?
    a. If you did not have this group, how would things change for you?

17. How do you think your lupus-related problems would change if you had more emotional support?

18. How confident are you that you can manage your lupus with the support that you have?
    a. What are some ways your emotional support helps you manage your lupus?
    b. What are some ways you might better manage your lupus if you had more emotional support?

19. Is there anything else you would like to share with me about emotional support and lupus?

Appendix B: Codebook

1.0 Introduction/Other Information
  Any introductory information before the content of the interview and any other information that arises that cannot be coded into one of the following codes.

2.0 Lupus specifics
  2.1 Details of individual lupus diagnosis
    This includes age of diagnosis, and any health issues as a result of lupus.
  2.2 Depression and lupus
    How lupus has affected mental health and whether it has caused any depressive symptoms.

3.0 Family and friends understanding lupus
  Participant explanations of whether her family or friends are aware of lupus diagnosis, whether they understand what lupus is, and whether they have made an effort to continue to learn about lupus.

4.0 General Support

  4.1 Who is there for support
    The individuals that come to mind that provide support for the participant
  4.2 Types of support
    The participants' description of types of support available to them to help manage their lupus diagnosis

5.0 Emotional support
  5.1 Emotional challenge of lupus
    The participant's description of how lupus can be difficult emotionally, any emotional struggles they have because of lupus
    5.1.1 Relying on other people
      Having to rely on other people for things such as transportation, housing, etc.
    5.1.2 Not being able to do normal things
      Expressing that she is not able to be active or social as others
    5.1.3 Change in abilities since pre-diagnosis (including job-loss)
      The participant compares her behaviors to pre-diagnosis behaviors and discusses what has changed since being diagnosed
  5.2 Who is there for emotional support
    The individuals that come to mind that provide emotional support for the participant
  5.3 Role of lupus on emotional support (more)
    How has having lupus impacted the amount of emotional support available to the participant? Do they have more because people are around helping when needed?

  - 5.4 Role of lupus on emotional support (less)
    - How has having lupus impacted the amount of emotional support available to the participant? Do they have less support because they feel excluded and unable to participate because of physical limitations?
  - 5.5 Most useful types of emotional support
    - The types of emotional support that the participant values and finds the most supportive
  - 5.6 Types of emotional support that is lacking
    - Any kinds of emotional support the participant wishes they had or had more of
  - 5.7 Doctor's role in providing emotional support
    - Any ways in which the doctor provides the participant with emotional support. Also, how the doctor could provide better emotional support
  - 5.8 Role of religion in providing emotional support
    - How does religion or faith influence the participant's emotional support? Do they feel as if fellow church members act as a support system?
  - 5.9 Role of lupus support groups in providing emotional support
    - The participant's activity in a support group and how this has influenced their feelings of emotional support

- 6.0 Ability to manage lupus
  - The participants' ability to manage their lupus with the support they have available to them
  - 6.1 Influence of added emotional support
    - If the participant had more emotional support, how would their quality of life or lupus-related symptoms change?

- 7.0 Good Quotes
  - Any quotes that stand out to you