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Relationships among organ damage, social support, and depression in African American women with systemic lupus erythematosus

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Abstract

Objectives: Systemic lupus erythematosus (SLE) disproportionately strikes African American women. Social support can potentially reduce disease impact. The purpose of this study is to understand the relationship between organ damage and depression in African American women and how social support influences this relationship.

Methods: We used a mixed methods design, analyzing self-reported data on lupus-related organ damage, depression, and social support in 437 African American women with SLE recruited in the Georgians Organized Against Lupus (GOAL) cohort. Moreover, we conducted interviews among 15 GOAL participants to gather patients' perspectives about the role of social support in people who live with lupus.

Results: We found a significant association between organ damage and depression ($r = 0.163$, $p = 0.001$), as well as between depression and social support ($F = 17.574$, $p<0.001$). The quantitative analysis did not render social support as a significant moderator in the organ damage–depression relationship. Interviews, however, revealed that African American women with the most severe organ damage have the greatest need for support.

Conclusions: Social support is a key resource for lupus patients with high disease burden. Overall, these findings highlight the importance of monitoring depressive symptoms in this population and developing interventions aimed to increase social support available to lupus patients. *Lupus* (2019) **28**, 253–260.

Keywords

African American; depression; lupus; organ damage; social support; systemic lupus erythematosus

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Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that causes inflammation and potentially affects any organ system in the human body. SLE disproportionately strikes childbearing age women, and health problems stemming from SLE range from mild to life-threatening. The most common clinical manifestations include skin rashes, arthritis, serositis, vasculitis, nephritis, as well as a variety of mental illnesses.[1]

While the overall incidence of SLE is approximately 5.5 per 100,000 individuals per year, it occurs much more frequently in women and in African Americans. The incidence rate for women is approximately 9 per 100,000 per year and, more specifically, the incidence rate for women in the Georgia Lupus Registry is 9.2 per 100,000 women per year. In contrast, the incidence rate for men in this registry is 1.8 per 100,000 men per year.[2] African American women in the Georgia Lupus Registry had an incidence rate of 13.4 compared with 4.7 in Caucasian women.[2] African Americans are 2.3 times more likely to have SLE than Caucasians, and African Americans diagnosed with SLE are also more likely to develop renal disease.[3] Even though African American women have three to four times higher rates of SLE than the rest of the population, very few studies have focused solely on this population.

Due to the challenging nature of the disease, its diagnosis and treatment, as well as its impact on the central nervous system, patients with SLE are more likely to have depression, anxiety, or other mental illnesses.[4] Depressive symptoms have been reported in up to 75% of patients with SLE, and approximately 50% will have a diagnosis of major depressive disorder in their lifetime.[1,5–7] However, the reported prevalence and impact of depression varies depending on the methodology and depressive definition used.[8] Additionally, depression among African American individuals is often under-diagnosed and undertreated, leading to high burden of depression-related morbidity in this demographic group.[9–11] Although depression has been linked with disease activity among people with SLE, there is limited research assessing the relationship between organ damage and depression in this population.[1]

Similarly, few studies have looked at the effect of emotional and social support upon lupus patients. A qualitative study found that women with SLE considered family and friends as very important in maintaining quality of life. Being part of a family and able to socialize helped these women, as did having family and friends who understood their disease manifestation.[12] Another study of 44 SLE patients found that pain and helplessness contributed to depression; however, family support did not.[13] Thus, while social support has been linked with reduced depression among people with other chronic diseases,[14] whether this is true among people with SLE has not been studied.

In summary, few studies have focused solely on African American women, a high-risk group for SLE. Moreover, the relationship between SLE-related damage and depression has not been studied, nor has whether or not social support has an effect upon such a relationship. To address these gaps, this study focused on the following research questions:

1. Is there a relationship between organ damage and depressive symptoms in African American women?
2. Does social support buffer the impact of organ damage on depression?

Methods

Design

This study used a mixed-methods approach to answer the research questions. Quantitative survey data were supplemented with qualitative interview data to examine the role social support plays for African American women with SLE.

Participants

Quantitative—We used self-reported data collected among African American women enrolled in the Georgians Organized Against Lupus (GOAL) cohort. GOAL is a longitudinal cohort primarily derived from the Georgia Lupus Registry (GLR). GLR is a population-based registry of individuals with a validated diagnosis of SLE established in the large metropolitan Atlanta to have more accurate estimates of the incidence and prevalence of SLE. Participant eligibility and procedures for the GOAL study are discussed elsewhere.[15] Briefly, eligible participants were adults (aged ≥18 years) with a documented diagnosis of SLE (≥four revised American College of Rheumatology (ACR) criteria, or three ACR criteria with a diagnosis of SLE by the patient's treating board-certified rheumatologist;).[2] Since 2011, GOAL participants have been assessed annually with validated patient-reported tools on a variety of social determinants of health and outcomes. A total of 437 African American women who responded to the 2013 GOAL survey were included in the current study.

Qualitative—GOAL African American female participants receiving treatment at the Lupus Clinic located at the Grady Memorial Hospital were invited to participate in the qualitative interviews. Grady Memorial Hospital is the only safety-net facility for a large indigent population from metropolitan Atlanta and the state of Georgia. Recruitment took place in the clinic among GOAL participants who had a follow-up visit in January 2015. Participants were not chosen based on their levels of organ damage or depression. A total of 15 participants were recruited to participate in the interviews.

The Emory University Institutional Review Board, Grady Health System Research Oversight Committee, and the Georgia Department of Public Health Institutional Review Board approved the study protocol. All study participants gave informed signed consent.

Measures

Quantitative

Depression: Depression was assessed with the Patient Health Questionnaire (PHQ-9), a validated self-administered instrument that has been used in epidemiological studies and multiple settings.[16–18] PHQ-9 measures the frequency of symptoms of a major depressive episode in the last two weeks through scores that range from 0 to 27. A score of 10 or higher

has excellent sensitivity (88%) and specificity (88%) to classify a major depressive episode. In addition, five categories of severity of depressive symptoms have been suggested as follows: Minimal (PHQ-9 score 0–4); Mild (PHQ-9 score 5–9); Moderate (PHQ-9 score 10–14); Moderately severe (PHQ-9 score 15–19), and Severe (PHQ-9 score ≥20).[17]

Organ damage accrual: We used a validated self-reported version of the Brief Index of Lupus Damage (BILD) to assess cumulative organ damage related to SLE. This tool was validated in the GOAL cohort.[19] The BILD has a test–retest correlation score of 0.93 ($p < 0.0001$) and has a moderately high Spearman's rho correlation ($r = 0.59$, $p < 0.0001$) when compared with the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI).[19]

Social support: We used the question ''How often do you get the social and emotional support that you need?'' that was included in the 2013 GOAL survey to assess social support needs met. Answer choices were built using a five-point Likert scale: Always, Usually, Sometimes, Rarely, and Never.[15]

Qualitative—The aim of the interviews was to supplement the quantitative findings by exploring the perceived importance of social support and how lupus-related damage impacts an individual's ability to receive and seek out social support. Example questions 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—For descriptive analyses, patient characteristics were summarized using frequency and percentage for categorical variables, and mean and standard deviation (SD) for continuous variables. A Pearson correlation was used to examine the association between organ damage accrual and depression. Analysis of the role of social support in this relationship employed a multiple linear regression with depression as the dependent variable and organ damage as the independent variable, adding in social support as a possible moderating variable and exploring the interaction between social support and lupus-related damage. Three correlations were conducted to examine whether social support mediated the association between organ damage and depression.

Qualitative—Face-to-face in-depth interviews took place immediately prior to or after participants' scheduled physician appointment. The women provided consent prior to the start of the interview. 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 in the clinic, and lasted no more than 30 minutes. Following the completion of all interviews, the recordings were transcribed verbatim and two coders developed a codebook based on common themes in the transcripts. Coders used MAXQDA (VERBI Software, Version 12) to assist in coding the transcripts. To ensure validity of the themes identified by coders, any

discrepancies were discussed to achieve consensus. All audio recordings were destroyed following completion of the analyses.

Results

Quantitative

Participants meeting the eligibility criteria are described in Table 1. These African American women ranged in age from 21 to 87, with a mean age of 48.28 (SD = 12.7). 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. Just over one-third of participants, 147 (34.0%) reported never having been married, followed by 118 (27.3%) who reported being married, and 84 (19.4%) who reported being divorced.

The PHQ-9 scores of the participants ranged from 1 to 27 with a mean of 8.3 (SD = 6.4), in the mild range. When dichotomized, 164 (37.5%) participants reported moderate, moderately severe, or severe depression on the PHQ-9 (>10), while the remainder (n = 273, 62.5%) reported minimal or mild depression. The BILD scores ranged from 0 to 16 with a mean of 2.5 (SD = 2.5) and a median of 2. When asked how often they received the social and emotional support they needed, 145 (33.2%) participants reported *always*, 104 (23.8%) reported *usually*, 97 (22.2%) reported *sometimes*, 53 (12.1%) reported *rarely*, and 38 (8.7%) reported *never*.

A Pearson correlation test was performed to examine the association between organ damage and depression. A statistically significant, positive association between organ damage and depression (r = 0.163, p = 0.001) demonstrated that, as organ damage increased in this sample, depression also increased.

To examine whether social support moderated the association between organ damage and depression, two multiple linear regressions were performed (Table 2). The first showed that organ damage was a statistically significant predictor of depression (β = 0.152, p = 0.001), as was social support (β=−0.311, p < 0.001). While organ damage was associated with increased depression, social support was associated with decreased depression. When the interaction term of organ damage and social support was added into the model, organ damage (β = 0.319, p = 0.018) and social support remained statistically significant correlates of depression (β =−0.254, p < 0.001); however, the interaction term was not statistically significant (β =−0.184, p = 0.189). Thus, social support did not significantly moderate the effect of organ damage upon depression.

Qualitative

Participants in the qualitative interviews ranged in age from 35 to 64, had been diagnosed with lupus at various ages, and had been aware of their lupus diagnosis for varying amounts of time ranging from 3 to 30 years. 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.

Family and friends' understanding of lupus

One support-related theme that participants discussed was what their family and friends understand about lupus. The families and friends of participants seemed to either know a lot about lupus and appeared 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.

In contrast, other participants 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 did not understand because the only people who understand lupus are the people who have it. As 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 did not think anyone would understand or listen to her.

Who provides support to patients?

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

Many of the participants reported that their doctor provided good social 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, saying:

> 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 social support. Many stated that they felt like they had a church family they could rely on for social 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 whether they had ever attended a lupus support group and if they had, how this affected their feelings of social support. Of the participants who had attended a 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 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 social support available to them. Many participants said they felt they had more social support after being diagnosed with lupus because people were available to help out with whatever was needed. In contrast, some participants mentioned that because they are physically limited, they feel isolated and excluded. In the words of one participant,

> 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 with support

Finally, participants were also asked to describe how confident they are managing their lupus with the social support they have available to them. All of these African American women said that, regardless of their support level, they are confident they can manage their lupus. Participants who did not have a lot of social support available to them stated that they have found ways to manage their lupus on their own, while participants with a lot of social 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.’’

Discussion

Our quantitative study indicates that there is a significant positive correlation between organ damage and depression in African American women with SLE. Moreover, we found that social support had a direct, protective relationship with depression, but it does not serve as a moderating variable in the relationship between organ damage and depression. The qualitative data suggested potential explanations for the lack of association between lupus damage and social support. The impact of lupus on support was varied and having lupus could either increase or decrease the amount of social support a woman received.

Divergent experiences of added versus reduced support, and accepting versus avoiding support suggest that the association between support and organ damage is neither straightforward nor linear. Some of these African American women reported that having lupus increased their support, with people reaching out and even researching their condition. Others noted that their health limitations had isolated them and reduced their support. Similarly, while some participants stated that their family and friends had a strong understanding of lupus, others said their family and friends did not know much about lupus or did not try to learn about the condition. When family and friends did not understand much about lupus, participants felt frustrated that they were battling the disease on their own without support. Participants also described the social challenges due to the change in their abilities since being diagnosed with lupus and how this could lead to them 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 sense of purpose when they were working and once they had to stop, this was taken away from them. No longer receiving an income also meant many participants had to rely on others.

Strengths and limitations

This study had both strengths and limitations. A primary strength is that it was a mixed methods study that used multiple sources of information to draw conclusions. Without the qualitative portion of the study, it would have been difficult to fully understand the complex nature of social support for lupus patients and its association with lupus-related organ damage. The study also targeted African American women with SLE. This is a population that although being at high risk for SLE and poor outcomes, is underrepresented in SLE research. Furthermore, 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 social support and their lupus. The combination of methods helped to promote understanding in a previously understudied topic. Other strengths are the use of validated measures and the large sample size for the quantitative portion of the study. Data from a total of 437 participants were analyzed.

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 associations among social support, depression, and organ damage and depression. In addition, the quantitative study measured depressive

symptoms, not depression diagnosis. Many of those who reported depressive symptoms may not be diagnosed with clinical depression. Additionally, measures of social support were based on a simple ad hoc question. Using a validated to assess social support may have produced different results. Furthermore, while the results of the quantitative study are generalizable to the female African American SLE population in Atlanta, they may not be generalizable to other populations of lupus patients. A limitation of the qualitative results is that those who chose to participate in interviews may have done so because they either had a lot of support or because they had very little. These interviews are not generalizable to African American women outside of the group interviewed.

Implications and future research

Primarily, the results of this study demonstrate that lupus-related organ 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 SLE patients, regardless of race, especially those with multiple, permanent negative health outcomes as a result of having SLE. It will be important to identify early signs of depression and when necessary to refer them for mental health treatment. The results of this study also demonstrated a strong, protective relationship between social support and depressive symptoms. This indicates the importance of utilizing social support to limit depressive symptoms in SLE patients. Healthcare providers of lupus patients should help to provide resources to SLE patients to assist them in asking for support. The results also suggest that the care professionals themselves are a valuable source of social support. Although the exact nature of how social support influences depression in patients with SLE and organ damage is still unknown, public health practitioners should stress the importance of a support system for these patients. Among these African American women in particular, it may be important to encourage the patient's network to offer support before the person with SLE feels the need to ask. The challenging nature of this disease makes a support system very helpful for patients, as many physical activities become challenging due to joint pain. This support can come from family and friends, religion/the person's faith, or support groups; certain forms of support will work better for some individuals than others.

Future research should continue to explore how social support influences depression in patients with SLE, especially those with organ damage, since it correlates strongly with depression. Because of the complex nature of social support, future research should aim to understand whether people with SLE seek out social support because of necessity and/or whether social support prevents damage and depression from developing. Exploring these questions could help us understand effective ways of working with patients. While this study demonstrated that social support is important, research should be conducted to understand the other needs of SLE patients; this study demonstrated that social support may affect the association between lupus-related organ damage and depression, but there are undoubtedly other factors that influence these outcomes. It is important to recognize these factors and target them among patients with SLE in order to encourage effective management.

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Table 1

Characteristics of 437 African American women with systemic lupus erythematosus

Characteristic	*Value*[a]
Age, years (mean±SD)	48.28±12.65
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)

[a]Indicates *N*(%), unless otherwise specified; SD: standard deviation.

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
Social support	−0.311	<0.001	−0.254	<0.001
Lupus-related damage, Social support interaction			−0.184	0.189