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BRIDGING THE SOCIAL SUPPORT NEEDS GAP FOR AFRICAN AMERICAN WOMEN WITH LUPUS THROUGH THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAM

BY

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Degree to be awarded: M.P.H.
Career MPH

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M.P.H., Emory University, 2013
M.S., Georgia State University, 2000
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An abstract of
A Thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements of the degree of
Master of Public Health in the Career MPH program
2013

Abstract

BRIDGING THE SOCIAL SUPPORT NEEDS GAP FOR AFRICAN AMERICAN WOMEN WITH LUPUS THROUGH THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAM

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Purpose: Lupus, as a chronic disease with heterogeneous phenotypes of varying disease severity, has led to a higher burden of disease associated with women of color. Low cost high-impact interventions that inform and encourage effective disease self-management are needed. The Chronic Disease Self-Management Program (CDSMP), as a low cost evidence-based intervention, is beneficial and acceptable to the socioeconomically disadvantaged targeted cohort of African American (AA) women with lupus in this study. This program is designed to improve self-management skills and enhance social relationships. This study seeks to understand the social support needs of AA women with lupus and the ways in which the CDSMP addresses these needs. The theoretical perspectives hypothesize that social relationships contribute to overall health.

Methods: Participants were recruited from a public hospital's lupus clinic. A triangulation approach was utilized with qualitative data from forty-five participants who completed the CDSMP, and the two CDSMP leaders. Data was collected from focus groups, questionnaires, and semi-structured leader interviews.

Data Analysis: Focus group transcripts were analyzed using thematic analysis. A thematic code dictionary was developed, informed by the qualitative data and the study's theoretical perspectives, including Cohen's definitions of social relationships and resources. Focus group data were analyzed utilizing ATLAS.ti and SPSS. Other data were clustered based on social support relevance defined by the code dictionary.

Results: Six key social support themes emerged that depicted the emotion- and problem-focused supportive channels of the CDSMP. The program promoted healthy behaviors directly and indirectly addressing issues leading to more productive and rewarding social interactions. Participants reported feeling empowered to be more proactive in their medical care. The avoidance and reduction of stress effects were indicated as major components for active self-care, referred to as "self-love" by the participants.

Summary: This qualitative study provided a greater understanding of the role of social support in this cohort of AA women with lupus. The person-environment relationships were shown to have a significant role in the ability to cope with stress and self-manage their chronic disease. The CDSMP offered the psychological resources to enhance resilience and coping capacities, healthy behaviors, and overall well-being.

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ACKNOWLEDGEMENTS

Special thank you to those who supported me throughout this Thesis process:

- Committee Chair: Hannah Cooper, ScD
- Field Advisor: Cristina Drenkard, MD, PhD
- Thesis Topic Development Brainstorming Advisor: Kathleen R. Miner, MPH, PhD
- Research Coder: Terrika Barham, MPH
- Thesis Organizational Brainstorming Coach: Aba Essuon, PhD, MPH, MSW
- My Husband, Touch Stone & Thesis Supporter: Kevin E. Thomas

Bridging the Social Support Needs Gap For African American Women with Lupus Through the Chronic Disease Self-Management Program

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November 2013

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Chapter I – Introduction

Lupus is a chronic disease whose presence has been known longer than diseases such as sickle cell anemia or infections such as HIV; however, it has commanded much less public health attention and understanding [1-4]. Lupus is unique in the disease pathology, clinical manifestations, and methods of diagnosis. Additionally, there are different etiology hypotheses (i.e., more or less links to environment, genetics, biology, or hormones) and limited treatment options with minimal side effects [5, 6]. Although the etiology is debatable, research has shown gender and racial differences in that women are more susceptible than men, and Blacks are more susceptible than Whites [7, 8]. Given the higher burden of disease among women of color, greater efforts should be made to reach this population[9, 10]. However, socioeconomic factors associated with many of the women of color with lupus indicate the need for low cost high impact interventions that will inform and encourage effective disease self-management.

Patients who practice good self-management of health issues and/or concerns are more likely to facilitate early and accurate diagnosis[11]. With a disease as complex and difficult to diagnose as lupus, skillful self-management is imperative. The disease related information and resources that are obtained through skillful self-management often results in improved social support[12]. People are conditioned to seek social interactions that may influence their perception of themselves and their circumstances (i.e., health, education, employment, etc.)[13-15]. This human characteristic, which may manifest as self-efficacy, contributes to the social support theory, Bandura’s social cognitive theory, and the transactional model of stress and coping that ultimately yield the desired behavioral change. The successful use of these theories and model to explain and influence health-related behaviors and outcomes drives the development of the conceptual framework for this study (Figure 1). Figure 1 is the conceptual model designed for this research identifying factors and theoretical concepts to understand better the social support influences on health for African American (AA) women with lupus from socioeconomically disadvantaged communities.

The theoretical perspective of this research posits that social support resources are building blocks through which healthy social relationships are cultivated. As the social support stress and coping perspective hypothesizes, these relationships contribute to overall health by providing a buffer to the adverse effects of stress leading to healthy coping allowing for the utilization of educational resources to enhance self-management behaviors. Reinforcing these social relationships can possibly reduce the overall impact of lupus. It is important to assess the social needs as well as cost-effective interventional approaches that enhance the social support system for the person with lupus. The Chronic Disease Self-Management Program (CDSMP) is a low cost evidence-based intervention that is beneficial to and accepted by the targeted group of AA women with lupus[16]. This program is designed to improve self-management skills and enhance social relationships.

Socioeconomically disadvantaged AA lupus patients represent a population who often encounter significant barriers toward receiving adequate medical care. Limited resources and inadequate self-management skills often lead to poor outcomes. This may be a key contributor to racial and socioeconomic disparities in lupus. This research offers an opportunity to explore the concept of social support as an interventional focal point. The social support needs of the targeted population, and the perceived needs addressed and not addressed by the intervention are identified. The broad concept of social relationships is defined according to Cohen's social support and social integration descriptions[17]. Social support consists of the social network's provisions, and social integration comprises of the range of relationships. This may offer the consideration toward the addition of other chapters or contextual factors within the CDSMP, as well as other self-management and social support programs.

Research Aims

The purpose of this research is to seek an understanding of the social support needs and the CDSMP influences of social support on the health of AA lupus patients who participated in the CDSMP as part of the parent study. The primary research questions are:

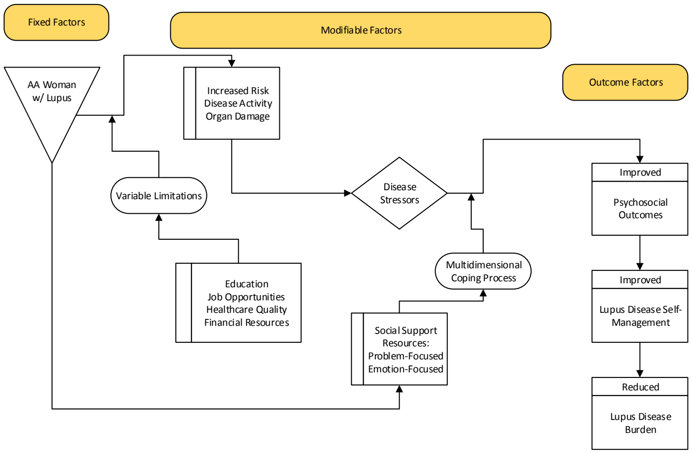
(1) What are the social support needs of participants?

(2) What are the types of social support experiences of participants during the CDSMP?

(3) How does the CDSMP social support influence the health behavior of participants?

The significance of this exploration is that it will provide evidence regarding the processes through which self-management education may help to develop and maintain social support relationships and resources in a cohort of socioeconomically disadvantaged AA women living with lupus in metropolitan Atlanta, Georgia. These skills may serve as a tool to strengthen chronic care systems leading to health improvements among minorities. A refined understanding of the social relationships role, and positive and negative influences on health is crucial in the design of effective interventions to enhance health promotion in communities [14].

Figure 1. Social support conceptual framework identifying factors and theoretical factors.



Chapter II - Review of Literature

Lupus Definition

According to the Centers for Disease Control and Prevention (CDC), lupus is one of approximately 100 rheumatic diseases within the category of arthritis [18]. Lupus is a chronic autoimmune multisystem disease of unknown etiology [19]. The disease predominantly strikes women and people of color. Complex pathogenic mechanisms translate into heterogeneous phenotypes with disease outcomes from mild to severe. There is no single biomarker to confirm lupus; consequently, the diagnosis depends on the compilation of symptoms and clinical measures by experienced physicians. Furthermore, only a few medications are available to treat the vast array of disease manifestations, and most of them are not lupus-specific. With such multiple dimensions influencing the clinical expression, diagnosis, management and outcomes, epidemiological research of lupus is tremendously challenging. Consequently, disease treatment advancements are hindered. There have been great advances in the study of 20th century diseases (e.g., sickle cell anemia, HIV) with known etiologies [1, 2, 4]. However, the advancements within the study and treatment of lupus have been slow, with far less public health attention and understanding [3].

There are four categories of lupus based on clinical disease manifestation: systemic, cutaneous, drug-induced and neonatal. This research will focus on systemic lupus formally called systemic lupus erythematosus (SLE) and will use the term lupus as a reference to this category. Moreover, this research will focus on the demographic group of higher susceptibility for lupus in the United States, AA women [20]. It is important to understand the pathology, epidemiology and treatment, as well as disease burden and disparities when examining potential interventions toward improved outcomes for people with lupus. Furthermore, the inclusion of the patient-perspective especially as it pertains to daily activity impediments and distresses is fundamental. This multi-dimensional exploration illuminates the significant social influences and public health relevance. This information provides the foundation necessary for disease self-management and improved quality of life for people with lupus.

Pathology

The pathology of lupus starts with the autoimmune classification which defines diseases that develop in response to an overactive immune system [21]. By definition, the immune system functions as a complex communication network in order to defend the body against “foreign antigens” (e.g., bacteria, parasites, toxins) that can cause cell death or damage, while tolerating the multiple components of our own body, which is known as self-tolerance [19, 21]. When the immune system loses the mechanisms involved in self-tolerance, it overreacts producing autoantibodies that target receptors (antigens) located in the cells of one’s body. This leads to the development of inflammatory responses and potential destruction of cells and tissues.

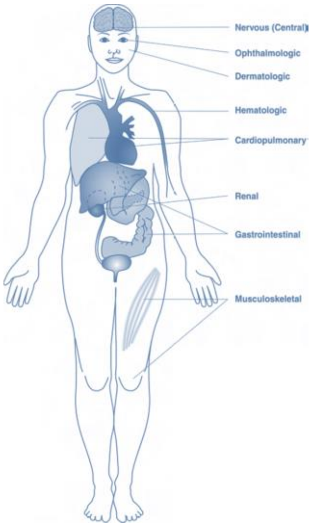
The immune system dysfunction in lupus is characterized by the production of a large amount of autoantibodies that are not specific to receptors of a particular tissue or specialized cell [22, 23]. Consequently, the resulting damage is not directed at a single organ, as it happens in organ-specific autoimmune diseases (e.g., autoimmune thyroiditis) [19]. Since B cells have a fundamental role in producing antibodies, targeting these cells to reduce pathogenic autoantibodies is an important treatment goal [22].

There are genetic, hormonal and environmental factors that potentially promote abnormal immune responses in lupus[23]. However, the degree and mechanisms for which those factors cause autoimmune responses are not totally understood [19]. The increased prevalence of lupus in first- and second-degree relatives suggests a role of genetic factors in the etiopathogenesis of the disease [11, 23-26]. Studies have found that gene expression in lupus follows a polygenic model that includes interactions of genes with each other as well as the environment [25, 27]. Environmental triggers (e.g., ultraviolet light, occupational/non-occupational respirable silica exposure, pesticides, tobacco smoke, viruses) may initiate immune system dysfunction leading to disease development in individuals with a genetic predisposition [11, 28-30]. Additionally, given the disease's gender and age predisposition, hormonal influences are germane to lupus pathology. Hormones, especially estrogen, are noted to activate B cell regulators leading to the onset and progression of the disease [11, 31, 32]. The interplay of the various factors contributing to the dysfunction presents uniquely in each individual body.

Clinical Manifestations, Diagnosis and Treatment

Lupus is characterized by a constellation of clinical manifestations that can include skin rashes, arthritis and the involvement of internal organs. The clinical manifestations of lupus may appear with vague symptoms for several years, resulting in an arduous diagnostic process for patients and health care providers [11]. There is no single test that can be used to diagnose lupus; instead, a battery of laboratory tests and skin or kidney biopsies are needed frequently. According to National Institute of Arthritis, Musculoskeletal and Skin Diseases, the most common symptoms of lupus are (a) joint or muscle pain, (b) skin rashes, (c) alopecia, (d) inflammation associated with joints, glands in the neck, legs, or around the eyes, (e) oral ulcers, (f) fatigue, (g) photosensitivity, and (h) chest pain. These symptoms are the result of disease activity in various body systems. Figure 2 displays the potential systems affected by lupus.

Figure 2. Potential systems affected by lupus.



Note. Figure from *Lupus: A Patient Care Guide for Nurses and Other Health Professionals* by J. Freeman and A. Brown Rodgers, 2006, National Institute of Arthritis and Musculoskeletal and Skin Diseases.

The course of the disease is often unpredictable with alternating periods of active disease and quiescence [33]. This variability brings additional challenges to case ascertainment and case definition for epidemiological research of lupus. In order to have a consistent case definition that allows comparability across research studies, the American College of Rheumatology (ACR) developed classification criteria for SLE, which have been used worldwide since the 1980's [19]. Generally, a lupus patient is selected for research studies if four or more of the 11 criteria is fulfilled at any time during the disease course [34]. Table 1 describes the 11 criteria and exemplifies the heterogeneity of lupus [19].

Table 1. ACR classification criteria for SLE.

SYMPTOM	**CRITERIA**
Oral/Nasopharyngeal Ulcer	Observed by physician
Photosensitivity	Skin rash as a result of unusual reaction to sunlight by patient history or physician observation
Malar Rash	Fixed erythema, flat or raised, over the malar eminences, tending to spare the nasolabial folds
Discoid Rash	Erythematous raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions
Arthritis	Nonerosive arthritis ≥ 2 joints, characterized by tenderness, swelling, or effusion
Serositis	Pleuritis (pain, rub, or effusion) or Pericarditis (ECG, rub, or effusion)
Neurologic Disorder	Seizures or Psychosis Both in the absence of offending drugs or known metabolic derangements (i.e., uremia, ketoacidosis, or electrolyte imbalance)
Anti-nuclear Antibody	Positive – an abnormal titer of antinuclear antibody by immune-fluorescence or an equivalent assay at any point in time in the absence of drugs
Hematologic Disorder	Any of the following: a.) Hemolytic anemia < 9 or Hematocrit < 28 &/or Reticulocytes > 3 b.) Leukopenia (WBC < 4.0) X 2 c.) Lymphopenia (lymphocytes < 1.5) d.) Thrombocytopenia (platelets < 100K)
Renal Disorder	Any of the following: a.) Proteinuria (protein in 24-h urine > 0.5 gm./day or > 3+) or b.) Cellular casts in urine (RBC, WBC, granular, tubular, or mixed)
Immunologic Disorder	Any of the following: a.) Anti-DNA abnormal + b.) Anti-Sm + c.) Anticardiolipin: serum level IgG or IgM lupus anticoagulant (standard method) + false-positive serologic test for syphilis (positive for at least 6 months – confirmed by treponema palladium immobilization or fluorescent treponemal antibody absorption test)

Note. Table data taken from *Dubois' Lupus Erythematosus and Related Symptoms, 8th edition, 2013, Philadelphia, PA.*

Managing lupus requires a detailed examination including patient history and follow-up by specialized physicians, such as rheumatologists. The treatment typically entails a combination of medications and lifestyle recommendations to treat both the disease manifestations and complications that occur as consequence of lupus activity (lupus flares) and medication side effects [21, 35, 36].

The first drugs to treat lupus activity, quinine (antimalarial medication) and immunosuppressants (cyclosporine, azathioprine, and corticosteroids) were used in 1894 and 1952, respectively [6]. However, these medications were not initially developed for lupus. In 2011, a biologic drug, named belimumab (Benlysta) was approved by the Food and Drug Administration (FDA) as a B-cell modulating agent to treat clinical manifestations of disease activity in patients with lupus [37]. However, at the time of FDA approval, this medication has not been fully tested in AA lupus patients [38]. This is especially disconcerting given both the higher risk of lupus and worse disease outcomes described in lupus patients of racial minorities. Studies to assess the effectiveness of treatment options and accessibility to medications are needed, particularly among people from disadvantaged socioeconomic groups, who are at high risk for poor outcomes.

Disease Burden and Health Disparities

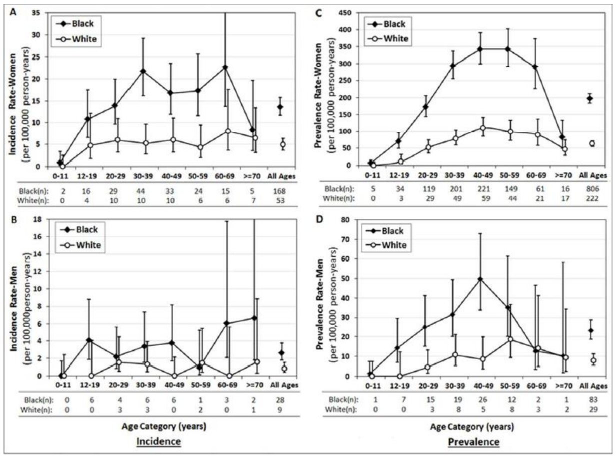
Lupus places a significant burden on the patient, family, and society. Examining the cost of lupus in terms of diagnosis and treatment, economic productivity loss associated with work disability and premature mortality, and quality of life is crucial for policy makers to determine the allocation of resources. Furthermore, gender and racial disparities in the incidence, prevalence, disease activity, health-related quality of life and mortality of lupus have been described in populations around the world illustrating the higher burden of disease among women of color [9, 39-41]. According to the Minority Health and Health Disparities Research and Education Act of 2000, "health disparity populations refer to a population where there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population" [42]. In terms of justice, there is a recommendation that "all individuals should be able to achieve the optimal level of health afforded to them on the basis of genetic endowment"[p.644[43]]. The overall challenge for public health and medicine is to allocate available resources effectively to reduce disease burden and health disparities [44, 45].

Incidence and Prevalence

According to data provided by the Lupus Foundation of America, in the U.S., the prevalence of lupus for AA women may be as high as 1 per 245 people, and 1 per 700 for Caucasian women [46]. However, the assessment of disease burden in lupus is challenging given the difficulties in both defining and ascertaining potential cases. Thus, lupus surveillance in the United States has been characterized with data collected from convenience patient samples (e.g., academic private lupus clinics) or national health surveys that showed a wide range of incidence and prevalence estimates. For instance, lupus data collected during the years of 1988 through 1994 from a U.S. national survey, Third National Health and Nutrition Examination Survey (NHANES III), calculated the adult prevalence as 241 per 100,000 people [47]. This survey captured self-reported diagnosis of lupus by a physician, and medication treatment. There were 20,050 survey responders (42.3% white, 27.4% black, 26.5% Mexican-American, and 3.8% other). Forty people (32 women, 8 men) reported a lupus diagnosis and were treated with the at least one of the lupus medications. However, there are people with lupus who do not require medication treatment. Based on the criteria used in this survey study with a select inclusion of people with lupus currently taking medication, this prevalence is likely a gross underestimate. Studies utilizing the ACR criteria have offered a more definitive standard through which the epidemiology of lupus can be conducted. However, there were limitations because of the small study population size [48, 49].

More recently, the CDC-funded lupus registries have implemented novel methodologies to have more accurate estimates of the incidence and prevalence of lupus across different racial groups in the U.S.[20, 50]. The methodology employed to maximize case ascertainment and accuracy included multiple sources of data and the collection of uniformly defined data elements[7]. There are five national lupus registries, two (Georgia and Michigan) with final estimates and three (San Francisco, New York and The Indian Health Services) ongoing, that share best practices through teleconferences facilitated by the CDC. However, this is a laborious undertaking involving the abstraction of data from multiple sources (i.e., hospitals, clinics, and chemistry and pathology labs). Incidence and prevalence rates from the Georgia Lupus Registry (GLR) were estimated at 5.6 per 100,000 and 73 per 100,000 person-years by ACR criteria, respectively[7]. GLR findings also support racial disparities in Georgia with AA having incidence and prevalence rates over 3 times higher and onset at younger ages (peak 30-50) than Caucasians [7]. Figure 3 illustrates the significant racial and gender incident and prevalent differences as found in the GLR.

Figure 3. GLR incidence and prevalence of racial and gender differences.



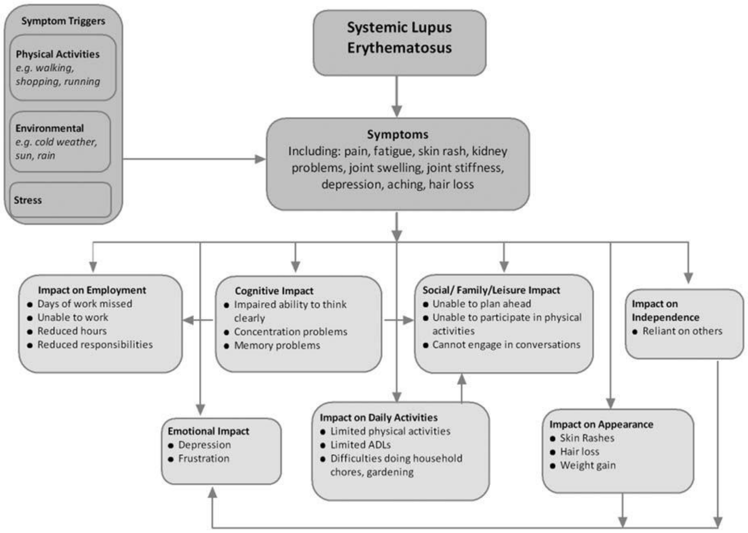
Note. Figure reproduced from *The Incidence and Prevalence of Systemic Lupus Erythematosus, 2002-2004: The Georgia Lupus Registry* by Lim, S. et al., 2013, Arthritis & Rheumatism.

Direct and Indirect Costs

In addition to economic evaluations and assessments, health related quality of life (HRQL) measures are used to assess the impact of disease and its treatment on the individual. Patient-reported measures that capture HRQL include domains on physical, psychological, and social functioning. Multiple studies have shown a profound impact of lupus in these three domains [33, 51-53]. Moreover, there is a strong relationship between lupus and psychological stress compounded by an disengaging coping style [54].

Despite the importance of qualitative studies for better understanding daily living challenges and concerns from the lupus patient perspective, only a few studies have been conducted using this methodology. A literary review reports the top five health issues from the patient perspective as (a) “fatigue, energy, or vitality”; (b) “depression”; (c) “pain”; (d) “helplessness”; and (e) “inability to cope with the disease” [53]. A conceptual model based on the information gathered from lupus patients regarding the nature of symptoms and impact of HRQL experienced suggested that routine activities of lupus patients are significantly impacted by the symptoms of fatigue, depression, pain, sleep disturbances, cognitive dysfunction, headaches, and hair loss [33]. Furthermore, there was evidence of a disconnect regarding disease treatment priorities between lupus patients and their health care providers. For instance, lupus patients may focus more on symptoms that interrupt their daily activities rather than solely on the prevention of further organ damage. Seven themes related to the impact of HRQL emerged in this study: (a) appearance, (b) cognition, (c) daily activities, (d) emotions, (e) employment activities, (f) independence and (g) social, family, leisure activities. This model (see Figure 4) offers a comprehensive and holistic view that demonstrates the need for the evaluation of HRQL in lupus patients [33]. It is essential for health providers to surpass the disease symptoms and consider the individual priorities and values of lupus patients as it pertains to functioning [52, 53].

Figure 4. Conceptual model of HRQL



Note. Figure reproduced from *Development of Conceptual Model of Health-Related Quality of Life for Systemic Lupus Erythematosus from the Patient's Perspective* by Gallop, K., et al., 2012, Lupus.

A literature review of direct costs of adult lupus patients in the U.S. found only seven U.S. studies published from 2000 to 2010 [55]. The cost categories comprised of inpatient costs at 16 – 50% of total expenditures, outpatient costs at 24 – 56%, and pharmaceutical costs at 19 –

30%. Based on the variability of disease manifestations, direct medical costs may vary from year to year especially during the first year of diagnosis.

A retrospective U.S. study utilizing administrative data from 2006 to 2008 to identify lupus patients, health care resource utilization, and medical costs found 15,590 lupus patients (89% female; mean age 48 years) with approximately 7% having nephritis (kidney inflammation) [56]. The mean 12-month direct medical care costs (pharmacy services, outpatient services, inpatient hospitalizations) were found to be $13,305. The mean 12-month direct costs of lupus patients with nephritis were more than twice the amount for patients without nephritis ($30,652 versus $12,029, respectively). These costs are of particular relevance for the target region of study, Georgia, where the GLR found significant differences in the proportion of end stage renal disease (ESRD) with a sevenfold greater involvement in Blacks[7]. Based on GLR patient estimates in two counties for the year 2002 (n=1362 lupus cases) and the estimate from the economic studies ($12,029), lupus medical costs in these counties could be more than 16 million dollars. This is not based on an actual economic evaluation, but roughly used as a general reference point (pertinent to this study) for the potential estimates regarding direct medical costs in these counties of interest from which lupus participants in this study reside. Moreover, the need to make this loose estimate is reflective of the absence of state-focused economic lupus studies.

Considering that lupus primarily affects women during their highest wage earning ages, identified by the Bureau of Labor Statistics for AA women in 2010 as 25-years to 54-years (66% of the AA women ≥ 16 years of age), it would be expected that indirect costs such as work disability would represent a significant portion of the burden of this disease [57]. A study that reviewed relevant research studies pertaining to work disability in lupus patients in Europe and

North America found that work disability is a common element, with a range from approximately 15% to 51% of patients reportedly unable to work approximately 3 to 15 years after diagnosis [58]. This review suggested that work disability was associated with demographic factors (e.g., lower levels of education, older age), higher physical job demands, disease activity, disease damage, and clinical features including neurologic symptoms, fatigue, and joint symptoms.

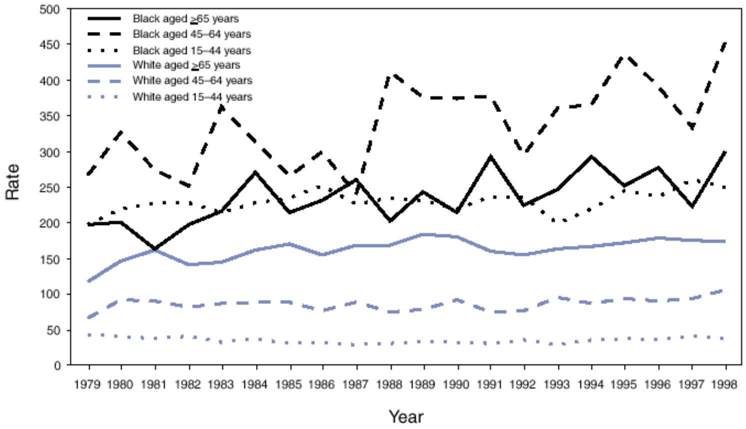
The economic burden is especially heavy given the 2010 census AA employment statistics: 45% of AA families were maintained by women without a spouse, and these families are less likely to have an employed member (unemployment rate 16% AA vs. 9% Whites), and 53% of these households were living below the poverty level [57]. Additionally, AA women are at an economic disadvantage when compared to Caucasian women with median weekly earnings reported at $595 versus $684. AA women were also less likely to be in management, professional, and related occupations, and more likely in production, transportation, and material moving occupations [57]. Consequently, it is important to develop other resources to assist socioeconomically disadvantaged AA women with lupus.

A longitudinal study conducted with data from the Lupus Outcomes Study (LOS) cohort in San Francisco, California, examined the impact of lupus on employment in various industry areas [59]. The industry areas for these participants (90% female, 65% white, 51% college graduate) were 42% government, 18% retail, wholesale, or finance, 17% professional, media, or technical services, 13% service industry, and 10% goods-producing industry. This study describes patterns of employment associated with thrombotic (including deep vein thrombosis, pulmonary embolism, stroke, myocardial infarction, retinal vein thrombosis, other blood clots, or second/third trimester miscarriage), musculoskeletal (including severe muscle pain, muscle weakness, pain or stiffness in joints, or swelling in joints), and neuropsychiatric (including depression, cognitive dysfunction, or seizures) manifestations. Study findings suggest an association between disease activity in these areas and the in ability to work. There was an apparent spectrum regarding the immediacy of work ability, with incident thrombotic events associated with a more immediate inability to work and the development of musculoskeletal and neuropsychiatric events associated with a more delayed inability [59]. Participants in the LOS cohort are not representative of the targeted population for this study, however, the study illustrates the heightened economic impact based on disease characteristics. The prevalence of multi-organ damage, diabetes, end-stage renal disease and cardiovascular disease is 3 to 6 times higher in African Americans compared with Caucasians [60-63]. Additionally, disease activity and organ damage may also be augmented by lower education attainment [64].

Mortality

During 1979-1998, the crude death rate for lupus increased from 39 to 52 per 10 million population, with a total number of deaths of 22,861; and increased markedly among AA women aged 45 – 64 years [65]. Figure 5 shows the death rates by age group and race in the U.S. between 1979 and 1998. Ethnic minorities show overall mortality rates significantly higher than Caucasians, and die at younger ages [66, 67]. A mortality study conducted by a multi-center international cohort (collaborating centers in U.S., Canada, England, Scotland, Iceland, Sweden, and South Korea) found that 24% of their cohort deaths (1970 – 2001) were directly attributed to lupus, and most not-directly associated deaths were attributed to circulatory diseases (e.g., heart, arterial, cerebrovascular) [66]. In addition to circulatory diseases, the estimated risk of death was higher in lupus patients than the general population for infections, renal disease, hematologic malignancies, and lung cancer. Although throughout the years, there has been a 60% decrease in the overall mortality rates, there has been no decrease in the rates associated with circulatory diseases. This noted distinction further demonstrates the importance of addressing preventive measures (e.g., utilization of social support resources) addressing circulatory diseases in lupus. It is also necessary to develop preventive measures that specifically address inequalities in health.

Figure 5. Trends in deaths for lupus in the U.S. 1979 – 1998



* Per 10 million population.

Note. Reproduced from *Trends in Deaths from Systemic Lupus Erythematosus—United States, 1979-1998, 2002, JAMA.*

<u>Self-Management</u>

Based on the variations in lupus disease activity, skillful self-management of health-related behaviors, outside of clinical care, is imperative. Health self-management whether intentional or unintentional is determined by the individual's levels of compliance with medical treatments, behavior adjustments, and coping. This is especially pertinent for people with lupus who experience psychological manifestations (e.g., depression, anxiety, anger) that may be associated with disease activity [68, 69]. The access and knowledge-based utilization of disease-related information and resources can influence the way in which a person with lupus manages their lupus daily. Self-management education does not isolate the patient with individual tasks, but aims to empower individuals in the utilization of social support resources to optimize health and reduce the impact of disease on daily functioning [12]. Thus, self-management education is a process helping patients to bridge the gap between disease knowledge and health-related behaviors. Lorig identifies five core skills that enhance self-management: (a) problem solving, (b) decision making, (c) resource utilization, (d) formation of patient-clinician partnerships, and (e) taking action [70]. However, this process is highly individualistic, as the needs, goals and strategies of each patient diversify. It is essential to determine the significant health concerns from a patient perspective.

Individual priorities and values appear to be linked especially to psychological well-being [52, 53, 71]. Self-management education integrates the view of patients with health professionals by coupling patients' health beliefs and concerns with the health professional knowledge regarding the management of chronic diseases [70, 72]. Thus, self-management education ultimately contributes to the patient's ability to cope with their disease. A systematic review of qualitative lupus studies (15 countries, 95% female) identified five top themes describing lupus patient experiences and beliefs as restricted life style, disrupted identity, societal stigma and indifference, gaining resilience, and treatment adherence [73]. These findings provide an encore illustration on the value of educating beyond the signs and symptoms of lupus to include global functioning.

Developing a self-management program specific for lupus would not be cost-effective, given the relatively low prevalence of this disease. However, generic self-management programs for patients with chronic diseases appear appropriate for a complex disease that often carries co-morbid conditions such as hypertension and diabetes. People with chronic diseases deal with multiple self-management activities involving treatment adherence, lifestyle behavior changes, and controlling emotional distress.

Chronic Disease Self-Management Program

The Chronic Disease Self-Management Program (CDSMP) is a group-based educational program developed by Stanford University School of Medicine Patient Education Research Center, utilized across the world, that has strong evidence regarding the benefits, especially regarding improved health behaviors, and appropriateness in patients with a variety of chronic conditions [74, 75]. This program consists of six-week sessions facilitated by two trained leaders. The main components of the program include weekly action plans, behavior modeling, different management techniques, group problem solving, and individual decision-making through goal setting and support. Contents of the CDSMP include depression, anger/fear/frustration, fatigue management, better breathing, exercise, healthy eating, medication management, working with health professionals, and cognitive techniques for relaxation and symptom management. It has shown short- and long-term benefits in self-efficacy, self-care behaviors, health status, and health services utilization in the U.S. [76-79]. Moreover, positive results in patient outcomes were demonstrated among participants with common chronic diseases across different racial and socioeconomic groups in several countries [80, 81].

The CDSMP program is grounded in the theory of self-efficacy that suggests that confidence in abilities determines expectancies for success, which leads to behavior patterns [82, 83]. Confidence building is an important component in sustained positive health behaviors, especially regarding motivated people with chronic conditions. In order to promote positive behavior change, social learning environment that teaches and reinforces this change is needed. People are motivated to engage in activities that are important to them (beliefs, values, goals) and adaptable to their cultural environments. There are many evidence-based studies demonstrating the effectiveness of the CDSMP, however, it is also essential to evaluate with attention to cultural sensitivity as it pertains to AA patients. A study with AA adults with arthritis and other chronic conditions found that self-management programs especially within a mutual-help framework were consistent with AA cultures [76]. Self-management programs targeting this population would be more impactful with the inclusion of culturally relevant elements. For instance, social support appears to be a great motivator for AA patients to engage in self-management programs [84]. A pilot study demonstrated the effectiveness and acceptability of the CDSMP for AAs (91% female, mean age 65, mean education 11) with chronic conditions (mean number of chronic conditions 2.7) [79]. Participants in this study suggested the addition of physical activity demonstrations, cooking sessions on ways to make cultural foods healthier, and the integration of spiritual beliefs and practices. Tailoring self-management interventions to include these elements may encourage participation that leads to improved self-efficacy and coping.

Two studies from Asian countries support the role of self-efficacy and coping skills in improving health functioning in lupus patients [85-87]. Moreover, findings from the parent study of the present research indicate significant improvements after the CDSMP in physical health, self-efficacy and self-management behaviors among AA women with lupus from a public lupus clinic in Atlanta, GA [16]. Qualitative findings of the parent study indicated that the CDSMP was acceptable, relatable, and valuable to this population of AA lupus patients [88]. Education, social support and skill development were important contributors. Participants valued group peer interactions and relationships. According to Bandura’s self-efficacy theory, confidence in abilities through social learning is impacted by accomplishments, vicarious experiences, verbal persuasion, and emotional arousal [82]. These studies provide evidence of the key role of social learning in positive disease self-management. However, similarly to the etiology of lupus, this social learning process involves multifaceted interactions. This research study abstracts one element as it pertains to social support. On a psychosocial level, the process through which this learning occurs within a safe socially integrative environment provides a forum through which participants can develop social relationships and learn to enhance family and friend relationships. This is especially beneficial given that the quality of social relationships have been found to be associated with health outcomes [13, 17].

Social Support

Definition

Social support is a broad concept with a variation of applications and meanings. This research will utilize Cohen's social constructs of social support and social integration [17]. "Social support refers to the social network provisions of psychological and material resources intended to benefit an individual's ability to cope with stress (p.676)." These emotional, informational, and material resources (i.e., family, friends, support groups, counselors, and medical professionals) can serve as a buffer during stressful events. The cushion is provided through a range of resources including physical assistance with daily activities, financial support and fellowship. This is especially relevant based on the lupus disease burden. Additionally, there appears to be an association between social support and general satisfaction with health care support [89]. Table 2 shows the mechanisms through which social constructs operate.

Table 2. Social constructs' mechanisms and processes toward influencing health.

Social Construct	**Mechanism**	**Process**
Social Support	Stress buffering	Reduces effects of stress by promoting less threatening interpretations of adverse events and effective coping strategies.
Social Integration *(relationship status, network size, network participation)*	Main effect	Provides information and is a source of motivation promoting positive psychological states.

Studies have shown the influences of social interactions on perceptions of self as well as associated circumstances such as health, education, and employment. Moreover, studies have found an association of positive social integration with both reduced mortality risk and improved health outcomes [13-15]. Although this reduction in mortality was claimed to be independent of sociodemographic factors, it is still plausible that the mortality shift might have been influenced by these factors (e.g., gender, race, economic status, social structure). However, the etiology of these interactions is unclear. Physiological functioning especially involving the immune, neuroendocrine, and cardiovascular systems, is hypothesized as one of the pathways indicating that social environment does "get under the skin (p.448)" [14]. Study findings illuminate the significance of understanding the modifiable social elements that can potentially reduce the negative influences of biology, genetics and environment. Interventions including self-management education targeting minorities may offer tools to augment positive health behaviors and consequentially influence overall health [90].

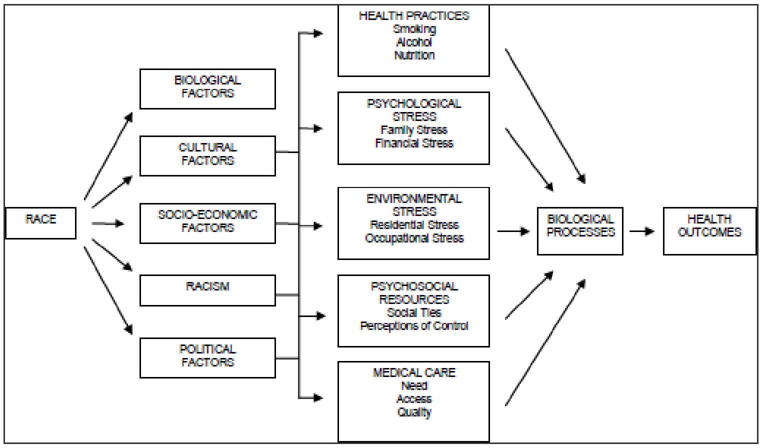
Theoretical Perspectives

The Social Support Theory and Transactional Model of Stress and Coping both contend that the need for social interactions may serve as a catalyst for behavioral change. The theoretical perspectives of social support include stress and coping, self-esteem and self-regulation, and relationships [91]. These perspectives are dependent on individual interpretations of the social world. The theory of social support offers the underpinning for understanding the social influences of a chronic disease such as lupus that involves various physical and psychological features. Research evidence supports the notion for a causal impact of social relationships on health. However, there are various apparent confounders and moderators within this association based on individual attributes, such as health behaviors (e.g., self-management), general health (e.g., disease severity), and resistance, as well as the quality and quantity of social relationships [13, 15, 92]. Resistance stems from the person-environment relationship and the ability of the individual to cope with stressful life events. The concept of coping integrates cognitive and behavioral efforts (i.e., problem-focused or emotion-focused) in the management of stressful life events [93]. Social support can serve as a useful tool in the development and reinforcement of coping strategies [94].

A better comprehension of the influences of the social environment on health may be useful in addressing health disparities. Individual characteristics and social conditions determine the resources influencing resilience and coping capacities, and associated behaviors. In essence, this understanding defines the foundation of an individual's health and well-being. However, the influential pathways are unclear. Figure 6 displays a framework that includes biologic, cultural, social and environmental factors in the relationship between race and health[42].

Two AA women health studies indicate that stress (race, gender, and generic) and coping mechanisms add significant elements to health [71, 95]. The "superwoman" role as described by Woods-Giscombé is a phenomenon that influences stress in AA women. This phenomenon comprises of obligations of strength, emotional suppression and helping others, as well as a determination to succeed. Two perceived liabilities of this phenomenon pertinent to this study are the strain in interpersonal relationships and stress related behaviors (i.e., emotional eating, smoking, dysfunctional sleep patterns and postponement of self-care) [71]. A participant in the Woods-Giscombé et al. study was quoted as saying, "what doesn't kill you makes you stronger" (p.12).

Figure 6. A framework for understanding the relationships between race and health.



Note. Figure reproduced from *Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities, Fiscal Years 2002-2006*, 2002, National Institutes of Health and Trans Working Group on Health Disparities.

Lupus Health Associations

Lupus studies have provided supportive evidence of the importance of social support in the mental and physical well-being of patients [14, 96-98]. Patient perceptions of what makes them feel cared, valued, and integrated in their society offer elements toward improving health outcomes. This becomes challenging when many need help with daily living activities and report psychological issues due to fatigue [99]. Among the unmet needs identified especially by young adults was social support, as it relates to coping with lupus and psychosocial problems to explain the circumstances of the disease to people around them, and to express their feelings to other people [100]. According to a community-based social work study, problems with social support stemmed from the lack of community and family disease awareness, and the loss of friendships due to diminished energy for social engagement activities [98].

The LUMINA (lupus in minority populations, nature versus nurture) cohort measured the impact of social support on lupus outcomes among AA, Caucasian, and Hispanic patients receiving care at university centers in the South U.S. [97]. One component of the study utilized Cohen's Interpersonal Support Evaluation List (ISEL), which measures perceptions regarding the availability of social support through four support scales, tangible, belonging, self-esteem, and appraisal [101]. Caucasian patients from the LUMINA cohort exhibited stronger overall social support and had more "appropriate" illness-related behaviors than AAs and Hispanics. The reasons for these differences were obscure. However, this researcher speculates that with the race differences presented within two sociodemographic features (i.e., age and poverty level), it appears likely that the availability of and access to social support resources are reflected in study findings. As suggested in the LUMINA and other studies, a higher level of social support is needed to improve disease outcomes of lupus patients, particularly among those from ethnic minority groups. Furthermore, morbidity and mortality studies intimate that social and access to health care factors contribute to ethnic health disparities in lupus [10, 102].

Chapter III – Methods

Description

The interest in the exploration regarding the concept of and need for social support for people with lupus was fueled by the qualitative results of the pilot study (referred to as the "parent study"), and the overall daily management challenges of this disease. The parent study used qualitative and quantitative measures to assess the acceptability, relevance, and benefits of the CDSMP among low-income AA women with lupus. Detailed descriptions of participants and procedures of the parent study have been published.[16] This research exploration was designed with a methodological approach in which focus group data, pre- and post-intervention interviews data, the post-intervention satisfaction survey and data from semi-structured CDSMP leaders' interviews were triangulated. The qualitative component of this approach allowed for the development of details regarding the story of social support needs in addition to the provisions of the CDSMP from the participant perspective. Data were used to measure relationships and consistency of specific concepts. Parent study data were analyzed as secondary data for this exploration utilizing ATLAS.ti, a computer-aided qualitative data analysis software, and SPSS statistical software.

Setting. The parent study was conducted with lupus patients who received medical care at the lupus clinic within Grady Health System (GHS). GHS is an internationally recognized teaching hospital committed to the healthcare needs of uninsured and underserved individuals from Fulton and DeKalb counties in Atlanta, Georgia.

Recruitment and Eligibility Criteria. The eligibility requirements for participants recruited in the parent study were: (a) African American woman aged ≥ 18 years, (b) diagnosis of lupus by a rheumatologist, and (c) attended at least one active visit to the GHS Lupus Clinic during the six months prior to study enrollment. Seventy-two African American women who met the eligibility criteria were randomly selected and invited to participate in the study. Fifty-seven participants were consented, and forty-nine enrolled in one of four CDSMP workshops conducted between September 2009 and September 2010. Enrollment was based on the availability of participants.

Intervention. The CDSMP intervention, which is a small group educational workshop, was conducted in weekly sessions of 2.5 hours in length for six weeks. Participants were provided with a copy of “Living a Healthy Life with Chronic Conditions”, third edition and a relaxation CD, as recommended by the program design. According to the CDSMP guidelines, two certified lay instructors facilitated the classes following the leader manual. Both leaders were AA women with chronic diseases, and one reported being diagnosed with lupus. These two facilitators led all four CDSMP workshops to lupus participant in the parent study.

Data Collection

Pre- and Post- Surveys. Forty-nine participants completed pre-intervention survey-based interviews (within 1 week of intervention) and attended the 6-week intervention CDSMP workshop. Forty-five participants attended at least four of the six classes, and were considered "completers". Only completers underwent post-intervention interviews (10 weeks after intervention) and were invited to participate in focus group discussions (1 to 4 months after intervention). The pre- and post-intervention survey-based interviews included identical self-reported instruments capturing (a) self-efficacy, (b) cognitive symptoms, (c) exercise behaviors, (d) communication with physician, (e) self-reported medication-taking, (f) health survey (SF36), and (g) depression (CES-D). This writer conducted most of the pre- and post- survey-based interviews by telephone. Interviews lasted between 35 and 60 minutes.

At the end of each workshop (end of last day), participants completed a satisfaction survey. The survey included nine Likert-scale questions (health education impact questionnaire) and three open-ended questions (developed for the parent study). The open-ended survey questions responses were transferred verbatim to an excel worksheet for collective viewing by this writer. An exhaustive summary list of individual responses was developed for each question, and parent study codes were applied.

Semi-structured Interviews with Workshop Leaders. Semi-structured telephone interviews were conducted with the two CDSMP workshop leaders at the end of each 6-week workshop. The goal of the semi-structured interviews was to capture the leaders' perceptions regarding the acceptability of the CDSMP in this sample of AA lupus patients. Seven open-ended questions were asked (see Appendix A). The same interviewer (TB) conducted all of the telephone interviews. These interviews were audio recorded and fully transcribed to a text document. For the parent study data analysis, three coders (this writer, TB, NB) coded transcripts utilizing the double coding reliability technique and created an exhaustive list of themes related to the parent study aims of acceptability, relevance, and value.

Focus Groups. Twenty-seven completers participated in one of four focus group discussions. The first two focus groups comprised of participants from the first and second CDSMP workshop groups. The second two focus groups comprised of participants from the third and fourth CDSMP workshop groups. All four focus groups were moderated by this writer, with the use of a guide developed collectively through the parent study team discussions. The focus group guide is included in Appendix B. The moderator began each focus group with an introduction of general rules to guide the discussion process. The goal of each focus group was to obtain insight into the acceptability of the CDSMP, and the relevance and usefulness of its components. In addition, participants were asked to provide feedback regarding the location and time of the workshops to gain understanding of the potential suitability within the general community settings. Focus group discussions consisted of open-ended questions capturing participant CDSMP experiences and personal relevance. Participants were prompted to discuss program experiences, challenges, motivations, lessons learned, and behavior changes as well as recommendations for program improvement. Focus group discussions lasted between 70 and 90 minutes, and were audio recorded. Audio recordings were professionally transcribed verbatim. For the parent study data analysis, the same three coders of the leaders' interviews utilized the same technique in creating focus group themes associated with the parent study aims.

Data Analysis

For this research, the four focus group transcripts were examined using thematic analysis as described by Boyatzis[103]. Based on the small number of transcripts and uniqueness of the unit of analysis (i.e., lupus patients) thematic coding was descriptively applied. A thematic code dictionary (Appendix C) was developed, driven first by parent study qualitative data regarding the identification of the concept of social support; secondly by the theoretical perspective, and then refined by Cohen's definitions of social relationships and resources. The first level of descriptive coding was according to participant need or program provision. Then the codes were further differentiated based on social support elements. Codes were applied to focus group transcripts, reworded for compatibility, and examples were added. In order to promote high inter-coder reliability and credibility each code included five elements [103]:

- A code label (naming code)
- A brief definition of the theme
- A full definition of the theme
- A description of qualifications
- Examples

Reliability. The code dictionary and transcripts (in sequence) were shared with coder (TB). TB is a trained qualitative coder. A double coding method was implemented, as each focus group was independently read and coded, with the goal of capturing views that were relevant to social support. After each focus group was coded, this writer reviewed both sets of codes highlighting coded elements that were not captured by both coders. This fueled the discussions between coders to reach agreement on the removal or addition of coded elements. Codes were accepted after both coders met full agreement. Coders also reviewed the code dictionary during each of the four discussions for a consistency of judgment. Telephone coding discussions generally lasted 60 to 70 minutes with the exception of the 90 minutes for the first discussion. Individual coded transcripts as well as the final agreed coded data were entered in ATLAS.ti. This writer clustered the coded quoted data into social support conceptual domains: (a) problem-focused and (b) emotion-focused based on the conceptual framework.

The double coding technique was used for inter-coder reliability.[103] Discrepant coded elements were checked against the code definitions, which were then expanded for clarity based on discussions during the first and second focus group discussions. During the first focus group coding discussion, coders engaged in detailed discussions regarding the *social support barriers* and *social support instrumental* program provision codes. It was decided that "parent study design" factors would also be included in the *social support barriers*. However, certain factors (i.e., research stipends) would be excluded from *social support instrumental* program provision coding. During the second focus group discussion, coders discussed more about the *healthy behaviors* code, which then was expanded to include cognitive elements (i.e., reasoning, acknowledgements of healthy practices, skill set) in addition to actions. In addition, the *social support emotional* code was expanded to include spiritual elements. The coded social support CDSMP provisions and participant needs were calculated into percentages based on the frequency of codes for the four focus group discussions.

Survey measures relevant to this study. Survey measures were reviewed to abstract questions relevant to this social support exploration. Two questions regarding the numbers of close relatives and friends were examined: (1) About how many relatives do you have that you feel close to, or feel at ease with, or can call on for help? Include your children and in-laws in this number. (2) About how many friends do you have that you feel close to, or feel at ease with, or can talk to about private matters, or can call on for help? Nine Likert-scale questions (included in Appendix D) and two open-ended questions from the post-intervention satisfaction survey were selected. The Likert scale responses were on a positive gradient from 1 (strongly disagree) to 5 (strongly agree). The selected open-ended questions are (1) What did you like most about this program? (2) If there is something you could change about the program, what would it be?

Significant themes from the semi-structured interviews with leaders. The "relevance" and "usefulness" themes of the leaders' interviews developed from the parent study were clustered as problem- and/or emotion-focused social support resources.

Chapter IV – Results

Description of Focus Group Participants

Twenty-seven participants completed the CDSMP and attended one of four focus groups. The characteristics of these participants are displayed in Table 3. In terms of potential social support resources, most participants were not currently married, although living with at least one adult, and unemployed, disabled with a low household income. However, most participants did have health insurance.

Table 3. Characteristics of focus group (N=27) participants.

Characteristic	Mean	Standard Deviation (range)
Age at enrollment (years)	45.15	11.38 (21 – 63)
Educational attainment (years)	13.30	1.94 (9 – 18)
Lupus Disease Duration (years)	12.26	9.29 (0.50 – 34)

Characteristic	Frequency	Percentage
Marital Status		
Never Married	9	33
Married/Living as Married	5	18.5
Separated	3	11.1
Divorced	7	25.9
Widowed	3	11.1
Annual household income		
Less than $10,000	12	44.4
$10,000 - $19,999	9	33.3
≥ $20,000	4	14.8
Undisclosed	2	7.4
Household		
Adults		

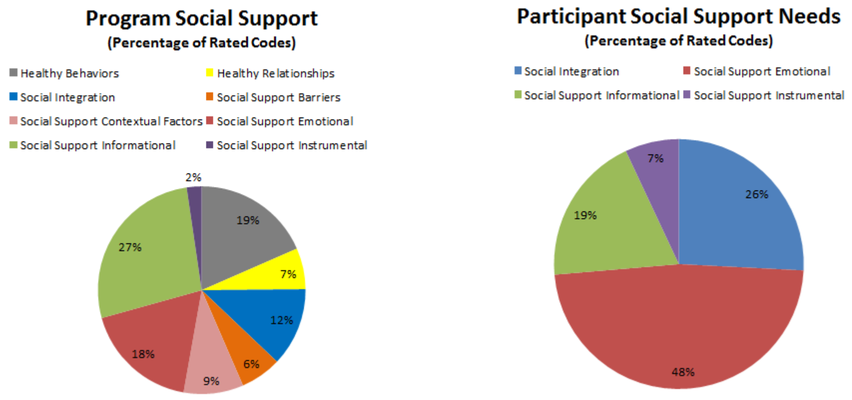
Characteristic	Frequency	Percentage
1 (self)	8	29.6
2	9	33.3
3 or more	10	37.1
Children		
0	15	55.6
1-2	10	37
3-5	2	7.4
Disability Income		
No	10	37.0
Yes	17	63.0
Employment Status		
Working Full-Time	2	7.4
Working Part-Time	1	3.7
Unable to Work	24	88.9
Health Insurance		
None	8	29.6
Medicaid	8	29.6
Medicare	10	37.0
HMO/PPO	1	3.7
Number of Comorbid Conditions*		
0	3	11.1
1 – 3	21	77.8
4 – 6	3	11.1

*Hypertension, depression, cardiovascular disease, lung disease, hypercholesterolemia, osteoporosis, anxiety, diabetes mellitus, or cancer

Focus Group Transcript Codes

Informational support was the most frequently rated code as a CDSMP provision and a participant need. Instrumental support was the least frequently rated code as a provision and need. Figure 7 displays these percentages.

Figure 7. Percentages of rated codes for program social support and participant reported social support needs.



Data from the focus group coding revealed six prominent social support themes of need associated within the emotion-focused and problem-focused dimensions of the CDSMP. These include mental health, personal empowerment, person-centered support, interpersonal relationships, communication, and physical health. Each is summarized herein along with representative quotes from program participants.

Emotion-focused

From the participant perspective, the CDSMP provided resources for emotional mental health. These mental health resources provide strategies to address stress, depression, and coping with disease. According to one participant, *"it's been a great mental change, and if I mentally keep my head straight, my physical being will follow"*. Emotional mental health resources included addressing depression and disease coping. *"When we started this class, I think I was going into a depression. Besides looking at my kids and watching them live their lives day to day, I was like what is my purpose. I look forward to every Thursday when we got a chance to express our emotion. It helped me overcome what I was dealing with. I was just lying in my room in the dark when my kids were going to school a lot of days and do nothing. Now, if am not at work at my job, I'm volunteering at my daughter's school."* Another participant stated, *"...saw the heaven sent to me to bring me out of all what I had been going through and saved me from a lot of things…because had I not had those six weeks here, I may not be where I am today physically, mentally, and spiritually".*

The CDSMP provided personal empowerment resources. These resources provided strategies toward accomplishing daily tasks and goals, and balancing responsibilities; increasing levels of motivation and self-esteem; and inspiring spiritual renewal. *"This program empowered us in lots of ways, lots of ways. And we were excited to come every day to it."* This included motivation with daily tasks and goals. One participant stated, *"after the class, someone has given you ammunition to go out and conquer"*. Another participant stated, *"my goals each week helped me to come out of the darkness and it wasn't until I came into the program…that I even thought about that…I just was dying slowly really"*. The personal empowerment resources provided a spiritual boost and inspiration. *"Like going to church, you get what you need."* Another participant stated, *"it boosted my spirits…sometimes you just need that extra motivation from somebody who just knows your pain"*. This empowerment also gave one participant *"a more compassionate outlook"* that made her *"inspired and very encouraged".*

The CDSMP offered participants a supportive person-centered safe environment. This is a caring, motivating, integrative environment open for participants to help each other. Participants reported being motivated to participate in the program for *"support and the we can thing"*. Another participant stated, *"[God is] always going to put somebody in your path that's going to be able to help. …that is the way I felt when I came to that class cause you always meet somebody"*. Participants felt cared for as illustrated by a participant, *"…there was actually somebody somewhere so concerned about what was going on with us that you even bother to take time to do it"*. Another participant discussed the isolation associate with illness and the group connection, *"…the benefits are going to be great because in that meeting you're going to meet other people…they do have an illness. And that's what connects all the people in that group"*. This support was illustrated as symbiotic, *"encourage somebody else that helped to lift their stress and that helped strengthen you, and help you be [healthier] when you reach out and help someone else".*

Participants were provided with resources to developing better interpersonal relationships including coping with problematic relationships. A participant expressed her difficulties with her mother and how the program helped her, *"…what the girls did every week was they helped me come up with different ways that I could find it within myself some peace being around my mom".* Resources also included building new friendships, accepting others, and better socialization. One participant summed up many of the general expressions of other participants, *"I have truly gathered friends and not associates. They're friends that I call to see".* A participant recounts her experience with another participant, *"and she was such a blessing during our class because she kept me company some evenings because I got the opportunity to take her home... showed her my garden".*

Additionally, in general, the CDSMP enhanced communication by providing an opportunity for *"open conversation and feedback".*

The themes from the leader perspective provide support for the emotion-focused attributes of the CDSMP as illustrated with the following quotes: *"Group felt supported…together with other individuals with similar challenges." "…reduction of loneliness and sense of isolation."*

Problem-focused

The CDSMP provided problem-focused mental health resources especially pertaining to stress management, depression, and pain management. *"We have learned a lot about stress relief…meditation, doing your hobbies, listening to music, hot baths, massages, me time, pampering ourselves."* Many participants agreed with this participant's motivation for taking part in the CDSMP, *"that's what made me sign up when she was talking about stress and depression and how to treat your fatigue and pain and stuff like that. That's what really made me do it".* The program reportedly provided a forum through which participants could *"release the pressure that you've been toting on your shoulder every week".* Resources also provided assistance with pain management, clarity of thought, relaxation, and sleep. Here are two excerpts from participants: "*Relax your mind…prolongs your life. A lot of times I call it being in this fog…and the CD helps you to discern and clear your mind so that your thoughts are crisper." " Very therapeutic and relaxing…sometime when I go into a high pitch motion and everybody's getting on my nerves and I want to be by myself, I turn off the lights and put that CD on and just think, breathe, and relax. It may drift me off to sleep, but if not I'll be composed again where I am able to come out and deal with whatever the situation."*

The program provided problem-focused personal empowerment that allowed participants to be more proactive about their own care and self-love. This was illustrated by a participant physician choice, *"I'm changing my primary right now because I told my primary care doctor he doesn't touch me. How could you know what's going on if you don't even put a stethoscope to my chest? And I'm your heart patient. They taught us to be proactive about your own care. Nobody will tend to you unless you speak out".* Another quote illustrates the importance of self-love, *"I would say it's good for us because we as women in general especially AA women, we have been taught, you get what you get and you don't ask questions. You just go with the flow and to me I believe we are not taught to care for us. Right here it teaches you, you have to care for yourself. [If] you don't care about what's going to happen to you, no one else will. It's the self-love and that's something you got to find it".*

The CDSMP offered person-centered support focused on the need to talk and reducing loneliness. Here are two quotes to illustrate this concept: *"And in times [when] we needed to talk, you can call that person [program buddy]. ...sometimes we get to eat together and we go to [each other] house." " You feel lonely enough with this disease. If there's an opportunity to* *share any time or space with someone, who if they're not going through what you're going through at least they understand…then you should always utilize that, always."*

The program enhanced interpersonal familial relationships through the sharing of program material resources as well as improved interactions. *"What I have learned in my group, I took home to my father [who does not have lupus, but skin problems]."* Another participant shared the program text with her aunt, sister and brother. Other participants developed action plans that promoted more interactions with family. *"The group really helped me and my family because we are exercising. My mama needed to, me and her started walking around the track." " …with the action plan, I actually said you got to get up and go play with your baby. My action plan is to spend more time with my girl…do some hopscotch or something."*

The CDSMP encouraged better communication with pharmacists, physicians, family and friends focused on problem solving. *"Communication was one of those big things that it was one of those first things they had on the board every week. We have to communicate with our doctors, with our loved ones, with each other."* In regards to communication with doctors, a participant stated *"…they gave us a lot of good information that we could use like when you go to the doctor, how to talk to your doctor. One of the things that really helped me…type up your medication [list] and take it with you cause every time I go to different doctor I need it".* A participant also recalled that the program stressed the importance of knowing your pharmacist. The program also motivated participants to be lupus advocates, as illustrated by two participant quotes: *"And I came out of my shell and told people [I have lupus]. That was the first time one of the ladies at the school ever heard of the disease. So when I go into the school I bring pamphlets and leave them in her office." " It was a good experience, it made me open and now it made me where if somebody wants to know about it, I can explain. And she gave me a lot of* *brochures for those that don't really understand."* The program also promoted better communication with friends through role-play, as illustrated by a participant during role-play dealing with emotions when canceling plans with friends, *"[instead of] I really don't feel good and the friend was like you always canceling on me. [another approach] is maybe we could just have lunch here."*

The CDSMP provided many solutions toward the reduction of physical health issues (e.g. obesity, sleep, pain, and smoking cigarettes). One aspect of physical health that was promoted is physical activity as illustrated through these participant quotes: *"None of them exercised but from being in the class they learned how important exercise was to their wellbeing and now together they walk." "They suggested things that people could do, like yoga. I bought a yoga tape. ...we had so many great ideas from each other, not just the directors. One pushed a vacuum cleaner." " I know I needed to lose weight…cause I would go up the 3 steps and would be out of breath panting. And now, I can run up that hill." " Exercise walking helped to regulate bowels."* Another aspect of physical health that was promoted is nutrition. *"*I *started eating a lot of healthy stuff, strawberries, bananas…I was going to the store trying to get the little snacks [healthy snacks eaten in the classes]. ...you learn by examples."* Another participant was motivated to juice vegetables and fruits that she never ate before. Participants also reported better management of their medication as well as pain. They were introduced to a "vial for life" used to organize their medications and help take on time. Participants also reported a reduction in medication need as illustrated through these quotes: *"...Just self-control, self-control, it's all in your mind." " ... It gave us options [to dealing with the pain]."* For example, *"the relaxation CD helps because it takes your mind off the pain and releases [it]."*

The themes from the leader perspective provide support for the problem-focused attributes of the CDSMP as illustrated with the following quotes: *"[Participants] demonstrated in class the different things learned [for better] communication with family and medical professionals." "[They learned] constructive ways to do and handle some the different things that they come in contact with on a consistent basis." "Gave options to live with."*

Social Support Relationship Needs Not Addressed by the CDSMP

Participants discussed two focused areas that they wished were also included in the CDSMP to promote and enhance social relationships. One area involved communication as well as body acceptance (appearance/skin lesions) during moments of intimacy. This need was illustrated in this quote, *"and what we going to do when they don't understand how you had two or three good days and now why you [not in the mood] today. Or you don't want to have sex today because my hip is hurting. Or [because] of body sores".* Another area involved the inclusion of a significant family member or friend in the program. Participants reported difficulties stemming from significant supporters not understanding the issues related to chronic disease. *"You don't have the understanding from people. They just don't get it so you just shut down…like lock yourself in." " You look good and they don't see it." " And don't understand what you're going through."*

Overall Workshop Satisfaction

Responses from forty-five completers, across the nine satisfaction questions, were averaged resulting in a satisfaction score of 4.83 (range 4 [agree] to 5 [strongly agree]). However, there was one individual question outlier score of 2, indicating a disagreement with feeling that everyone had the chance to speak if wanted to. Themes from two open-ended questions are classified according to Social Support definitions. Table 4(a) identifies the areas within the social support elements that are most liked by the questionnaire respondents. The most frequent social informational, emotional and integration memorable aspects are summarized as the learning opportunity, personal support, and interpersonal interactions, respectively.

Table 4(a). Liked themes from Workshop Satisfaction Questionnaire.

Social Support Elements	Liked Most About Program
Instrumental	Refreshments
Informational	Materials Learning Problem solving Helped deal with stress and pain Talking about health Feedback Making goals and action plans Variety of information
Emotional	Interactions Open discussions Sharing Support Communication Compassion
Social Integration	Group peers and leaders Interactions Confidence leaders had in group Group unity Fellowship Meeting women with similar issues

Table 4(b) identifies the supplementary social support elements needed by participants. Participants frequently noted the importance of having a supportive family member included in the program, and more assistance with coping strategies.

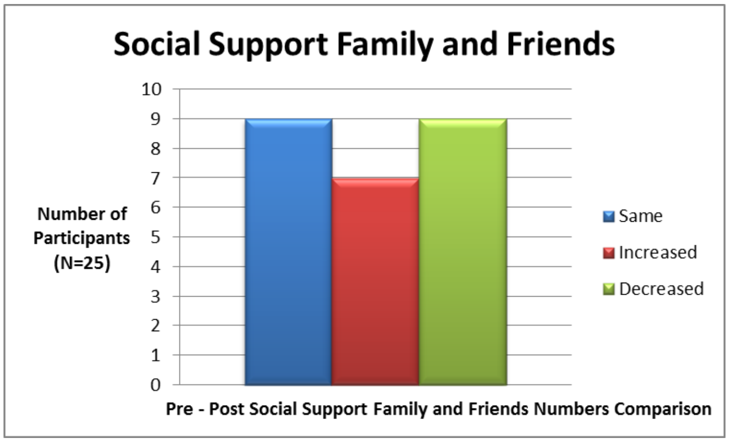
Table 4(b). Need themes from Workshop Satisfaction Questionnaire

Social Support Elements	Would Like to Change about Program
Instrumental	More discussions about personal help
Informational	More information about nutrition, exercise, and everyday health advice.
Emotional	Learn how to focus on happy events during bad days
Social Integration	More interactive activities Divide groups by age Family inclusion
Other	Longer program More time Additional follow-up meeting

Quantity of Personal Social Support

The number of relatives and friends with whom 25 focus group participants reported as being close to before and after the CDSMP was individually averaged. There was no significant change in pre- and post- intervention numbers. Two participants had missing data and were excluded from this calculation. Figure 8 depicts the number of participants whose quantity of individual social support at post-intervention increased, decreased, or stayed the same when compared to pre-intervention.

Figure 8. A comparison of pre- and post- intervention social support family and friends numbers.



Chapter V – Discussion

This qualitative study provides useful information in understanding the role of social support in the self-management process for disadvantaged AA women with lupus. Six key social support themes emerged that depicted the supportive channels of the CDSMP: (1) mental health, (2) personal empowerment, (3) person-centered support, (4) interpersonal relationships, (5) communication and (6) physical health. The program resources promoted healthy behaviors that directly and indirectly addressed issues that led to more productive and rewarding social interactions. Furthermore, participants reported feeling empowered to be more proactive in their own medical care and treatment. The avoidance and reduction of the effects of stressors are indicated as major components of their active self-care, referred to as “self-love” by the participants. This illustrates the important role that social support has in the self-management paradigm for this targeted group of women with lupus[104]. Cohen’s social constructs of social support and social integration provides the stage for this exploration. This process appears similar to the concept of “discovery” presented in the Rucker-Whitaker study where AA with heart disease began to contemplate and make behavioral changes through the self-management intervention [84]. Participants’ accounts indicate mental and physical state improvements that led to more rewarding productive lives.

Based on social support themes, the CDSMP provides emotion- and problem-focused resources to help participants cope with lupus. Psychosocial factors (e.g., less social support, lower self-efficacy, greater learned helplessness, maladaptive responses to illness) may have important effects on morbidity [105]. AA women have a higher susceptibility for lupus in the U.S., and the morbidity and mortality are significantly higher than Caucasians [20, 40, 41, 67, 106]. The characteristics of this sample of AA lupus patients illustrate, as described in other studies, the significant burden that lupus places on the patient, patient supporters, and community[33, 51-53]. The two most prevalent characteristics of the participants were experiencing more than one comorbid condition and an inability to maintain employment. The qualitative results of the parent study introduced the concept of and need for social support for people with lupus[88]. Studies showed that lupus patients felt like their illness was often trivialized (i.e. lack of understanding, empathy, support) by family and friends because of the “invisible” symptoms[73]. This often led to social isolation.

It was interesting to see that there is no significant change in the pre- and post- numbers of social support family members and friends for participants. This identifies the need for further exploration regarding the quality of individual social support. It is not discernible, from this study data, the level of satisfaction associated with this individual-level support. Ward (1999) found that having more appraisal social support or a greater availability of confidants was associated with less lupus activity[105]. It is plausible that the CDSMP did not promote the expansion of this level of individual support; or that this expansion was not visible in the duration of the parent study post-intervention collection period.

Participants appeared to crave self-health information especially regarding nutrition and physical exercise in addition to coping with depression and physically incapacitating days. This was also apparent in the leaders' accounts. The success of the CDSMP in addressing these participant needs is supported by the quantitative and qualitative data from the satisfaction surveys. An inability to cope with the disease is one of the top five health concerns for people with lupus [53]. Moreover, participants demonstrated an intense desire for family, friends, and their communities to comprehend the impact of lupus on their mental and physical attributes. This shared understanding could allow for improved social integration. A study that reviewed qualitative lupus studies identified societal stigma and indifference as one of the top five themes describing the experiences of people with lupus; and a value of the mutual understanding by those experiencing similar illness [73]. Interventions focused on social support resources may improve their social experiences.

Limitations

Social support is a broad concept and this study's use of only one construct (Cohen's) may introduce limitations in this study. Moreover, since the parent study was not designed to explore this concept, other collection measures could have been incorporated for a stronger triangulation in capturing the voice of the sample population. This qualitative data, by definition, is not generalizable and tied to the sample. This study is also restricted based on the limitations of the parent study focus group design that did not allow for the discernment of responses by individuals. Therefore, it is not clear whether responses are reflective of the majority or minority of focus group participants. The parent study focus groups represented only 60% of the eligible CDSMP completers. The opinions of those who did not participate may have added more data leading to more themes.

Summary

This qualitative study provides an enhanced understanding of the role of social support in this population of socioeconomically disadvantaged AA women with lupus. It is evident that the person-environment relationships have a significant role in this population's ability to cope with stressors and self-manage the heterogeneous dimensions of their chronic disease. The theoretical perspective presented offers the groundwork for understanding this causal impact. Social support offers a buffer leading to more healthy problem-focused and emotion-focused cognitive and behavioral efforts in managing stressful life events. This is illustrated through the various examples expressed during focus group discussions.

This research offers the public health community a social support approach toward improving the health of communities. It is important to understand the impact of person-environment relationships in the reduction of the effects of stress especially pertaining to a chronic disease, such as lupus with a socioeconomically and racially disadvantaged group of people. While the study of lupus continues, an evidence-based cost-effective intervention, the CDSMP, offers the psychological resources to enhance resilience and coping capacities, healthy behaviors, and overall well-being.

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Appendix A

POST-WORKSHOP SATISFACTION SURVEY

Please mark the box to indicate how satisfied you were with the program:

	1	**2**	**3**	**4**	**5**
	Strongly Disagree	***Disagree***	***Neither Disagree or Agree***	***Agree***	***Strongly Agree***
1. I intend to tell other people that the program is very worthwhile.					
2. The program has helped me set goals that are reasonable and within reach.					
3. I trust the information and advice I was given in the program.					
4. Course leaders were very well organized.					
5. I feel it was worth my time and effort to take part in the program.					
6. I thought the program content was very relevant to my situation.					
7. I feel that everyone in the program had the chance to speak if they wanted.					
8. The people in the group worked very well together.					
9. I feel like the program site was a good place for this program.					

10. Overall, how did you like this program?

11. What did you like most about this program?

12. If there is something you could change about the program, what would it be?

Thank you for your providing this information.

Appendix B

Ucan Grady Lupus Initiative
Focus Group Questions

Introductory Statement: Would like to capture your views and experiences of the program.

- **Introduce Terrika and her note-taking role**
- **Tape recording notice and explanation**
- **Rules of discussion**
    - **Don't need to speak in order**
    - **One person speak at a time (recording)**
    - **Confidential – 1st names use only**
    - **No right/wrong answers**
    - **Acceptable to disagree**
    - **Moderator not an expert**
    - **Share comments with group**

Warm-up questions:

- How long have you lived in GA?
- How long have you had lupus?
- Which Ucan Group were you in? (3 or 4)

Initial perceptions of program:

- Before the program began, what were your initial thoughts about the program?
- What motivated you to participate in this program?

Experiences of program:

- What challenges did you face as the program progressed?
    - Transportation, Childcare, Work, Family, Health etc.
    - What did you have to do to make it through these challenges?
    - Did you miss program classes?
    - If we did not offer compensation for this program, would you still participate?
- As the program progressed, what motivated you to continue to attend classes?
- Did you notice any changes in your behaviors or symptoms as the program progressed?

Perceptions of completed program:

- What memories do you have about participating in the program that stands out in your mind?
- Overall, how valuable was this program to you?
- What aspects of the program were important to you?
    - Probe for:
        - Topics or book chapters
            - Learning about lupus
            - Self-management tools
        - Creating an action plan
        - Socializing/developing new relationships with group members
        - Group discussions
            - Being able to open up
            - Talking to people who would understand (empathy)
    - Why were these aspects important to you?
- What were the aspects that you did not like about the program? Why?
- What tools did you receive from the program?
    - Probe for:
        - Information about SLE
        - Self-management tools (breathing exercise)
        - Ways to talk to the doctor
    - Have you noticed any changes in your behavior?

    - Do you still actively use these tools? (Follow action plans, meditate, etc.)
- What were some of the benefits of the program?
- What were some of the challenges that you faced in participating in the program?

Perceptions of future implementation of program:

- Do you think this is a valuable program for lupus patients like you? Why or Why not?
    - What would you change about the program to make it more valuable to lupus patients like you?
        - Probe for:
            - Adding or removing certain chapters or topics
            - Location of program
            - Time of program
            - Including family members/caregivers in the program sessions
            - Continuing the program beyond 6 weeks
    - Did you find any aspect that you think does not work for people with lupus like you?
        - IF so, what were these aspects?
        - Why wouldn't these aspects work for lupus patients like you?
- Would you recommend this program to people with lupus like you?
    - Why or why not?
- If this program were offered to people with lupus like you in your community to take the classes with people with other chronic diseases, such as arthritis or diabetes, would you attend?
    - Why or why not?

What else would you like to share?

Appendix C

UCAN Initiative Focus Groups: Qualitative Social Support Data Code Book

Classifications	Descriptions
Code	Social Support: Instrumental (Participant Need)
Coding Acronym	SSIns-P
Brief Definition	Participant's need for a social network's provision of material aid.
Full Definition (Cohen, 2004)	Participant's need for a social network's provision of material resources intended to benefit an individual.
When to Use	To describe types of material resources needed by the participant. (i.e., food, financial, help with daily tasks)
Example	*"…the Y has given me my scholarship and I pay $5 a week to go to the Y…I can use every facility, every trainer, everything…" (p.4 T1)*
Code	Social Support: Informational (Participant Need)
Coding Acronym	SSInf-P
Brief Definition	Participant's need for a social network's provision of relevant information.
Full Definition (Cohen, 2004)	Participant's need for a social network's provision of relevant information intended to help the individual cope with current difficulties.
When to Use	To describe types of information needed by the participant. (i.e., advice, guidance)
Example	*"That's what made me sign up…she was talking about the stress and depression and you know how to treat your fatigue and pain and stuff like that. That what really made me do it." (p.8 T1)* *"Communication is the number one process through all the things that we're talking about, doctors, medical, stress, everything but I would like to see communication be a bigger portion…In communicating with others." (p.34 T1)*
Code	Social Support: Emotional (Participant Need)
Coding Acronym	SSEmo-P
Brief Definition	Participant's need for a social network's provision of the expression of empathy, caring, reassurance and trust.
Full Definition (Cohen, 2004)	Participant's need for a social network's provision of the expression of empathy, caring, reassurance, and trust and provision of opportunities for emotional expression and venting.
When to Use	To describe types of emotional support needed by the participant.
Example	*"Because you know before I started on that class I wouldn't talk to nobody about my situation. If somebody was staring at me I'm like what you looking at, you know. I don't just tell people…some people just ain't understanding." (p.12 T1)*
Code	Social Integration (Participant Need)
Coding Acronym	SInt-P
Brief Definition	Participant's need to participate in a broad range of social relationships.
Full Definition (Cohen, 2004)	Participant's need to participate in a broad range of social relationships that include active engagement in

Classifications	Descriptions
	social activities and relationships as well as a sense of community identification with one's social roles.
When to Use	To describe types of social relationships needed by the participant.
Example	*"I was [glad] this idea came up cause I got tired of, sick and tired of sitting at home." (p.10 T1)* *"…to me you really needed to have a talk about relationships really, male and female relationships or whatever in regards to taking everything else you need to have one for relationships. Cause you'll make them understand whether dating him or marrying him you'll make him understand." (p.33 T1)*
Code	Social Support: Instrumental (Program Provision)
Coding Acronym	SSIns-CDSMP
Brief Definition	CDSMP provision of material aid.
Full Definition (Cohen, 2004)	CDSMP provision of material resources intended to benefit an individual.
When to Use	To describe types of instrumental support provided by the program. (i.e., food, financial, help with daily tasks)
Example	*"You know the little snacks they used to give, the little oranges and stuff like that. That helped me out too. I was like cause stuff I used to eat in the morning was like, you going to eat that for breakfast?" (p.10 T2)*
Code	Social Support: Informational (Program Provision)
Coding Acronym	SSInf-CDSMP
Brief Definition	CDSMP provision of relevant information.
Full Definition (Cohen, 2004)	CDSMP provision of relevant information intended to help the individual cope with current difficulties.
When to Use	To describe types of informational support provided by the program. Educational opportunities.
Example	*"…action plan because that's my life." (p.8 T1)*
Code	Social Support: Emotional (Program Provision)
Coding Acronym	SSEmo-CDSMP
Brief Definition	CDSMP provision of opportunities to express empathy, caring, reassurance and trust.
Full Definition (Cohen, 2004)	CDSMP provision of the expression of empathy, caring , reassurance, and trust and provision of opportunities for emotional expression and venting.
When to Use	To describe types of emotional support provided by the program.
Example	*"Just to go over the weeks…the issues that took, transpired in our homes or whatever we did, unbiased, nobody talked about each other when they walked out…we felt like we was a you know a family." (p.10 T1)*
Code	Social Integration (Program Provision)
Coding Acronym	SInt-CDSMP
Brief Definition	CDSMP elements that contribute to the increased participation in a broad range of social relationships.
Full Definition (Cohen, 2004)	CDSMP elements that contribute to the increased participation in a broad range of social relationships that include active engagement in social activities and relationships as well as a sense of community identification with one's social roles.

Classifications	Descriptions
When to Use	To describe types of social relationships developed or enhanced through the program.
Example	*"I have truly gathered and not associates, they're friends that I call to see." (p.8 T1)*
Code	Healthy Behaviors (Program Influences)
Coding Acronym	HBeh-CDSMP
Brief Definition	CDSMP elements that contribute to the development of healthy life-styles.
Full Definition	CDSMP elements that contribute to the development of healthy life-styles in terms of the way people live.
When to Use	To describe healthy practices such as better communication, nutrition, sleep, exercise, and stress reduction.
Example	*"And it's been a great mental change and if I mentally keep my head straight and my physical being will follow…" (p.14 T1)* *"So the group really helped me and my family because we are exercising." (p.37 T1)*
Code	Healthy Relationships (Program Influences)
Coding Acronym	HRel-CDSMP
Brief Definition	CDSMP elements that affect relationships.
Full Definition	CDSMP elements that affect relationships in terms of the way people interact with others. These elements contribute to the various levels of engagement, conflicts, companionship, intimacy, and social skills.
When to Use	To describe contributors to building relationships with family, friends, health professionals and community. (i.e., communication)
Example	*"You know when I got to tell the class it made me open up cause I never talk to nobody. …It was a good experience, it made me open and now it made me where somebody wants to know about it I can explain." (p.12-13 T1)* *"So the group really helped me and my family because we are exercising." (p.37 T1)*
Code	Social Support Barriers (Program)
Coding Acronym	SSBar-CDSMP
Brief Definition	Factors of the CDSMP design that served as a barrier to the enhancement of social relationships.
Full Definition	Factors of the CDSMP design and/or facilitation that impeded the enhancement of social relationships including social networks and the quality and quantity of interactions. Or did not address important social support elements.
When to Use	To describe factors of the program that prevented the development of social networks (i.e., exclusion of significant others, missing/incomplete topic discussions)
Example	*"…we never got a chance to get through it [chapter 13 – sex/intimacy]. I think that's important though because you don't know how to relate in relationships and marriage and dealing with not being able to. ….It shows your body being sore and stuff like that…" (p.17 T1)*

Classifications	Descriptions
Code	Social Support Contextual Factors (Program)
Coding Acronym	SSCFac-CDSMP
Brief Definition	Group dynamics leading to the effectiveness of the CDSMP.
Full Definition	Characteristics of the CDSMP environment that are related to effective collaboration. Group factors that created this environment and fostered learning.
When to Use	To describe factors of the program that enhanced collaboration. (i.e., role-playing, buddy partnerships, group process discussions, facilitators).
Example	*"The directors initiated that for us and we took their lead but it's great. I miss ya'll." (p.10 T1)* *"But then we reiterated what was said in the reading and clarified it for some of us that didn't understand it… We deciphered it just like you do in any class." (p.32 T1)*

Appendix D

Ucan Grady Lupus Initiative
Feasibility Interview Guide
Debriefing Telephone Interview with CDSMP Leaders

Introduction: The purpose of this discussion is to explore your perceptions on how well this program seemed to work for this African American population with lupus. We would like to understand not only the outcomes of the program but also the participants' reactions to the program. The interview should take about 45 minutes to complete. You may decline to answer any of the questions that you do not wish to answer. Please note that I am recording this discussion so that we can have a transcript that will be used for further analysis.

1. From your perspective, overall, how well did this program seem to fit or meet the needs of the participants? Please explain your answer

2. What parts of the program, if any, worked particularly well with these participants (or were particularly engaging to these participants)?

3. What parts, if any, seemed less relevant, or less clear to these participants?

4. Did you have any surprises or anything unexpected that happened while leading the class?

5. In what ways were the reactions of these participants to the program similar, and different than past participants you have worked with in the program?

6. What suggestions do you have at this time for making the program more relevant or engaging to African Americans with lupus?

7. Any other thoughts you want to share will us based on this first experience of leading the class for a group of African Americans with lupus?

Thank you for sharing your thoughts.