

Research Article

“If You Don’t Put it in Your Mind, then it Don’t Matter”: A Phenomenological Study of Coping Self-Efficacy in African American Women Diagnosed with Lupus

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Key Points

- Systemic lupus erythematosus is a chronic autoimmune inflammatory disease treated through complex lifestyle and medication regimens, however it has no cure.
- Lupus disproportionately impacts women and African Americans in prevalence, morbidity, and mortality.
- Evidence based treatment and behavioral programs have been used to help lupus patients, but African American women have been underrepresented in such examinations and are less responsive to those programs when included.
- Herein interviews were conducted to explore the lived experiences and perceptions of coping self-efficacy among African American women diagnosed with lupus.
- Six major themes emerged including self-awareness, religion and spirituality, a sense of connectedness, stigma, empowerment, and peer perceptions.

Findings can be applied to care and practice in order to better tailor such endeavors to the specific needs of this demographic group in order to address the ongoing health disparity.

ABSTRACT

Lupus is a chronic debilitating rheumatic autoimmune disease that disproportionately affects African American women. A phenomenological approach was used to conduct confidential semi-structured qualitative interviews to explore “*lived experiences*” of coping and self-efficacy among 10 African American women diagnosed with lupus. Six major themes identified included self-awareness, religion and spirituality, a sense of connectedness, stigma, empowerment, and peer perceptions. These themes highlighted human agency and coping self-efficacy exhibited by African American women

that facilitate chronic disease management and self-care. Perceptions of coping self-efficacy varied and the women’s “*use of self*” was instrumental to their individualized way of coping with their lupus diagnosis. Study findings increase cultural awareness, understanding, and potentially empathy from providers, employers/colleagues, and family members about African American women’s experiences of living with lupus.

Keywords: African American; Women; Systemic lupus erythematosus; Coping; Self-efficacy, Interviews

Introduction

Lupus is a chronic multisystem inflammatory autoimmune disease in which the immune system attacks healthy tissue resulting in inflammation that often occurs in periods of increased severity known as flares [1]. Symptoms of lupus include loss of mobility, debilitating chronic pain, fatigue, and problems with activities of daily living [2]. Although a number of treatments are effective at controlling lupus symptoms and survival rates have increased, no cure for the disease exists [3].

Lupus prevalence and incidence vary by socio-demographics. Annual lupus prevalence from 2003 to 2008 ranged from 81.1 per 100,000 in 2003 to 102.9 per 100,000 in 2008 in a large

managed care population [4]. Lupus incidence during those same years was 6.6 cases per 100,000 person-years [4]. Among Medicaid enrollees, lupus prevalence was 143.7 per 100,000 and incidence was 23.7 per 100,000 person-years between 2000 and 2004 [5]. Medicaid enrollees in the US Southern states have higher prevalence rates than other geographical regions (163.5 per 100,000 compared to 140.7-125.2 for other regions). Women have higher incidence of lupus than men (11.1 vs 1.9 cases per 100,000 person-years;), and African American women have disproportionately higher incidence and prevalence of lupus than white women [4,5]. Prior evidence suggests lupus incidence among African American women is nearly three times the rate of white women and prevalence nearly twice the

rate of white women (286.4 vs 150.1 per 100,000; Ward, [5-8]. African American women also experience greater morbidity and mortality associated with lupus than other racial/ethnic groups [7,9,10]. Overall, African Americans experience more disease activity and damage over time, more severe clinical manifestations, and faster disease progression than white lupus patients [7].

Lupus also negatively impacts health-related quality of life in mental, social, psychological, and sexual domains [11]. Unexpected flares, medical regimen side effects, access to care difficulties, and decreased social standing have been associated with feelings of depression and demoralization among lupus patients [12,13]. Health-related quality of life in lupus patients is influenced by disease activity and damage, clinical manifestations, and patients' feelings of helplessness and ability to cope with having lupus [7]. A higher degree of helplessness and abnormal coping styles have been consistently demonstrated by African Americans who also experience worse disease outcomes [8,14]. Social support is protective against negative outcomes among lupus patients resulting in health behavior change, better coping styles, and improved outcomes [7]. Given African American women have higher incidence and prevalence of lupus and poor disease outcomes compared to other racial/ethnic groups, social support and coping styles that improve patient outcomes are essential to decrease morbidity and mortality.

The chronic disease self-management program has utility for improving health outcomes among lupus patients in that it assists individuals with chronic illnesses in dealing with the consequences of their illness; focusing on problem solving, decision making, and self-confidence; and developing partnerships with health care professionals. Disease management and self-care by lupus patients are indicative of coping self-efficacy, mental well-being, and health-related quality of life [15-18]. Self-care, disease management, and social support from family and other patients are predictors of increased self-efficacy among individuals living with lupus [18]. Coping self-efficacy leads to changes in health behavior that include greater effort to participate in activities of daily living, confidence in planning, and determination to overcome challenges [19]. The Arthritic Self- Management Program was found to be effective in reducing depression, increasing relaxation and self-management activities, improving pain management, decreasing the number of patient medical visits due to disease complications, and improving health-related quality of life [20].

Although evidence from both CDSMP and ASMP indicate promising outcomes for self-efficacy and health-related quality of life for lupus patients, most intervention research among lupus patients has been conducted on white women [20-23]. This suggests a limited understanding of factors promoting self-efficacy and disease self-management among African American women in the medical literature. In a predominantly African American sample of women with lupus, travel costs were identified as a barrier to access to care and disease self-management suggesting that access to self-management education may be restricted for African American women diagnosed with lupus suggest that peer mentoring may be

effective among culturally diverse lupus patients, and emerging evidence from a culturally-tailored intervention based on CDSMP and ASMP suggests peer mentoring may increase self-efficacy among African American women diagnosed with lupus [24-27]. The current study explored African American women's experiences of coping with lupus and self-efficacy regarding self-care and disease management to identify individual-level factors influencing these behaviors.

Methods

A phenomenological approach was used to explore coping self-efficacy among African-American women who were diagnosed with lupus and received care at the Medical University of South Carolina (MUSC). This study received human subjects' approval from the MUSC and University of South Carolina Institutional Review Boards.

Eligible participants and recruitment

Eligible participants were African American women listed in the MUSC Multidisciplinary Clinical Research Center (MCRC) Systemic Lupus Erythematosus (SLE) database, a network-based system of current or former patients of the MUSC Rheumatology Clinic who gave permission for their names to be included in the database for future clinical research studies. There were 465 African American women in the SLE database who were residents of South Carolina. Flyers posted by South Carolina rheumatologists and arthritis health professionals, MUSC lupus clinics, and local chapters of the Lupus and Arthritis Foundations were also used to recruit potential participants.

Screening involved telephoning the 465 African American women in the database and receiving telephone calls from women who called the number on the flyer. All women were screened for the study's inclusion criteria using a telephone screening script. If women did not wish to participate, they were thanked for their time and the next woman on the list was called. Once 10 women agreed to participate, screening ended. Interviews were later scheduled at MUSC, the University of South Carolina, and the homes of women meeting inclusion criteria to accommodate their medical condition and transportation difficulties.

Measure

A semi-structured interview guide was adapted from the *Understanding Quality of Life in African Americans with Lupus (UQAN)* [28]. The guide provided a brief definition of self-efficacy followed by questions about the African American women's personal definition of self-efficacy, activities related to self-efficacy, if they felt they possessed self-efficacy, and difficulties achieving self-efficacy. Self-efficacy was defined as a belief in their ability to complete tasks and reach goals. Self-reported demographics included age in years, race/ethnicity, marital status, employment status, number of children, and age of children. Lupus diagnosis characteristics included age at diagnosis, year of diagnosis, and length of diagnosis. Demographic information was collected for 9 of 10 African American women because one woman could not be reached during member checking.

Semi-structured interviews

Semi-structured qualitative interviews were conducted with 10 African American women. Verbal informed consent was received prior to proceeding with the interview protocol. Nine interviews were conducted face-to-face and one interview was conducted over the telephone. All interviews were audio recorded using Super Notes[®], saved as audio files, transcribed verbatim, and saved as Microsoft[®] Word files. Member checking was conducted through follow up phone calls during and after analysis to ensure validity, credibility, and accuracy of responses [29]. On average, interviews lasted 12.68 minutes and ranged from 7 to 23 minutes in length.

Data analysis

All transcripts and audio files were imported into NVIVO 10 for data analysis. Deductive coding identified themes related to coping self-efficacy and coping mechanisms followed by open and *in vivo* coding [30]. The research team identified similarities and differences among participants that emerged from the data. Codes were compiled to identify major themes and subthemes. A codebook was created with detailed definitions of major themes and subthemes.

Results

African American women who participated in this study self-identified as Black/African-American and female. Their average age was 48 years old ($sd=14.61$) and ranged from 21 to 65 years old. They were diagnosed with lupus between 1982 and 2013 with a mean age at lupus diagnosis of approximately 30 years old and mean diagnosis length of 19 years. The majority (77%, $n=7$) had children and were unemployed (55%, $n=5$). Themes identified pertaining to coping self-efficacy included 1) self-awareness, 2) religion and spirituality, 3) a sense of connectedness, 4) stigma, 5) empowerment, and 6) peer perceptions.

Theme 1: Self-awareness

Self-awareness is defined as sharing or possessing knowledge about one's self in relation to effectiveness in tasks and comfort toward personal life [31,32]. African American women in this study expressed the importance of knowing how personal motives and desires impacted their ability to accomplish specific goals. Subthemes that emerged were motives and desires, self-management, abilities of daily living, and religion and spirituality. Additional factors such as pain and fatigue were articulated as common barriers to physical activity and activities of daily living as well as indicators of their limited mobility.

Motives and desires: Each day can be different for someone who has been diagnosed with lupus. Every case is unique and treatment regimens are patient-specific based on the severity and frequency of symptoms. As a result, the discomfort experienced varies depending on patient response to physical and psychological treatment regiments. A 41-year-old, part-time employed, woman diagnosed for 11 years stated:

"I meet with different doctors there. I actually have a rheumatologist that I meet with there in Lima. I went on a gluten

free diet—gluten free, lactose free, soy free diet. I cut a lot of red meat out of my diet. Had to change some of the medications. I didn't benefit well from CellCept[®] in just kind of gaging [from] some of the medications I was [prescribed]; reducing the amount of prednisone that I was on and then going into counteracting the weight gain with weight loss and exercise".

Tasks that may be require little effort for someone living without chronic pain can be extremely difficult for someone who is living with lupus. A 51-year-old, unemployed, married woman diagnosed for 20 years stated:

"[As] a person with lupus, a lot of times you have to tell yourself to get up when you don't want to get up. I guess you just have to have a mindset to say like the children's book the Little Engine that Could, 'I think I can, I can'. Sometimes you have to go through those motions to do certain things that someone that is well would think 'oh that's nothing', but to you that's a lot."

This same woman also reported:

"I mean my whole lifestyle has changed since I've been diagnosed with lupus. A lot of places I would have gone or things that I would have done, I just don't do it because of the lupus; because sometimes I may say tomorrow 'Ms. Johnson (name changed to protect confidentiality), Let's go out to lunch.' Then tomorrow comes and I feel so bad."

Activities of daily living: African American women living with lupus, over the years, have learned about new limits to their physical abilities and warning signs in response to their body being affected by lupus (e.g., an upcoming flare). A 55-year-old, part-time employed, single woman diagnosed for 24 years reported:

"I think self-awareness and information about the disease and my personal condition because lupus affects everybody differently, so I know what I can and cannot do. Knowing my limitations and not pushing myself and trying to do more than I am capable of."

A 65-year old, unemployed, separated woman diagnosed for 21 years stated:

"Well I know I can't move as fast as I use to and to do that means getting out of breath, I have to wait, calm down...so I know that I have to go at a slower pace. Even with cleaning my house I have to. If I'm going to mop, I'm gonna get an area... got my bucket and everything...my chairs so I can go and sit down until I can move because I have back problems with all of that too".

Self-management: In the African American community, health issues and diagnoses are rarely spoken about among its members due to stigma and mistrust of the medical community [33]. African American women in this study felt that it was their responsibility to ensure that they continued to push and motivate themselves to regain the physical ability they had prior to their lupus diagnosis. A 65-year-old, unemployed, separated woman diagnosed for 21 years stated:

"Nobody else in my family [has]this and nobody else [has] been through all of the things that I've been through just kind of

seeing myself through their eyes, you know would make me just want to make sure that I keep things moving.”

Theme 2: Religion and spirituality

In Charleston, South Carolina, religious beliefs and spirituality are prominent due its location within the *Bible Belt* and nickname of *The Holy City*. Given the vast majority of African Americans residing in this region, religion and spirituality are central to their experiences of health and illness [34]. African American women and their belief in a higher spiritual being or their religious beliefs, were perceived to be beneficial to coping with lupus. A 60-year old, married, unemployed woman diagnosed for 34 years noted:

“I love going to church so when I’m down you know I’m down because I can’t go to church and that’s what I love the most”.

Religious activities: African American women in this study described how they used religion to overcome mentally and physically difficult days as a result of being diagnosed with lupus. When asked *‘What other things do you do, if any, to increase self-efficacy directly tied to your disease?’* One woman, who did not supply any demographic information, reported: *“By reading my Word and praying”*. Another African American woman indicated her weekly practice of religion and spirituality was instrumental to increasing her self-efficacy. A participant who chose not to supply any demographic information stated *“Church”* helped to increase her self-efficacy.

Some participants had no set routine for how they engaged in religious and/or spiritual activities. A 52-year-old, married, unemployed woman diagnosed for 28 years stated:

“I pray a lot to get through the day”.

Theme 3: Sense of connectedness

African American women revealed that they did not have an extensive social network outside of their physician with whom to discuss their symptoms or feelings. When asked *“What types of activities do you believe really work to increase self-efficacy tied to your lupus?”*, a 30-year-old, part-time employed, woman who has been diagnosed for 5 years stated:

“I’ll say the things that the doctor has told me or speaking with other females that I met that have lupus as well”

Familial ties: Participants acknowledged that living with lupus can be difficult. The unpredictability of their disease makes understanding the symptoms and changes to their body challenging and confusing. Creating connections and spreading knowledge about their diagnosis with other patients, friends, and family members is vital to coping with lupus. Participants stated that they relied on their family members as their primary source of support. A 55-year-old, part-time, employed woman who had been diagnosed for 24 years reported:

“If you don’t have a family member . . . like in your case, you’re doing a study so I feel comfortable talking to you because I know you understand what it is; but people don’t understand lupus and sometimes I probably don’t understand a lot of the issues”.

Although family is often the biggest source of help, participants also stated that they felt they were a hindrance to their family. A 58-year-old, single, unemployed woman who has been diagnosed for 18 years noted:

“I don’t like depending on them too much ‘cause its wears thin. I have to be pretty desperate for me to do that part.”

Community connection: African American women believed that family and community members with whom they hold daily conversations are an avenue for gaining additional support, as well as increasing their knowledge of lupus symptoms. A 65-year-old, separated, unemployed woman who had been diagnosed for 21 years stated:

“Well I have a membership at the Y[MCA] and the instructors there you know they are very good with the senior citizens. You know I claim that title proudly. They work with me and they tell me things. I can talk to them. You know my whole thing is, I don’t have a lot of friends. . . I don’t have any friends. My family. So I can talk to her because you know she gives me different things I can do. So I think that is a big thing for me. A big part of that for me. You know I can talk to her and she has different things. I didn’t know that balance was a part of lupus because I lose my balance all the time and I thought it was being clumsy and what not and when I told her that I was diagnosed with lupus and she asked me about my balance. So I found out that she knew a lot about my disease that I had no clue of.”

Patient community: African American women in the study stated that they searched the local community, but were often unable to locate social resources needed to deal with the emotional, physical, and mental toll of lupus. A 58-year-old, single, unemployed woman diagnosed for 18 years noted:

“. . .my only issue with different support groups was that they were never close to where I live at. I did go to one, one time that was in Mt. Pleasant, but Mt. Pleasant is nearly 50 miles from where I actually live so you know I wasn’t gonna go there too often. I know that there are several down here in Charleston, but they’re also nearly 50 miles from where I actually live. So if there were some that was closer to where I live, I figure I would go more because there, there probably be people there who would know what it is to have lupus. I mean they may not have the same symptoms that I have ‘cause I know lupus varied from person to person, but at least they would understand. Now that’s what I would really appreciate.”

Theme 4: Stigma

Participants felt isolated by family and friends as a result of their lupus diagnosis. Needing to rely on others for assistance placed a strain on how they felt about themselves and how they believed others felt towards them. Additionally, they expressed how others viewed them because of their diagnosis and how joining or participating in activities became difficult. A 21-year-old, single, unemployed woman diagnosed for 7 years stated:

“They try to pity me just because I have lupus and like certain things they won’t call you to hang out because they’re going this place because they think I can’t do it or something”

A 65-year-old, separated, unemployed woman who had been diagnosed for 21 years stated:

"So I feel [un]comfortable going 'cause I'm not a person that like to get undressed in front of people."

Self-stigma: Lupus symptoms often affects one's physical appearance and African American women tended to become more critical of their physical appearance. They perceived that others paid more attention to their physical abnormalities which negatively impacted their perception of their beauty. If participants believed they did not fit the stereotypical embodiment of a 'strong' African American woman, they felt self-conscious. Adapting to their altered physical appearance could also lead to lower self-confidence. A 51-year-old, married, unemployed woman diagnosed for 20 years noted:

"I had this long, thick, beautiful hair, well I guess I still have long hair when you go to the Chinese store and buy it; but still I miss having my own hair. Sometimes that bothers me. When I first got lupus, I used to have so many sores on my arm that looked so terrible. I still have the marks to prove it. Sometimes when I put on a sundress I feel a little self-conscious. I have to put on a 'lil jacket to go with it".

Social stigma: Hair loss and the butterfly rash were uncontrollable symptoms that participants concerns about because of how society would perceive them. A 30-year-old, married, part-time employed woman diagnosed for 7 years stated:

"I would say the biggest difficult part would be learning how I deal with when my lupus starts to affect my outer appearance. Since I have a lot of organ involvement, when it's all internal no one can actually see it; but when the butterfly rash comes or when I started losing my hair it's how other people perceive you".

Theme 5: Empowerment

African American women voiced their need for support from immediate family members as well as their community in overcoming lupus symptoms that may make daily living difficult. Participants reported continuously having to self-motivate in mentally and physically challenging situations. A 41-year-old, divorced, part-time employed woman diagnosed for 11 years stated:

"It's just showing self-determination. You have to have a positive mindset that this is something that you're gonna be. It's a mind over matter. That if you don't put it in your mind then it doesn't matter because you're always going to be in pain regardless. That's gonna be something always as a hindrance, but you have to push through it".

Self-empowerment: As these women lived with lupus, the daily stressors that they encountered proved to be challenging for some to overcome. Many of the African American women who participated in the study reported having a limited support system and needing to muster energy to push themselves to overcome the pain they experienced. Many had families that were dependent upon them financially and to complete

household responsibilities which were determined by how well they could personally manage their disease. Achieving successful disease management for the sake of dependent family members was why they refused to surrender to their illness. A 30-year-old, married, part-time employed woman diagnosed for 7 years stated:

"I push myself even though I have lupus, I'm still a mother of 4 children. I push myself. Then some days I can't push myself so it's kind of iffy when it comes to lupus".

Disempowerment: The difficulties accompanying a lupus diagnosis for some African American women can be devastating because of the clinical manifestations and damage caused by lupus. Remaining optimistic proves challenging and tiresome after the extensive medication regimens and numerous physician visits. The participant who chose not to provide any demographic information stated:

"It's hard 'cause in the beginning it deteriorated my right hip and I had to have my hip replaced. I'm always fatigued and tired. I can't function well. I'm always in pain and just out of it most of the time. I can't even get up. Sometimes I just want to lay in bed for days and it stresses me out. Makes me depressed".

Theme 6: Peer-perceptions

Altered physical appearance and ability greatly affected the self-confidence and social interactions of the patients we interviewed. There was a sense of relief and optimism in the presence of others who shared similar daily pain and could empathize with their emotions. In the presence of peers, the experiences of African American women who have lupus were normalized. A 65-year-old, separated, unemployed woman who had been diagnosed for 24 years reported:

"I didn't want to be an angry person or somebody that always walked around with a frown on their face because that was never me. I was always a happy go lucky type of person unless you made me mad; but you know very rarely that happened. That's why I don't have a lot of friends or what not because I learned not to trust."

Discussion

This phenomenological study explored the lived experiences of coping self-efficacy among African American women diagnosed with lupus. Six major themes identified were self-awareness, religion and spirituality, sense of connectedness, stigma, empowerment, and peer perception. Existing qualitative and quantitative studies often focused on coping or coping self-efficacy as a variable. The current study builds upon this body of knowledge by holistically examining coping self-efficacy among African American women diagnosed with lupus to provide a sociocultural context regarding how their self-perceptions and activities of daily living have been altered by this chronic illness. Understanding health and illness among culturally diverse populations is critical to the development of culturally-tailored interventions designed to improve patient outcomes and reduce health disparities.

Human agency among African American women in this study prompted self-reflection, intentionality and forethought, self-regulation by self-reactive influence, purpose and meaning of one's life pursuits, and improved health-related quality of life [16]. Participants were self-reflective about how lupus affected their lives, disease self-management, and their social interactions. African American women described how their level of physical functioning had declined as well as strategies used to regain physical functioning. Additionally, they detailed emotional difficulties resulting from clinical manifestations of lupus.

A strength of this study is its focus on an understudied population which differs from prior studies that had samples composed of predominately Caucasians or Caucasian women [7,11,23,35]. Thus, these findings deepen our understanding of an understudied population with more lupus disease activity and damage, and faster disease progression [7]. However, these results have limited generalizability due to the homogeneity our sample and small sample size. Additionally, self-reported data are subject to recall bias. Nonetheless, there are noteworthy implications for clinical practice.

No two African American women had the same lived experience regarding their disease activity and course. This may, in part, account for the negative self-perceptions and life challenges African American women face living with lupus. For these women, seeing that their disease is different from others, coupled with the limited knowledge and understanding about lupus among family and friends likely exacerbates feelings of social isolation, depression, and anxiety. The coping strategies reported by these women revealed that chronic disease self-management was reflective of their individual experience with lupus. African American women who were more recently diagnosed abided strictly by to their physicians' recommendations; whereas, women who were more experienced with managing lupus discovered their own strategies for dealing with how lupus altered their physical and emotional functioning. Self-efficacy came through self-discovery and acceptance of how lupus changed their lives. Psychosocial factors have the largest impact on lupus patients from the time that they are diagnosed and are therefore targeted by the incorporation of effective strategies for coping among individual patients to increase positive health outcomes.

African American women's experiences of coping with lupus and associated self-efficacy have implications for chronic disease self-management. Arthritis self-management education delivered by small-group, home study, computer, or internet modalities have demonstrated significant improvements in health distress, self-reported global health, and activity limitation, with trends toward improvement in self-efficacy and mental stress management [20,36-45]. However, African Americans and women are still disproportionately impacted by lupus [46-52]. Persistent disparities may be due to current program's inability to cater to the unique needs of this demographic group [53-57]. The unique disease experiences and coping methods that African American lupus patients utilize further warrants contextualized and culturally

competent programs in order to address the unique needs of this disparately affected population [26]. Specifically, the isolation African American with lupus expressed in the current study, coupled with their desire to interact with peers, lends further credibility to the utility of peer mentoring disease management programs in this population [58,59]. Increasing health related quality of life, through coping self-efficacy among African American women with lupus would help with its promotion within this ethnic/racial minority group as well as others. Increased awareness of coping-self efficacy would prompt research that would reinforce the necessity for finding alternatives ways to address the unique challenges that this population faces.

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