Corticosteroid use, emotional health and work/regular daily activities: ethnic differences in women with systemic lupus erythematosus

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CORTICOSTEROID USE, EMOTIONAL HEALTH AND WORK/REGULAR DAILY ACTIVITIES: ETHNIC DIFFERENCES IN WOMEN WITH SYSTEMIC LUPUS ERYTHEMATOSUS

by

Dorcey L. Applyrs

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Abstract

Systemic Lupus Erythematosus has profound effects on women, families and society causing a loss of self-esteem, a loss in earning potential and higher health care costs.\textsuperscript{1,2} SLE affects women during their most productive years of life, causing women to further experience particularly poor health-related quality of life (HRQoL) as well as financial hardship.\textsuperscript{3} The purpose of this study is to investigate the associations among corticosteroid use, emotional and physical health, and work and regular daily activities in a racially-and ethnically-diverse sample of women with SLE and controls using data from the Medical University of South Carolin\textsuperscript{a} (MUSC) Lupus Database. This study sample consisted of 284 women (224 women with SLE and 60 controls): 57 (20\%) were Caucasian American, 86 (30\%) were non-Gullah African American and 141 (50\%) were Gullah African American. All analyses were performed using version 9.3 of SAS. Results of this study indicate that when compared to emotional health, physical health has a statistically significant larger association with decreased work and regular daily activities compared with emotional health. Additionally, significant ethnic differences were observed in the association between emotional health and work and regular daily activities among women with SLE. Emotional health outcomes were better for women with SLE when compared with controls. These high scores may be influenced by racially- and culturally-related factors such as unique disease coping mechanisms, the adoption of the Superwoman role\textsuperscript{4} and behaviors related to cultural accommodation.\textsuperscript{5}
Acknowledgments

Completing this dissertation has been a rewarding, life changing and character building endeavor. I recognize that without God and a village of people standing with me, completing this body of work would not have been possible. I dedicate this dissertation to women living with Systemic Lupus Erythematosus and the village that poured into me through their finances, time, sacrifice, mentoring, words of encouragement and prayers. I would be remised if I did not recognize one of the villagers, my unwavering, loving and supportive husband, Don Applyrs. I am grateful that we are closing this chapter as we started, in love!
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1. Introduction

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune condition with significant morbidity and mortality. Currently, there are 1.5 million Americans living with SLE. The disease is more prevalent in women than in men, with a ratio of 9:1. African American women are disproportionately impacted by SLE, with the incidence and prevalence of the disease two to three times higher in African Americans than in Caucasian Americans. Poor emotional and physical health, which is associated with the SLE, can compromise women’s ability to perform work and regular daily activities. The disease often has profound effects on women, families and society, causing a loss of self-esteem, a loss in earning potential and higher health care costs. Despite their effectiveness in treating SLE, corticosteroids have emotional side effects, which can further compound women’s emotional distress. Although emotional health and physical health can affect work and daily activities, no study has explored these health-related quality of life (HRQoL) factors in relation to corticosteroid use in an ethnically-diverse sample of women with SLE. This study adds to the knowledge base on SLE by exploring the relationship among corticosteroid use, emotional and physical health, as well as work and regular daily activities among an ethnically-diverse sample of non-Gullah African American, Gullah African American and Caucasian American women with SLE and controls.
1.1. **Statement of the Problem**

SLE has the most striking disparities in outcomes compared to other rheumatic diseases.\(^{18-20}\) In particular, HRQoL outcomes are poorer for individuals with SLE when compared to population norms.\(^{8,20-22}\) Emotional health, physical health, employment and work and regular daily activities are HRQoL factors considered essential to an individual’s quality of life and well-being.\(^{23}\) Consequently, women with SLE, disproportionately experience a decline in each of these areas.\(^{21}\) This decline in HRQoL is due to the unpredictable nature of SLE symptoms. SLE is characterized by periods of high disease activity interspersed with periods of low disease activity or remission. Major organ involvement and irreversible organ damage are also common.\(^{21,23}\) A decrease in HRQoL outcomes can have far-reaching negative implications. For example:

- **Individual level:** a loss in self-esteem, an inability to maintain employment and accumulate wealth, an inability to care for children and family members, and an increase in stress and disease activity (lupus flares)
- **Family:** an increase in economic demands and care-giver responsibilities
- **Societal:** a decrease in workforce and increased healthcare burden and costs

1.2. **Theoretical Framework**

Women with SLE are inundated with stressors caused by the disease and by the side-effects of treatments.\(^{24,25}\) In individuals diagnosed with a chronic disease like SLE, a loss of HRQoL and an increase in stress is likely. Frequently, individuals with SLE consider their disease as uncontrollable, limiting and threatening.\(^{26}\) Studies indicate poor
HRQoL in women with SLE since the disease can be severe and unpredictable.\textsuperscript{8,27,28} Among women with SLE, the course of the disease and emotional well-being are influenced by women’s coping strategies and the ability to deal with stress and negative emotions.\textsuperscript{29} Despite African American women’s disproportionate burden of SLE and evidence that suggests health disparities in SLE outcomes related to racial and ethnic-specific environmental stressors,\textsuperscript{30} there has been limited research on stress-related coping strategies for this population. Woods-Giscombe’s Superwoman Schema (SWS) framework\textsuperscript{4} was chosen as the theoretical framework for this study because it describes the link between stress-related coping and its impact on HRQoL in the lives of African American women. The Superwoman Schema describes the consideration of the unique sociocultural and historical factors that influence stress and coping in the lives of African American women. Given the fact that African American women with SLE are part of this study sample, these important sociocultural factors must be considered.

The SWS framework conceptualizes the life experiences of African American women to include historical events and sociocultural factors such as racism, race-and-gender-based oppression, disenfranchisement, and limited resources. All of these factors contribute to African American women taking on the roles of mother, nurturer, and breadwinner.\textsuperscript{4} The Superwoman feels obligated to demonstrate many characteristics including strength, the ability to suppress emotion, resistance to vulnerability and dependence, the determination to succeed, and the obligation to help others.\textsuperscript{4} The ability to play Superwoman role has been described as an asset and a survival strategy for African American women, who cope well with adversity and tremendous hardship.\textsuperscript{4} For this study, the SWS framework considers the negative impacts of this phenomenon on the
health outcomes of African American women. According to this SWS framework, a woman’s ability to demonstrate strength in the quest for survival may potentially lead to negative coping strategies. These include delayed self-care, inadequate sleep, as well as anxiety, depression, and impaired physical health. The added stress of maintaining the Superwoman role, feeling the need to help others while suffering with SLE may result in women’s poor management of the disease. African American women diagnosed with SLE who have accepted the Superwoman role and all its stressors may display more debilitating health outcomes.

As described in the conceptual model (see Appendix A), the sociocultural factors associated with the adoption of Superwoman role generate stress-related coping strategies among women. Negative coping strategies create a cyclical process in which stress triggers SLE flares; these flares result in disease activity, decreased HRQoL and compounded stress that re-starts the process. Women who experience more active disease have higher levels of anxiety and depression. African American women with SLE are more likely to experience more severe disease activity compared to their Caucasian American counterparts. Consequently, African American women are at a greater risk of experiencing anxiety and depression. Given African American women’s disproportionate burden of SLE damage and mortality compared to Caucasian Americans, the theoretical framework for this study relies on the SWS framework to focus on racial and ethnic- differences in the life experiences of this study sample.
1.3. **Health Related Quality of Life**

Researchers have focused on the impact of HRQoL outcomes (e.g. emotional health, physical health and work and regular daily activities) on population health since the World Health Organization (WHO) expanded its definition of health to include not only the absence of disease and infirmity but also the presence of physical, mental, and social well-being.\textsuperscript{34} HRQoL is an important outcome measure for SLE because it suggests the individual’s perception of the impact of the disease and its treatments on their physical, mental and social well-being.\textsuperscript{3} Decreased HRQoL among women with SLE has been well documented in the literature\textsuperscript{3,19,21,26,35} Assessing HRQoL as part of a woman’s health picture helps health care and service providers with developing holistic and comprehensive treatment plans for women living with SLE.\textsuperscript{36}

1.4. **Work and Regular Daily Activities**

There is a growing body of literature examining the impact of SLE on work and regular daily activities.\textsuperscript{1,2,37,38} The inability to perform work and other daily activities is common in women with SLE as a result of disease severity and a variety of symptoms.\textsuperscript{37,39} In one study of 114 individuals with SLE using a self-administered questionnaire,\textsuperscript{6} two-thirds of participants reported that their illness affected their ability to perform work and regular daily activities. It is estimated that one-third of individuals with SLE become disabled within three to 12 years of diagnosis.\textsuperscript{39}
1.5. Emotional Health

It is well documented that women with SLE experience difficulty coping with the emotional impact of the disease. The emotional effects of SLE can be attributed to the illness itself, changes in physical appearance, fatigue, concerns about the future, unpredictability and the financial costs associated with the condition. Disease activity and severity have been found to be highly correlated with emotional health outcomes. Women with SLE are often isolated from families and support networks because of disease symptoms. In turn, this isolation further exacerbates poor emotional health. Prior studies indicate that emotional distress is so profound among individuals with SLE that depression and anxiety in this population were higher compared with individuals living with arthritis and cancer.

1.6. Corticosteroid Use

Corticosteroids are widely used to treat SLE. Given the proportion of women with SLE who use corticosteroids, the emotional side effects of the drug have been cited as a factor that contributes to poor emotional health among this population. The emotional effects of SLE can interfere with work and regular daily activities. In a cross-sectional study of 147 individuals (95 percent of them women), 74 percent of individuals reported poor emotional health as a reason for not being able to work.

1.7. Physical Health

Difficulty coping with the physical strain of having SLE is common for women. SLE can cause fatigue, fever, arthritis and severe organ damage, all of which contribute
to chronic morbidity for women.\textsuperscript{1,2,43} Morbidities for SLE contribute to a woman’s inability to perform work and regular daily activities.\textsuperscript{1,6} Findings from a study involving 112 individuals with SLE using a self-administered questionnaire found that physical symptoms were the most reoccurring main concern.\textsuperscript{42}

**1.8. Ethnicity and Work and Regular Daily Activities**

Ethnicity, a construct that encompasses genetic, geographic, cultural, social and other characteristics shared by a population,\textsuperscript{9} has been associated with higher rates of work disability in SLE.\textsuperscript{44} A meta-analysis of 22 studies with a total of 9,886 SLE participants revealed that African Americans had higher rates of work disability when compared to Hispanic Americans and Caucasian Americans.\textsuperscript{1,44} Mok et al.\textsuperscript{44} suspected these differences were associated with lower socioeconomic status, more serious disease manifestations, as well as organ damage. Consistent with the literature, African American women with SLE are more likely to experience more severe disease activity and have higher mortality when compared to their Caucasian American counterparts.\textsuperscript{9,12,30,32,33}

**1.9. Purpose of the Study**

The purpose of this study was to explore the associations among factors in the SLE literature, including corticosteroid use, emotional and physical health, and work and regular daily activities; the study population consisted of a racially- and ethnically-diverse sample of non-Gullah African American, Gullah African American and Caucasian American women. A unique feature of this study is the inclusion of the Gullah, a sub-population of African Americans from the Sea Islands of South Carolina.\textsuperscript{33} Due to
the Gullah’s geographical isolation on the Sea Islands, they have been able to preserve a strong sense of community reflecting cultural customs and traditions rooted in their African heritage. Unlike African Americans, who are dispersed throughout the United States, the Gullah offers the chance to study an isolated population. The findings from this study can be used to inform the development of culturally-appropriate supportive care and interventions. In particular, findings from this study could lead to improving the quality of life for women with SLE, by developing public health interventions and policies and strategies to address emotional and physical health. In turn, these policies and strategies can help women with SLE maintain their work lives as well as other daily activities.

This cross-sectional study utilized data from the Medical University of South Carolina’s (MUSC) web-based lupus database, which is longitudinal and observational in nature. The study population consisted of 284 women (224 women with SLE and 60 controls); 57 of these women were Caucasian, 86 were non-Gullah African American and 141 were Gullah African American. The overarching specific aims of the study were as follows:

- **Specific Aim 1:** To determine if a sample of women with SLE and controls reports that emotional health has a greater association with decreased work and regular daily activities compared with physical health and also, to determine if those relationships are exacerbated by corticosteroid use.

- **Specific Aim 2:** To evaluate if there are ethnic differences in associations among corticosteroid use, emotional health and work and regular daily
activities in non-Gullah African American, Gullah African American and Caucasian American women with SLE.
2. Literature Review

The poor emotional and physical health associated with Systemic Lupus Erythematosus, or SLE, can compromise women’s ability to perform work and regular daily activities.\(^{12-14}\) Compared to most chronic conditions, SLE inflicts more physical and functional disability, thus resulting in high health care costs to women, their families and society.\(^{45}\) Since SLE affects women during their most productive years of life, it causes women and their families to experience financial hardship and it significantly decreases their ability to accumulate wealth due to the financial burden associated with the disease.\(^{1,39,45}\) The diverse symptoms of SLE contribute to poor emotional and physical health among women.\(^{21}\) There are a variety of treatments used for SLE. However, corticosteroids are the most common treatment for SLE symptoms. These steroids are known to cause depression, anxiety, and severe mood disorders.\(^{15,46}\) Thus, corticosteroid use can exacerbate poor emotional health among women with SLE.\(^{15,24}\) SLE research findings have established that emotional and physical health impact work and daily activities.\(^{8,12,28,35,39}\) However, research on corticosteroid use and its association with SLE is scant. This study explored the relationship between corticosteroid use, emotional and physical health, and work and regular daily activities in a racially- and ethnically-diverse sample of women with SLE. The sample includes Gullah African Americans from the Sea Islands of South Carolina, non-Gullah African Americans and Caucasian Americans.
2.1. Systemic Lupus Erythematosus

SLE is a chronic, inflammatory autoimmune disease that affects the body’s organs and systems. The onset of SLE typically occurs between the late teens and early forties. This condition primarily affects the skin, joints, blood and kidneys but can also affect the brain, heart and lungs. In SLE, the body’s immune system no longer distinguishes between antigens and body tissue. As a result, the immune system attacks cells and tissues within the body. SLE symptoms occur as a result of damage caused by so-called autoantibodies, those antibodies that react to body tissue. Individuals with SLE have a higher concentration of autoantibodies than do healthy individuals.

Environmental factors believed to be associated with the etiology of SLE include sunlight, cigarette smoke, toxic exposures, infectious agents such as viruses and stress. It is important to highlight that environmental stressors and stress-related coping mechanisms vary by ethnicity and influence disparities in health outcomes such as SLE. These stressors include, daily hassles or discrimination; access to medical care, including financial access, medical insurance and organizational access; and social capital (stable neighborhoods and civic engagement).

2.1.1. SLE Incidence, Morbidity and Mortality

The incidence of SLE has increased due to improvements in diagnostic testing and heightened awareness among physicians. In the United States, it is estimated that 1.5 million individuals are living with SLE. Lupus rates range from 1.8 to 7.6 per 100,000 person-years. SLE incidence and prevalence rates vary by gender, ethnicity, age and familial aggregation. Women are eight to 10 times more likely to receive a
lupus diagnosis.\textsuperscript{52} As a result, women comprise 90 percent of participants in SLE studies.\textsuperscript{9}

There are glaring health disparities in SLE incidence, morbidity and mortality.\textsuperscript{30,53} African American women are three to four times as likely to develop SLE compared to their Caucasian American counterparts.\textsuperscript{52} African American women are also more likely to experience more severe clinical manifestations, abrupt disease onset and disease activity and have a two- to three-fold higher mortality risk compared to Caucasian Americans.\textsuperscript{9,54} Health disparities in SLE outcomes are associated with genetic and non-genetic components such as socioeconomic status, access to medical care, and life stressors.\textsuperscript{12,30,53}

The course of SLE is variable, with some individuals experiencing more severe symptoms than others. The disease sometimes affects people in a cyclic fashion, with periods of high disease activity alternating with periods of low or stable disease activity. Sometimes, individuals experience a remission in their symptoms.\textsuperscript{21} In addition to SLE symptoms, individuals with SLE are at increased risk of developing comorbidities such as cardiovascular disease.\textsuperscript{48} In fact, risk for heart attack and stroke is 10 times higher in this population.\textsuperscript{48} There is a higher occurrence of SLE in first- and second-degree relatives of people with SLE.\textsuperscript{12} An individual who has a first-degree family member with SLE has a five to 10 percent increased risk of developing SLE.\textsuperscript{8,48} Despite advances in medical treatment, SLE is still a debilitating disease with severe implications. In its more severe forms, lupus causes high rates of kidney disease and end-stage renal disease.\textsuperscript{28}
2.2. **SLE and Work and Regular Daily Activities**

SLE as a chronic condition imposes significant limitations on women, restricting their ability to work and perform daily activities.\(^6,9,5,6^\) Women with SLE typically suffer a range of difficult symptoms that include fatigue, joint pain, swelling, weakness and emotional distress.\(^12,21^\) In a cohort study, data from 897 individuals with SLE collected in telephone interviews revealed that lupus most frequently interfered with home repairs (83.9 percent) paid work (70.7 percent), and housework (67.8 percent).\(^57^\) These findings were consistent with reports from qualitative studies assessing the impact of SLE on work and regular daily activities. In a qualitative study with 23 participants in a focus group, results suggested that a major issue was the inability of participants to maintain regular work activities (57 percent).\(^58^\) Another qualitative study\(^21^\) using in-person interviews with 22 individuals reported that SLE symptoms interfered with a woman’s ability to complete normal daily activities including housecleaning, gardening, cooking, laundry and grocery shopping. All participants in this study indicated that SLE had a negative effect on employment activities; because of the disease, women were forced to reduce their hours at work or stop working altogether. Some women reported taking early retirement.\(^21^\)

A systematic review\(^1\) of 26 studies (N=9886) revealed that 32.5 percent of individuals with SLE reported work disability. The researchers defined work disability as the inability to do paid work due to illness.\(^37^\) These findings were consistent with a cross-sectional study of 147 individuals, which found that 37 percent of the 105 patients who were working at the time they were diagnosed with SLE lost their ability to do paid work.\(^44^\) In a longitudinal study\(^39^\) examining outcomes in individuals with SLE, 19 percent
of study participants (n=273) employed at enrollment reported work disability. In a study conducted by Campbell and colleagues, individuals with SLE were eight times more likely to have stopped working due to health reasons when compared to controls. Yelin et al. studied 832 individuals with SLE using a structured telephone survey to track changes in employment. The study results indicated that the proportion of individuals with SLE who stopped working increased over time (15 percent after five years and 63 percent after 20 years, respectively).

2.3. **Ethnicity and Work and Regular Daily Activities**

Similar to health outcomes in SLE, there are ethnic differences in the way SLE affects employment and other daily activity outcomes for women. African American women with SLE have higher rates of work disability when compared with their Caucasian American counterparts. In a cohort of 829 individuals with SLE interviewed by telephone, results indicated that ethnicity was associated with impairments that led to functional limitations and ultimately to disability.

Bertoli et al. found that self-reported disability rates were higher for African Americans (25 percent) compared with Hispanics from Texas (19 percent) and Caucasian Americans (18 percent) at five years in a longitudinal study with 273 participants. These ethnic differences were associated with factors such as socioeconomic status, severe disease manifestation and organ damage. These findings are supported by the Carolina Lupus Study, a community-based case-control study which revealed that among women, lower educational levels and disease severity were associated with job loss even after adjusting for ethnicity. Similar to Bertoli’s study, this study assessed ethnic differences
in work-related outcomes among an ethnically-diverse sample. However, Bertoli et al. did not include Gullah African American women in their sample nor did they account for corticosteroid use and its potential to moderate the association between emotional health and work and regular daily activities. Additionally, emotional health was not considered a variable of interest.

According to the literature, the complexities of SLE among women, including symptoms and disease manifestation, can result in severe emotional impacts. African American women in general tend to experience more difficulty with the emotional effects caused by SLE. However, the majority of previous studies have failed to include the Gullah African American population. A study conducted by Barnado and colleagues assessing the physical and emotional health of a sample of Gullah African Americans residing on the Sea Islands of South Carolina bears examination. This study concluded that African American Gullah women had poorer physical health compared to population norms; however, these women had significantly better emotional health. These findings further underscore the need for research to examine the association between emotional health and work and daily activities in Gullah African Americans and other ethnically-diverse populations.

2.3.1. Gullah African Americans

Gullah also referred to as Geechie describes a unique African American population residing on the Sea Islands of South Carolina. Sea Islanders is also a term that has been used to characterize the Gullah/Geechie population; both Gullah and Geechie are derogatory names that instill inferiority among African Americans.
Gullah are descendants of enslaved rice plantation workers whose ancestral origins lie in Sierra Leone and the Ivory Coast. Creole (not French Creole) is the language spoken by Gullah African Americans and it is tied to the vocabulary and grammar of the African continent.

In the 1700s, the Gullah’s ancestors were brought to America and forced to live and work on the Sea Islands because of their experience in rice farming. As a result of enslavement, most African Americans were dispersed throughout the United States. However, the Gullah remained isolated on the Sea Islands. This isolation contributed to enculturation (adoption of shared beliefs, values and customs), preservation of culture and low non-African genetic mixing among the Gullah. As a result, the Gullahs have greater genetic homogeneity when compared to other African Americans. It is believed that genetic homogeneity and limited environmental heterogeneity have resulted in preservation of cultural pride, customs (weaving sweet grass baskets, oral story-telling and language) and close-knit family structures among the Gullahs, underscoring their unique characteristics.

Johnson-Spruill and Tripp-Reimer conducted a folknaography study to describe the construct of culture in the context of the Gullah population. The total study sample consisted of 625 Gullah families who completed a 22-page questionnaire used to assess health behaviors, beliefs and practices. Johnson-Spruill and Tripp-Reimer argue that the Gullah culture is heterogeneous within the African American population due to cultural influences, beliefs, practices and behaviors. They also suggest that the Gullah’s health belief system is rooted in racial and cultural experiences. The Gullah’s culture, resiliency and family pride have been instrumental in their survival and health maintenance.
Gullahs have maintained their own indigenous medical practices which entail focusing on the cause of an illness not just the manifestation of an illness.\textsuperscript{5} Among the Gullah, illnesses are regarded as either natural or un-natural. According to Johnson-Spruill and Tripp-Reimer, natural illnesses are caused by stress, cold, improper eating habits or lack of moderation.\textsuperscript{5} However, un-natural illnesses are linked to evil influences and can only be healed by a root doctor.\textsuperscript{5} Although Gullah African Americans are a heterogeneous subpopulation of African Americans; their mutual racial and socioocultural experiences that influence shared stress appraisal and coping strategies. Among Gullah African Americans, slavery, racism, Jim Crow laws and segregation have contributed to the marginalization and adoption of survival mechanisms such as masking emotions, practicing accommodating behaviors to appease Caucasians and “making do.”\textsuperscript{5} These shared experiences include the Superwoman role and its characteristics: an obligation to manifest strength, emotional suppression, a resistance to vulnerability and dependence, the determination to succeed and an obligation to help others.\textsuperscript{4}

\section*{2.4. Emotional Health and Work and Regular Daily Activities}

An extensive review of the SLE literature reveals that emotional health is characterized using various terms, including emotional impact,\textsuperscript{21} emotional effect,\textsuperscript{12} emotional distress, emotional experience\textsuperscript{20} and emotional strain.\textsuperscript{8} This literature review used emotional health as an inclusive term to capture the breadth of terminology used in SLE research. Women with SLE experience poor emotional health and are particularly vulnerable to feelings of grief, depression, anxiety, mood swings, anger and hopelessness.\textsuperscript{12,20,28,42,58,64} Unlike the physical manifestations of SLE, which vary by individual, the
emotional effects of SLE are general manifestations that affect women universally.\textsuperscript{12} Among women with SLE, poor emotional health is associated with the inability to perform work and regular daily activities.\textsuperscript{1,12,37}

In a cross-sectional study\textsuperscript{28} that examined unmet needs among 378 individuals with SLE, poor emotional health was caused by changes in appearance due to SLE and limitations in physical abilities. Women in this study had the most difficulty coping with depression and anxiety.\textsuperscript{28} These findings were consistent with a study by Danoff-Burg and Friedberg which found that among individuals in the study (N=112), there was a substantial need for assistance with feelings of anxiety (78 percent) and depression (71 percent).\textsuperscript{28} Prior research findings concluded that African Americans report higher vulnerability for SLE-related emotional effects and tend to require more psychosocial assistance than do Caucasian Americans.\textsuperscript{8,28}

Research findings from a cross-sectional study with a sample of 1137 individuals found that women with SLE who self-reported their inability to work, were more likely to be depressed.\textsuperscript{37} Results from a longitudinal cohort of 1204 individuals revealed that depression was associated with the loss of paid work.\textsuperscript{38} In a systematic review of a total of 9886 individuals with SLE, anxiety and depression were associated with work loss.\textsuperscript{1} These findings were consistent with a cross-sectional study of 147 individuals (95 percent women), which showed that 74 percent of individuals self-reported emotional health as a reason for not being able to work.\textsuperscript{44} Results from a representative household panel survey conducted in Australia surveying 3160 women (N=5,846) revealed that aspects of emotional health, particularly depression and anxiety, predicted unemployment.\textsuperscript{65}
Based on a review of the literature, the emotional impact associated with SLE and its link to decreased work and regular daily activities is well documented. However, a qualitative study (N=22) did not support this mounting evidence. Study participants did not report that emotional health had an impact on employment or daily activities, even when asked to describe the impact of SLE on both. Due to the small sample size, study findings cannot be generalized to all women with SLE.

2.5. *Corticosteroids are Effective in Treating SLE but Have Side Effects*

Corticosteroids have become the cornerstone treatment for SLE. It is common for women to use corticosteroids because generally these drugs are well tolerated and effective in symptom management. Types of corticosteroids include prednisone, hydrocortisone, methylprednisolone and dexamethasone. Corticosteroids are drugs that resemble cortisol, a hormone produced by the adrenal glands. Corticosteroids suppress the immune system, reduce tissue inflammation and fatigue, and relieve muscle and joint pain. They also are used to control major organ involvement. Women with SLE are prescribed corticosteroids when symptoms do not improve or when they are not responding to other SLE treatments such as nonsteroidal anti-inflammatory drugs (NSAIDS) and antimalarials. Some women with SLE require corticosteroids only during flare-ups while others may require long-term use to treat severe disease or serious organ involvement.

Over the last 20 years, mortality rates for women with SLE have significantly improved. Ninety percent of women newly diagnosed with SLE will have a five-year survival rate. This rate compares very favorably to the survival rate calculated in a study
with 99 individuals who were observed between 1949 and 1953; that study concluded that 50 percent of women would have a five-year survival rate. Improved survival rates for women with SLE have been attributed to corticosteroids, earlier diagnosis and improvements in healthcare. Although corticosteroids are effective in treating SLE, women can experience serious emotional effects.

There is a substantial amount of literature documenting the emotional effects of corticosteroid use. Corticosteroids are known to cause the following side effects: anxiety, mood and panic disorders, severe depression and suicidal thinking. Prior research suggests that between three and 10 percent of individuals receiving corticosteroids experience emotional distress, among other psychiatric effects. According to the literature, women with SLE can experience the emotional side effects of corticosteroids within two to 28 days after starting treatment. A recent study suggested that the risk of depression increases with prolonged or chronic exposure to corticosteroid use.

The strong association between corticosteroids and emotional effects in SLE study findings suggests that corticosteroids can exacerbate poor emotional health among women with SLE. Despite evidence of this association, no studies have examined this association in the context of corticosteroid use in a racially-and ethnically-diverse sample of women. The relationship between corticosteroid use and emotional health underscores the need for health professionals to focus on women’s emotional health in addition to their physical health. Many physicians and researchers tend to focus more on the physical aspects of SLE that may cause organ damage and other morbidity rather than on a patient’s emotional health, which also influences women’s daily lives.
2.5.1. Study Innovation

Corticosteroid use is common among women with SLE and is associated with poor emotional health outcomes. The present study is the first to explore the association between corticosteroid use, emotional and physical health, and work and daily activities in a sample comprised of African American, Gullah African American and Caucasian American women with SLE and controls. It is critical to know if racial and ethnic-differences exist within this association because ethnicity has been associated with higher rates of inability to perform work and daily activities in women with SLE.

A unique feature of this study is the inclusion of Gullah African Americans. Findings from a case-control study with 37 controls and 89 cases conducted by Barnado et al. found that African American Gullah women had poorer physical health compared to the general population; however, these women displayed significantly higher emotional health.\(^{35}\) These findings are contrary to prior research findings suggesting that African American women with SLE have poor emotional health compared to the general population.\(^8,28\) Barnado et al. speculated, based on study findings that the Gullah population has coping mechanisms influenced by cultural pride, close-knit family and community structures.\(^{35}\) Moreover, Bernado et al. suggested that the positive emotional health outcomes among the Gullah may be connected to the unique support systems that the culture provides to families with multiple cases of SLE.
2.6. Research Questions and Hypotheses

Based on the study purpose and variables of interest, the research questions and hypotheses are as follows:

**Research Question 1:** Which has a stronger association with decreased work and regular daily activities, emotional health or physical health?

**Hypothesis 1:** Among an ethnically-diverse sample of women with SLE and controls, emotional health has a greater association with a decrease in work and regular daily activities than physical health and corticosteroid use will exacerbate poor emotional health.

**Research Question 2:** Which ethnic differences exist in associations among corticosteroid use, emotional health, and work and regular daily activities among Gullah African American, non-Gullah African American and Caucasian American women with SLE?

**Hypothesis 2:** Ethnicity will moderate the relationship between corticosteroid use and emotional health with non-Gullah African American women. Specifically, non-Gullah African Americans are more likely to experience a decrease in emotional health and work and regular daily activities compared with Gullah African Americans and Caucasian women with SLE.
3. **Research Methods and Design**

3.1. **Research Design**

A cross-sectional design was used for this study to identify relationships among variables specific to SLE among a racially-and ethnically-diverse sample of women. The cross-sectional design was chosen because of its usefulness in describing the characteristics of the variables under study; this design is also useful in examining the relationships that exist among the study sample and multiple variables at a single point in time. In this particular study, comparisons were made across non-Gullah African American, Gullah African American and Caucasian American women, in relation to corticosteroid use, emotional and physical health and work and regular daily activities.

3.1.1. **Parent Study**

The MUSC Lupus Database Project was developed to establish a web-based database of clinically well-characterized SLE patients and age, race and gender-matched controls that could be followed longitudinally for the performance of observational clinical research. The total MUSC Lupus Database sample was comprised of 864 individuals. Within the database is a sub-study that consists of Gullah African Americans only. In the Systemic Lupus Erythematosus in Gullah Health (SLEIGH) study there were 623 participants. Of the 623 participants, 237 were cases, 166 were un-related age-and gender-matched controls and 220 were family-member controls.

Eligibility for patients’ (individuals with SLE) enrollment in the MUSC Lupus Database included all ages; patients who met three of 11 criteria based on the SLE criteria set forth by the American College of Rheumatology (ACR) also qualified.
Controls had fewer than three ACR criteria, were matched with cases by age, race and gender and did not have a known first-degree relative with SLE. Data were collected during initial and follow-up visits at an MUSC-affiliated setting which included one of the following three sites: Rheumatology outpatient clinics (Rutledge Tower, West Ashley Specialty Care, East Cooper, and North Charleston), the Clinical and Translational Research Center (CTRC), and the MUSC hospital. Subjects seen in the specified MUSC facilities were identified by Rheumatology physicians as fulfilling three or more ACR criteria for SLE or were confirmed as being non-SLE controls.

During in-person visits demographic, physical examination findings, disease damage, quality of life and medication use data were collected. Patients had an initial visit and follow-up onsite visits approximately every 3 to 4 months with urine and blood collected at each visit. Controls had an initial on-site visit and follow-up was done by phone or by mail. The SLE Database was completed as part of a participant’s routine medical care and visits were scheduled at a frequency determined by a primary rheumatologist. Controls were recruited through the dissemination of news and information about the MUSC parent study among families and friends of cases and by a website and newsletter accessible to the community. Questionnaires were given to participants at the visit for completion on site, conducted over the phone, or mailed for completion. All subjects underwent informed consent procedures. Study data were collected and managed using REDCap electronic data capture tools hosted at MUSC. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data gathering for research studies, providing: 1) an intuitive interface for validated data entry has been identified; 2) audit trails for tracking data manipulation and
export procedures are in place; 3) there are automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources are in place.

### 3.2. Sample and Setting

The purpose of this study was to conduct a secondary analysis of data from the MUSC Lupus Database to assess the associations among corticosteroid use, emotional and physical health, and work and regular daily activities in a racially- and ethnically-diverse sample of non-Gullah African American, Gullah African American and Caucasian American women with SLE and controls.

#### 3.2.1. Sample

This study sample consisted of 284 women (224 women with SLE and 60 controls). Of the total sample, 57 (20%) were Caucasian American, 86 (30%) were non-Gullah African American and 141 (50%) were Gullah African American women.

#### 3.2.2. Selection Criteria

The selection criteria for this study were adopted from parent study criteria. However, for the purpose of this study, participants were included if they were female and at least 14 years old, self-identified as African American (including Gullah African American) and Caucasian American, and met at least three out of 11 classification criteria as designated by the American College of Rheumatology (see Appendix B the ACR classification criteria for SLE). Women with SLE were compared to controls to assess differences in HRQoL outcomes based on disease status. Controls were included if they had fewer than three ACR criteria and information regarding history of corticosteroid use.
was available. Individuals were excluded if they were male, not African-American or Caucasian American and information regarding history of corticosteroid use was unknown. A complete list of selection criteria for this study can be found in Table 1.

<table>
<thead>
<tr>
<th>Table 1. Inclusion and exclusion criteria for study participants</th>
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<tbody>
<tr>
<td><strong>Inclusion Criteria</strong></td>
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<tr>
<td><strong>Cases</strong></td>
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<tr>
<td>• Female, age $\geq$ 14 years at the time of baseline visit</td>
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<tr>
<td>• Self-identify as African American (including Gullah African American) and Caucasian American</td>
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<tr>
<td>• Diagnosed with SLE by meeting at least three out of 11 classification criteria as designated by ACR</td>
</tr>
<tr>
<td><strong>Controls</strong></td>
</tr>
<tr>
<td>• Fewer than 3 ACR criteria at enrollment</td>
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<tr>
<td>Participant information available regarding history of corticosteroid use</td>
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</table>

3.2.3. **Procedures**

This study was carried out with the approval of the Institutional Review Boards at the State University at Albany, State University of New York (IRB Protocol#: 13163-01) and the Medical University of South Carolina (IRB Protocol#: 10852 and 15014).
3.3. Measures and Instruments

3.3.1. Outcome Variable

Work and regular daily activity were conceptualized as paid work or daily activities that included, but were not limited to, house cleaning, gardening, cooking, laundry and grocery shopping. Work and regular daily activities were measured using two separate scales: one measured the degree to which emotion affected women as they performed work and regular daily activities and the other measured how physical ailments affected work and regular daily activities. Both scales were taken from the Expanded Health Survey developed by the MUSC. The Expanded Health Survey is comprised of scales from the SF-36, v2. The SF-36 is a generic self-administered instrument designed to measure the impact of disease on quality of life, and is valid and reliable for use with individuals living with SLE. The SF-36 consists of 36 items that have been constructed into eight scales, these include, Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE) and Mental Health (MH). These eight scales are combined into two summary measures, Physical Component Summary (PCS) and Mental Component Summary (MCS). Several studies have used the SF-36 with samples from various racial and ethnic backgrounds including both non-Gullah African American and Gullah African American women with SLE. In these studies, the Cronbach’s $\alpha$ exceeded the criterion of .70.

The role of emotion and its effect on work and regular daily activities-role emotional was measured using a three-item, five point Likert scale with a range from one (all of the time) to five (none of the time) and a score ranging from zero to 15 points. An
example of an item includes, “During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems? Cut down the amount of time you spent on work or other activities.” A high score indicated a positive outcome for work and regular daily activities outcome.

The effect of physical illness on work and regular daily activities-role physical was measured using a four item, five point Likert scale with a range from one (all of the time) to five (none of the time). Scores range from zero to 20 points. An example of an item includes, “During the past four weeks, have you had any of the following problems with your work or other daily activities as a result of your physical health? Had difficulty performing work or other activities.” A high score indicated a positive outcome for work and regular daily activities.

3.3.2. Exposure Variables

Emotional health was conceptualized as a state of being in terms of feelings and an individual’s personal outlook on life. Emotional health was measured using five-item, five-point Likert scale with a range from one (all of the time) to five (all of the time) and a score range from zero to 25. This scale was taken from the SF-36, v2 Mental Health subscale. Items have a positive connotation (e.g. “How much of the time during the past four weeks have you felt calm and peaceful?”) or a negative connotation (e.g. “How much of the time during the past four weeks have you felt so down in the dumps that nothing could cheer you up?”). The meanings of the composite scores are determined in the
analysis section. Items with a negative connotation were recoded. A high composite score indicated good emotional health.

Physical health was conceptualized as the ability to carry out activities that involve muscle strength. Physical health was measured as a categorical variable on a ten-item, three-choice scale which ranged from one (yes, limited a lot) to three (no, not limited at all). The score ranged from zero to 30. Examples of items include, “Lifting or carrying groceries,” and “Climbing several flights of stairs.” This scale was taken from the SF-36, v2 Physical Functioning subscale. A high composite score indicated good physical health.

3.3.3. Sociodemographic and Health Variables

Demographic data were collected on selected individual characteristics including, race/ethnicity, age, education, employment status, corticosteroid use and comorbid medical conditions. Race/ethnicity was measured as a categorical variable using two items (labeled race and SLEIGH study subject) from the subject registration form. For race, options included African American, or Caucasian. For Gullah ethnicity, the SLEIGH study subject item included two responses, yes (Gullah African American) or no (non-Gullah African American). For data analysis purposes, ethnicity was recoded using dummy variables with non-Gullah African Americans used as the referent group. Age was measured as a continuous variable. Education was measured as a categorical variable with six options: less than high school, some college, college, technical or trade and post graduate. Employment status was measured as a categorical variable with five options: retired, homemaker, disabled, unemployed and other.
Corticosteroids use was measured as a continuous variable by years to establish the mean duration of treatment years. However, for data analysis purposes, corticosteroid use was recoded as a dichotomous variable yes (corticosteroid use) or no (no corticosteroid use). Comorbid medical conditions were ascertained using a past medical history form which included 16 diseases including: diabetes, stroke, fibromyalgia and cancer. For data analysis purposes, comorbid medical conditions were measured using a dichotomous variable yes (at least one comorbid medical condition) or no (no comorbid medical condition).

SLE disease damage was measured by the Systemic Lupus International Collaborating Clinics/American College of Rheumatology damage index (SLICC/ACR DI) questionnaire.\textsuperscript{17,83,84} SLICC/ACR DI is an indicator of bodily damage as a result of SLE. Damage has been described as a non-reversible change, not related to active inflammation, occurring since the onset of lupus, ascertained by clinical assessment and present for at least six months unless otherwise stated.\textsuperscript{84} The SLICC/ACR DI measures cumulative and irreversible organ damage. It is a summary scale that uses 12 categories representative of organ systems: ocular, neuropsychiatric, renal, pulmonary, cardiovascular, peripheral vascular, gastrointestinal, musculoskeletal, skin, premature gonadal failure, diabetes, and malignancy. The summary scores ranged from zero (no damage) to 46 (maximum damage).\textsuperscript{17,85}

3.4. \textit{Data Analyses}

The analysis plan included both univariate and multivariate analyses. Univariate analyses provided information about the characteristics of the samples to assist in
confirming that the planned analyses were appropriate. Linear regression analysis was used to test and explain the relationships among variables. All analyses were performed using version 9.3 of SAS and were based on the following research questions and study hypotheses:

**Research Question 1:** Which has a stronger association with decreased work and regular daily activities, poor emotional health or poor physical health?

**Hypothesis 1:** Among an ethnically-diverse sample of women with SLE and related controls, poor emotional health has a greater association with a decrease in work and regular daily activities than physical health and corticosteroid use will exacerbate poor emotional health.

The statistical model for hypothesis one (see Appendix C) depicts the association among corticosteroids, emotional health, physical health and work and regular daily activities. Two separate models were constructed to assess which variable (emotional health or physical health) had a stronger association with work and regular daily activities; the result of this assessment is the outcome variable.

Descriptive, bivariate and linear regression analytic test were used to test hypothesis one. Descriptive analysis was conducted to examine sample characteristics of variables: race/ethnicity, age, education, employment status, corticosteroid use, disease damage and comorbid medical conditions. Bivariate analysis was conducted to assess the association between variables: emotional health versus work and regular daily activities-role physical and physical health versus work and regular daily activities-role emotional. A chi-square test was used for categorical variables and the two-sample student’s t-test was used for continuous variables to assess crude (unadjusted) differences in the means.
of the summary scores between groups. The *Wilcoxon rank sum test*, was used to compare differences between women with SLE and controls for scores pertaining to physical health, work and regular daily activities-role emotional, and work and regular daily activities-role physical. Instead of comparing two sample means, two population medians were compared. The Spearman rank correlation coefficient was used to measure the strength of the association between variables of interest: emotional health versus work and regular daily activities-role physical, physical health versus work and regular daily activities-role emotional and corticosteroid use.

Linear regression analyses were performed to assess the association among corticosteroid use, emotional health, physical health and work and regular daily activities-role physical. There were a total of three regression equations for research question one. The following were tested: (1) whether there was an association between emotional health and work and regular daily activities-role physical; (2) whether there was an association between physical health and work and regular daily activities-role emotional; and (3) whether the association between emotional health and regular daily activities-role physical was exacerbated by corticosteroid use. See linear regression equations below:

**Regression Equations:**

- **Sub-aim 1a:** To assess the association between emotional health and work/regular daily activities among women with SLE and related controls:
  
  \[ Y \text{ (work and regular daily activities-role physical)} = i + \beta_1 X \text{ (emotional health)} + e \]
• **Sub-aim 1b:** To assess the association between physical health and work/regular daily activities among women with SLE and related controls

  o \[ Y \text{ (work and regular daily activities-role emotional)} = i + \beta_1 X \text{ (physical health)} + e \]

• **Sub-aim 1c:** To determine if the association among emotional health and work and daily activities are exacerbated by corticosteroid use among women with SLE

  o \[ Y \text{ (work and regular daily activities)} = i + \beta_2 X \text{ (emotional health)} + \beta_3 Z \text{(corticosteroid use)} + e \]

**Research Question 2:** Which ethnic differences exist in the association between emotional health, and work and regular daily activities among Gullah African American, non-Gullah African American and Caucasian American women with SLE?

**Hypothesis 2:** Ethnicity will moderate the relation between emotional health and work and regular daily activities. Specifically, non-Gullah African Americans are more likely to experience a decrease in emotional health and work and regular daily activities when compared to Gullah African Americans and Caucasian women with SLE.

The statistical model for hypothesis two (see Appendix D) depicts the moderating effects of ethnicity on emotional health and work and regular daily activities-role physical among women with SLE only. Bivariate analysis was conducted to assess the association between variables: emotional health and work and regular daily activities-role physical. The chi-square test was used for categorical variables and the one-way ANOVA F test was used for continuous variables to assess crude (unadjusted) differences in means of the summary scores between groups. The Tukey-Kramer post hoc test was used
to determine whether the means among the three ethnic groups differed significantly. The Kruskal-Wallis test, was used to compare ethnic groups (Gullah African Americans, non-Gullah African Americans and Caucasian American women with SLE) for work and regular daily activities-role emotional.

Linear regression analyses were performed to assess the relationship between emotional health and work and regular daily activities-role physical and the potential moderating effect of ethnicity among women with SLE There were a total of six regression equations for research question two. The following were tested: (1) whether there was an association between emotional health and work and regular daily activities-role physical; (2) whether the association between emotional health and work and regular daily activities was exacerbated by ethnicity, a moderator variable; (3) whether the association between emotional health and work and regular daily activities-role physical was influenced by corticosteroid use; and (4) whether the association between emotional health and work and regular daily activities-role physical was influenced by covariates such as age, education, work status, disability status, stroke, dialysis and depression. Of the 16 comorbidities assessed, dialysis and stroke were included in the model since they are damaging conditions and more likely to cause depression when compared to the other comorbidities. Depression was included in the model since it is directly related to emotional health. See linear regression equations below:

**Regression Equations:**

- **Sub-aim 2a:** To assess the association between emotional health and work/regular daily activities among women with SLE
o Y (work/regular daily activities-role physical)= i+β₁X (emotional health)+e

- **Sub-aim 2b**: To assess the moderating effect of ethnicity on emotional health and work and regular daily activities
  o Y(work/regular daily activities-role physical)= i+β₁X (emotional health)+β₂Q (ethnicity) + emotional health*ethnicity)+e

- **Sub-aim 2c**: To assess the association among emotional health, ethnicity, corticosteroid use and work/regular daily activities among women with SLE.
  o Y(work/regular daily activities-role physical)= i+β₁X (emotional health)+β₃Z (potential corticosteroid use) +e

- **Sub-aim 2d**: To determine if the association among emotional health and work/regular daily activities is influenced by potential covariates which include, education, age, disability status, stroke, dialysis and depression
  o Y(work/regular daily activities-role physical)= i+β₁X (emotional health)+β₃Z (potential covariates) +e
4. **Results**

4.1. **Sample Characteristics**

Characteristics of the sample can be found in Table 2. Overall, the study sample included N=284 women. Of the total sample, 79% (n=224) were cases with SLE and 21% (n=60) were controls. Participants ranged in age from 14 to 67 and consisted of a racially and ethnic-diverse make-up of Gullah African Americans (n=141), non-Gullah African Americans (n=86) and Caucasian Americans (n=57). Among cases, non-Gullah African Americans (38%) and Gullah African Americans (39%) accounted for the majority of the sample. Controls were primarily Gullah African American (90%) while a small proportion included non-Gullah African Americans (3%) and Caucasian Americans (7%). Women with SLE were slightly younger with a mean age of 39 compared with controls 42. Ninety percent (90%) of the sample had at least a high school education while cases were more likely to have a college education compared with controls (11% vs. 4%).

As would be expected, women with SLE were more likely to be disabled as measured by employment status when compared with controls (28% vs. 3%). Corticosteroid use and disease damage as measured by the Systemic Lupus International Collaborating Clinics/American College of Rheumatology damage index (SLICC/ACR DI) are also described for cases in table 2. Among women with SLE, the mean duration of years was 5.57. Among women with SLE, the SLICC/ACR DI mean score was 2.41 with 24 percent of women with SLE experiencing disease damage. When evaluating comorbid medical conditions, women with SLE had higher rates of herpes (18% vs. 2%),
malignancy/cancer (8% vs. 0), Raynauds phenomenon (40% vs. 5%), dialysis (9% vs. 0%), depression (25% vs. 10%), and fibromyalgia (11% vs. 8%) (Appendix F, table 2a.).

4.2. Research Question One

Which has a stronger association with decreased work and regular daily activities, emotional health or physical health?

4.2.1. Disease Status Comparisons

Table Three shows correlation coefficients of study variables, emotional health, physical health, work and regular daily activities-role physical and work and regular daily activities-role emotional before and after adjusting for corticosteroid use. Higher emotional health scores were correlated with higher scores for work and regular daily activities-role physical (r-estimate=0.17, p <0.01). After adjusting for corticosteroid use, emotional health remained significantly correlated with work and regular daily activities-role physical (r-estimate=0.40, p <0.01). Similarly, higher physical health scores were correlated with higher scores for work and regular daily activities-role emotional (r-estimate=0.60, p <0.01).

Table Four shows results from group comparisons using the Student’s t-test, and the Wilcoxon rank sum test. Women with SLE reported higher emotional health scores than controls (18.16, vs. 11.08, p <0.01). In contrast, women with SLE reported lower scores in the areas of physical health (22.02 vs. 26.22, p <0.01), work and regular daily activities-role physical (13.40 vs. 16.91, p<0.01) and work and regular daily activities-role emotional (11.58 vs. 12.62, p<0.05) compared with controls.
Table Five shows linear regression analyses for the association between variables of interest: emotional health, physical health, work and regular daily activities-role emotional and work and regular daily activities-role physical. Model one was unadjusted and used to determine if there was an association between physical health and work and regular daily activities-role emotional. Higher physical health scores were associated with higher work and regular daily activities-role emotional scores ($\beta=0.36$, $p<0.01$). Model two also unadjusted, was used to assess the association between emotional health and work and regular daily activities-role physical. Emotional health was not significantly associated with work and regular daily activities-role physical ($\beta=0.04$, $p=0.43$). To further assess the relationship between emotional health and work and regular daily activities-role physical, the final model adjusted for the potential moderating effect of corticosteroid use. This analysis was restricted to women with SLE only. After adjusting for corticosteroid use in the model, emotional health was significantly associated with work and regular daily activities-role physical ($\beta= 0.38$, $p<0.01$). In summary, women with SLE had lower physical health scores when compared with controls. As seen by the model, emotional health scores were higher among women with SLE compared with controls. However, physical health had a stronger association with work and regular daily activities compared with emotional health. However, when the analysis was restricted to women with SLE only and adjustments were made for the effect of corticosteroids, emotional health was significantly associated with work and regular daily activities.
4.3. Research Question Two

Which ethnic differences exist in the association between emotional health, and work and regular daily activities among Gullah African American, non-Gullah African American and Caucasian American women with SLE?

4.3.1. Ethnic Comparisons

Group comparisons among women with SLE using chi-square test, the one-way ANOVA and the Kruskal-Wallis Test were used to assess the association among emotional health, work and regular daily activities-role physical and ethnicity. The following covariates were also added to the model corticosteroids, education, disability status, age, depression and hypertension. As seen in Table Six, racial and ethnic-differences were observed for emotional health scores (p<0.004) and work and regular daily activities-role physical scores (p<0.04). To further evaluate significant associations, a post-hoc analysis was conducted to determine differences among ethnic groups. With regards to emotional health, significant ethnic differences were observed between non-Gullah African Americans and Caucasians American women with SLE and Gullah African Americans and Caucasian American women with SLE (post-hoc p=0.004). Overall, non-Gullah African Americans reported similar emotional health scores compared to Gullah African Americans and lower scores when compared to Caucasian American women with SLE (17.46, 17.70 vs. 20. 10). For work and regular daily activities-role physical, significant ethnic differences were observed between Non-Gullah African American and Caucasian American women with SLE (post-hoc p<0.03). Non-
Gullah African Americans had lower scores in work and regular daily activities-role physical compared to Caucasian American women with SLE (12.74 vs. 14.94).

Table Six shows unadjusted and adjusted linear regression analyses for emotional health and work and regular daily activities-role physical. Model one was used to assess the association between emotional health and work and regular daily activities-role physical. Higher emotional health scores were significantly associated with higher scores for work and regular daily activities-role physical ($\beta=0.40$, p<0.01). Model two further assessed the association between emotional health and work and regular daily activities-role physical adjusting for the ethnicity. In this model, the association between emotional health and work and regular daily activities remained significant ($\beta=0.36$, p<0.01). To further examine the effect of ethnicity, a test for interaction between ethnicity and emotional health was conducted. The findings concluded that race/ethnicity acted as a moderator between emotional health and work and regular daily activities-role physical (p<0.01). In the third model, the adjusted effects of ethnicity and corticosteroid use were assessed. The association between emotional health and work and regular daily activities remained significant ($\beta=0.37$, p<0.01). The fourth model adjusted for the effects of ethnicity, education, age, disability status, stroke, dialysis, and depression. After adjusting for these variables, the association between emotional health and work and regular daily activities-role physical remained significant but was decreased ($\beta=0.23$, p<0.01).
5. **Discussion**

5.1. **Summary of Findings**

This study explored the relationship among variables related to everyday life for women with SLE, variables studied included emotional health, physical health, corticosteroid use and work and regular daily activities. The following were hypothesized: (1) poor emotional health has a greater association with a decrease in work and regular daily activities than physical health and (2) non-Gullah African American women are more likely to experience a decrease in emotional health and work and regular daily activities compared with Gullah African Americans and Caucasian women with SLE.

Results of this study indicate physical health has a statistically significant greater association with decreased work and regular daily activities compared with emotional health. Additionally, statistically significant ethnic differences exist in the association between emotional health and work and regular daily activities among women with SLE. Non-Gullah African American women with SLE had similar emotional health scores compared with Gullah African Americans and lower scores compared with Caucasian American women. However, non-Gullah African American women with SLE had lower scores for work and regular daily activities compared with Gullah African Americans and Caucasian Americans. Each of these associations was statistically significant. Based on the sample of women in this study, emotional health outcomes were better for women with SLE compared with controls. High emotional health scores reported by non-Gullah African Americans and Gullah African American women with SLE may be influenced by racial and cultural-related factors such as the adoption of the Superwoman role and
learned culturally-accommodating behaviors.\textsuperscript{5} African American women, both non-Gullah and Gullah, who adopt the Superwoman role are more likely to engage in emotional suppression which can lead to detrimental changes in immune functioning, illness and mortality.\textsuperscript{4,31}

Women with SLE in this study reported higher emotional health scores than controls. These findings are contrary to general themes in SLE studies which have concluded that individuals with SLE report poorer emotional health compared with controls.\textsuperscript{6,17,20,42,86-88} However, these findings closely parallel those of Bernado et al. who conducted a study comprised of Gullah African American women with SLE and found that women with SLE had better emotional health outcomes compared with controls and the general population. Again, high emotional health scores reported by women with SLE in this study may be influenced by cultural factors such as masking emotion,\textsuperscript{5} disease-coping mechanisms, religion and strong familial and social support due to the high prevalence of multi-patient families with SLE among the Gullah.\textsuperscript{35} As previously mentioned, here may have also been interplay between these cultural factors and the adoption of a Superwoman role by Gullah African Americans and non-Gullah African Americans who collectively comprised the majority of women with SLE (77\%) in the study sample. The Superwoman role, a survival mechanism adopted by African American women to cope with racism and oppression\textsuperscript{4,31} could have manifested in the form of stress-relating coping strategies such as an obligation to manifest strength, an obligation to suppress emotions, and resistance to being vulnerable. Despite the negative impact of certain aspects of the Superwoman role on health outcomes, there are also positive aspects of this phenomenon; these positive impacts have benefited African
American women who have managed historically to demonstrate strength in the face of adversity and tremendous hardship.\(^4\)

Correlation analysis revealed an association between emotional health and work and regular daily activities among women with SLE and controls. However, this association was not detected when linear regression analysis was conducted. The lack of a significant association detected between emotional health and work and regular daily activities-role physical was consistent with research findings of\(^{89}\) Almehed et al.; their research reported a lack of association between a related emotional health variable and working ability among 163 women with SLE. As suggested by Almehed et al., other variables such as social support and socioeconomic status may be more likely to demonstrate this dependence\(^{2,27,44,89}\) However, due to limitations in the data collected, these variables were not assessed in this study.

This study attempted to extend previous examinations of the association of emotional health and work and regular daily activities among cases and controls\(^{1,65,89}\) by assessing the moderated effect of corticosteroids, a common treatment in SLE known to cause emotional distress, mood disorders and psychiatric disorders\(^{15,24,25,66,90,91}\) Despite the well-documented side-effects of corticosteroid use, prior studies assessing the effects of corticosteroids and the associations between SLE and emotional health and work and regular daily activities are scant\(^{21}\) As previously mentioned, a significant association was not detected for emotional health and work and regular daily activities. However, after adjusting for corticosteroid use a significant association between emotional health and work and regular daily activities-role physical was detected. These findings suggest
corticosteroid use influences the strength of the association between emotional health and work and regular daily activities.

Racial and ethnic-differences were detected for emotional health scores among women with SLE only. Non-Gullah African American women reported poorer emotional health compared to Gullah African Americans and Caucasian American women with SLE. These findings are consistent with a study conducted by Alarcón et al. to determine baseline factors predictive of self-reported HRQoL early in the course of SLE.\textsuperscript{92} Similar to this study’s sample, Alarcón’s study included a racially-and ethnically diverse-sample comprised of Hispanics from Texas, Hispanics from Puerto Rico, African Americans and Caucasian Americans (N=1,351).\textsuperscript{92} According to Alarcón and colleagues, African American ethnicity was associated with poorer emotional health compared with Hispanic in Texas, Hispanics in Puerto Rico and Caucasian American women with SLE. Additionally, significant ethnic differences in emotional health scores were observed between Caucasian Americans and Gullah African Americans and Caucasian Americans and non-Gullah African Americans. However, significant emotional health differences were not detected between non-Gullah African Americans and Gullah African Americans. Although there are unique cultural differences between these two groups, significant differences in emotional health may not have been observed due to shared racial and sociocultural experiences, environmental stressors, coping strategies, and disproportionate disease activity and damage.\textsuperscript{4,5,9}

Women with SLE reported lower scores for physical health, a finding which is consistent with the empirical literature on SLE and HRQoL.\textsuperscript{6,17,23,26,35,88,92} Further analyses revealed that physical health, a finding which is consistent with empirical had a
greater association with work and regular daily activities compared with emotional health. These findings closely parallel empirical findings that have illuminated the fact that decreases in physical health and work and regular daily activities accompany SLE.\textsuperscript{6,13,23,87}

Consistent with previous research findings reported by Bertoli et al.,\textsuperscript{39} and Baker and Pope,\textsuperscript{1} racial ethnic differences in work and regular daily activities were observed in this study. In particular, significant differences were observed for non-Gullah African Americans and Caucasian American women with SLE. When examining this association, non-Gullah African Americans experienced more deficits in work and regular daily activities compared with their Caucasian American counterparts. These findings are consistent with previous research findings\textsuperscript{1,39} that revealed African Americans were more likely to report work disability, which falls under the broad category of work and regular daily activities.

5.2. Limitations

Several limitations were noted for this study. The sample came from a limited geographical area (South Carolina) and consisted of an ethnically unique sample of non-Gullah African American, Gullah African American and Caucasian American women. As a result of the unique quality of this sample, results from this population cannot be generalized to the broader U.S. population of women with SLE. Furthermore, the majority of controls consisted of Gullah African American women who did not match the entire sample of women included in this study, which may have introduced selection bias. “Family-member Gullah controls were included in this study. Since first-degree relatives of individuals with SLE are at increased risk for developing the condition, there may
have been controls with undiagnosed SLE in this study. However, this is unlikely given that all participants underwent an in-person evaluation by a rheumatologist to assess for signs or symptoms of autoimmune disease. In addition, all subjects had their blood tested for autoantibodies prior to final determination of case or control status. The inclusion of relatives of individuals with SLE may be confounding study findings; shared genetic profiles may have contributed to the outcome of interest not accounted for in the analysis. Future studies should compare individuals with SLE to unrelated controls separately from the combined control group and: a sensitivity analysis should be conducted to determine whether the use of related controls significantly influences the results of the analysis. Additionally, the inclusion of controls with other physical health and emotional health conditions (because controls were population-based and not necessarily healthy) may have influenced HRQoL outcomes.

This study utilized a cross-sectional design. Consequently, causal relationships between variables cannot be inferred. When assessing corticosteroid use among women with SLE, current use and history of use were not differentiated during the analysis. As a result, the influence of corticosteroid use may have influenced findings related to the association between emotional health and work and regular daily activities when the influence of corticosteroid use was examined. Future analysis should include corticosteroid use in the questionnaires completed by each individual in the study.

Although significant associations were detected among variables of interest, it is likely that variables other than those included in this study may affect work and regular daily activities. For instance, women with SLE who have a spouse, partner or strong social support may be more likely to leave the workforce after being diagnosed with a
chronic condition like SLE. However, for women who are the sole head of household or who lack social support, leaving the workforce may not be an option unless these women are forced to leave as a result of severe disease damage. Better physical health has been correlated with younger age, better self-efficacy for disease management, adequate social support and lower levels of disease activity and damage. Better emotional health has been correlated with adequate social support, higher family income and more knowledge about lupus. Unfortunately, data pertaining to social support, self-efficacy, socioeconomic status or knowledge about lupus was not examined in this study.

A major aim of this study was to understand differences among a racially and ethnically-diverse sample related to SLE. Little is known about how certain factors in SLE vary among women from different racial and ethnic groups. The scales used to measure study variables were limited in accounting for ethnic differences. For instance, the SF-36 scale used to measure emotional health may not have accurately measured the concept since aspects of emotional health may have had different meanings to each racial-ethnic group.

5.3. Implications

The findings from this study have implications for research and public health practice. Women with SLE represent a population disproportionately impacted by poor emotional and physical health, loss of self-esteem, and loss in earning potential when compared to the general U.S. population of women. Since women account for 47% of the workforce and are more likely to be caregivers for children and the elderly, SLE has profound effects on families and society. These effects are even more
pronounced for African American families. In 1970, 65 percent of African American families were headed by two parents.\textsuperscript{94} Census data from 2012 indicate that in recent years only 33 percent of African American families were headed by two parents.\textsuperscript{95} Fifty-six percent (56\%) were headed by single mothers.\textsuperscript{96} As a result, African American families are disproportionately disadvantaged when the mother is living with SLE and is unable to carry-out work and regular daily activities. Implications include loss in the ability to care for children and elderly parents and the inability to sustain a financially-stable household. Given the huge responsibility of single parenting, African American women with SLE who adopt the Superwoman role are more likely to adopt stress-related health behaviors: these include postponing self-care, engaging in emotional eating, and suffering from a lack of sleep.\textsuperscript{4,31} These behaviors in turn, increase risk for SLE flares and worsen disease damage.

Some of the stressors faced by African American women include, daily hassles or discrimination; limited access to medical care (including financial access, medical insurance and organizational access) and limited social capital, (stable neighborhoods and civic engagement).\textsuperscript{30} These stressors negatively affect coping strategies.\textsuperscript{30} To advocate effectively and develop interventions and promote public health strategies, practitioners and researchers must take into consideration the Superwoman role and the unique ethnic differences among women with SLE. Furthermore, racially-and ethnically-related sociocultural factors, environmental stressors, stress-related coping and emotional health outcomes must also be considered. Ignoring the heterogeneity and group differences among various populations can result in severe health consequences for women with SLE in terms of self-management, and treatment modalities.\textsuperscript{5} Culture is a broad construct that
strongly influences health behaviors and outcomes. Providers and researchers must critically examine this construct by conducting collaborative research with women living with SLE; this research can help identify important cultural factors that can be embedded in culturally competent health care practices and research studies to eliminate health disparities. Furthermore, the findings from this study support the need for collecting data pertaining to race and ethnicity. For studies conducted in the U. S., trial participants should be asked self-report questions about race and ethnic ancestral origin given the association among these variables with health outcomes.

Although corticosteroid use was not significantly associated with emotional health and work and regular daily activities, the negative emotional side effects of this treatment cannot be ignored. The threshold steroid dose for emotional effects is variable among different individuals and must also be considered. Healthcare providers must educate women with SLE regarding the emotional side effects associated with this treatment and encourage utilization of mental health services and the incorporation of stress-coping strategies into daily living.

The findings from this study shed light on the need for public health researchers and practitioners to investigate, develop and promote (1) culturally-relevant interventions focused on improving physical health, emotional health and stress-related coping strategies for women with SLE and (2) workplace policies and practices amenable to women with SLE and other chronic conditions that impact their ability to carry-out work-related activities and sustain employment. Considerations for developing and implementing culturally relevant interventions for women with SLE include elements that are ethnic specific, transportation, childcare and peer support. Effectively addressing
emotional and physical health outcomes, can help to reduce the societal financial burden associated with high health care costs connected to SLE, as well as the individual costs associated with decreased work productivity.97

5.4. Future Research

Future research examining emotional health and related HRQoL variables in women with SLE must include corticosteroid use and ethnicity which have a moderating effect as shown in this study. Future studies are also needed to explore modifiable risk factors associated with a decrease in work and regular daily activities among women with SLE. These studies must take into account ethnic differences related to work and regular daily activities and factors that contribute to these differences. For instance, stress and stress related-coping strategies play a significant role in health behaviors and health outcomes for women with SLE. One could argue that these stress-related coping strategies are related to work and regular daily activities due to their impact on emotional and physical health among women with SLE. It is important for researchers to investigate stress and stress-related coping among various ethnic groups in order to effectively examine its role in contributing to poor health outcomes and to develop appropriate interventions. In the current study, the SWS framework was used because it conceptualizes the experiences of African American women in terms of racism, race/gender-based oppression and disenfranchisement. The statistically significant ethnic differences in HRQoL outcomes detected in this study illustrate the important need to explore culturally-relevant stress scales and measures for the Superwoman Schema.

Although not assessed in the current study, lower socioeconomic status was found to be significantly associated with a decrease in work and regular daily activities in the
empirical literature.\textsuperscript{1,2,37,44,59} The similarity of the findings from the current study and research by Baker and Pope, Bertoli et al. and others strengthen the argument that ethnicity is strongly associated with a decrease in work and regular daily activities and point to the importance of examining related factors such as socioeconomic status.\textsuperscript{1,39} Although it can be difficult to address socioeconomic status through interventions it is important to acknowledge the role of socioeconomic status in SLE and HRQoL outcomes. Factors influenced by socioeconomic status include access to health care and preventive services, environmental stressors and residential neighborhood options, which influence exposure to toxic pollutants that cause adverse health outcomes.

5.5. Conclusions

In summary, findings from this study highlight the importance of targeting emotional health and physical health outcomes among individuals with SLE to prevent decreases in work and regular daily activities. Consistent with research conducted by Johnson-Spruill and Toni Tripp\textsuperscript{5} on Gullah African Americans, this study sought to examine differences within and across African American populations. In the U.S., African Americans also known as Black Americans are seen as a homogenous group.\textsuperscript{5} To the contrary, Blacks can be subdivided into the following groups: 1) those born into slavery; 2) those free before the Emancipation Proclamation and 3) Blacks who voluntarily immigrated to the United States.\textsuperscript{5} Despite the diversity that exists within the African American population, cultural differences are not always considered in public health research and practice. Since there are ethnic variations in SLE incidence, prevalence, disease damage and mortality, this study assessed ethnic differences in
variables of interest. Not only were differences in emotional health, physical health and work and regular daily activities detected between cases and controls, ethnic differences were also observed. HRQoL outcomes such as emotional health, physical health and work and regular daily activities play such a vital role in quality of life for women, families and communities. Since SLE is such a debilitating chronic condition, public health researchers and practitioners must put equal emphasis on improving quality of life and decreasing mortality. However, these improvements in SLE outcomes can only be accomplished if racial and ethnic-sociocultural factors are examined in research and accounted for in the development and implementation of interventions and public health strategies.
6. References


Ref Type: Generic


Ref Type: Generic


Ref Type: Online Source


(76) Saba J, Quinet RJ, Davos WE et al. Inverse correlation of each functional status scale of the SF-36 with degree of disease activity in systemic lupus erythematosus (m-SLAM). *Joint Bone Spine.* 2002;348-351.


(78) Ware, JE. SF-36 Health Survey Update. 2012. Ref Type: Online Source


Ref Type: Online Source


Appendices

APPENDIX A: Conceptual Model for Women with Systemic Lupus Erythematosus (SLE) and Controls
### APPENDIX B: American College of Rheumatology Classification Criteria for SLE*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. Malar Rash</td>
<td>Fixed erythema, flat or raised, over the malar eminences, tending to spare the nasolabial folds</td>
</tr>
<tr>
<td>2. Discoid rash</td>
<td>Erythematous raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions</td>
</tr>
<tr>
<td>3. Photosensitivity</td>
<td>Skin rash as a result of unusual reaction to sunlight, by patient history or physician observation</td>
</tr>
<tr>
<td>4. Oral ulcers</td>
<td>Oral or nasopharyngeal ulceration, usually painless, observed by physician</td>
</tr>
<tr>
<td>5. Nonerosive arthritis</td>
<td>Involving 2 or more peripheral joints, characterized by tenderness, swelling, or effusion</td>
</tr>
</tbody>
</table>
| 6. Pleuritis or pericarditis | 1. Pleuritis--convincing history of pleuritic pain or rubbing heard by a physician or evidence of pleural effusion  
   - **OR**  
   2. Pericarditis--documented by electrocardiogram or rub or evidence of pericardial effusion |
| 7. Renal disorder | 1. Persistent proteinuria > 0.5 grams per day or > than 3+ if quantitation not performed  
   - **OR**  
   2. Cellular casts--may be red cell, hemoglobin, granular, tubular, or mixed |
| 8. Neurologic disorder | 1. Seizures--in the absence of offending drugs or known metabolic derangements; e.g., uremia, ketoacidosis, or electrolyte imbalance  
   - **OR**  
   2. Psychosis--in the absence of offending drugs or known metabolic derangements, e.g., uremia, ketoacidosis, or electrolyte imbalance |
| 9. Hematologic disorder | 1. Hemolytic anemia--with reticulocytosis  
   - **OR**  
   2. Leukopenia--< 4,000/mm³ on ≥ 2 occasions  
   - **OR** |

* SLE: Systemic Lupus Erythematosus
<p>| | |</p>
<table>
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<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 3. | Lyphopenia—< 1,500/ mm³ on ≥ 2 occasions  
   | OR |
| 4. | Thrombocytopenia—<100,000/ mm³ in the absence of offending drugs |
| 10. Immunologic disorder | 1. Anti-DNA: antibody to native DNA in abnormal titer  
   | OR  |
|   | 2. Anti-Sm: presence of antibody to Sm nuclear antigen  
   | OR  |
|   | 3. Positive finding of antiphospholipid antibodies on:  
   |   | 1. an abnormal serum level of IgG or IgM anticardiolipin antibodies,  
   |   | 2. a positive test result for lupus anticoagulant using a standard method, or  
   |   | 3. a false-positive test result for at least 6 months confirmed by Treponema pallidum immobilization or fluorescent treponemal antibody absorption test |
| 11. Positive antinuclear antibody | An abnormal titer of antinuclear antibody by immunofluorescence or an equivalent assay at any point in time and in the absence of drugs |

APPENDIX C: Statistical Model for Hypothesis One

SPECIFIC AIM 1: To determine if a sample of women with SLE and controls report that emotional health has a greater association of decreased work/daily activities compared with physical health and if the relationship between emotional health is exacerbated by corticosteroid use.

- **Sub-aim 1a:** To assess the association between emotional health and work/regular daily activities among women with SLE and related controls
- **Sub-aim 1b:** To assess the association between physical health and work/regular daily activities among women with SLE and related controls
- **Sub-aim 1c:** To determine if the association between emotional health and work and daily activities is exacerbated by corticosteroid use among women with SLE

HYPOTHESIS 1: Among an ethnically-diverse sample of women with SLE and related controls, poor emotional health has a greater association with a decrease in work and regular daily activities than physical health and corticosteroid use will enhance poor emotional health.

STATISTICAL MODEL 1:

Regression Equations:

- **Sub-aim 1a:** To assess the association between emotional health and work/regular daily activities among women with SLE and related controls
  
  \[ Y \text{ (work and regular daily activities - role physical)} = \beta_1 X \text{ (emotional health)} + e \]

- **Sub-aim 1b:** To assess the association between physical health and work/regular daily activities among women with SLE and related controls
  
  \[ Y \text{ (work and regular daily activities - role emotional)} = \beta_1 X \text{ (physical health)} + e \]

- **Sub-aim 1c:** To determine if the association among emotional health and work and daily activities is exacerbated by corticosteroid use among women with SLE
  
  \[ Y \text{ (work and regular daily activities)} = \beta_1 X \text{ (emotional health)} + \beta_2 Z \text{(corticosteroid use)} + e \]
APPENDIX D: Statistical Model for Hypothesis Two

SPECIFIC AIM 2: To evaluate if there are ethnic differences in associations among corticosteroid use, emotional health and work and regular daily activities in non-Gullah African American, Gullah African American and Caucasian women with SLE.

HYPOTHESIS 2: Ethnicity will moderate the relation between emotional health and work and regular daily activities. Specifically, non-Gullah African American women will report a greater decrease in emotional health and work and regular daily activities compared with Gullah African Americans and Caucasian women with SLE.

- **Sub-aim 2a**: To assess the association between emotional health and work/regular daily activities among women with SLE
- **Sub-aim 2b**: To assess the moderating effect of ethnicity on emotional health and work and regular daily activities
- **Sub-aim 2c**: To assess the association among emotional health, ethnicity, corticosteroid use and work/regular daily activities among women with SLE.
- **Sub-aim 2d**: To determine if the association among emotional health and work/regular daily activities is influenced by potential covariates which include, education, age, disability status, stroke, dialysis and depression

STATISTICAL MODEL 2:

Regression Equations:
- **Sub-aim 2a**: To assess the association between emotional health and work/regular daily activities among women with SLE
  - \[ Y \text{ (work/regular daily activities-role physical)} = i + \beta_1 X \text{ (emotional health)} + e \]
- **Sub-aim 2b**: To assess the moderating effect of ethnicity on emotional health and work and regular daily activities
  - \[ Y \text{(work/regular daily activities-role physical)} = i + \beta_1 X \text{ (emotional health)} + \beta_2 Q \text{ (ethnicity)} + \text{emotional health*ethnicity} + e \]
- **Sub-aim 2c**: To assess the association among emotional health, ethnicity, corticosteroid use and work/regular daily activities among women with SLE.
Sub-aim 2d: To determine if the association among emotional health and work/ regular daily activities is influenced by potential covariates which include, education, age, disability status, hypertension, and depression

- \[ Y(\text{work/regular daily activities-role physical}) = \beta_1 X (\text{emotional health}) + \beta_2 Z (\text{potential corticosteroid use}) + e \]
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>SLE cases (n=224)</th>
<th>Related controls (n=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Gullah African American n (%)</td>
<td>84 (38)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Gullah African American n (%)</td>
<td>87 (39)</td>
<td>54 (90)</td>
</tr>
<tr>
<td>Caucasian American n (%)</td>
<td>53 (24)</td>
<td>4 (7)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school n (%)</td>
<td>76 (31)</td>
<td>16 (7)</td>
</tr>
<tr>
<td>High school n (%)</td>
<td>27 (11)</td>
<td>18 (7)</td>
</tr>
<tr>
<td>Some college n (%)</td>
<td>28 (11)</td>
<td>9 (4)</td>
</tr>
<tr>
<td>College n (%)</td>
<td>37 (15)</td>
<td>8 (3)</td>
</tr>
<tr>
<td>Technical college or trade n (%)</td>
<td>17 (7)</td>
<td>4 (2)</td>
</tr>
<tr>
<td>Post graduate n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working (%)</td>
<td>82 (36)</td>
<td>39 (65)</td>
</tr>
<tr>
<td>Retired (%)</td>
<td>15 (7)</td>
<td>5 (8)</td>
</tr>
<tr>
<td>Homemaker (%)</td>
<td>9 (4)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Disabled (%)</td>
<td>62 (28)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Unemployed (%)</td>
<td>30 (13)</td>
<td>9 (15)</td>
</tr>
<tr>
<td>Other (%)</td>
<td>18 (8)</td>
<td>5 (8)</td>
</tr>
<tr>
<td><strong>Corticosteroid use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean duration years ± SD</td>
<td>5.57 ± 4.83</td>
<td>--</td>
</tr>
<tr>
<td><em>SLICC Disease Damage Index</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean ± SD (%)</td>
<td>2.41 ± 1.7 (24)</td>
<td>--</td>
</tr>
</tbody>
</table>

*SLICC: Systemic Lupus International Collaborating Clinics/American College of Rheumatology damage index
Table 2a. Past Medical History of Participants (N= 284)  

<table>
<thead>
<tr>
<th>Condition</th>
<th>SLE cases (n= 224)</th>
<th>Related controls (n=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension (%)</td>
<td>119 (56)</td>
<td>25 (42)</td>
</tr>
<tr>
<td>Hyperlipidemia (%)</td>
<td>46 (23)</td>
<td>15 (25)</td>
</tr>
<tr>
<td>Coronary Artery Disease (%)</td>
<td>6 (3)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Myocardial Infarction (%)</td>
<td>5 (2)</td>
<td>0</td>
</tr>
<tr>
<td>Congestive Heart Failure (%)</td>
<td>5 (2)</td>
<td>0</td>
</tr>
<tr>
<td>Stroke (CVA) (%)</td>
<td>16 (8)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Herpes Zoster (Shingles) (%)</td>
<td>36 (18)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Malignancy/ Cancer (%)</td>
<td>16 (8)</td>
<td>0</td>
</tr>
<tr>
<td>Raynauds Phenomenon (%)</td>
<td>83 (40)</td>
<td>3 (5)</td>
</tr>
<tr>
<td>Thrombosis (blood clot) (%)</td>
<td>24 (12)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Vasculitis (%)</td>
<td>9 (4)</td>
<td>0</td>
</tr>
<tr>
<td>Dialysis (%)</td>
<td>18 (9)</td>
<td>0</td>
</tr>
<tr>
<td>Osteoporosis (%)</td>
<td>39 (20)</td>
<td>0</td>
</tr>
<tr>
<td>Bone Fracture (%)</td>
<td>17 (11)</td>
<td>8 (25)</td>
</tr>
<tr>
<td>Depression (%)</td>
<td>51 (25)</td>
<td>6 (10)</td>
</tr>
<tr>
<td>Fibromyalgia (%)</td>
<td>19 (11)</td>
<td>3 (8)</td>
</tr>
</tbody>
</table>
Table 3. Association among Emotional Health, Physical Health and Work and Regular Daily Activities Before after Adjusting for Corticosteroid use using Spearman Rank Correlation Coefficient for Cases and Controls

<table>
<thead>
<tr>
<th>Variables</th>
<th>R-estimate</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Health vs. Work and Regular Daily Activities-role physical</td>
<td>0.17</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Physical Health vs. Work and Regular Daily Activities-role emotional</td>
<td>0.60</td>
<td>&lt;0.01*</td>
</tr>
</tbody>
</table>

* Adjusting for Corticosteroid use

<table>
<thead>
<tr>
<th>Variables</th>
<th>R-estimate</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Health vs. Work and Regular Daily Activities-role physical</td>
<td>0.40</td>
<td>&lt;0.01*</td>
</tr>
</tbody>
</table>

* Significant differences detected
### Table 4. Differences in HRQoL scores between women with SLE and controls

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>SLE cases (n=244)</th>
<th>Controls (n=60)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ± SD</td>
<td>Mean ± SD</td>
<td></td>
</tr>
<tr>
<td>Emotional Health</td>
<td>18.16 ± 4.80</td>
<td>11.80 ± 7.32</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Physical Health</td>
<td>22.20 ± 5.89</td>
<td>26.50 ± 5.53</td>
<td>&lt;0.01†</td>
</tr>
<tr>
<td>Work and Regular Daily Activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role Physical</td>
<td>13.40 ± 4.94</td>
<td>16.91± 4.52</td>
<td>&lt;0.01†</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>11.58 ± 3.67</td>
<td>12.62 ± 3.60</td>
<td>0.02†</td>
</tr>
</tbody>
</table>

* Significant difference based on a Student’s t-test
† Significant difference based on Wilcoxon rank sum test
<table>
<thead>
<tr>
<th>Model</th>
<th>Variables</th>
<th>Work and Regular Activities</th>
<th>Role Emotional</th>
<th>Physical Health</th>
<th>Emotional Health</th>
<th>Corticosteroids</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>β</td>
<td>p-value</td>
<td>β</td>
<td>p-value</td>
<td>β</td>
</tr>
<tr>
<td>1</td>
<td>Physical Health</td>
<td>0.36</td>
<td>&lt;0.01†</td>
<td>0.04</td>
<td>0.43</td>
<td>0.38</td>
</tr>
<tr>
<td>2</td>
<td>Emotional Health</td>
<td>--</td>
<td>--</td>
<td>0.38</td>
<td>&lt;0.01†</td>
<td>-1.80</td>
</tr>
<tr>
<td>3</td>
<td>Corticosteroids</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>0.51</td>
</tr>
</tbody>
</table>

Models 1 and 2: Unadjusted. Model 3: Adjusted

† Significant difference detected
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Non-Gullah African Americans (n=79)</th>
<th>Gullah African Americans (n=83)</th>
<th>Caucasian Americans (n=50)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional Health</strong></td>
<td>17.46 ± 4.70</td>
<td>17.70 ± 5.18</td>
<td>20.10 ± 3.80</td>
<td>0.004*</td>
</tr>
<tr>
<td><strong>Work and Regular Daily Activities</strong></td>
<td>12.74 ± 5.03</td>
<td>13.52 ± 4.65</td>
<td>14.94 ± 4.84</td>
<td>0.04*</td>
</tr>
<tr>
<td>Role Physical</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Significant difference were observed for non-Gullah African Americans and Caucasian American women and Gullah African Americans and Caucasian American women with SLE post-hoc p < 0.05
Table 7. Linear regression models for the association between Emotional Health, Physical Health and Work and Regular Daily Activities before and after adjusting for corticosteroid use

<table>
<thead>
<tr>
<th>Model</th>
<th>Variables</th>
<th>β</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>*Emotional Health</td>
<td>0.40</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>2</td>
<td>*Emotional Health</td>
<td>0.40</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>Caucasian American</td>
<td>1.46</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td>Gullah African American</td>
<td>1.13</td>
<td>0.12</td>
</tr>
<tr>
<td>3</td>
<td>*Emotional Health</td>
<td>0.37</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>Caucasian American</td>
<td>1.24</td>
<td>0.19</td>
</tr>
<tr>
<td></td>
<td>Gullah African American</td>
<td>1.39</td>
<td>0.12</td>
</tr>
<tr>
<td></td>
<td>Corticosteroid use</td>
<td>0.07</td>
<td>0.38</td>
</tr>
<tr>
<td>4</td>
<td>*Emotional Health</td>
<td>0.23</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>Caucasian American</td>
<td>0.13</td>
<td>0.26</td>
</tr>
<tr>
<td></td>
<td>*Gullah African American</td>
<td>1.66</td>
<td>0.03</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>0.72</td>
<td>0.29</td>
</tr>
<tr>
<td></td>
<td>*Age</td>
<td>-0.04</td>
<td>0.05</td>
</tr>
<tr>
<td></td>
<td>*Disability Status</td>
<td>-3.21</td>
<td>&lt; 0.01</td>
</tr>
<tr>
<td></td>
<td>Stroke</td>
<td>-0.60</td>
<td>0.43</td>
</tr>
<tr>
<td></td>
<td>Dialysis</td>
<td>-1.33</td>
<td>0.26</td>
</tr>
<tr>
<td></td>
<td>*Depression</td>
<td>-1.77</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Model 1: Unadjusted – Models 2, 3 and 4: Adjusted
*Significant difference were observed