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Association of Social Support and the Well-being of Patients with Systemic Lupus Erythematosus: Analysis of the Georgians Organized Against Lupus (GOAL) Cohort Study

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Abstract

Introduction: Systemic lupus erythematosus (SLE) is a disabling, chronic, multisystem autoimmune disease that occurs in women of childbearing years (15-40) and spans a lifetime. Little is known about the relevance that social support has in the context of mental health wellbeing for patients with SLE. Physicians may be an adequate source of support when it comes to SLE. Since there are arrays of triggers for depression, there is a need to understand the SLE experience to help with disease management.

Objective: To examine the association of social support from a physician and the mental health wellbeing of SLE patients.

Methods: We examined 652 SLE patients from the Georgians Organized Against Lupus (GOAL) cohort. Descriptive analysis was performed. Univariate analysis was performed to examine the associations of the main dependent variables (Short Form Health Survey (SF-12) and Patient Health Questionnaire (PHQ-9)) and each independent variable. Both, univariate and multivariate logistic regression analyses were conducted to determine associations between selected characteristics and main independent variables (emotional or social support and social support from a physician) with the categorized mental component score and PHQ9 depression score, individually and together. Ninety-five percent confidence intervals were used to determine statistical significance.

Results: SLE patients who perceived having enough emotional/social support were found to have an overall better mental health status than the average American, and 64% less likely to be depressed compared to patients who did not have enough emotional/social support. Patients who were categorized as having social support from a physician were found to be in poorer mental health statuses, as measured by the MCS SF-12 and PHQ9 depression score.

Conclusion: The findings of this study show that emotional or social support is associated with a better mental health well-being for SLE patients. SLE patients who have enough emotional or social support were found to have above normal general mental health and less depression. This study did not show any direct associations between physician social support and mental health wellbeing.

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CHAPTER 1

INTRODUCTION

The salience of social support for patients with chronic diseases gains increased recognition in public health for the last two decades. Notably, it has become of interest to other academic disciplines including behavioral medicine and health psychology (Mazzoni & Cicognani, 2011; Lincoln & Chae, 2012; Seawell & Danoff-Burg, 2004). However, little is known about the relevance that social support has in the context of mental health well-being for patients with systemic lupus erythematosus (Breslau, Kendler, Su, Gaxiola-Aguilar, & Kessler). SLE is a disabling, chronic, multisystem autoimmune disease that occurs most often in women of childbearing years and spans a lifetime (Beusterien et al., 2013). Due to the unpredictability of symptom manifestations and SLE mimicking other common diseases, SLE is difficult to diagnose (Robinson, Cook & Currie 2010). Patients often endure several years of multiple, often different, doctor visits before receiving a proper diagnosis. An efficient support system for patients with SLE is needed in order to offset the mental health deterioration that accompanies the physical damage due to such a chronic disease (Pennix et al., 1997).

In general, chronic illnesses are ranked as a major cause of death and disability in the United States of America (Kung, Xu & Murphy, 2005). For patients with a chronic disease, depression is one of the most common complications (Moussavi et al., 2007). The psychosocial experiences SLE offers the opportunity to explore the unmet needs of patients in terms of psychological needs. SLE patients often have to deal with the unpredictability of the disease while dealing with everyday stressors. There is a need to understand SLE experience in order to manage the disease effectively (Beckerman & Sarracco, 2012).

In chronic disease management, social support has been found to affect functionality and pain, as well as psychosocial feelings of isolation (Brooks, Andrade, Middleton, & Wallen, 2014). The findings of Brooks et al. (2014) suggest that social support is beneficial to SLE patients' general well-being. The findings of Mazzoni and Cicognani (2011) corroborate previous findings on the benefits of social support and how more support can provide better health. However, the results of Brooks et al., suggest that the type of support (emotional, informational, or institutional), rather than the amount, is most beneficial in improving patient's health outcomes. Understanding whether support from a family member, friend or a physician is more associated with better well-being of patients with a chronic disease is critical. The overall relationship between social support and well-being of SLE patients is relatively broad; researchers have not developed the best way to understand which aspects of social support are critical for SLE patients (Zheng et al., 2009).

Since previous studies show evidence that any type social support is relevant to the patient's improved health outcome (Brooks et al., 2014), this study specifically examines emotional social support. This study hypothesizes that the emotional support from a physician is a good approach to meeting the health needs of SLE patients. Therefore, this study examines the role a physician plays in the emotional support of SLE patients. Specifically, this study investigates the effect of social support in the form of emotional support from a physician on the mental health well-being of SLE patients.

To understand SLE patient mental health well-being, we utilized the mental health component score from the Short Form Health Survey (SF-12) instrument and a depression screener from the Patient Health Questionnaire (PHQ-9) instrument. The central questions addressed in this study are:

1. Is emotional and social support (from any source) associated with mental health of SLE patients?

2. What is the association between social supports from a physician mental health of SLE patient?

This study uses two different measures of social support and patient well-being to (a) further corroborate previous literature about the efficacy of social support on patient well-being (b) operationalize social support from physicians, and (c) provide empirical evidence to physicians on the benefits of serving as another source of social support for patients.

CHAPTER 2

LITERATURE REVIEW

Systemic Lupus Erythematosus

SLE has been defined as a disabling, chronic, multisystem autoimmune disease with high morbidity and mortality rates (Beusterien et al., 2013; Sacks, Helmick, Langmaid, & Sniezek 2002). SLE has periods of symptom remission, flares, and progression; a flare is the exacerbation of previous symptoms and progression is the worsening of newer symptoms (Robinson et al., 2010). Common symptoms of lupus include extreme fatigue, kidney problems, painful or swollen joints and skin rashes (Ehrenstein & Isenberg, 2004). SLE flares were found to be triggered by several occurrences: ultraviolet light exposure, sulfa medications, infections, exhaustion, pregnancy and stress (Ferenkeh-Koroma, 2012). Although the etiology of this disease has eluded researchers for years, it has been theorized that genetics, environment and hormonal factors contribute to disease manifestation (Robinson et al.).

Despite the ambiguous etiology of SLE, the immunology of the illness is definitively understood. The immune system is generally responsible for fighting off viruses, bacteria, and germs (foreign intruders) but has proven to not properly work for SLE patients (Rahman and Isenberg 2008). The body's natural alert system, inflammation, is triggered when a foreign intruder has invaded, and the body produces proteins or antibodies to eliminate the threat. Symptoms associated with SLE occur because of the presence of autoantibodies (self-attacking antibodies) that are programmed to attack and destroy healthy tissue, ribonucleoproteins, chromatin (chromosomal material), and phospholipids (Arbuckle et al., 2003; Rigby & Vinuesa, 2008). Symptom manifestations are preceded by autoantibody productions and suggest direct

causality in end-organ disease (Arbuckle et al., 2003; Rigby & Vinuesa, 2008). SLE is a contributory factor in inflammation and tissue damage in any organ of the body (Ferenkeh-Koroma, 2012)

SLE manifestations include varying symptom features that comprise renal, dermatologic, neurological, and hematological involvement (Robinson, 2011). Since SLE symptoms have been found to mimic other common diseases and there is no definitive test to diagnosis SLE, the American College of Rheumatology developed a set of criteria widely used for diagnosis (Hochberg, 1997). In order for a patient to be positively diagnosed with SLE, four of the following 11 criteria must be met: malar rash, discoid rash, photosensitivity, oral ulcers, non-erosive arthritis, pleuritic or pericarditis, renal disorder, neurologic disorder, hematologic disorder, immunologic disorder, and/or positive antinuclear antibodies (ANAs) (Hochberg 1997). A positive ANA test is a common standard for diagnosing SLE, but it is also associated with other connective tissue diseases like Sjögren's syndrome, scleroderma, and rheumatoid arthritis (Gill et al., 2003; Robinson et al., 2010). Even though the patient may manifest several of the symptoms of SLE, they can fail to meet the criteria for SLE diagnosis (Wallace 2008).

SLE and Health Well-being

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization [WHO], 1946). For a patient with SLE, disease activity and organ damage serve as a proxy for poor well-being. Recent studies have attempted to define SLE in the context of the WHO definition of overall wellness. Hence, there has been a recent surge in physical, mental

and psychosocial health research in SLE (Seawell & Danoff-Burg, 2004). All three components of health are interrelated; treating physical health alone will not yield a salubrious well-being. Since the symptoms of SLE can take many years to manifest, disease management should promote a healthy mental and social well-being (Beckerman & Sarracco, 2012).

Socio-economic Background of SLE

SLE most frequently occurs in young women of color, particularly African Americans (D'Cruz 2006). Females have been found to be nine times more likely to develop SLE than males; however, males who develop SLE tend to have more severe disease activity than their female counterparts (Kasitanon, Magder, & Petri, 2006). African American women are 3-4 times more likely to develop SLE and 3-6 times more likely to develop severe complications such as multi-organ damage, end-stage renal disease, or cardiovascular disease- at an early age, resulting in higher overall mortality rates, compared to their Caucasian counterparts (Drenkard et al., 2014; Gallop et al., 2012). Although evidence suggests that SLE disease activity and damage are linked to ethnicity, it is not well known if this association is primarily due to a patient's social-economic status (Moses, Wiggers, Nicholas, & Cockburn) or is related to genotypic disease variations that exist amongst various ethnic groups (Jolly, Mikolaitis, Shakoor, Fogg, & Block, 2010).

In addition to the racial disparity in SLE, patient well-being for African Americans is unequal to Caucasian patients due to differences in SES. In the United States, ethnic minorities are associated with lower SES statuses as represented by lower levels of education, access to health insurance or healthcare, and inadequate housing (González, Toloza, McGwin, &

Alarcón, 2013). Barriers to healthcare are associated with poorer clinical outcomes and the combination of these factors, along with general nuances for proper diagnosis, leads to poor treatment adherence and less effective treatments (Law et al., 2009). As a result, ethnic minorities accrue more organ damage and higher mortality; African Americans with SLE have a two-threefold higher risk of death than Caucasians (González et al., 2013). Although studies on depression show that African Americans have lower prevalence rates, African Americans have a higher persistence rate and impairment associated with depression compared to Caucasians (Breslau, Kendler, Su, Gaxiola-Aguilar, & Kessler, 2005; Dunlop, Song, Manheim, Lyons, & Chang, 2003; Lincoln & Chae, 2012; Williams et al., 2007).

Mental Well-being and Depression

Mental health is a component of overall health as defined by the WHO definition (WHO, 1946). Poor mental health is associated with poor overall health promotion. Recent emphasis on mental health has fostered the growth of empirical research identifying the psychosocial experiences of SLE patients and providing insight into understanding how to better serve patients (Beckerman & Sarracco, 2012). Since depression is one of the most common psychosocial disorders, most patients receive diagnosis and treatment from a primary care physician rather than a mental health specialist (World Health Organization [WHO], 2012). In 2000, it was the leading cause of disability and premature mortality in the United States (Lincoln & Chae 2012). Depression is chronic and has phases of exacerbation or remission, similar to SLE characteristics. SLE and depression have the potential to inhibit functioning at work, school and coping with life, the combined effect they have on patients may be overwhelming. The findings of Philip, Lindner and Lederman (2009) show that the majority (56%) of their study (n=154) has

moderate/clinical depression due to the impact of the disease. In another study of SLE patients, a positive correlation between emotional states and the disease activity and duration were observed, and patients were found to be more susceptible to negative emotions if they presented with symptoms (Kulczycka, Sysa-Jedrzejowska, & Robak, 2010). The findings of Beckerman & Sarracco (2012) show that loss and coping with uncertainty are the commonalities that pose psychosocial challenges for patients with SLE and their families. These findings are in concurrence with an earlier study that findings show women with SLE experience acute psychosocial distress that is linked to the loss of valued social roles such as being a wife, mother, sister, daughter, and friend (Karasz & Ouellette, 1995).

Defining social support

There are multiple definitions used to conceptualize social support. One common consensus when looking at SLE literature defines 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" (Mazzoni & Cicognani, pg 1118, 2011). Another definition of social support refers to a "social network's provision of psychological and material resources intended to benefit an individual's ability to cope with stress" (Cohen, pg 676, 2004). These definitions address the source of social support. Additionally, they introduce conceptual items of support and give a definite directionality of its benefit. These definitions limit the need for social support to only dealing with stress and do not account for the possible adverse effects of social support (Shumaker & Brownell, 1984). This study defines social support as "an exchange of resources between at least two individuals perceived by the provider or recipient to be intended to enhance the well-being of the recipient" (Shumaker & Brownell, pg 13, 1984). This definition allows social support to not only deal with

stress, but opens it up to other mental health issues the recipient may be experiencing; it allows for an exchange among at least two participants (Shumaker & Brownell, 1984).

Despite the variations in social support definition, researchers agree that social support has three components: emotional, instrumental, and informational (House & Kahn 1985). Emotional support is what people do to make one feel they matter, instrumental support is the tangible aid one offers others, and informational support relates to the bestowing of information (Shumaker & Brownell, 1984). Although all three types of social support are positively associated with better health outcomes in SLE patients, emotional support is the most widely used of the three measures (Brooks et al., 2014; Lincoln & Chae, 2012; Mazzoni & Cicognani, 2011).

Emotional support

Emotional support is crucial in helping to alleviate the negative emotions SLE patients endure. In the Gallop et al study (2012), SLE patients report having feelings of anger, helplessness, depression and incompetence due to SLE; 14% of participants felt too fatigued to engage in conversations; 14% of participants also desired to be alone during a flare, affecting their social activities and relationships. However, study participants are able to cope with these negative emotions by having a readily available network of interpersonal relationships. Patients perceive networks to be reliable for providing emotional support and readily available during periods of pain and disability (Mazzoni & Cicognani, 2011). The study further suggests that SLE support groups are essential to meeting patient needs. An open environment with peers of SLE patients is necessary for alleviating negative feelings among study patients. SLE support

groups are a primary source of emotional support for enhancing the psychological well-being of patients (Ng & Chan, 2007).

Gaps in social support

There are main drawback to measuring social support in empirical data. There is a lack of a universal definitive measure for social support. There are many constructs for social support measurement; hence it is difficult to draw comparative conclusions. In Lincoln & Chae (2012), social support is a measure of the perceived frequency on how often family members make the participant feel loved and cared for, listen to their issues, and express concern for their well-being. In Brooks et al (2014), social support is a measure of the individual's perception of support as it relates to their illness asking "who or what provides your strongest source of social support to cope with your illness and related symptoms?" Zheng et al. (2009) study uses the Social Support Rate Scale (SSRS) questionnaire, where higher social support scores indicate a better level of social support. Although use of an objective measure would make analyses stronger, the authors of the three studies used their own measure of social support but they all suggest that social support is beneficial.

Physicians and Social Support

A physician's contribution to the patient's social network can be overlooked when assessing the interpersonal source of support. The findings of Brooks et al. (2014) show that seven individuals claim health professionals are a source of social support but most consider it informational support. When looking at social support from a physician as informational only,

patients do not experience the total benefits that come along with emotional support. Emotional support can act as a barrier to negative mental health states like depression, anxiety or stress. The findings of Lincoln & Chae (2012) suggest that although social support from physicians is enthusiastic in nature, what physician's extrapolate as necessary for SLE patients is not relevant to the patient's needs. Since SLE patients report the inability to connect with friends and family due to coping with the disease (Beckerman & Sarracco, 2012; Ng & Chan, 2007), SLE patients often resort to other source of support.

Physicians can be a supplemental source of support when it comes to SLE patients. Physicians can alleviate feelings of being burdensome because there is no need for reciprocity, unlike in familiar relationships that are characterized by an even exchange of helping and receiving (Dunkel-Schetter, 1984). Physicians are able to maintain an ongoing relationship with the patients and not be intimidated by the disease activity needs (Shumaker & Brownell, 1984). Also, physicians provide expert information in comparison to other sources of social support. (Shumaker & Brownell, 1984).

CHAPTER 3.

METHODOLOGY

Data Source

The Georgians Organized Against Lupus (GOAL) is a longitudinally designed cohort that encompasses a broad cross-section of consented adults with a validated diagnosis of SLE (Drenkard et al., 2012). The overall aim of the GOAL cohort is to ascertain the impact of SLE on the lives of Georgians living with the disease to better inform patients, health care providers, and policy makers (Drenkard et al., 2014). The GOAL survey, administered annually since 2011, includes questions on socio-economic demographics, work status, access to healthcare, lifestyle factors, validated measures of disease outcomes, health status, and mental health screening.

The sample population is taken from the Georgia Lupus Registry (GLR), a CDC-funded population-based registry that seeks to estimate the prevalence and incidence of SLE in the metropolitan Atlanta, Georgia area. The GLR was initiated through a partnership between the Georgia Department of Public Health (GADPH) and Emory University in which Emory investigators were permitted to collect protected health information and clinical data from medical records without written patient consent (under the Health Insurance Portability and Accountability Act Privacy Rule, 45 Code of Federal Regulations, parts 160 and 164). Moreover, the GADPH approved Emory investigators request to recruit GLR SLE patients into the GOAL cohort.

Patients were recruited into the GOAL cohort via mail, phone and in person to complete annual self-reported surveys. Approximately 70% of patients enrolled in the GOAL study were

obtained through the GLR. The remaining enrollees came from lupus clinics at Emory University and Grady Memorial Hospital, as well as from community rheumatologists from the greater metropolitan Atlanta area. All GOAL participants gave informed consent. The Emory University Institutional Review Board (IRB), Grady Health System Research Oversight Committee, and the GADPH Institutional Review Board approved the GOAL study protocol.

Study Design

Georgia State University IRB provided exempt approval (IRB Number: H15143) for this cross-sectional study analysis conducted on the self-reported data collected from Wave 3 GOAL survey of SLE patients from the greater metropolitan Atlanta, Georgia area.

Inclusion and Exclusion Criteria

The sample for this thesis consisted of 652 SLE patients who responded to the survey delivered between September 2013 and September 2014. Only respondents that answered all the questions for the studied variables were included in the analysis.

Study Variables

Study variables included self-reported measures of means, standard deviations (SD) and proportions (%):

1. Age at the survey (mean ± SD): self-reported as MM/DD/YYYY but converted to the nearest year in age.

2. Sex (%): self-reported as male or female. Males were initially coded as one but recoded as 0. Females were initially coded as two but recoded as 1.

3. Race (%):In the GOAL survey race includes, American Indian or Alaska Native, Asian, Black or African-American, Native Hawaiian/Pacific Islander, or White, coded 1-5, respectively. This study was restricted to White, Black or African American, and Other (American Indian or Alaska Native, Asian or Native Hawaiian/Pacific Islander), recoded as 0-2 respectively.

4. Disease duration at the survey (mean ± SD): self-reported as MM/YYYY but converted to the nearest year.

5. Education level (%): In the GOAL survey, respondents self-report their highest grade or level of schooling completed coded as 1 -23. In this study, education was categorized as High school and below, some college/university, or more than a college/university level, coded 0-2 respectively;

6. Marital status (%): In the GOAL survey, marital status was reported as never married, married or cohabited, separated, divorced, widowed, or living with a partner but not married, originally coded 0-4 respectively. This study was restricted to married or cohabited, and all other (never married, separated, divorced, widowed or living with a partner but not married) recoded as 0,1 respectively.

7. Annual household income (%): In the GOAL survey, annual income was reported as less than $10,000; $10,000-$19,000; $20,000-$29,000; $30,000-$39,000; $40,000-$49,000; $50,000-$59,000; $60,000-$69,000, and more than $70,000; coded as 1-8. This study was restricted to less than $29,999; $30,000-$49,999; and more than $50,000; recoded as 0-2.

8. Currently employed (%): In the GOAL survey, respondents reported working full-time, working part-time, retired, homemaker, student, and unemployed, coded 1-5 and 7 respectively. This study was restricted to currently employed and not employed, recoded as 1 and 0 respectively.

9. Insurance coverage (%): In the GOAL survey, insurance coverage was coded as 0 for no and 1 for yes when reporting private insurance, Medicaid, medicare, military health care, Grady card, other or no insurance. This study was restricted to uninsured, private, or Medicaid/Medicare, recoded as 0-2 respectively.

10. Visit a psychiatrist in the past 12 months (%): In the GOAL survey, visiting a psychiatrist, psychologist or mental health counselor was coded 0=no and 1=yes.

11. Due to evidence that suggests that disease activity and organ damage are associated with, adverse mental health (Jolly et al., 2010) we used the Systemic Lupus Activity Questionnaire (SLAQ) and Brief Index of Lupus Damage (BILD) scores to control for disease conditions. SLAQ is a validated survey that provides a 3-month range of recall and a score that ranges from 0 to 44 (Karlson et al., 2003; Yazdany et al. 2008). High scores denote a higher degree of self-reported disease activity. SLAQ was recoded to represent mild (0-10), moderate (11-16) and severe (≥ 17) as 0-2, respectively. BILD is also a patient reported-validated instrument used in the GOAL cohort studies (Yazdany et al., 2011). BILD scores represent no damage (0), mild (1-2), and severe (3 ≤), recoded as 0-2 respectively.

12. Social Support (%): In the GOAL survey, Emotional support (section XII) is the item used in this analysis: "How often do you get the social and emotional support you need? (This is support from any source)." Responses were divided into five categories (always, usually, sometimes, rarely, never). This study restricted the categories to patients who report enough emotional support

(always, usually, sometimes) and patients who report not having enough emotional support (rarely, never), coded as 0 and 1 respectively.

13. Physician Social Support: In the GOAL survey, Mental Health Screening (section XIII) is the item from the Mental Health screening section used in this analysis: "Over the past 12 months, has your Primary Care Doctor (Internal Medicine, Family Practice, General Practitioner, Gynecologist, etc.), Rheumatologist (lupus doctor) or another doctor) asked if you have been feeling down, depressed or hopeless?" Responses were coded as 0 for no and 1 for responses answered in the affirmative.

14. Depression (%): The Patient Health Questionnaire (PHQ-9) is a self-reported measure of depression module. It is based on the nine criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) for the diagnosis of clinical depression. The PHQ-9 has been determined to be a reliable screening measure for depression (Moldovan et al., 2011). It can be evaluated either by a diagnostic algorithm to identify major depressive disorder (MDD) or as a continuous measure with scores ranging from 0 to 27 with defined cut points indicating severe levels of depression: 5 (mild), 10 (moderate), 15 (moderately severe), and 20 (severe) (Kroenke, Spitzer, Williams, & Lowe, 2010). Similar to previous publication (Kroenke, Spitzer, & Williams, 2001), the PHQ9-Depression scores were restricted to minimally/moderately depressed (score range of 0-9) or moderate/severe depression (score range of 10-27), coded as 0 and 1 respectively.

15. Mental Health Well-being (%): The Short Form family of health status instrument is a widely used measure and a robust, validated health status assessment tool (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). The GOAL survey measured mental health well-being using the self-administered SF-12. The self-administered SF-12 is derived from the 36 item short form (SF-36), which has two principal measures (physical component summary and mental health

summary) and 8 subscale domains (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health). The SF-12, however, can only provide the physical component summary and mental component scores (MCS-SF12), with higher scores indicating a better healthy well-being (Tamayo, Fischer-Betz, Beer, Winkler-Rohlfing, & Schneider, 2010). MCS-SF12 scores were coded as 0 for being below the U.S. population average score of 50 and 1 for being above the U.S. population average score of 50.

Statistical Analysis

Subjects with missing data on the main variables were excluded from this analysis. Preliminary test for normality were conducted before statistical analysis was done using SPSS (version 22) software. Descriptive statistics, including means with standard deviations (SD) for continuous variables were used to compare continuous variables across studied dependent variables. Kendall's Tau-b was used to determine the relationship between the measures of social support, PHQ9 depression scores and SF-12 scores. Independent T-tests were conducted to compare respondents who received social support from a physician to those who did not receive social support from a physician using the mental component scores and the PHQ9 depression scores. Binary logistic regression analysis was performed to assess the likelihood that respondents would be categorized as having a below average mental component score or above average. Both, univariate and multivariate logistic regression analyses were conducted to determine associations between selected characteristic and main independent variables with the mental component score and PHQ9 depression score, individually and together. Ninety-five percent confidence intervals were used to determine statistical significance.

Chapter 4.

Results

A total of 652 SLE respondents participated in the GOAL study, which was conducted in the period between late September 2013 and early September 2014. As shown in Table 1, 93% of eligible participants were women, 78.4% African American, 19.5% white, and 2.1% other races. The mean ± SD for age at survey and disease duration at survey was 48.9 ± 13.1 years and 16.0 ± 9.7 years, respectively. Although 47% had at least some college education, 65% were unemployed, and 11.7% were uninsured. Among those insured, 35.6% had private insurance and 52.8% had Medicaid or Medicare. 44.9% of SLE patients have severe disease activity and 39.9% have severe organ damage. The mean ± SD for the mental component score PHQ9 depression score was 44.50 ± 11.41 and 7.98 ± 6.23, respectively. The majority of the SLE patients (58.1%) reported always having enough emotional or social support from any source while 41.9% report not having enough emotional or social support. Majority of the SLE patients across all variables did not have a physician serve as a source of social support nor visited a psychiatrist over the past 12 months. Majority (62.4%) of the patients who reported having enough emotional and social support did not receive any from physicians in the past 12 months.

Table 1. Socio-demographics of Systemic Lupus Erythematosus patients in the GOAL study

Characteristic	GOAL Cohort (N=652)	Has a physician served as a role of social support?	
		No (N=489)	Yes (N=163)
Age at survey, years (mean ± SD)	48.9 ± 13.1	48.7 ± 13.4	49.3 ± 11.9
Disease Duration, years (mean ± SD)	16.0 ± 9.7	16.3 ± 9.6	15.4 ± 9.8
Gender			
Male	43 (6.6)	29 (5.9)	14 (8.6)
Female	609 (93.4)	460 (94.1	149 (91.4)
Race			
White	127 (19.5)	101 (20.7)	26 (16.0)
African American	511 (78.4)	377 (77.1)	134 (82.2)
Other	14 (2.1)	11 (2.2)	3 (1.8)
Education Level			
≤ High School	199 (31.1)	142 (29.6)	57 (35.6)
Some College	303 (47.3)	224 (46.7)	79 (49.4)
≥ College/University	138 (21.2)	114 (23.8)	24 (15.0)
Marital Status			
All other	383 (58.7)	279 (57.1)	104 (63.8)
Married/Cohabitated	269 (41.3)	210 (42.9)	59 (36.2)
Annual Household income			
≤ $29,999	315 (52.9)	230 (51.6)	85 (57.0)
$30,000-$49,999	83 (13.9)	57 (12.8)	26 (17.4)
≥ $50,000	197 (33.1)	159 (35.7)	38 (23.3)
Currently employed			
No	424 (65.0)	191 (39.1)	126 (77.3)
Yes	228 (35.0)	298 (60.9)	37 (22.7)
Insurance Type			
Uninsured	76 (11.7)	58 (11.9)	18 (11.0)
Private	232 (35.6)	192 (39.3)	40 (24.5)
Medicare/Medicaid	344 (52.8)	239 (48.9)	105 (64.4)

Disease Activity Score			
Mild (0-10)	194 (29.8)	164 (33.5)	30 (18.4)
Moderate (11-16)	165 (25.3)	134 (27.4)	31 (19.0)
Severe (≥ 17)	293 (44.9)	191 (39.1)	102 (62.6)
Organ Damage Score			
No Damage	147 (22.5)	129 (26.4)	18 (11.0)
Mild (1-2)	245 (37.6)	179 (36.6)	66 (40.5)
Severe (≥3)	260 (39.9)	181 (37.0)	79 (48.5)
Visit a Psychiatrist in past 12 months?			
No	546 (86.3)	442 (93.1)	104 (65.8)
Yes	87 (13.7)	33 (6.9)	54 (34.2)
Receiving enough emotional support			
Not enough	272 (41.9)	183 (37.6)	89 (54.9)
Enough	377 (58.1)	304 (62.4)	73 (45.1)
Mental Component Score (mean ± SD)	44.50 ± 11.41	46.7 ± 10.6	38.0 ± 11.2
Depression Screener Score (mean ± SD)	7.98 ± 6.23	6.89 ± 5.8	11.2 ± 6.4

Tables 2 and 3 show results from the independent-samples t-test that were conducted to compare the mental component scores and the PHQ9 depression scores for the main independent variables. There was a significant difference in scores for both test variables. The mental component score for those categorized as having enough emotional or social support was greater (M=48.1, SD= 10.4) than those who were categorized as not having enough emotional or social support (M=39.6, SD=10.9); t (507)=8.89, p <.001. The PHQ9 depression score was lower for those who were categorized as having enough emotional or social support (M=6.2, SD=5.3) than those who did not have enough emotional or social support (M=10.5, SD=6.5); t(621)= -9.76, p< 0.001.The mental component score for those categorized as having social support from a physician was lower (M=38.0, SD= 11.2) than those who were not categorized as having social support from a physician (M=46.7, SD=10.6); t(624)=8.73, p <.001. The PHQ9 depression score was higher for those who were categorized as having social support from a physician (M=11.2, SD=6.4) than those who did not have social support from a physician (M=6.9, SD=5.8); t (254) = -7.67, p< 0.001.

Table 2. Comparison of Mental Component and Depression Screener Scores by Physician Social Support Using the Student's t-Test

	Has a physician served as a role of social support?			
Variable	No	Yes	t	df
Mental Component Score	46.7 ± 10.6	38.0 ± 11.2	8.73*	624
PHQ9 Depression Score	6.89 ± 5.8	11.2 ± 6.4	-7.67*	254

*** p < .001**

Table 3. Comparison of Mental Component and Depression Screener Scores by Emotional Support Using the Student's t-Test

	Does patient have enough emotional or social support?			
Variable	Not Enough	Enough	t	df
Mental Component Score	39.6 ± 10.9	48.1 ± 10.4	8.89*	507
PHQ9 Depression Score	10.5 ± 6.5	6.2 ± 5.3	-9.76*	621

*** p < .001**

Kendall's tau b correlation coefficient was used to investigate the relationship amongst the independent variables (age at survey; sex; race; disease duration at survey; education level; marital status; annual household income; employment status; insurance coverage; disease activity; organ damage; and status on visiting a psychiatrist in the past 12 months), Table 4. There was a weak, positive correlation for disease activity (tau = .19, p <.01), disease organ damage (tau = .14, p < .01), and type of insurance (tau = .11, p < .01) with social support from a physician. There was a moderate, negative correlation between disease activity score and emotional or social support, tau=-.20, p <.01. There was a weak, negative correlation for education (tau = -.08, p <.05) and current employment status (tau = -.15, p <.01) with social support from a physician. There was a strong, positive correlation between psychiatrist visited in past 12 months and social support from a physician, tau=.34, p <.01. Kendall's tau b correlation coefficient was used to investigate the relationship amongst the independent variables and the dependent variables MCS-SF12 score and PHQ9 score, Table 5. There was a moderate, positive correlation between emotional or social support and MCS-SF12 scores (tau = .29, p < .01), and a strong, negative correlation for emotional or social support and PHQ9 depression scores (tau = -.30, p< .01). There were moderate correlations for MCS-SF12 scores (tau = -.25, p <.01), and PHQ9 scores (tau = .29, p< .01) with social support from a physician. Disease activity had a strong, negative correlation with MCS-SF12 scores (tau = -.426, p< .01) and a strong, positive correlation with PHQ9 depression scores (tau = .49, p <.01).

Table 4. Correlation Between Physicians' Emotional or Social Support and Social support

	Emotional or social Support	Physician social support
Disease Activity Score	**-.204****	**.189****
Disease Organ Damage Score	-.055	**.138****
Age at Survey	.034	.019
Disease Duration	.016	-.040
Sex	-.020	-.046
Education	**.079***	**-.083***
What is your current relationship status?	.076	-.059
Type of Insurance	.002	**.113****
Annual income	.073	-.067
Currently employed	**-.002**	**-.149****
Visit a psychiatrist in past 12 months?	**-.081***	**.342****

Values are Kendall's Tau b Coefficients

**. Correlation is significant at P<0.01 level (2-tailed).

*. Correlation is significant at P< 0.05 level (2-tailed).

Table 5. Correlation Between Mental Component Score and PHQ9 Depression Score

	MCS-SF12 Score	PHQ9 Depression Score
Emotional or social Support	**.294****	**-.298****
Physician social support	**-.248****	**.293****
Age at Survey	.035	-.016
Disease Duration	.051	-.001
Sex	-.004	**.106****
Education	.057	-.070
Marital Status	-.003	-.006
Type of Insurance	-.055	.055
Annual Income	**.087***	**-.153****
Currently employed	**.152****	**-.191****
Visited a psychiatrist in the past 12 months?	**-.213****	**.224****
Disease Activity Score	**-.426****	**.485****
Disease Organ Damage Score	**-.097***	**.170****

Values are Kendall's Tau b Correlation Coefficients
**Correlation is significant at P<0.01 level (2-tailed).
*Correlation is significant at P<0.05 level (2-tailed).

Three types of models were completed for the mental component scores and PHQ9 depression scores: one for all characteristic variables separately, all characteristic variables with one of the main independent variables entered into the model, and all variables entered into the model altogether. Table 6 and 7 shows the association of the individual variables (univariate regression) and the full model (multivariate regression) analyses with mental component scores. A few statistically significant findings were found in both the univariate and multivariate analysis for mental component scores; patients who have social support from a physician have an unadjusted odds ratio of .24 (95% CI 0.15 – 0.38, $p < .001$) and an adjusted odds ratio of .34 (95% CI .19 - .60, $p < .001$). For patients reporting enough emotional support, there was an unadjusted and adjusted odds ratio of 3.87 (95% CI 2.66 – 5.62, $p < .001$) and 3.27 (95 CI 2.07 – 5.14, $p < .001$), respectively. Disease activity and psychiatrist visits in the past 12 months were also statistically significantly associated with decreased mental component scores in the univariate and both multivariate regressions. Patients with moderate or severe disease activity scores had an unadjusted odds ratio of 0.29 (95% CI 0.19 – 0.45, $p <.001$) and 0.09 (95% CI 0.06 – 0.14, $p < .001$), respectively. Patients with moderate disease activity scores had an adjusted odds ratio for the model containing physician support, 0.28 (95% CI 0.15 – 0.44, $p <.001$) and 0.32 (95% CI 0.19 – 0.55, $p < .001$) for the model containing emotional or social support. Severe disease activity had an unadjusted 0.09 (95% CI 0.05 – 0.16, $p < .001$) and an adjusted odds ratio for the model containing social support from a physician of 0.10 (95% CI 0.06 – 0.18, $p < .001$). Patients who visited a psychiatrist in the past 12 months had an unadjusted and adjusted odds ratio (model containing physician support model and emotional or social support model) of 0.16 (95% CI 0.08 – 0.35, $p < .001$), 0.36 (95% CI 0.16 – 0.83, $p < .05$), and 0.25 (95% CI 0.11 – 0.57, $p < .01$). Patients who received social support from a physician, had greater disease activity

or visited a psychiatrist within the year are more likely to have a below U.S. normal average mental component score than those without social support from a physician, no disease activity or no psychiatrist visit. Patients who reported having enough emotional or social support had greater odds of having an above average mental component score than those who report not having enough support.

Annual income and employment status were significantly associated with increased mental component and PHQ9 depression scores in the univariate regression analyses but not in the multivariate regressions. Organ damage was significantly associated with decreased mental component and PHQ9 depression scores in the univariate regression analyses but not in the multivariate regressions. Having an annual income over $50,000 (OR =1.55, 95% CI 1.06 – 2.26, $p < .05$) or being employed (OR= 1.93, 95% CI 1.37 – 2.71, $p < .001$) yielded a greater odds of having an above average mental component score than having an annual income below $30,000 or being unemployed, respectively. Greater organ damage was associated with a greater odds (OR= 0.56, 95% CI 0.36 – 0.86, $p < .01$) of having a below average mental component score than those with no organ damage.

Table 6. Results of the Univariate and Multivariate Logistic Regression Analyses of the Association of Physician Social Support with Other Characteristics Using the Mental Component Score

	Univariate Regression			Multivariate Regression		
	OR	95% CI	p-value	OR	95% CI	p-value
Physician Social Support						
No		Ref			Ref	
Yes	.237	.147 - .383	≤.001**	.339	.191-.601	≤.001***
Age	1.00	.995-1.02	.257	1.007	.988-1.027	.467
Sex						
Male		Ref			Ref	
Female	.966	.491-1.898	.919	1.128	.505-2.522	.708
Race						
White		Ref			Ref	
Black	1.046	.690-1.587	.831	1.612	.928-2.798	.090
Other	1.446	.471-4.443	.519	1.099	.257-4.696	.899
Disease Duration	1.014	.997-1.032	.097	1.009	.985-1.034	.456
Education Level						
≤ High School		Ref			Ref	
Some College	1.005	.681-1.484	.979	.840	.502-1.406	.508
≥ College/University	1.462	.925-2.310	.104	1.113	.587-2.110	.744
Marital Status						
All other		Ref			Ref	
Married/Cohabitated	.989	.709-1.380	.949	1.008	.631-1.611	.972
Annual Household income						
≤ $29,999		Ref			Ref	
$30,000-$49,999	1.036	.612-1.754	.895	1.170	.588-2.325	.655
≥ $50,000	1.546	1.060-2.255	.024*	.887	.446-1.766	.734
Currently employed						

No		Ref			Ref	
Yes	1.927	1.371-2.708	≤.001**	1.454	.839-2.521	.182
Insurance Type						
Uninsured		Ref			Ref	
Private	1.444	.822-2.536	.202	.848	.389-1.851	.679
Medicare/Medicaid	.974	.563-1.685	.925	1.319	.625-2.783	.467
Disease Activity Score						
Mild (0-10)		Ref			Ref	
Moderate (11-16)	.288	.185-.450	≤.001**	.281	.154-.443	≤.001***
Severe (≥ 17)	.089	.057-.139	≤.001**	.091	.052-.158	≤.001***
Organ Damage Score						
No Damage		Ref			Ref	
Mild (1-2)	.689	.449-1.056	.087	1.265	.731-2.191	.401
Severe (≥3)	.558	.362-.858	.008**	1.159	.628-2.139	.637
Visit a Psychiatrist in past 12 months?						
No		Ref			Ref	
Yes	.164	.078-.348	≤.001**	.361	.156-.834	.017*

*p < .05, **p < .01, ***p < .001

Table 7. Results of the Univariate and Multivariate Logistic Regression Analyses of the Association of Emotional Support with Other Characteristics Using the Mental Component Score

	Univariate Regression			Multivariate Regression		
	OR	95% CI	p-value	OR	95% CI	p-value
Emotional Social Support						
Not enough		Ref			Ref	
Enough	3.87	2.66-5.62	≤.001	3.27	2.07-5.14	≤.001
Age	1.00	1.00-1.02	.26	1.01	.99-1.03	.59
Sex						
Male		Ref			Ref	
Female	.97	.49-1.90	.92	1.12	.49-2.57	.78
Race						
White		Ref			Ref	
Black	1.05	.69-1.59	.83	1.58	.90-2.77	.12
Other	1.45	.47-4.44	.52	.93	.21-4.08	.93
Disease Duration	1.01	1.00-1.03	.10	1.01	.99-1.04	.39
Education Level						
≤ High School		Ref			Ref	
Some College	1.01	.68-1.48	.98	.86	.51-1.44	.56
≥ College/University	1.46	.93-2.31	.10	1.03	.54-1.96	.99
Marital Status						
All other		Ref			Ref	
Married/Cohabitated	.99	.71-1.38	.95	.91	.57-1.46	.70
Annual Household income						
≤ $29,999		Ref			Ref	
$30,000-$49,999	1.04	.61-1.75	.90	1.15	.58-2.29	.70
≥ $50,000	1.55	1.06-2.26	.02*	.91	.45-1.82	.78
Currently employed						
No		Ref			Ref	
Yes	1.93	1.37-2.71	≤.001	1.73	.99-3.04	.06

Insurance Type						
Uninsured		Ref			Ref	
Private	1.44	.82-2.54	.20	.79	.36-1.77	.57
Medicare/Medicaid	.97	.56-1.69	.93	1.22	.57-2.59	.61
Disease Activity Score						
Mild (0-10)		Ref			Ref	
Moderate (11-16)	.29	.19-.45	≤.001	.32	.19-.55	≤.001
Severe (≥ 17)	.09	.06-.14	≤.001	.10	.06-.18	≤.001
Organ Damage Score						
No Damage		Ref			Ref	
Mild (1-2)	.69	.45-1.06	.09	1.17	.672-	.58
Severe (≥3)	.56	.36-.86	.008**	1.21	2.046	.55
					.652-	
					2.245	
Visit a Psychiatrist in past 12 months?						
No		Ref			Ref	
Yes	.16	.08-.35	≤.001***	.25	.11-.57	.001**

*p < .05, **p < .01, ***p < .001

Table 8 and Table 9 show the association between selected independent variables with the PHQ9 depression scores. Social support from a physician was significantly associated with depression in both univariate and multivariate analyses. Having social support from a physician yielded 3.93 unadjusted greater odds (95% CI 2.72 – 5.70, $p < .001$) of being moderately/severely depressed than those without physician support. Having social support from a physician yielded 3.67 adjusted greater odds (95% CI 2.21 – 6.11, $p < .001$) of being moderately/severely depressed than those without physician support. Having enough emotional support was also found to be significantly associated with depression. Patients who reported having enough emotional or social support had approximately 70% less odds (unadjusted OR = 0.28, 95% CI 0.20 – 0.39, $p < .001$; adjusted OR= 0.32, 95% CI 0.21 – 0.50, $p < .001$) of being moderately depressed than those who did not have enough emotional or social support. Disease activity and psychiatrist visits in the past 12 months were also statistically significantly associated with PHQ9 depression scores in the univariate and both multivariate regressions. Patients with moderate or severe disease activity scores had an unadjusted odds ratio of 7.02 (95% CI 3.30– 14.94, $p <.001$) and 32.28 (95% CI 15.88– 65.59, $p < .001$). Patients with moderate disease activity scores had an adjusted odds ratio of 7.71 (95% CI 3.13 – 19.01, $p <.001$) and 5.87 (95% CI 2.42 – 14.29, $p < .001$) for the model containing physician support and emotional or social support, respectively; severe disease activity had an adjusted odds ratio of 32.39 (95% CI 13.54 – 77.50, $p < .001$) and 25.72 (95% CI 11.00 – 60.32, $p < .001$) for the model containing physician support and emotional or social support, respectively. Patients who visited a psychiatrist in the past 12 months had an unadjusted and adjusted odds ratio (model containing physician support model and emotional or social support model) of 0.16 (95% CI 0.08

– 0.35, p < .001), 0.36 (95% CI 0.16 – 0.83, p < .05), and 0.25 (95% CI 0.11 – 0.57, p < .01), respectively.

In the univariate analyses, sex, education, annual income, employment status and organ damage were significantly associated with depression. However, in the full model these variables were no longer significant. Female SLE patients (OR = 2.97, 95% CI 1.30 – 6.79, p < .05), having a mild organ damage (OR = 1.71, 95% CI 1.07 – 2.73, p <.05) or having severe organ damage (OR = 2.78, 95% CI 1.76 – 4.40, p < .001) were associated with increased odds of moderate/severe depression compared to males and subjects with no organ damage, respectively. Having a college/university (OR = 0.62, 95% CI 0.39 - 0.996, p < .05), an annual income that is greater than $50,000 (OR = 0.44, 95% CI 0.30 – 0.66, p < .001), or being employed (OR = 0.41, 95% CI 0.28 – 0.59, p < .001) were associated with decreased odds of moderate/severe depression compared to subjects with a high school education or lower annual income less than $30,000, or unemployed, respectively.

Table 8. Results of the Univariate and Multivariate Logistic Regression Analyses of the Association of Physician Social Support with Other Characteristics Using the PHQ9-Depression Score

	Univariate Regression			Multivariate Regression		
	OR	95% CI	p-value	OR	95% CI	p-value
Physician Support						
No		Ref			Ref	
Yes	3.90	2.72 – 5.70	≤.001	3.67	2.21- 6.11	≤.001
Age	1.00	.99-1.01	.72	.99	.97-1.01	.20
Sex						
Male		Ref			Ref	
Female	2.97	1.30-6.79	.010**	3.26	1.17- 9.06	.02
Race						
White		Ref			Ref	
Black	1.01	.67-1.51	.97	.62	.34- 1.13	.12
Other	.50	.13- 1.87	.30	.67	.10- 4.25	.67
Disease Duration	1.00	.98-1.01	.10	1.01	.98- 1.03	.67
Education Level						
≤ High School		Ref			Ref	
Some College	.90	.62- 1.31	.59	1.09	.65- 1.83	.73
≥ College/University	.62	.391-1.00	.05*	.90	.45 – 1.79	.76
Marital Status						
All other		Ref			Ref	
Married/Cohabitated	.98	.70- 1.35	.88	1.22	.74- 2.00	.43
Annual Household income						
≤ $29,999		Ref			Ref	
$30,000-$49,999	.91	.55- 1.49	.91	.64	.33- 1.27	.21
≥ $50,000	.44	.30- .66	≤.001	.63	.30- 1.32	.22
Currently employed						
No		Ref			Ref	
Yes	.41	.28- .59	≤.001	.74	.41- 1.35	.33

Insurance Type						
Uninsured		Ref			Ref	
Private	.57	.33- .97	.04	1.60	.71- 3.59	.25
Medicare/Medicaid	.93	.56- 1.54	.77	.80	.39- 1.64	.53
Disease Activity Score		Ref			Ref	
Mild (0-10)		3.30- 14.94			3.13- 19.01	
Moderate (11-16)	7.02	15.88-	≤.001	7.71	13.54-	≤.001
Severe (≥ 17)	32.28	65.59	≤.001	32.39	77.50	≤.001
Organ Damage Score						
No Damage		Ref			Ref	
Mild (1-2)	1.71	1.07- 2.73	.026*	.83	.44- 1.57	.58
Severe (≥3)	2.78	1.76-4.40	≤.001**	1.27	.65- 2.47	.48
Visit a Psychiatrist in past 12 months?						
No		Ref			Ref	
Yes	3.65	.08-.35	≤.001***	2.04	1.08- 3.86	.03*

*p < .05, **p < .01, ***p < .001

Table 9. Results of the Univariate and Multivariate Logistic Regression Analyses of the Association of Emotional support with other characteristics Using the PHQ9-Depression Score

	Univariate Regression			Multivariate Regression		
	OR	95% CI	p-value	OR	95% CI	p-value
Emotional Social Support						
Not enough		Ref			Ref	
Enough	.28	.20 - .39	≤.001	.32	.21- .50	≤.001
Age	1.00	.99-1.01	.72	.99	.97-1.01	.35
Sex						
Male		Ref			Ref	
Female	2.97	1.30-6.79	.010**	3.48	1.20 – 10.12	.02
Race						
White		Ref			Ref	
Black	1.01	.67-1.51	.97	.71	.39- 1.29	.26
Other	.50	.13- 1.87	.30	.85	.14- 5.31	.86
Disease Duration	1.00	.98-1.01	.10	1.00	.98- 1.03	.89
Education Level						
≤ High School		Ref			Ref	
Some College	.90	.62- 1.31	.59	1.09	.65-1.83	.74
≥ College/University	.62	.391-1.00	.048*	.90	.45-1.79	.90
Marital Status						
All other		Ref			Ref	
Married/Cohabitated	.98	.70- 1.35	.88	1.30	.79- 2.13	.30
Annual Household income						
≤ $29,999		Ref			Ref	
$30,000-$49,999	.91	.55- 1.49	.91	.72	.37-1.43	.35
≥ $50,000	.44	.295- .66	≤.001	.65	.311-1.34	.24
Currently employed						
No		Ref			Ref	
Yes	.41	.28- .59	≤.001	.63	.34-1.15	.13

Insurance Type						
Uninsured		Ref			Ref	
Private	.57	.33- .97	.04	1.67	.74- 3.77	.22
Medicare/Medicaid	.93	.56- 1.54	.77	.91	.44- 1.90	.81
Disease Activity Score						
Mild (0-10)		Ref			Ref	
Moderate (11-16)	7.02	3.30- 14.94	≤.001***	5.87	2.42- 14.29	≤.001
Severe (≥ 17)	32.28	15.88- 65.59	≤.001***	25.72	10.97- 60.32	≤.001
Organ Damage Score						
No Damage		Ref			Ref	
Mild (1-2)	1.71	1.07- 2.73	.03*	.92	.49- 1.72	.79
Severe (≥3)	2.78	1.76-4.40	≤.001**	1.35	.70- 2.62	.38
Visit a Psychiatrist in past 12 months?						
No		Ref			Ref	
Yes	3.65	.08-.35	≤.001	2.88	1.53- 5.39	.001**

*p < .05, **p < .01, ***p < .001

Table 10 shows the results for the full multivariate regression analysis using mental component score and PHQ9 depression scores as dependent variables. In both models, only physician social support, emotional support, disease activity, and psychiatrist visits were significantly associated with increased or decreased odds of having an above US average mental health score and being depressed. Having social support from a physician was associated with a 64% decreased odds (OR= 0.36, 95% CI .20 - .660, p <.01) of having an above average US mental component score compared to subjects without social support from a physician. Having social support from a physician was also associated with a 3.43 times greater odds (95% CI 2.02 – 5.82, p <.001) of being moderately/severely depressed compared to patients without social support from a physician. Having enough emotional or social support was associated with 3.13 increased odds (95 % CI 1.97 – 4.96, p < .001) and 64% decreased odds (OR= 0.36, 95% CI 0.23 – 0.56, p < .001) of having an above average mental component score and being minimally/mildly depressed, respectively. Moderate and severe disease activity yielded odds ratios of 0.31 (95% CI 0.18 – 0.53, p < .001) and 0.11 (95% CI 0.06 – 0.19, p < .001), respectively, for the mental component score model. In the PHQ9 depression score model, moderate and severe disease activity yielded odds ratios of 6.39 (95% CI 2.57 – 15.90, p < .001) and 27.70 (95% CI 11.51 – 66.66, p < .001), respectively. Psychiatrist visits yielded adjusted odds ratios of 0.35 (95% CI 0.15 – 0.82, p < .05) and 2.02 (95%CI 1.05 – 3.89, p < .05) for the models containing mental component scores and PHQ9 depression scores, respectively. For the PHQ9 depression model, gender was found to be statistically significant; adjusted for all the other variables in the model, females had a 3.52 (95% CI 1.19 – 10.39, p < .05) greater odds of being moderately/severely depressed than their male counterparts.

Table 10. Results of the Multivariate Logistic Regression Analyses of the Associations of Mental Component Score with the PHQ9-Depression Score

	MCS-SF12 Score			PHQ9-Depression Score		
	OR	OR 95% CI	p-value	OR	OR 95% CI	p-value
Emotional support						
Not enough Support		Ref			Ref	
Enough Support	3.13	1.97 – 4.96	≤.001	.36	.23 - .56	≤.001
Physician Social Support						
No		Ref			Ref	
Yes	.36	.20- .66	.001**	3.43	2.02 – 5.82	≤.001
Age	1.01	.99 – 1.03	.57	.99	.97 – 1.01	.37
Sex						
Male		Ref			Ref	
Female	1.06	.46 – 2.40	.90	3.52	1.19 – 10.39	.02*
Race						
White		Ref			Ref	
Black	1.67	.94 – 2.94	.08	.64	.35 – 1.18	.16
Other	.08	.23-4.31	1.00	.87	.14 – 5.65	.89
Disease Duration	1.01	.99 – 1.04	.41	1.01	.98 – 1.03	.73
Education Level						
≤ High School		Ref			Ref	
Some College	.84	.49 – 1.42	.51	1.13	.66 – 1.92	.66
≥ College/University	.95	.49 – 1.83	.87	1.03	.50 – 2.09	.94
Marital Status						
All other		Ref			Ref	
Married/Cohabitated	.92	.57 – 1.48	.73	1.39	.83 – 2.32	.21
Annual Household income						
≤ $29,999		Ref			Ref	
$30,000-$49,999	1.30	.64 – 2.63	.47	.603	.30 – 1.22	.16
≥ $50,000	1.00	.49 – 2.03	1.00	.58	.27 – 1.25	.17
Currently employed						

No		Ref			Ref	
Yes	1.70	.96 – 3.00	.07	.67	.36 – 1.24	.20
Insurance Type						
Uninsured		Ref			Ref	
Private	.75	.33 – 1.68	.48	1.73	.75– 3.98	.20
Medicare/Medicaid	1.25	.58 – 2.69	.57	.89	.42 – 1.88	.75
Disease Activity Score						
Mild (0-10)		Ref			Ref	
Moderate (11-16)	.31	.18 - .53	≤.001	6.39	2.57 – 15.90	≤.001
Severe (≥ 17)	.11	.06 - .19	≤.001	27.70	11.51 – 66.66	≤.001
Organ Damage Score						
No Damage		Ref			Ref	
Mild (1-2)	1.28	.73 – 2.24	.40	.79	.41 – 1.50	.46
Severe (≥3)	1.25	.67 – 2.34	.48	1.21	.61 – 2.39	.58
Psych visit in past 12 months?						
No		Ref			Ref	
Yes	.35	.15 - .82	.02*	2.02	1.05 – 3.89	.03*

*p < .05, **p < .01, ***p < .001

Chapter 5.

Discussion

Discussion of Research Questions

The purpose of this study was to examine the association between social support and the mental health well-being of SLE patients. Study findings suggest that perceived emotional support was associated with improved mental health outcomes, regardless of other known triggers of negative mental health status. Patients who reported having enough emotional support had significantly better mental health well-being than patients who report not having enough emotional support. The result of this investigation also showed that social support from a physician was significantly correlated with disease activity, organ damage, education, insurance, employment status, and visiting a psychiatrist in the past 12 months. The result of this investigation also showed that social support from a physician was negatively correlated with mental component scores and positively correlated with PHQ9 depression scores. The final aim of this study was to determine whether or not physicians' serving as a source of social support is associated with a better mental health well-being for SLE patients. Despite the positive findings on social support, social support from a physician yielded unexpected results. Patients who were categorized as having social support from a physician were found to be in poorer mental health statuses, as measured by the MCS SF-12 and PHQ9 depression score. One potential explanation for the findings of this study may be explained in the context that physicians probably tend to target patients who they notice are feeling down, anxious or depressed. This approach aligns with common physician practices used in treating acute conditions and not chronic illnesses (Neurocom, 2012). If physicians commonly ask all of their SLE patients about their mental health well-being, there might be a more representative association between social support from a physician and patient mental health well-being.

Study Strengths

First, the strength of this study lies on its originality. To the best of our knowledge, no other studies measuring the impact of social support from a physician on patient mental health well-being is available. Knowledge from this study can provide key information and insight into SLE disease management. Second, the use of validated instruments of measures in the analysis of mental health and depression strengthens results. Study findings are comparable to previous literature using these same instruments. Finally, the gender and racial makeup of this study is similar to that described by epidemiologic studies with a large number of SLE patients (Hochberg, 1997).

Study Limitations

The results of this study should be interpreted with caution. Using secondary data that was not designed to address the research questions, it is not possible to determine whether or not physician support predated SLE patient health outcomes, including depression or organ damage. This study was also unable to determine the baseline mental health assessment of the patients before physician support was utilized. A longitudinal study would allow us to establish whether evidence of poor mental health by the patient facilitated social support from a physician or whether social support from a physician was provided as a preemptive strike against poor mental health. Furthermore, this study was unable to rule out recall bias. The data used is self-reported and the longest recall period was 12 months. Lupus patients often experience what is known as a "lupus fog," having feelings of confusion, fatigue, memory impairment and the inability to express their thoughts (Sterling et al. , 2014). Comparatively, a long recall would be hard for

non-SLE patients to completely adhere to because memory is fallible. Finally, measures of comparison for mental component scores on the SF-12 is not optimized for this analysis. Theoretically, an SLE patient should have a lower mental health score compared to the general United States population average. The score of 50 on the MCS SF-12 is an average of healthy and acutely or chronically ill patients; those with severe health issues are skewing this average score downward. It may be more feasible to find the average mental component score of SLE patients to better understand the severity of a patient's mental health.

Future Research

Further research and attention to the association of social support and SLE patient mental health well-being are needed. Our shortcomings suggest that a longitudinal study may be of great benefit when exploring the relationship of social support from a physician and mental health well-being. Since the data used in this study is derived from the 3rd wave of the GOAL cohort data collection, future studies should look at how measured mental health outcomes changed over time. By examining the role if social support from a physician, initiatives to increase better mental well-being in SLE patients can be developed. Studies that compare the role that social support from a physician has on the mental health status of SLE patients to other chronic diseases, like obesity, may provide additional knowledge on the healthcare provider's social support in health. Such studies may give those unfamiliar with SLE, physicians and the general public alike, a benchmark for understanding the importance of social support. If the role of social support from physicians on SLE patient is found to be different than that of obese patient, better disease management techniques can be implemented across different diseases.

Public health Relevance

It is of public health interest to improve physician practices for SLE patients. The SLE community is unique in that disease activity, etiology and symptoms are so complex that it takes more resources for disease management. The findings of this study suggest that physicians should ensure that patients have an adequate amount of emotional support for a better mental health well-being. Regardless of whether having enough emotional or social support predates the mental health state in question, physicians should work towards providing emotional support for SLE patients. Fluctuation in disease activity can bring about unstable mental health states that physicians should be conscious about when providing care. Implementing cross trainings between non mental health physicians and mental health professionals may lead to a better understanding of how to engage SLE patients on an emotional level. Physicians should also work on techniques to better serve patients of low SES (annual income, employment status and education level). Limitations in access to healthcare that accompanies a low SES should prompt physicians to adjust disease management accordingly. Cultural sensitivity trainings may be of benefit to physicians in understanding the varying experiences of patients and providing individualized care.

Conclusion

The findings of this study show that emotional or social support is associated to the mental health well-being of SLE patients. SLE patients who have enough emotional or social support were found to have above normal general mental health and less depression. Patients who have social support from a physician were found to have below normal general mental

health and moderate or severe depression. There is a need for more robust studies to examine the exact role social support from physician's play in patient's mental health well-being.

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