January 2013

Sickle Cell Disease: The Role of Self-Care Management

Nadine Matthie
University of South Florida, nmatthie83@gmail.com

Scholar Commons Citation
Matthie, Nadine, "Sickle Cell Disease: The Role of Self-Care Management" (2013). *Graduate Theses and Dissertations.*
http://scholarcommons.usf.edu/etd/4538

Sickle Cell Disease: The Role of Self-Care Management

by

Nadine S. Matthie

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
College of Nursing
University of South Florida

Major Professor: Susan McMillan, Ph.D., ARNP
Jason Beckstead, Ph.D.
Constance Visovsky, Ph.D., ACNP
William Haley, Ph.D.

Date of Approval:
March 5, 2013

Keywords: self-efficacy, social support, socio-demographics, pain, health functioning

Dedication

I dedicate this work to my family and friends who supported me throughout the years. Thank you for your prayers, encouragement, advice, and for simply lending a listening ear. The journey was a little easier because of you.

Acknowledgments

The completion of this work would not have been possible without a number of individuals. I would like to thank my friends whose experiences sparked my interest in sickle cell disease and whose strength inspired me to contribute to the body of knowledge in this area. I thank Dr. Coretta Jenerette at the University of North Carolina at Chapel Hill for entrusting me with her data for use in this study, for her advice and support, and for always helping no matter the time of day. I thank each member of my committee for their time, guidance, and advice in making this effort a success. Dr. Haley, thank you for your feedback. It helped me to produce better outcomes. Dr. Visovsky, thank you for your feedback, support, and kind words. They were particularly helpful in stressful times. Dr. Beckstead, your statistical expertise is remarkable. Thank you for your assistance with the methodology used in this study and for handing down statistical knowledge that will be instrumental to my work in the future. Dr. McMillan, your continual guidance and support as my faculty advisor and dissertation chair were outstanding. Thank you for believing in me and for pushing me to achieve my full potential.

Table of Contents

List of Tables

List of Figures

Abstract

Sickle cell disease is the most common genetic disorder in the United States. Approximately 90% of the hospitalizations in this patient population occur due to the most common complication, pain crises. Prevention of these crises is therefore essential and requires the patient to assume an active role in his or her disease management. Studies suggest that further research is needed to examine the self-care management process and to identify factors influencing self-care behaviors. The relationships among these factors must be clearly defined before interventions to improve self-care management can be determined. The aims of the study were threefold. The first aim was to evaluate the relationships among psychosocial variables (SCD self-efficacy and social support) and socio-demographic variables (age, gender, education, employment status, income, and living situation) in understanding individual differences in self-care management variables (perceived self-care ability and self-care actions). It was hypothesized that higher SCD self-efficacy, greater social support, being employed, living with family or friends, increased age, more years of education, higher income, and being male are each associated with having higher perceived self-care ability and more frequent self-care actions. The second aim was to evaluate the relationships among psychosocial variables (SCD self-efficacy and social support), socio-demographic variables (age, gender, education, employment status, income, and living situation), and self-care management variables (perceived self-care ability and self-care actions) in understanding hospital visits for crises. It was hypothesized that higher perceived self-care ability and more frequent self-care actions are associated with fewer hospital visits for crises. The third aim was to evaluate the mediational role of perceived self-care ability and self-care actions in the relationships among psychosocial variables (SCD self-efficacy and social support), socio-demographic variables (age, gender, education, employment status, income, and living situation), and the number of hospital visits for crises. It was hypothesized that SCD self-efficacy, social support, and the socio-demographic variables have both a direct and an indirect relationship with the number of hospital visits for crises. In 103 young Black adults (ages 18-30) with sickle cell disease (SCD), an exploratory , correlational study was conducted, via secondary analysis of data, to examine the relationships among SCD self-efficacy, social support, socio-demographic variables, self-care management (self-care ability and self-care actions), and the number of hospital visits for crises. Bivariate correlations and regression analyses were conducted to evaluate the relationships among the variables and to examine the mediational role of self-care management. Sickle cell disease self-efficacy, social support, years of education, and income were significantly related to perceived self-care ability and self-care actions. Social support accounted for the majority of the variance in each self-care management variable. The hypothesis that higher SCD self-efficacy and greater social support are associated with higher perceived self-care ability and more frequent self-care actions was supported. Education was also associated with higher perceived self-care ability and self-care actions as hypothesized. The overall model with SCD self-efficacy, social support, years of education, income, perceived self-care ability, and self-care actions was not significant in predicting the number of hospital visits for crises. There were no significant associations noted among age, annual household income, living situation, employment status, and the self-care management variables. The hypothesis that higher perceived self-care ability and more frequent self-care actions are associated with fewer hospital visits for crises was not supported. Further, there was no adequate evidence to support a direct relationship between SCD self-efficacy, social support, years of education, and the number of hospital visits for crises. The indirect relationship, through self-care management, among the variables was also non-significant. There was however a significant direct relationship noted between income and the number of hospital visits for crises. The outcomes of the study may be important for clinical care, patient education, and health outcomes in the SCD population. Findings may be used to conduct larger confirmatory studies and to develop interventions that may be used to supplement therapy in the clinical setting and to enhance patient self-care management at home. Additional studies are needed, however, to clarify what additional variables may affect the number of hospital visits for crises and to identify specific pain prevention and management strategies used by SCD patients.

Chapter 1: Introduction

Sickle cell disease (SCD) is a group of genetic disorders that is characterized by the development of abnormal hemoglobin (Hgb S), abnormal red blood cells, and the resultant complications (Olowoyeye & Okwundu, 2010). This disease has a high prevalence in Africa, the United States (U.S.), the Caribbean, Central and South America, Saudi Arabia, India, and the Mediterranean (Centers for Disease Control and Prevention, 2011a). Approximately 90,000 to 100,000 Americans are affected by SCD, making it the most common genetic disorder. In the U.S., this disease primarily affects African Americans. Within this group, there is an incidence of one in 500 births and the sickle cell trait occurs in about one in 12. Sickle cell disease is an autosomal recessive disorder, and males and females are affected equally (Pack-Mabien & Haynes, 2009). Diagnosis of SCD is typically made at birth during newborn screening. Disease management focuses on pain, hydration, and preventing infections and other complications that result in vaso-occlusive crises (Lee, Askew, Walker, Stephen & Robertson-Artwork, 2012). The annual estimated costs of medical care for SCD patients total over $1.1 billion; 80.5% of the costs are attributed to inpatient hospital care, 3.2% to emergency department (ED) use, 0.9% to physician visits, and 3.6% to prescription drug use (Kauf, Coates, Huazhi, Mody-Patel & Hartzema, 2009). These facts altogether suggest that SCD has a high public health importance as it places a burden on not only the community of the affected population but also the health care infrastructure.

Abnormal, c-shaped or sickle-shaped, hemoglobin molecules impede circulation through the blood vessels (Olowoyeye & Okwundu, 2010). The cells adhere to each other and to the walls of blood the vessels, blocking blood flow, resulting in decreased circulation to body tissues, decreased oxygen capacity of the red blood cells, organ damage, and pain (vaso-occlusive pain crises). These abnormal red blood cells have short lives and hemolyze frequently, leaving the affected individual in a constant deficiency of red blood cells that results in anemia. Four major types of SCD exist with sickle cell anemia being the most common (Centers for Disease Control and Prevention, 2011b; Fosdal & Wojner-Alexandrov, 2007). Major complications of SCD include vaso-occlusive pain crises, acute chest syndrome, acute splenic sequestration, pneumococcal disease, and cardiovascular accidents (Dick, 2008). These complications, along with chronic renal failure and pulmonary disease, are associated with risk of early death in this patient population (U.S. Department of Health and Human Services, 2002). The only cure for SCD is bone marrow transplantation, but there are few potential donors available, and the procedure can have fatal side effects (Ataga, 2009). Hematopoietic stem cell transplantation has shown promising outcomes, particularly when donors are human leukocyte antigen (HLA) matched siblings; however, older age (transplantation has optimal outcomes during childhood) and advanced disease are associated with poor transplant outcomes (Buchanan, Vichinsky, Krishnamurti & Shenoy, 2010).

The sickling of the cells causes impaired blood circulation which results in pain. This is the most common complication of sickle cell disease. It can begin as early as infancy and can happen unpredictably throughout life (Fosdal & Wojner-Alexandrov, 2007; Jacob, 2001). Sites of pain often include the long bones, joints, the back, the abdomen, and the chest (Smith et al., 2008). The pain may be mild, moderate, or severe, and has been described as sharp, throbbing, stabbing, deep, achy, lacerating, or shooting (Ballas et al., 2010). These pain episodes are the most common reason for hospital visits (Dunlop & Bennett, 2009; Yusuf, Atrash, Grosse, Parker & Grant, 2010). On average, adults with SCD visit emergency departments (ED) over 197,000 times annually; 67% of individuals report pain or unspecified pain as the reason for the ED visit and 29% result in hospital admissions (Yusuf, Atrash, Grosse, Parker & Grant, 2010). Approximately 90% of hospital admissions are for the treatment of acute pain (Dunlop & Bennett, 2009). The frequency of pain crises is indicative of disease severity as they were found to be associated with premature death in individuals over 20 years of age (Pack-Mabien & Haynes, 2009). Pain episodes are most frequent between ages 19 and 39 (Jacob, 2001; Yusuf, Atrash, Grosse, Parker & Grant, 2010). On average, adults have at least one vaso-occlusive pain episode annually (Taylor, Stotts, Humphreys, Treadwell & Miaskowski, 2010). Utilization of the acute care system, however, is highest (3.61 instances per patient per year) for 18 to 30 year olds and in this group, the rate of re-hospitalization within 30 days is 33.4% (Brousseau, Owens, Mosso, Panepinto & Steiner, 2010). Further, patients ages 18 to 30 are more likely to visit multiple hospitals for acute care; this may result in poorly coordinated and poor quality of care (Panepinto, Owens, Mosso, Steiner & Brousseau, 2012). A typical crisis lasts for approximately 10 days, with women reporting longer episodes than men. Physical exertion, extreme temperatures, and stress were noted as aggravating factors (Taylor, Stotts, Humphreys, Treadwell & Miaskowski, 2010). A typical medication regimen for an individual with frequent pain episodes includes hydroxyurea therapy, analgesics, and possible red blood cell transfusion therapy (Pack-Mabien & Haynes, 2009).

Prevention of pain crises is essential to the health maintenance of individuals suffering from SCD. Management of this disorder primarily occurs at home and the focus is on these crises as they often result in ED visits and hospitalizations (U.S. Department of Health and Human Services, 2002). General recommendations from the Centers for Disease Control and Prevention (2010) are that these individuals should receive regular checkups at least annually, stay hydrated, eat a healthy diet, get enough rest, avoid temperature extremes, and prevent infections. Other strategies for managing pain at home include medications, massage therapy, hot showers, distraction, and relaxation (Conner-Warren, 1996; U.S. Department of Health and Human Services, 2002). The use of massage and relaxation/meditation was noted to increase with higher pain intensity (Dampier, Ely, Eggleston, Brodecki & O'Neal, 2004). Analgesic therapy, both opioids and non-opioids, is commonly used to treat acute pain in the home setting. Non-opioids most frequently include non-steroidal anti-inflammatory drugs (Niscola, Sorrentino, Scaramucci, Fabritiis & Cianciulli, 2009). Ibuprofen, acetaminophen, and an acetaminophen codeine mixture are used often (Dampier, Ely, Brodecki & O'Neal, 2002). Opioids may include morphine, hydromorphone, oxycodone, methadone, codeine, or tramadol (Niscola, Sorrentino, Scaramucci, Fabritiis & Cianciulli, 2009). Exchange transfusions and hydroxyurea therapy are also used as preventive strategies to reduce levels of Hgb S and have been helpful in decreasing pain, but these do not completely prevent crises (Dunlop & Bennett, 2009; Pack-Mabien & Haynes, 2009). Some barriers to providing effective pain relief in the home were identified as limited knowledge of coping strategies and inadequate knowledge about the use of analgesics to control pain (Dampier, Ely, Brodecki & O'Neal, 2002).

Several studies have been conducted to assess self-care behaviors utilized by SCD patients. Overarching strategies used by patients to manage their symptoms include self-awareness, emotional support, career selection and success factors, nutrition, advocacy, knowledge, physical activity, as well as complementary and alternative medicine. The most important of these was noted to be self-awareness or the mindfulness of specific behaviors that positively or negatively affect health (Tanabe, Porter, Creary, Kirkwood, Miller, Ahmed-Williams & Hassell, 2010). Additional research on specific strategies used daily by SCD patients in the home setting to maintain health and prevent pain crises is still needed.

Statement of the Problem

Approximately 90,000 to 100,000 individuals in the United States have sickle cell disease (Centers for Disease Control and Prevention, 2011a). Adults of African ancestry experience a significantly higher prevalence of sickle cell disease than other racial or ethnic groups. Without proper self-care in the home setting, the frequency of pain crises and subsequent hospitalizations is likely to increase. Further research is needed regarding self-management of the disease process for reducing the incidence of hospital visits related to pain crises. In addition, factors that affect self-management behaviors need to be further assessed and the interrelationship among variables needs to be clarified in order to effect a change in the health outcomes of SCD patients. The purpose of this exploratory, correlational study was to examine the role of self-care management in young, Black adults (ages 18 to 30) diagnosed with sickle cell disease. To understand hospital visits for crises, the relationships among SCD self-efficacy, social support, socio-demographic variables, and self-care management variables (perceived self-care ability and self-care actions) were examined. Although pain episodes are noted to be most frequent between ages 19 and 39 (Jacob, 2001; Yusuf, Atrash, Grosse, Parker & Grant, 2010), the rates of health care utilization and re-hospitalization are highest between ages 18 and 30 (Brousseau, Owens, Mosso, Panepinto & Steiner, 2010). As such, this study evaluated sickle cell disease patients ranging in age from 18 to 30.

Specific Aims

The aims of the study were threefold. The specific aims and hypotheses are described here.

Aim 1: To evaluate the relationships among psychosocial variables (SCD self-efficacy and social support) and socio-demographic variables (age, gender, education, employment status, income, and living situation) in understanding individual differences in self-care management variables (perceived self-care ability and self-care actions) in young (ages 18 to 30), Black adults with sickle cell disease.

Hypothesis 1a. Higher SCD self-efficacy and greater social support are associated with higher perceived self-care ability and more frequent self-care actions.

Hypothesis 1b. Employment, living with family or friends, increased age, more years of education, and higher income are each associated with higher perceived self-care ability and more frequent self-care actions.

Hypothesis 1c. Males will report having higher perceived self-care ability and more frequent self-care actions than females.

Aim 2: To evaluate the relationships among psychosocial variables (SCD self-efficacy and social support), socio-demographic variables (age, gender, education, employment status, income, and living situation), and self-care management variables (perceived self-care ability and self-care actions) in understanding hospital visits for crises in young (ages18 to 30), Black adults with sickle cell disease.

Hypothesis 2. Higher perceived self-care ability and more frequent self-care actions are associated with fewer hospital visits for crises.

Aim 3: To evaluate the mediational role of perceived self-care ability and self-care actions in the relationships among psychosocial variables (SCD self-efficacy and social support), socio-demographic variables (age, gender, education, employment status, income, and living situation), and the number of hospital visits for crises in young (ages 18 to 30), Black adults with sickle cell disease.

Hypothesis 3. Sickle cell disease self-efficacy, social support, and socio-demographic variables have both a direct and an indirect relationship with the number of hospital visits for crises. Further, the relationships among SCD self-efficacy, social support, socio-demographic variables, and the number of hospital visits for crises are mediated by self-care management.

Definitions of Relevant Terms

The following terms are based on previous research and are defined for the purposes of this study. *Sickle cell disease self-efficacy* is a person's belief in his or her ability to perform daily functional activities despite having SCD (Jenerette & Murdaugh, 2008). Self-efficacy is a major construct in Albert Bandura's social learning theory, later renamed social cognitive theory. It is an individual's perception as to his or her ability to perform specific behaviors that result in specific outcomes. It determines how people feel, think, motivate themselves, and behave (Bandura, 1994). Self-efficacy links self-perceptions with individual actions, is a mediator of health behaviors, and is considered crucial to chronic disease management (Frei, Svarin, Steurer-Stey & Puhan, 2009). *Social support* refers to an individual's perception of available social support; may include positive words, behavior or view affirmation, or giving aid (Jenerette & Murdaugh, 2008). *Socio-demographics* include age, gender, income, education, employment, and living situation. *Self-care management* refers to perceived *self-care ability* and *self-care actions*. *Self-care ability* is the ability to participate in therapeutic behaviors aimed at enhancing and/or maintaining health status and quality of life. *Self-care actions* involve participating in therapeutic activities and using resources to enhance health status and quality of life. These include practices used by patients in the daily management of disease symptoms. Practices may include rest, nutrition, hydration, adherence to medication therapy, use of analgesics, pain management, and other strategies used to prevent crises (Dampier, Ely, Brodecki & O'Neal, 2002; U.S. Department of Health and Human Services, 2002).

Significance to Nursing

Individuals with chronic disease need to engage in both surveillance and health maintenance practices in order to achieve a health status that prevents deterioration and optimizes wellness. An individual has to be knowledgeable about the risk and benefits of various health practices, have a sense of self-efficacy that he or she can control his or her health habits, and have expectations about the costs and benefits of different habits (Bandura, 2004). In order to achieve optimum health, individuals have to set health-related goals, specific steps to achieve the stated goals, and consider the facilitators and obstacles to achieving health-behavior change. One aspect of the treatment plan for chronic illness focuses on self-management of physical conditions over time. In the case of SCD, self-care management and self-efficacy in the home setting may be integral to self pain management thus crisis prevention. As such, an understanding of the mechanisms of self-efficacy and self-care behaviors is important for enhancing health and well-being, especially in this population. Knowledge concerning the disease course, risk for complications, triggers for pain crisis and hospitalization, and medical appointment and medication adherence are aspects of self-care management that can potentially be increased by effective educational efforts. Healthcare professionals can better equip patients with the resources and skills necessary to effectively participate in their disease management. There are limited studies, however, that evaluate the relationship of self-efficacy to SCD self-care management and identify factors that may affect self-efficacy in individuals with SCD. Further, while the literature is replete with studies focused on children and adolescents with sickle cell disease, few studies have been completed with adults. Therefore, this study may shed light on important variables related to self-care management in adults, and how self-care management practice may correlate with the number of hospital visits for pain crises in the adult population with SCD.

Chapter 2: Review of the Literature

A review of literature related to sickle cell disease (SCD) is presented here. The information is organized according to critical concepts associated with management of the disease. These concepts include self-efficacy, social support, socio-demographic variables, and self-care management. Principles of chronic disease management related to these variables are also included here.

Self-efficacy

Sickle cell disease self-efficacy was evaluated in this study; however, the term is not widely published in the literature. In the absence of this information and for the purposes of this study, the principles of self-efficacy were applied to SCD self-efficacy. Self-efficacy links self-perceptions with individual actions, is a mediator of health behaviors, and is considered crucial to chronic disease management (Frei, Svarin, Steurer-Stey & Puhan, 2009). In studies that evaluated chronic conditions, higher levels of self-efficacy were linked to decreased pain severity and fewer self-reported symptoms (Clay & Telfair, 2007) as well as lower levels of depression, stress, and anxiety (Edwards, Telfair, Cecil & Lenoci, 2001). Lower levels of self-efficacy were correlated with more symptoms, higher pain severity, and frequent physician visits. In addition, higher levels of self-efficacy were associated with increased use of adaptive coping mechanisms, decreased anxiety and stress, as well as increased adherence to medical regimens (Edwards, Telfair, Cecil & Lenoci, 2001). In a study involving cancer patients experiencing pain, lower self-efficacy for pursuing medical information was associated with greater barriers to pain management. An inverse relationship between distress and self-efficacy for coping was also noted (Mosher, DuHamel, Egert & Smith, 2010). In SCD, self-efficacy was negatively correlated with the number of crises per year (Jenerette & Valrie, 2010). It was also noted that self-efficacy beliefs were inversely related to symptomatology and health care utilization, and that these beliefs may be predictive of future changes in SCD symptomatology (Clay & Telfair, 2007; Edwards, Telfair, Cecil & Lenoci, 2001).

Social Support

The quality and availability of social support may influence the health outcomes of individuals with chronic illness and may positively affect self-care behaviors (Chlebowy & Garvin, 2006). Types of social support include emotional, instrumental, informational, and appraisal support. Support may be obtained from family, friends, work, and the community (Ngamvitroj & Kang, 2007). Patients' perceptions of satisfaction with this support are important as they have been linked with adherence to medication self-monitoring in individuals with chronic conditions. In chronic disease states, social support from various sources is important. Family support may decrease depression and increase compliance, while support from healthcare providers might increase satisfaction with the healthcare system and decrease perceived discrimination (Nash, 1994). Children with family social support were found to have better disease management behaviors (Sin, Kang & Weaver, 2005). Healthcare provider support improves long-term self-care management and the ability to manage chronic conditions (Loeb, Penrod, Falkenstern, Gueldner & Poon, 2003). In addition, social support was noted to be helpful in following treatment plans (Cox, 2002; Haynes, McDonald & Garg, 2002; Loeb, Penrod, Falkenstern, Gueldner & Poon, 2003).

Socio-demographic Variables

Socio-demographic variables are strong predictors of health related quality of life in individuals with SCD. These variables include age, sex, income, education, employment, and marital status (Jenerette & Murdaugh, 2008). Panepinto and Bonner (2012) note that health related quality of life (HRQL) in adults with SCD is significantly impaired and may be worse than in other chronic diseases. Variables affecting HRQL in SCD include age, gender, family demographics (education and income), disease-related symptoms, rural versus urban residence, and employment. Age and socio-economic status, for example, negatively affect HRQL. African

Americans with SCD were more likely to be less educated, have lower income, and were more likely to be unemployed or disabled when compared to African Americans without SCD (Laurence, George & Woods, 2006).

Socio-demographic variables appear to significantly affect patient outcomes. Researchers typically operationalize these variables using age, income, education, and employment or occupation. Given that minorities are typically disadvantaged in the majority of these areas and are primarily affected by SCD, these variables should be accounted for when attempting to improve health outcomes. Further research is needed regarding assessment of and strategies for dealing with socio-demographic problems experienced by SCD patients (Laurence, George & Woods, 2006; Palermo, Riley & Mitchell, 2008).

Self-care Management

The concepts of self-care and self-care management (often used interchangeably with self-management) have been increasingly studied over the years. This is due in part to the rising prevalence of chronic diseases and higher rates of healthcare utilization. In light of this finding, self-care management is important in improving health outcomes, enhancing quality of life, and decreasing healthcare costs (Riegel, Jaarsma & Stromberg, 2012; Ryan & Sawin, 2009). Self-care refers to learned, routine, positive, and practical activities performed by individuals to maintain life, health, and well-being (Orem, 1971). Self-management is the ability of an individual with a chronic disease, to participate in a daily, self-motivated, collaborative (conducted with family, social, and healthcare provider support) process to manage symptoms (Schulman-Green et al., 2012). This process involves the domains of focusing on illness needs, activating resources, and living with a chronic illness. In chronic conditions, an individual’s ability to perform behaviors that will alleviate the pain experience is instrumental in adapting to pain long-term (Kratz, Molton, Jensen, Ehde & Nielson, 2011). Common definitions of self-management, however, are somewhat broad and cover not only a variety of behaviors but a variety of conditions, thus leading to confusion regarding its application to research and practice (Modi et al., 2012). Given this finding, it is important to understand self-care management and self-care behaviors in the context of SCD. Overall self-care management strategies specific to SCD have been identified. In a study assessing strategies used by adults with SCD to manage their illness, themes included self-awareness, emotional support, career selection and success factors, nutrition, advocacy, knowledge, physical activity, and complementary and alternative medicine (Tanabe et al., 2010). In middle-aged and older adults, identified self-care recommendations were physiologic (warmth, hydration, rest, good food, and avoiding drinking, smoking, and using drugs), psychological (knowledge and understanding of the disease, listening to and learning about the body, prayer, and social support), and provider-related (knowledgeable health care providers and following providers' orders) (Jenerette, Brewer & Leak, 2011). There are many benefits of self-care management; therefore, it is important to understand which factors affect self-care management. Further, an evaluation of self-care management in the young adult age-group is necessary.

The Relationship among Concepts

According to the theory of self-care management for SCD, vulnerability variables (socio-demographics and health needs) negatively affect health outcomes (health status) and self-care management resources (including self-efficacy, social support, self-care ability, and self-care actions) (Jenerette & Murdaugh, 2008). Self-care management and coping may be correlated with self-efficacy in that it reduces the effects of stressors and facilitates positive health behaviors (Edwards, Telfair, Cecil & Lenoci, 2001). In a study conducted with diabetics, another population requiring self-care, self-efficacy was significantly correlated with positive outcome expectations in the prediction of diabetes self-management and hemoglobin A1C (Iannotti et al., 2006). When positive expectations were high, high self-efficacy was related to better self-management. Self-efficacy, in conjunction with self-care ability, assertiveness, and social support, may assist with the management of daily activities necessary for coping in SCD (Jenerette & Murdaugh, 2008). Socio-demographic variables affect functional ability and health related quality of life (Palermo, Riley & Mitchell, 2008; Panepinto & Bonner, 2012); therefore, these variables likely affect perceived self-efficacy, the availability of needed resources and social support, and participation in self-care management.

In the majority of the studies reviewed, data was obtained mainly or only using self-report. Researchers often consider this a study limitation as participants responses can be variable and unreliable, even on similar measures used within a given study. There are benefits, however, to using this method of data collection. Direct reports from participants about their experiences provide rich information. This adds depth to and enhances the understanding of the phenomenon of interest; qualitative data adds meaning to quantitative data. Also, for concepts such as pain and perceived self efficacy, subjective report is the only way to obtain accurate information, making it the gold standard.

Conceptual Framework

In regard to sickle cell disease and the number of hospital visits for crises, self-care management, self-efficacy, social support, and socio-demographic variables appear to be the most significant constructs discussed in the literature. To address the relationships among these variables, a Model of Health Functioning was developed by the author to explain the mechanisms of self-care management as it relates to sickle cell disease (Figure 1); it outlines the predictors, mediators, and outcome. The model also provides the framework for conducting data analysis. According to the model, SCD self-efficacy, social support, and socio-demographic variables are related to self-care management (perceived self-care ability and self-care action) (Chlebowy & Garvin, 2006; Edwards, Telfair, Cecil & Lenoci, 2001; Frei, Svarin, Steurer-Stey & Puhan, 2009; Jenerette & Murdaugh, 2008; Levenson et al., 2008). Sickle cell disease self-efficacy, social support, and socio-demographic variables (age, gender, level of education, employment status, income, and living situation) are associated with self-care management which in turn is associated with the number of hospital visits for crises in this population. There are also direct relationships among SCD self-efficacy, social support, and socio-demographic variables in understanding hospital visits for crises. In addition, self-care management plays a mediating role between the predictors and the outcome. Although depressive symptoms also appear to be associated with self-care management, thus the number of hospital visits for crises, they were not evaluated in this study; this is a study limitation.

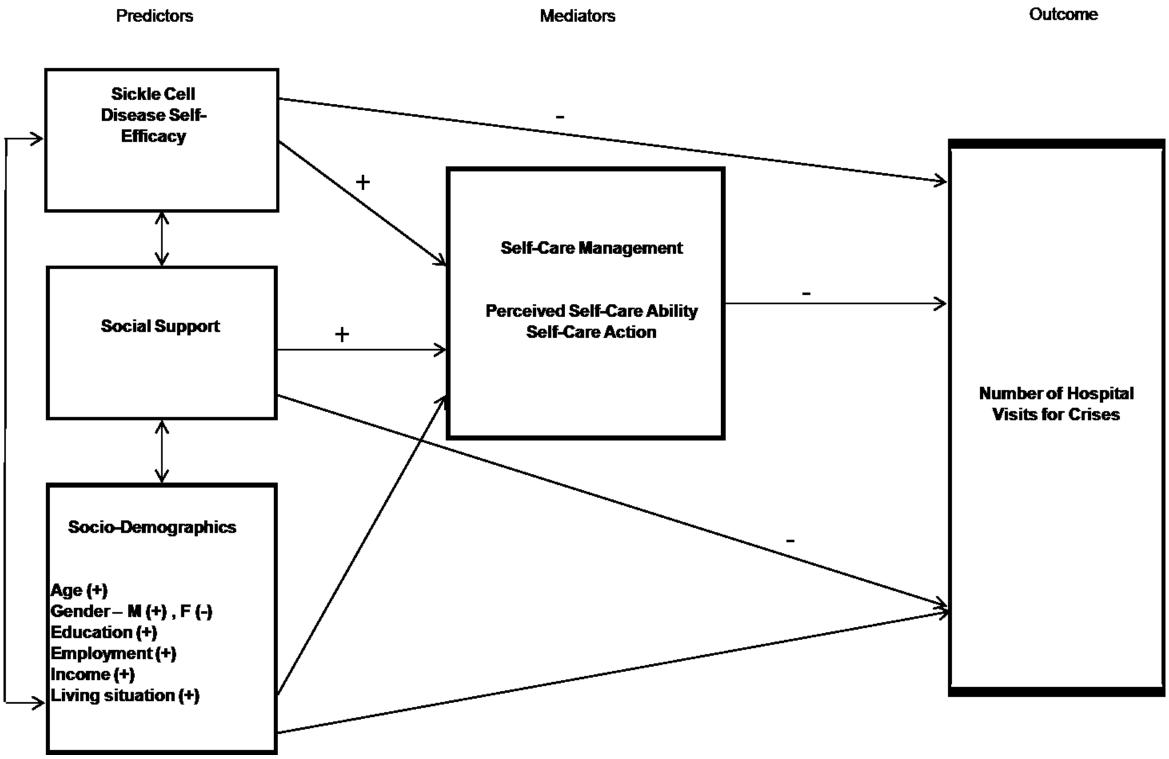


Figure 1. Model of Health Functioning

Summary

To decrease the number of hospital visits for crises, prevention is imperative. Self-efficacy and self-care in the home setting may be integral to pain self-management and thus crisis prevention (Edwards, Telfair, Cecil & Lenoci, 2001). Self-care is correlated with a number of variables, but it is unclear which one has the greatest correlation with decreased pain severity for SCD patients. The mechanism of this relationship also needs to be clearly defined. Studies show a positive correlation between self-efficacy, social support, and self-care activities in SCD patients (Frei, Svarin, Steurer-Stey & Puhan, 2009), but there is still some question as to which self-care activities are most effective and which variables affect self-efficacy and social support.

In addition, it would be beneficial to further evaluate socio-demographic variables in relation to SCD. Variables that play a role in the number of hospital visits for crises need to be identified and the relationship quantified before interventions can be formulated. This study examined the relationships among SCD self-efficacy, social support, socio-demographic variables, self-care management, and the number of hospital visits for crises.

Chapter 3: Methods

An exploratory, correlational study was conducted, via secondary analysis, to examine the relationships among sickle cell disease (SCD) self-efficacy, social support, socio-demographic variables, self-care management (perceived self-care ability and self-care actions), and the number of hospital visits for crises. This section includes a discussion of the parent study and outlines the research methods that were used for the secondary study. Study design, setting, population and sample, instruments, procedures, and data analysis for this study are then addressed here.

Parent Study

The parent study employed a cross-sectional, descriptive design with a convenience sample of 232 adults (age 18 to 73; mean 35 years) with SCD (Jenerette & Murdaugh, 2008). The purpose was to describe factors predicting quality of life in persons with SCD. The study involved testing the Theory of Self-Care Management for Vulnerable Populations using structural equation modeling. The research questions were related to the fit of measurement and the structural model underlying the theory. Prior to data collection, study approval was obtained from the Institutional Review Board at the Medical University of South Carolina and the University of North Carolina at Chapel Hill. Between September 2003 and April 2004, the primary investigator and a trained registered nurse recruited 232 participants from two SCD clinics in the southeastern United States. Inclusion criteria consisted of the ability to read, write, or understand English, age of at least 18 years old, and a diagnosis of SCD. Participants provided written consent and completed a questionnaire packet (requiring a maximum of 60 minutes) during a SCD clinic visit. For completing the study, participants received $25 (Jenerette & Murdaugh, 2008).

Sample

The sample for this study consists of 103 young, Black adults (ages 18 to 30) with sickle cell disease. This study involves a secondary analysis of data therefore recruitment is complete.

Instruments

The following instruments were used in the parent study and in other studies involving SCD patients. Scores obtained from the studies conducted in this population show evidence of validity and reliability (Edwards, Telfair, Cecil & Lenoci, 2000; Jenerette & Murdaugh, 2008; Sherbourne & Stewart, 1991); this evidence is discussed here. Additional evidence of instrument validity and reliability are reported with results of this secondary study.

Socio-demographic variables and hospital visits for crises. A demographic questionnaire was used in the parent study to gather information from participants regarding age, gender, level of education, employment status, annual household income (estimated based on participants' reported zip code), living situation (living alone, living with family, or living with friends), and the number of times per year that individuals were in the hospital for crises (Jenerette & Murdaugh, 2008). The level of measurement is nominal (gender, employment status, and living situation), interval (age, level of education, and annual household income), and ratio (the number of hospital visits for crises).

Sickle cell disease self-efficacy. Sickle cell disease self-efficacy was measured using the Sickle Cell Self-Efficacy Scale (SCSES). This scale is a nine-item instrument which uses a summated rating method to evaluate an individual's perceived ability to participate in daily functional activities despite having SCD. The level of measurement for the total scale is interval; responses range from 1 ("not at all sure") to 5 ("very sure"). Item responses are summed to obtain a total score; higher scores indicate higher self-efficacy (Edwards, Telfair, Cecil & Lenoci, 2001). The total score was used for the final analysis in this secondary study. In the parent study, an estimate of convergent validity was obtained as a result of significant correlations between self-efficacy and self-esteem (r=.39), sense of mastery (r=.45), and internal health locus of control (r=.41) (Edwards, Telfair, Cecil & Lenoci, 2000). The internal consistency reliability was .87 (Jenerette & Murdaugh, 2008); .89 was reported previously (Edwards, Telfair, Cecil, & Lenoci, 2000).

Social support. Social support was measured with the Medical Outcomes Study Social Support Survey (MOS-SSS). This survey measures perceived availability of social support on four subscales (emotional/informational, affectionate, tangible, and positive social interaction) using a 19 item summated rating scale. The level of measurement of the scale is interval; scores range from 1 (“none of the time”) to 5 (“all of the time”). The responses are totaled and higher perceptions of available support are reflected in higher scores (Jenerette & Murdaugh, 2008). The total score was used for the final analysis in this secondary study. Internal consistency reliabilities for the subscales and the total scale are above .91 (Sherbourne & Stewart, 1991); the reliabilities of the subscales from the parent study were .92 for emotional/informational, .82 for affectionate, .80 for tangible, and .87 for positive social interaction (Jenerette & Murdaugh, 2008). Overall construct validity as it relates to the correlation of the health measures with social support measures were determined and all correlations were significant at $p < .01$; loneliness (r=-.67), family functioning (r=.53), marital functioning (r=.56), mental health (r=.45), current health (r=.22), physical functioning (r=.11), physical role limitations (r=-.20), emotional role limitations (r=-.29), energy/fatigue (r=.28), effects of pain (r=-.20), pain severity (r=-.19), social activity (r=.30), and physical symptoms (r=-.23) (Sherbourne & Stewart, 1991).

Self-care management. Self-care management refers to perceived self-care ability and self-care actions. The Appraisal of Self-Care Agency Scale (ASA) was used to measure perceived self-care ability. Self-care ability is defined as the ability to participate in therapeutic behaviors aimed at enhancing and/or maintaining health status and quality of life. Responses on the 24-item scale are summed to obtain a total score and higher scores correspond with higher levels of self-care ability. The level of measurement of the scale is interval and scores range from 1 (“totally disagree”) to 5 (“totally agree”). The total score was used for the final analysis in this secondary study. In the parent study, the content validity index for the ASA was .88 and the internal consistency reliability was .75 (Jenerette & Murdaugh, 2008).

The eight-item Jenerette Self-care Assessment Tool (JSAT) was used to measure self-care actions; defined as participation in therapeutic activities and using resources to enhance health status and quality of life. Responses on the items are totaled; a greater frequency of self-care actions results in higher scores. The scale uses an interval level of measurement and scores range from 1 (“never”) to 4 (“almost always”). The total score was used for the final analysis in this secondary study. A significant negative correlation with the Center for Epidemiologic Studies Depression Scale (r=-.19) and a significant positive correlation with the Functional Status Questionnaire (r=.49) were used as estimates of construct validity in the parent study. Internal consistency reliability was .72 (Jenerette & Murdaugh, 2008).

Procedures

A subset of the data from the parent study was used to conduct this study. A de-identified data file, with records for 103 young, Black adults (ages 18 to 30) with sickle cell disease, was provided by the principal investigator of the parent study. The data were cleaned prior to conducting analyses. Descriptive statistics were used to evaluate the range, means, medians, standard deviations, and normality of the variables. Missing data were also identified, evaluated according to the pattern, extent, and reason for missingness, and replaced using mean substitution.

Data Analysis

Statistical procedures. Statistical Package for the Social Sciences (SPSS, version 21), was used to analyze the data collected from the study instruments. Before addressing the specific aims, the data were examined for quality. Descriptive statistics were used to examine the socio-demographic variables. Frequency distributions were used to examine age, gender, level of education, employment status, annual household income, and living situation. Means and standard deviations were computed for age, level of education, annual household income, and the number of hospital visits for crises. Internal consistency (Cronbach's alpha) was calculated for the multi-item instruments; SCSES, MOS-SSS, ASA, and JSAT.

Aim 1: To evaluate the relationships among psychosocial variables (SCD self-efficacy and social support) and socio-demographic variables (age, gender, education, employment status, income, and living situation) in understanding individual differences in self-care management variables (perceived self-care ability and self-care actions) in young (ages 18 to 30), Black adults with sickle cell disease. To address this aim, the following analyses were conducted.

Step 1. Bivariate correlations were used to examine the relationships among the continuous variables while regression analyses were used to evaluate the relationships among the categorical variables. Socio-demographic variables that correlated (.20 or higher) with or were significantly related to perceived self-care ability and self-care actions were considered clinically important thus included as predictors in the model. At this model building stage, including variables with a correlation of at least .20 aids in determining the importance of each. Variables with low correlations, when evaluated collectively, can be important predictors of the outcome of interest (Hosmer & Lemeshow, 2000).

Step 2. Each of the self-care management variables were treated in a separate regression. Perceived self-care ability was regressed onto SCD self-efficacy, social support, and the influential socio-demographic variables identified in step 1 (education and income). Similarly, self-care actions were regressed onto SCD self-efficacy, social support, education, and income.

Aim 2: To evaluate the relationships among psychosocial variables (SCD self-efficacy and social support), socio-demographic variables (age, gender, education, employment status, income, and living situation), and self-care management variables (perceived self-care ability and self-care actions) in understanding hospital visits for crises in young (ages 18 to 30), Black adults with sickle cell disease. This aim was addressed by conducting regression analyses guided by Figure 1. Hospital visits for crises were regressed onto SCD self-efficacy, social support, education, income, perceived self-care ability, and self-care actions.

Aim 3: To evaluate the mediational role of perceived self-care ability and self-care actions in the relationships among psychosocial variables (SCD self-efficacy and social support), socio-demographic variables (age, gender, education, employment status, income, and living situation), and the number of hospital visits for crises in young (ages 18 to 30), Black adults with sickle cell disease. To address this aim, the following analyses were conducted. The mediational role of perceived self-care ability and self-care actions was tested using the regression approach proposed by Baron and Kenny (1986). This approach provides a statistically conservative test of mediation (Cerin, Taylor, Leslie & Owen, 2006). This four-step approach to evaluating how mediation occurs involves performing a series of regression analyses then looking at the size and significance of the coefficients at each step. If significant relationships are noted in steps one through three, then step four is performed. In step four, mediation is present if the role of the mediator remains significant after controlling for the predictors. If the predictors are not significant when the mediator is controlled, then there is full mediation. On the other hand, if the predictors are still significant, then there is partial mediation. The process is outlined for perceived self-care ability here. Identical steps were followed for self-care actions.

Step 1. A regression analysis was conducted with SCD self-efficacy, social support, and any influential socio-demographic variables as identified in Aim 1 (education and income) predicting the number of hospital visits for crises.

Step 2. A regression analysis was conducted with SCD self-efficacy, social support, education, and income predicting perceived self-care ability.

Step 3. A regression analysis was conducted with perceived self-care ability predicting the number of hospital visits for crises.

Step 4. A regression analysis was conducted with SCD self-efficacy, social support, education, and income, *as well as* perceived self-care ability predicting the number of hospital visits for crises.

Statistical power. This project involved a planned analysis of a secondary dataset of a predetermined size. Given the current sample size of 103, correlations of .271 or larger will have an 80% chance of being significant at an alpha of .05. At the current sample size, conducting regression analysis using a model with 10 predictors has a power of .80 to detect an R^2 of .148.

Methodological issues and limitations. Use of secondary data often leads to study limitations. This secondary analysis may be affected by the methods used in the parent study. The data collected in the parent study may not answer all secondary research questions. In this case, information regarding ethnicity was not collected in the parent study. Although this may be a negligible limitation given the nature of the disease (disease incidence of one in 500 births and the sickle cell trait occurs in about one in 12 individuals of African ancestry), the ethnicity of participants , African American versus African or Caribbean for example, could not be determined. Cultural differences could play a role in patient self-care management. Information regarding the specific type of SCD was not collected. This poses a limitation because the pain experience varies by type of SCD; there are four common types with sickle cell anemia being the most common and most severe type (Centers for Disease Control and Prevention, 2011b; Fosdal & Wojner-Alexandrov, 2007). In the parent study, there was no distinction made between emergency department (ED) visits and inpatient admission in the measurement of the number of hospital visits for crises. This affects the evaluation of the outcome variable in this study. Patients who present to the hospital in pain crises are often stabilized in the ED with fluids, oxygen, and pain medication then discharged; however, discharge does not necessarily indicate resolution of the crisis (Ballas, Gupta & Adams-Graves, 2012). More severe cases or cases worsened by delayed analgesia result in admission for further symptom management and/or treatment of the underlying problem (Ballas, 2011). An objective measure of pain severity was not specifically used in the parent study. Thus, the effects of self-care actions on pain severity, for example, could not be assessed in this study. In addition, although depression may play a role in the self-efficacy and self-care management of these patients, it was not measured in the parent study and thus could not be assessed in this study. Use of cross-sectional data can also pose methodological issues such as an inability to analyze changes over time and obtaining misleading results based on the data available. Also, patients in worse disease states are likely to experience more hospital visits, thus may have lower perceived SCD self-efficacy.

Chapter 4: Results

A description of the study findings are presented in this section. Outcomes of preliminary data analyses, specific aims and hypothesis testing, and exploratory analyses are presented here.

Sample

The majority of the 103 participants were female (61.2%), unemployed (35%), and lived with family (73.8%) (Table 1). On average, participants were 24 years old, had 12 years of education, and an annual household income of $35,724. The majority (67%) experienced 1 to 3 crises per year with an average of approximately three hospital visits for crises per year (Table 2).

Preliminary Analyses

Prior to addressing study aims, the data were assessed for quality; including accuracy, missing data, linearity, and normality. All values were within range and the means and standard deviations were plausible. There were no out-of-range numbers for the discrete variables. The distributions of the variables were both peaked and flat, and reflected both positive and negative skewness. These findings suggest deviations from normality but these deviations may or may not affect the means (Keppel & Wickens, 2004). Nonetheless, these measures provide a description of the distribution of the data.

There were a number of missing values within the data set that reduced the sample to 65 cases with complete data; approximately 63% of the total. The number of missing values varied across the measures but some values were missing for sickle cell disease (SCD) self-efficacy, social support, income, perceived self-care ability, self-care actions, and the number of hospital visits for crises. Three of these variables (SCD self-efficacy, social support, and perceived self-care ability) had cases with missing values that exceeded more than 5% of the sample; the

Table 1. Frequency and Percent of Patients by Socio-demographic Variables

Variable	Category	N	Frequency	Percent
Age	18-20	103	19	18.4
	21-25		50	48.6
	26-30		34	33.0
Gender	Female	103	63	61.2
	Male		40	38.8
Years of Education	8-12	103	78	75.7
	13-16		25	24.3
Employment Status	Unemployed	103	36	35.0
	Disabled		34	33.0
	Full-time		19	18.4
	Part-time		14	13.6
Annual Household Income	$17,843 - $27,714	100	28	27.4
	$28,616 - $37,975		37	36.2
	$38,470 - $48,251		22	21.6
	$50,701 - $65,375		13	12.6
	Missing		3	2.2
Living Situation	Share house with family	103	76	73.8
	Live alone		18	17.5
	Share house with friends		9	8.7
Number of Hospital Visits for Crises (per year)	0	99	9	8.7
	1-3		67	65.0
	4-6		18	17.5
	7-10		3	3.0
	12-20		2	2.0
	Missing		4	3.8

Sample size (N) varies due to missing data

highest percentage of missing values was noted in perceived self-care ability (21.4%). The problem could not be localized to a specific participant; multiple participants missed at least one item on various instruments. One participant missed 16 items across three instruments; Sickle Cell Disease Self-Efficacy Scale (SCSES), Medical Outcomes Study Social Support Survey (MOS-SSS), and Appraisal of Self-Care Agency Scale (ASA). Another participant missed 12 items on the 24-item ASA, while two participants missed all the items on the Jenerette Self-Care Assessment Tool (JSAT). An evaluation of the randomness of the data was conducted using grouping variables and t-tests to evaluate whether the missing and valid items had different

Table 2. Means and Standard Deviations

Variable	N	Mean	Standard Deviation
Age	103	23.87	3.403
Years of Education	103	12.08	1.473
Annual Household Income	100	$35,724	$10,487
Sickle Cell Disease Self-Efficacy	97	31.84	6.370
Social Support	90	75.34	15.752
Perceived Self-Care Ability	81	86.98	8.822
Self-Care Actions	101	27.84	3.171
Number of Hospital Visits for Crises	99	2.75	2.822

Sample size (N) varies due to missing data

relationships with other variables in the data set. Some missing items had a statistically significant relationship with the other variables, therefore, the pattern was considered to be missing not at random. This pattern is important because it may be related to the outcome variable and the hypothesized relationships among the variables; there could possibly be purposeful patterns of nonresponse. The missing values could potentially interfere with the results so they could not be overlooked (Tabachnick & Fidell, 2007).

Missing data can affect statistical analyses so they should be dealt with in order to retain as much data from study instruments as possible and to obtain meaningful results. Excluding participants with missing data can result in a decreased sample, larger errors, and decreased power to find significant results (Kaambwa, Bryan & Billingham, 2012). In addition, although participants may not have complete data, they can still be of value in the analyses; the reason for the missing data may be important in understanding the phenomenon of interest. To address missing data, one can substitute the missing values for a variable with the mean of that variable (Tabachnick & Fidell, 2007). In an attempt to retain as many cases as possible to improve statistical analysis and increase the accuracy of the population estimates, mean substitution was conducted; the resulting sample size was 103. Mean substitution is a conservative method in that it allows for inclusion of as many people in the data set as possible without altering the mean of the sample and falsely strengthening correlations (Tabachnick & Fidell, 2007). Correlations among the variables were assessed before and after mean substitution (Table 3). The direction and magnitude of the majority of the correlations remained essentially the same, suggesting that the use of mean substitution was appropriate in this case. Although the majority of the correlations were low to moderate, they were significant.

Table 3. Pearson Correlations for the Continuous Variables

	SCDSE	**SS**	**PSCA**	**SCA**	**HSCD**	**Age**	**Education**	**Income**
SCDSE	1	.502*	.391*	.309*	.015	-.226*	.253*	-.070
SS	.603*	1	.433*	.326*	.050	-.197*	.224*	.039
PSCA	.423*	.472*	1	.466*	-.098	-.153	.233*	-.047
SCA	.376*	.434*	.541*	1	.054	.062	.200*	.087
HSCD	.045	.044	-.148	.177	1	.006	-.157	-.219*
Age	-.278*	-.221*	-.241	-.042	-.010	1	.168	.098
Education	.299*	.324*	.264*	.264*	-.176	.136	1	.133
Income	-.110	-.004	-.045	.036	-.167*	.207	.211	1

Lower triangle – correlation without mean substitution; listwise N=65. Upper triangle – correlation with mean substitution; listwise N=103. SCDSE, sickle cell disease self-efficacy; SS, social support; PSCA; perceived self-care ability; SCA, self-care actions; HSCD, number of hospital visits for crises. *Correlation is significant at the .05 level.

Bivariate correlations between the continuous socio-demographics variables (age, years of education, and income) and the self-care management variables were evaluated. An important relationship (correlation of .20 or higher) was noted between education and perceived self-care ability (r=.233, p=.018) and between education and self-care actions (r=.200, p=.043) (Table 3). Age was not significantly related to the self-care management variables. There did not appear to be a significant relationship between income and the self-care management variables, but there was a significant association between income and the number of hospital visits for crises. A regression analysis was used to evaluate the relationships among the categorical variables (gender, employment status, and living situation) and the self-care management variables. There were no significant relationships noted among the variables so gender, employment status, and living situation were excluded from further analyses. Given the results of the correlation and regression analyses, years of education and income were included along with SCD self-efficacy, perceived self-care ability, and self-care actions as predictors in the model.

A regression was then conducted to determine which variables (SCD self-efficacy, social support, perceived self-care ability, self-care actions, education, and income) were predictors of the outcome variable (number of hospital visits for crises). The overall regression model with these six variables did not significantly predict the number of hospital visits for crises; R^2=.106, Adjusted R^2=.051, *F* (6,96)=1.905, and p=.088. The model accounted for approximately 11% of the variance in the number of hospital visits for crises. Of the predictors, only annual household income had a significant coefficient, suggesting a significant relationship between income and the number of hospital visits for crises. The largest proportion of the variance in the outcome variable (~ 5%) was attributed to income (Table 4).

Specific Aims and Hypothesis Testing

Aim 1. Bivariate correlations were used to examine the relationships among the psychosocial variables (SCD self-efficacy and social support), continuous socio-demographic variables (years of education, and income), and self-care management variables (perceived self-care ability and self-care actions) in young, Black adults with sickle cell disease. The results showed significant low to moderate correlations among these key variables (Table 3).

Perceived self-care ability was regressed onto SCD self-efficacy, social support, years of education, and income. The model with four predictors significantly predicted perceived self-care ability; R^2=.243, Adjusted R^2=.212, *F* (4,98)=7.860, and p<.001. The model accounted for

Table 4. Results of Multiple Regression

Model	**B**	**Standard Error**	**Standardized Coefficients (Beta)**	***t***	**Significance**	**Correlations**	
						Zero-Order	**Part**
Constant	8.744	3.580		2.443	.016		
SCDSE	.001	.052	.002	.018	.986	.015	.002
SS	.024	.022	.127	1.078	.284	.050	.104
PSCA	-.072	.042	-.204	-1.720	.089	-.098	-.166
SCA	.136	.099	.155	1.379	.171	.054	.133
Education	-.261	.193	-.139	-1.356	.178	-.157	-.131
Income	-6.108E-005	.000	-.228	-2.303	.023	-.219	-.222

N=103. SCDSE, sickle cell disease self-efficacy; SS, social support; PSCA; perceived self-care ability; SCA, self- care actions. Dependent variable: number of hospital visits for crises.

approximately 24% of the variance in perceived self-care ability. Of the four predictors, the largest percentage of the variance (~ 7%) in perceived self-care ability was attributed to social support. In a separate regression, self-care actions were regressed onto SCD self-efficacy, social support, years of education, and income. This model significantly predicted self-care actions; R^2=.151, R^2 adjusted=.117, *F* (4,98)=4.370, and p=.003. The model accounted for 15% of the variance in self-care actions, with approximately 3% of the variance attributed to social support.

Hypothesis 1a. It was hypothesized that higher SCD self-efficacy and greater social support are associated with higher perceived self-care ability and more frequent self-care actions. Higher SCD self-efficacy was associated with higher perceived self-care ability (r=.391, p=<.001) and more frequent self-care actions (r=.309, p=.002). Greater social support was associated with higher perceived self-care ability (r=.433, p=<.001) and more frequent self-care actions (r=.326, p=.001).

Hypothesis 1b. It was hypothesized that employment, living with family or friends, increased age, more years of education, and higher income are each associated with higher perceived self-care ability and more frequent self-care actions. Education was associated with higher perceived self-care ability ($r=.233$, $p=.018$) and self-care actions ($r=.200$, $p=.043$). There were no significant associations, however, between either age and the self-care management variables or annual household income and the self-care management variables. Further, regression analysis showed no evidence of significant relationships between either living situation and the self-care management variables or employment status and the self-care management variables.

Hypothesis 1c. It was hypothesized that males will report having higher perceived self-care ability and more frequent self-care actions than females. There was no evidence of a significant relationship between gender and the self-care management variables.

Aim 2. A regression analysis was conducted to evaluate the relationships among psychosocial variables (SCD self-efficacy and social support), influential socio-demographic variables as identified in Aim 1 (education and income), and self-care management variables (perceived self-care ability and self-care actions) in understanding hospital visits for crises in young, Black adults with sickle cell disease. Hospital visits for crises were regressed onto SCD self-efficacy, social support, years of education, income, perceived self-care ability, and self-care actions. The model with these six variables did not significantly predict hospital visits for crises; $R^2=.106$, Adjusted $R^2=.051$, $F\ (6,96)=1.905$, and $p=.088$.

Hypothesis 2. It was hypothesized that higher perceived self-care ability and more frequent self-care actions are associated with fewer hospital visits for crises. Neither perceived self-care ability nor self-care actions were significantly correlated with the number of hospital visits for crises.

Aim 3. The mediational role of perceived self-care ability and self-care actions in the relationships among psychosocial variables (SCD self-efficacy and social support), influential socio-demographic variables (years of education and income), and the number of hospital visits for crises was evaluated in young, Black adults with sickle cell disease. This was achieved by using the Baron and Kenny (1986) four-step approach. In step 1, the number of hospital visits for crises was regressed onto SCD self-efficacy, social support, years of education, and income. The model with these four variables did not significantly predict the number of hospital visits for crises; R^2=.073, Adjusted R^2=.035, *F* (4,98)=1.917, and p=.114. This finding suggests that these four predictors are not significantly correlated with the outcome variable. In step 2, perceived self-care ability was regressed onto SCD self-efficacy, social support, years of education, and income. The model significantly predicted perceived self-care ability; R^2=.243, Adjusted R^2=.212, *F* (4,98)=7.860, and p=.000. The model accounted for approximately 24% of the variance in perceived self-care ability. The largest percentage of the variance (~ 7%) in the outcome variable was attributed to social support. Self-care actions were then regressed onto SCD self-efficacy, social support, years of education, and income. The model with these variables significantly predicted self-care actions; R^2=.151, Adjusted R^2=.117, *F* (4,98)=4.370, and p=.003. The model accounted for 15% of the variance in self-care actions, with approximately 3% of the variance attributed to social support. This step shows that SCD self-efficacy, social support, years of education, and income were correlated with the hypothesized mediator, self-care management. In step 3, the number of hospital visits for crises was regressed onto perceived self-care ability. Perceived self-care ability did not significantly predict the number of hospital visits for crises; R^2=.010, R^2 adjusted=.000, *F* (1,101)=.973, and p=.326. The number of hospital visits for crises was also regressed onto self-care actions. Self-care actions did not significantly predict the number of hospital visits for crises; R^2=.003, R^2 adjusted=.007, *F* (1,101)=.293, and p=.589. Results of step 3 suggest that the self-care management variables do not affect the number of hospital visits for crises. In step 4, the number of hospital visits for crises was regressed onto perceived self-care ability, SCD self-efficacy, social support, years of education, and income. The model with these variables did not significantly predict the number of hospital visits for crises; R^2=.089, Adjusted R^2=.042, *F* (5,97)=1.888, and p=.103. The number of hospital visits for crises was also regressed onto self-care actions, SCD self-efficacy, social support, years of education, and income. This model was not significant; R^2=.079, Adjusted R^2=.031, *F* (5,97)=1.661, and p=.151. These findings suggest that the role of self-care management is not significant when

SCD self-efficacy, social support, years of education, and income are controlled; therefore, mediation is not present.

Hypothesis 3. It was hypothesized that SCD self-efficacy, social support, and socio-demographic variables have both a direct and an indirect relationship with the number of hospital visits for crises. Further, the relationships among SCD self-efficacy, social support, socio-demographic variables, and the number of hospital visits for crises was believed to be mediated by self-care management. There was no adequate evidence to support a direct relationship between SCD self-efficacy, social support, years of education, and the number of hospital visits for crises. The indirect relationship, through self-care management, among the variables was also non-significant. There was however a significant direct relationship between income and the number of hospital visits for crises (r=-.219, p=.026).

Reliability

Reliability refers to the position of a given score in relation to other scores in a distribution, regardless of when and how measured (Tabachnick & Fidell, 2007). Unreliable variables can affect statistical analyses in that they can introduce measurement error into the relationship between the predictors and the outcome variable, and means may be altered. The reliability (internal consistency) of each study instrument was evaluated and all were greater than .70 which is acceptable according to George and Mallery's (2003) rule of thumb (Table 5). Convergent validity was evaluated via correlation among SCD self-efficacy, social support, years of education, income, perceived self-care ability, and self-care actions as theorized in the Model of Health Functioning (Figure 1). Convergent validity was supported by the significant correlations among the variables (Table 3).

Exploratory Analyses

Overall, tests of the specific aims and the hypotheses did not yield fruitful outcomes but revealed some items requiring additional evaluation. Exploratory analyses were conducted to further assess instrument reliability and the effects of attenuation. Reliability estimates for the study instruments were acceptable to excellent (Table 5). A comparison of these estimates to the correlation values (Table 6) produced mixed results. Of all the instruments, the ASA had the highest correlation with the outcome variable, yet had a low reliability estimate. The MOS-SSS had the highest reliability estimate, but the correlation value was fairly low.

The correlation of one measure with another includes the true value along with some measurement error (Wetcher-Hendricks, 2006). The effects of this random measurement error can degrade the analysis by reducing or attenuating the correlation. The reliability of a measure can be used to quantify measurement error; a higher reliability suggests that a lower proportion of the observed variance is due to error (Charles, 2005). The following formula was used to calculate the dis-attenuated or corrected correlation (r_{xyc}) from the observed correlations (r_{xy}) and the observed reliabilities (r_{xx} and r_{yy}). After correction, the direction of the correlations remained the same (Table 6). Although the correlations remained low, there was a slight increase in the correlations; the largest increase occurred for the ASA.

$$r_{xyc} = r_{xy}/(\sqrt{r_{xx}})\ (\sqrt{r_{yy}})$$

Table 5. Reliability of Study Instruments

Instrument	Number of Items	Cronbach's Alpha	Interpretation
SCSES	9	.857	Good
ASA	24	.729	Acceptable
JSAT	8	.708	Acceptable
MOS-SSS	19	.953	Excellent
- Tangible Subscale	4	.802	Good
- Affectionate Subscale	3	.786	Acceptable
- Positive Social Interaction Subscale	4	.870	Good
- Emotional/ Informational Subscale	8	.916	Excellent

SCSES, Sickle Cell Disease Self-Efficacy Scale; ASA, Appraisal of Self-Care Agency Scale; JSAT, Jenerette Self-Care Assessment Tool; MOS-SSS, Medical Outcomes Social Support Survey

Table 6 – Reliabilities and Correction for Attenuation

Instrument	Variable Measured	Reliability Estimates Previously Reported	Observed Correlation with the Number of Hospital Visits for Crises	Reliability Estimates	Corrected Correlations
SCSES	Sickle cell disease self-efficacy	.87[a] .89[b]	.015	.857	.016
ASA	Perceived self-care ability	.75[a]	-.098	.729	-.115
JSAT	Self-care actions	.72[a]	.054	.708	.064
MOS-SSS	Social support	.91[c]	.050	.953	.051

SCSES, Sickle Cell Disease Self-Efficacy Scale; ASA, Appraisal of Self-Care Agency Scale; JSAT, Jenerette Self-Care Assessment Tool. MOS-SSS, Medical Outcomes Social Support Survey. a. Jenerette & Murdaugh (2008) b. Edwards, Telfair, Cecil, & Lenoci (2000) c. Sherbourne & Stewart (1991)

Summary

This study provided insight into self-care management and hospital visits for crises in a sample of young (ages 18 to 30), Black adults with sickle cell disease. Important relationships were noted among SCD self-efficacy, social support, select socio-demographic variables, perceived self-care ability, and self-care actions. The predictor variables (SCD self-efficacy, social support, age, gender, years of education, employment status, income, and living situation), however, were not correlated with the outcome variable (the number of hospital visits for crises). In addition, a mediational effect of self-care management did not exist and some study hypotheses were not supported by the data. Exploratory analyses, however, yielded results which may have clinical significance thus are discussed in Chapter 5.

Chapter 5: Discussion and Conclusion

In this section, the results of the study are discussed. The content includes the following: a discussion of study findings; implications for research, education, and practice; study strengths, weaknesses, limitations; and conclusions.

Specific Aims and Hypotheses

Aim 1. Clinical importance, correlation of .20 or higher with the self-care management variables, rather than statistical significance was used as the selection criterion for including socio-demographic variables in the model (Hosmer & Lemeshow, 2000). There was a significant association between education and perceived self-care ability and between education and self-care actions so education met that condition. Self-care management is learned (Orem, 1971) and individuals with chronic disease typically collaborate with health care professionals, among others, to master self-care management (Schulman-Green et al., 2012). Individuals with more years of education are likely to be more successful in this venture and they may also have additional knowledge of self-care management principles. Thus, they are more likely to have a stronger sense of self-care ability and more frequently perform self-care actions than individuals with less education. For example, poor pain management by patients in the home has been associated with insufficient knowledge of coping strategies and the use of analgesics for pain control (Dampier, Ely, Brodecki & O'Neal, 2002). Income did not satisfy the selection criterion but appeared to be important because of a significant relationship with the outcome variable as discussed earlier. As such, it was also included in the model for conducting further analyses.

In general, tests of the specific aims and hypotheses did not all yield expected outcomes but there were some encouraging findings. Sickle cell disease self-efficacy, social support, years of education, and income significantly predicted perceived self-care ability and self-care actions. This finding suggests that SCD self-efficacy, social support, years of education, and income are important in understanding self-care management. This confirms the findings of previous research. Individuals with higher SCD self-efficacy, social support, education, and income are likely to have higher perceived self-care ability and more frequently use self-care actions (Chlebowy & Garvin, 2006; Edwards, Telfair, Cecil & Lenoci, 2001; Frei, Svarin, Steurer-Stey & Puhan, 2009; Jenerette & Murdaugh, 2008; Levenson et al., 2008). The largest proportion of the variance in both perceived self-care ability and self-care actions was explained by social support. Individuals who perceive higher levels of social support are more likely to feel as though they can and should take better care of themselves, and may consider spending time their loved ones as an additional incentive to remain healthy for as long as possible. This finding also reinforces the importance of social support to self-care management as noted in the literature. The process of using self-care to manage disease symptoms is strengthened by support from family, friends, and health care professionals (Nash, 1994; Schulman-Green et al., 2012). Social support positively influences self-care behaviors and improves long-term disease management (Chlebowy & Garvin, 2006; Cox, 2002; Haynes, McDonald & Garg, 2002; Loeb, Penrod, Falkenstern, Gueldner & Poon, 2003; Ngamvitroj & Kang, 2007; Sin, Kang & Weaver, 2005).

Hypothesis 1a. Greater social support was associated with higher perceived self-care ability and more frequent self-care actions as explained above. Higher SCD self-efficacy was also associated with higher perceived self-care ability and more frequent self-care actions. An individual who strongly believes that he or she can accomplish daily activities despite having SCD is likely to have a high perception of self-care ability (a related concept) and thus may participate in more self-care activities. This result also validates previous research with states that self-efficacy is related to better self-management in chronic disease (Iannotti et al., 2006). Self-efficacy influences health behaviors and is important in disease management (Frei, Svarin, Steurer-Stey & Puhan, 2009). Along with self-care ability and other self-care resources, self-efficacy may influence daily disease management and coping in SCD (Jenerette & Murdaugh, 2008). In addition, higher self-efficacy is related to fewer symptoms and self-efficacy beliefs may predict future symptomatology (Clay & Telfair, 2007; Edwards, Telfair, Cecil & Lenoci, 2001).

These findings are all important in understanding what variables affect self-care management in SCD patients and thus can be useful in designing patient education programs.

Hypothesis 1b. As discussed earlier, increased years of education was associated with higher perceived self-care ability and more frequent self-care actions. Employment, living with family or friends, increased age, and income were not significantly associated with either higher perceived self-care ability or more frequent self-care actions. These findings did not support the expectations as discussed below; this was likely due to measurement error and/or the study sample. Further evaluation of these variables is indicated. As it relates to employment, the need to stay healthy to maintain a job may result in more frequent use of self-care actions. In this study, however, the majority of the participants were unemployed or disabled. This is in keeping with previous research findings which state that compared to African Americans without SCD, African Americans with SCD are more likely to be unemployed or disabled (Laurence, George & Woods, 2006). Living with friends or family suggests increased social support (Nash, 1994; Ngamvitroj & Kang, 2007, Sin, Kang & Weaver, 2005). This increase in social support may lead to an increased sense of self-care ability (as discussed earlier) thus more frequent use of self-care actions. Living with family (likely associated with disease management assistance) or alone (likely related to difficulty caring for self, at least initially) may be associated with less frequent use of self-care actions, particularly for younger patients. Although not strong or significant, age showed a trend toward a negative association with perceived self-care ability and a trend toward a positive association with self-care actions. The findings suggest that as age increases, perceived self-care ability may decrease and self-care actions may increase. As individuals transition from adolescence into adulthood, they take on more responsibility of caring for themselves (higher self-care actions) rather than being cared for by their parents/caregivers. They may feel poorly equipped to perform self-care (low perceived self-care ability) but may still attempt to do so. If self-care actions are not effective or if they feel that situations cannot be properly managed at home, then participants may utilize the healthcare system which also may be used more frequently for those with lower perceived self-care ability. The lack of association between income and self-care management was discussed previously.

Hypothesis 1c. A significant relationship between gender and the self-care management variables was not noted. Females often report longer episodes of pain crises than men (Taylor, Stotts, Humphreys, Treadwell & Miaskowski, 2010). It was therefore hypothesized that females would have lower perceived self-care ability and report less frequent use of self-care actions. The results of this study did not support that hypothesis. A possible explanation may be that there was not much variation in the self-care behaviors employed by male and female participants in this sample. Alternatively, given the slighter higher ratio of females to males in this sample, perhaps higher numbers of male participants would have shown significant results. Further studies should include a more equal distribution of participants by gender and may involve evaluating whether pain severity varies by gender.

Aim 2. Sickle cell disease self-efficacy, social support, education, income, perceived self-care ability, and self-care actions were not significant predictors of the number of hospital visits for crises in young Black adults with SCD. The combination of these predictor variables was not successful in explaining the variations in the outcome variable. Measurement error may have reduced the effects of the predictors. Further evaluation is needed to identify whether a hidden variable exists or whether the inclusion of additional variables, such as depression, may have been more effective.

Hypothesis 2. There was no adequate evidence of a significant association between the self-care management variables and the number of hospital visits for crises. Random error in the measurement of the self-care management variables may have decreased the chance of finding an effect in this study. Although not significant, perceived self-care ability showed a trend toward having a negative relationship with the number of hospital visits as expected; self-care actions showed a trend toward having a positive relationship with hospital visits. This result suggests that as perceived self-care ability increases, the use of self-care actions is also likely to increase, thus reducing the number of hospital visits. This validates previous studies which state that self-care management improves health outcomes, enhances quality of life, and reduces costs associated with healthcare use (Riegel, Jaarsma & Stromberg, 2012; Ryan & Sawin, 2009). This finding also suggests that as self-care actions increase, the number of hospital visits for crises may increase. It was theorized that more frequent use of self-care actions would result in fewer hospital visits as discussed above. The unexpected finding here suggests that individuals who perform more self-care actions may be more in tune with their bodies and aware of impending crises thus may present to the hospital for care more frequently than others; the goal being to prevent the situation from worsening.

Aim 3. Findings of the mediation analysis did not support the proposed mediational role of perceived self-care ability and self-care actions in the relationships among SCD self-efficacy, social support, years of education, income, and the number of hospital visits for crises. Important predictor variables were significantly associated with the self-care management variables but not the outcome variable. The choice of predictors and associated measurement error in major variables may have reduced the presence of a relationship in this case, if one truly existed.

Hypothesis 3. There was a direct relationship between income and the number of hospital visits for crises as discussed earlier. There was, however, no adequate evidence to support either a direct or indirect relationship between SCD self-efficacy, social support, years of education, and the number of hospital visits for crises as explained above. Perhaps the inclusion of depression as a variable or including self-care management as a predictor, rather than a mediator, may have favorably altered the results.

Conceptual Model

The Model of Health Functioning (Figure 1) was supported by the literature (Chlebowy & Garvin, 2006; Edwards, Telfair, Cecil & Lenoci, 2001; Frei, Svarin, Steurer-Stey & Puhan, 2009; Jenerette & Murdaugh, 2008; Levenson et al., 2008), but it was not validated in its entirety by the study findings. The substantive model, with SCD self-efficacy, social support, years of education, income, perceived self-care ability, and self-care actions predicting the number of hospital visits for crises, was not significant. The majority of the model, 89.4%, was attributed to error variance. This finding suggests that a number of the predictor variables were not associated with the outcome variable, resulting in a poor model. Perhaps the inclusion of alternate (depression for example) or fewer constructs would have garnered better results. The presence of outliers may have distorted the statistical analyses. Outliers influence regression coefficients much more than the rest of the cases and can lead to errors (Tabachnick & Fidell, 2007). In this study, outliers may have falsely increased significant correlations among the variables. Alternatively, missing data may have resulted in reduced power estimates to find significant results. Suppression may have also affected study outcomes. Suppressor variables decrease the criterion-irrelevant variance in the prediction of the outcome variable, thus they distort regression coefficients and their standard errors (Conger, 1974). This distortion makes interpretation of the regression weights challenging. Potential suppressor effects are indicated when part correlations are greater in magnitude than their zero-order counterparts (Velicer, 1978). Table 4 shows evidence that social support, self-care actions, and education may be functioning as suppressors when predicting hospital visits for crises. Suppression effects and an analytical approach to disentangle them are discussed by Beckstead (2012).

Of all the variables, income was most significantly and negatively related to the outcome variable; thus, it explained the largest proportion of the variance in the number of hospital visits for crises. This finding suggests that as income increases, the number of hospital visits for crises is likely to decrease. It is probable that individuals with more financial resources are better able to manage their disease at home and maintain a better state of health (are able to maintain a healthy lifestyle or utilize the health care system for preventive care and wellness), thus experience fewer crises and require less hospital visits. Also, higher income often affords more healthcare utilization and higher quality care. Interestingly, although income was important in understanding the outcome variable, it was not significantly associated with the self-care management variables. Individuals with sickle cell disease (SCD) are more likely to have lower income than those without SCD (Laurence, George & Woods, 2006). They may not be able to work or maintain a steady job given poor health and frequent crises. The ability to afford healthcare is often related to income, to whether healthcare is sought, and to the type and quality of care received. In addition, income often determines resources available for self-care management at home. It is likely, therefore, that in the absence of adequate income to obtain health care, self-care management may become much more important, but insufficient finances may also limit use of self-care. The lack of association between the self-care management variables and the number of hospital visits for crises in the overall model may be reducing a true effect here. Further study is needed in this regard.

Although they were not all significant (Table 3), the direction of variable associations, as noted in the Model of Health Functioning, existed as hypothesized for the majority of the relationships. The correlations among the study variables were somewhat congruent with expectations but the correlation strength, according to the rule of thumb for interpreting correlation coefficients (Hinkle, Wiersma & Jurs, 2003), only ranged from little to moderate for significant associations. The largest correlation (r=.502, p=.000) was between SCD self-efficacy and social support, and the smallest correlation (r=.006, p=.952) was between age and the number of hospital visits for crises. Given the fact that the study sample was relatively small, the observed little to moderate correlations may have been due to power estimates. The coefficient of determination (R^2) also reflected weak associations, with only a small proportion of the variance in the outcome variable being explained by the variance in the predictor variables used in the model. The presence of stronger, non-significant correlations may have indicated the need for a larger sample size to obtain significant effects. Random error in the measurement of the variables or the presence of a hidden variable may have degraded the model used in this study, thus reducing the strength of the correlations. Further study is needed in this area.

Study findings lend themselves to a revised model that reflects the observed relationships among the variables (Figure 2). In this model, SCD self-efficacy, social support, and education significantly predicted perceived self-care ability and self-care actions. Significant inter-correlations were also noted among SCD self-efficacy, social support, education, and age. Of the hypothesized predictors, only income was significantly related to the number of hospital visits for crises. In addition, neither perceived self-care ability nor self-care actions were significantly associated with the number of hospital visits for crises.

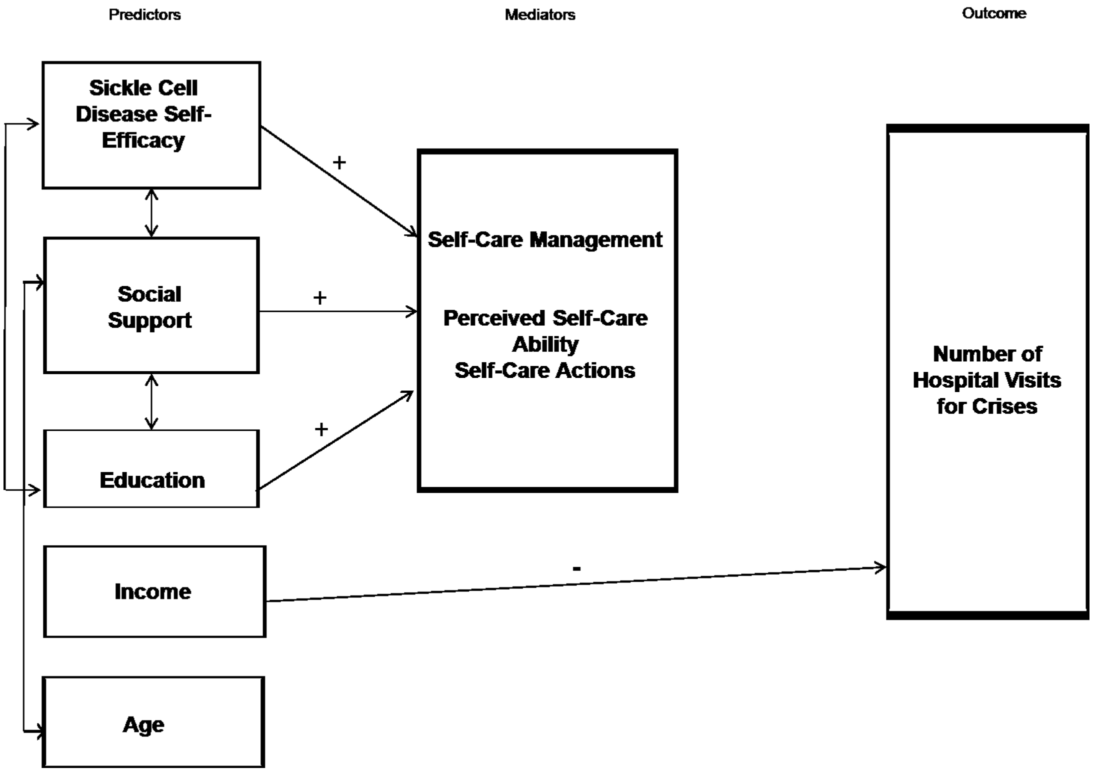


Figure 2. Observed Relationships

Sample

Characteristics of the sample may have influenced the study outcomes. Study participants were recruited from two SCD clinics in the southeastern United States. The majority of the participants had eight to twelve years of education and had annual earnings in the low income bracket. It may be that most of the respondents were from rural areas. Low income levels may have affected the healthcare resources available for preventive care and self-care management, and low education levels may have affected the response rate on study instruments. In addition, it is difficult to ascertain whether low levels of education were associated with location or illness. Annual household income was estimated for each participant based on zip code. This may have affected the study results in that income can vary within a given zip code. Further, the zip code can also be used an indicator of proximity to health care facilities. If participants lived in rural areas, then hospital distance may have had some bearing on their willingness to seek care at a hospital; however, the location of the home (rural, urban, or suburban) was not known. The majority of the participants (76%) also reported sharing a house with family. This finding may also be related to income constraints and may be a characteristic of rural living.

Previous research states that SCD affects males and females equally (Pack-Mabien & Haynes, 2009). In this sample, study participants were slightly more likely to be female (61.2%). It is unclear whether the number of females affected the outcomes. Future studies should include a sample that is more representative of the distribution of the SCD population. The mean age of the sample was 24 years old. Studies have shown that pain episodes are most frequent in the 19 to 39 age range (Jacob, 2001; Yusuf, Atrash, Grosse, Parker & Grant, 2010). In this study, age was not significantly associated with the number of hospital visits for crises so that finding was not validated. The restricted age range may have contributed to this finding. The average number of hospital visits for crises was three instances per year. This finding is in keeping with previous research which reports at least one pain crisis annually (Taylor, Stotts, Humphreys, Treadwell & Miaskowski, 2010) and use of the acute care system approximately 3.6 times per patient per year (Brousseau, Owens, Mosso, Panepinto & Steiner, 2010).

The most important relationships in this study were noted among SCD self-efficacy, social support, select socio-demographic variables, perceived self-care ability, and self-care actions. Before mean substitution was conducted, there were combinations of missing values on these items. These occurrences may have been due to purposeful patterns of nonresponse by participants. The patterns with some combination of values missing for SCD self-efficacy, social support, perceived self-care ability, income, and/or self-care actions may be related to participants' reluctance to report information, such as poor health habits or low self-perception, that they think may be perceived negatively. If so, then the inability to acknowledge these perceived shortcomings, if they do in fact exist, may have a negative effect on participants' actual self-care management thus the number of hospital visits for crises. These cases may have distorted the results, but if these individuals were removed from the data set, then the sample values on the number of hospital visits for crises may have been altered. It was necessary therefore to complete mean substitution for these items to retain the cases for analysis of the outcome variable.

Exploratory Analyses

Reliability and attenuation. Overall, study instruments appeared to be reliable; estimates were consistent with previous studies (Table 6). Although acceptable, the Jenerette Self-Care Assessment Tool (JSAT) and the Appraisal of Self-Care Agency Scale (ASA) were found to be less reliable than the other instruments. In the case of the JSAT, the reliability estimate obtained may be due to the length of the questionnaire (8 items); Cronbach's alpha can be affected by the length of the instrument (Tavakol & Dennick, 2011). The 24-item Appraisal of Self-Care Agency Scale (ASA) had the largest number of items missed (21.4%). There were a number of items on the questionnaire which appear to be closely related and measure the same concept. As such, reliability estimates should have been higher. This unexpected result may be related to this specific study sample; participant understanding, response bias, or perhaps frustration in repeatedly answering questions that appear to be similar. In addition, given that the ASA and the JSAT were both used to evaluate self-care management, participants may have had difficulty distinguishing between perceived self-care ability and self-care actions. As it relates to the relationships among the variables, perceived self-care ability (measured with the ASA) had the highest correlation (negative association) with the number of hospital visits for crises before and after correction for attenuation. This finding suggests that individuals with higher perceived self-care ability are likely to perform more frequent self-care actions, thus the number of hospital visits for crises is likely to decrease. The largest increase in the corrected correlations was made for the ASA; this result suggests that the observed correlations included some error. This error may also be related to the pattern of participant responses suggested above. The JSAT and ASA were used to evaluate the self-care management variables; therefore, the unreliability may have introduced measurement error into the hypothesized model, thus reducing the effects. For the purposes of data collection in future studies, it may be useful to consider using alternate or revised measures of self-care management which produce the highest reliability estimates while decreasing participant burden.

Relationships. A few correlations among study variables were low and were not statistically significant; however, two relationships may need further evaluation. The data suggest that there may be a trend toward a negative clinical relationship between age and perceived self-care ability in that as age increases, perceived self-care ability may decrease. As noted earlier, individuals with SCD take more of an active role in caring for themselves as they transition from adolescence to adulthood. As such, they may feel inexperienced in performing effective self-care thus may have low perceived self-care ability. Another clinically important observation is the relationship between years of education and hospital visits for crises. Data suggest there may be a trend toward a negative clinical relationship between years of education and the number of hospital visits for crises; as years of education increases, hospital visits for crises may decrease. As discussed earlier, individuals with more years of education are more likely to have a stronger sense of self-care ability and more frequently perform self-care actions than individuals with less education. These individuals are likely to be more knowledgeable about health practices so may participate in more health and wellness activities, thus may require fewer hospital visits.

Implications for Research, Education, and Practice

A number of observations in this study may have clinical significance and thus may be important to note. Sickle cell disease self-efficacy, social support, years of education, and income significantly predicted perceived self-care ability and self-care actions. Use of these variables in future studies involving self-care management may produce important outcomes. Further research is necessary to understand the potential associations between age and perceived self-care ability and between years of education and hospital visits for crises. Additional information is also needed to understand patterns of healthcare utilization by SCD patients; specifically, it would be important to identify reasons why they did or did not seek care at a hospital. Self-care management was noted to be an important construct in this study. Variables that were found to be important in understanding self-care management (SCD self-efficacy, social support, years of education, and income) can be useful in designing patient education programs aimed at improving self-care behaviors. Before doing so, additional information is needed regarding the relationship between self-care behaviors and pain severity, and the specific behaviors used by young adults to prevent and manage pain. In addition, information is needed regarding self-care behaviors and pain frequency because pain frequency also influences health care utilization. Further studies should include an equal distribution of participants by gender and may also include an evaluation of pain severity according to gender. All this information can be used to develop educational interventions that may be implemented as supplements to pharmacological treatment in the clinical setting and may be used to improve self-care management in the home setting. In addition, age, gender, employment status, and living situation proved to be non-influential variables in this study. As such, other researchers may choose not to include these socio-demographic variables as substantive predictors in similar studies.

Variables with the largest correlations have health policy and/or public policy implications. Income explained the majority of the variance in the number of hospital visits for crises. This finding suggests that resources should be used to make health care more accessible and affordable to SCD patients who often have low income and are unemployed or disabled. Social support accounted for the largest proportion of the variance in self-care management. This finding validates the importance of including friends and family in the process of planning care for patients. Health care providers can also encourage the use of support groups; this may assist with self-care management. The use and effectiveness of support groups in the SCD population needs to be evaluated further.

The presence of some non-significant results in this study limits the ability to make recommendations for research, education, and practice. In addition, correlation analysis only suggests relationships between variables, not a cause and effect. Overall, study findings suggest that further investigation is warranted in order to draw definitive conclusions. The use of alternate measures along with more diverse and larger sample sizes in future studies may produce significant results.

Study Strengths, Weaknesses, and Limitations

A few strengths are noted in this study. The exploratory, observational design was useful in understanding self-care management and identifying areas where future evaluation is needed. It was also possible to address research aims and hypotheses with few resources in an abbreviated time-frame. Testing hypotheses under these conditions can be beneficial in the event that no association is found among variables. In addition, findings of this study can be used to conduct larger confirmatory studies.

This secondary analysis may have been affected by the methods used in the primary study. Weaknesses were noted in this study by its author (Jenerette & Murdaugh, 2008). The presence of missing values in the data set may have affected the relationships among the variables despite the use of mean substitution. The decreased sample size due to missing data may have resulted in reduced power estimates to find significant results. In addition, the outcome variable could have been affected in that the correlations among the variables were possibly reduced due to a decrease in variance. As it relates to the number of hospital visits for crises, the lack of distinction between emergency department visits and inpatient admissions may have confounded the results of the study in terms of the evaluation of the outcome variable.

Limitations of this current study are also noted. The population of interest was restricted to SCD patients from ages 18 to 30 due to the frequency of crises and high healthcare utilization during that age range (Brousseau, Owens, Mosso, Panepinto & Steiner, 2010; Jacob, 2001; Yusuf, Atrash, Grosse, Parker & Grant, 2010). This may have affected analyses because age was included as a study variable. Correlations may have been decreased as a result of the restricted age range. Annual household income was estimated based on zip code; actual income was not available. This posed a limitation because income can vary within a given zip code; thus, study inferences may have been affected as a result. The self-care management variables were not significantly associated with the number of hospital visits for crises but they may have been associated with pain severity; pain is a frequent reason for emergency department treatment and/or hospital admission. An understanding of the effects of self-care management on pain severity was not possible in this secondary analysis because an objective measure of pain severity was not assessed in the parent study. Edwards, Telfair, Cecil, and Lenoci (2001) noted that depression may be associated with self-efficacy and self-care management. Depression was not measured in the parent study so it could not be assessed in this study. If the data were available, perhaps including depression as a predictor in the model would have produced more significant results. As such, future studies should include depression as a variable. Use of cross-sectional data limited the ability to analyze changes over time. For example, the relationship between the self-care management variables and an increase in age could not be evaluated. In addition, information regarding disease type (thus severity) was not obtained in the primary study. Therefore, the relationship between disease type and the predictors, particularly self-care management, could not be evaluated.

Conclusions

Using secondary analysis of an existing dataset, the purpose of this exploratory, correlational study was to better understand and describe the use and importance of self-care management in hospital visits for crises in young, Black adults (ages 18 to 30) with SCD. The study was successful in that it uncovered some important information about self-care management. Sickle cell disease self-efficacy, social support, years of education, and income are potentially important variables in understanding self-care management in this population. These potentially important relationships not only coincide with previous research, but have implications for clinical care of the SCD patient and educational strategies which may be used to improve self-care behaviors. These variables may also be important in predicting important health outcomes. Given the clinical significance of self-care management in SCD, further studies should be conducted to identify specific strategies used by individuals with SCD daily to prevent pain and to manage pain prior to seeking care; that information was not obtained from this study. In addition, this study identified one variable, income, which directly affects the number of hospital visits for crises. Further research is necessary to identify other variables which may influence hospital visits in this population. The lack of statistical significance in this study may suggest that there is no difference in the population or it may suggest that there is a possible difference that was not noted because of measurement error or reliability estimates. Further research is needed in this area.

References

Ataga, K. (2009). Novel therapies in sickle cell disease. *Hematology/The Education Program of the American Society of Hematology*, *1*, 54-61. Retrieved from http://asheducationbook.hematologylibrary.org/cgi/reprint/2009/1/54

Ballas, S., Gupta, K., & Adams-Graves, P. (2012). Sickle cell pain: A critical reappraisal. *Blood, 120*, 3647-3656. doi: 10.1182/blood-2012-04-383430

Ballas, S. (2011). Update on pain management in sickle cell disease. *Hemoglobin, 35*, 520–529. doi:10.3109/03630269.2011.610478

Ballas, S., Bauserman, R., McCarthy, W., Castro, O., Smith, W., Waclawiw, M. & Investigators of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia (2010). Hydroxyurea and acute painful crises in sickle cell anemia: Effects on hospital length of stay and opioid utilization during hospitalization, outpatient acute care contacts, and at home. *Journal of Pain and Symptom Management, 40*, 870-882. doi:10.1016/j.jpainsymman.2010.03.020

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education and Behavior*, *31*, 143-164. doi:10.1177/1090198104263660

Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior* (Vol. 4, pp. 71-81). New York: Academic Press.

Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.

Beckstead, J. (2012). Isolating and examining sources of suppression and multicollinearity in multiple linear regression. *Multivariate Behavioral Research, 47*, 224-246. doi:10.1080/00273171.2012.658331

Brousseau, D., Owens, P., Mosso, A., Panepinto, J., & Steiner, C. (2010). Acute care utilization and rehospitalizations for sickle cell disease. *The Journal of the American Medical Association, 303*, 1288-1294.

Buchanan, G., Vichinsky, E., Krishnamurti, L., & Shenoy, S. (2010). Severe sickle cell disease---Pathophysiology and therapy. *Biology of Blood and Marrow Transplantation, 16*, S64-S67. doi:10.1016/j.bbmt.2009.10.001

Centers for Disease Control and Prevention (2011a). *Data and statistics*. Retrieved from http://www.cdc.gov/NCBDDD/sicklecell/data.html

Centers for Disease Control and Prevention (2011b). *Facts about sickle cell disease*. Retrieved from http://www.cdc.gov/ncbddd/sicklecell/facts.html

Centers for Disease Control and Prevention (2010). *Living well with sickle cell disease*. Retrieved from http://www.cdc.gov/ncbddd/sicklecell/healthyliving-living-well.html

Cerin, E., Taylor, L., Leslie, E. & Owen, N. (2006). Small-scale randomized controlled trials need more powerful methods of mediational analysis than the Baron-Kenny method. *Journal of Clinical Epidemiology, 59*, 457-464. doi:10.1016/j.jclinepi.2005.11.008

Charles, E. (2005). The correction for attenuation due to measurement error: Clarifying concepts and creating confidence sets. *Psychological Methods, 10*, 206-226. doi: 10.1037/1082-989X.10.2.206

Chlebowy, D., & Garvin, B. (2006). Social support, self-efficacy, and outcome expectations: Impact on self-care behaviors and glycemic control in Caucasian and African American adults with type 2 diabetes. *The Diabetes Educator, 32*, 777-786. doi: 10.1177/0145721706291760

Clay, O., & Telfair, J. (2007). Evaluation of a disease-specific self-efficacy instrument in adolescents with sickle cell disease and its relationship to adjustment. *Child Neuropsychology, 13*, 188-203. doi:10.1080/09297040600770746

Conger, A. (1974). A revised definition for suppressor variables: A guide to their identification and interpretation. *Educational and Psychological Measurement, 34*, 35-46. doi: 10.1177/001316447403400105

Conner-Warren, R. (1996). Pain intensity and home pain management of children with sickle cell disease. *Issues in Comprehensive Pediatric Nursing*, *19*, 183-195.

Cox, L. (2002). Social support, medication compliance and HIV/AIDS. *Social Work in Health Care, 35*, 425-460. doi:10.1300/J010v35n01_06

Dampier, C., Ely, E., Eggleston, B., Brodecki, D. & O'Neal, P. (2004). Physical and cognitive-behavioral activities used in the home management of sickle pain: A daily diary study in children and adolescents. *Pediatric Blood & Cancer*, *43*, 674-678. doi:10.1002/pbc.20162

Dampier, C., Ely, E., Brodecki, D. & O'Neal, P. (2002). Home management of pain in sickle cell disease: A daily diary study in children and adolescents. *Journal of Pediatric Hematology/Oncology*, *24*, 643-647.

Dick, M. (2008). Standards for the management of sickle cell disease in children. *Archives of Disease in Childhood – Education and Practice Edition*, *93*, 169-176. doi: 10.1136/adc.2007.116699

Dunlop, R. & Bennett, K. (2009). Pain management for sickle cell disease in children and adults (review). *Cochrane Database of Systematic Reviews*, Issue 2. Art. no.: CD003350. doi: 10.1002/14651858.CD003350.pub2

Edwards, R., Telfair, J., Cecil, H. & Lenoci, J. (2001). Self-efficacy as a predictor of adult adjustment to sickle cell disease: One-year outcomes. *Psychosomatic Medicine, 63*, 850-858.

Edwards R., Telfair, J., Cecil, H., & Lenoci, J. (2000). Reliability and validity of a self-efficacy instrument specific to sickle cell disease. *Behaviour Research and Therapy, 38*, 951-963.

Evers, G., Isenberg, M., Phillipsen, G., Brouns, G., Halfens, R., & Smeets, H. (1986). The 'appraisal of self-care agency' ASA-scale: Research program to test reliability and validity. Proceedings of the International Nursing Research Conference New Frontiers in Nursing Research (p. 130). Edmonton, Canada: University of Alberta, Canada.

Fosdal, M. & Wojner-Alexandrov, A. (2007). Events of hospitalization among children with sickle cell disease. *Journal of Pediatric Nursing*, *22*, 342-346. doi:10.1016/j.pedn.2006.09.001

Frei, A., Svarin, A., Steurer-Stey, C. & Puhan, M. (2009). Self-efficacy instruments for patients with chronic diseases suffer from methodological limitations – a systematic review. *Health and Quality of Life Outcomes*, *7*, 1-10. doi:10.1186/1477-7525-7-86

George, D., & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference, 11.0 update* (4th ed.). Boston, MA: Allyn & Bacon.

Haynes, R., McDonald, H., & Garg, A. (2002). Helping patients follow prescribed treatment: Clinical applications. *The Journal of the American Medical Association, 288*, 2880-2883. doi:10.1001/jama.288.22.2880

Hinkle, D., Wiersma, W., & Jurs, S. (2003). *Applied statistics for the behavioral sciences* (5th ed.). Boston, MA: Houghton Mifflin Harcourt

Hosmer, D., & Lemeshow, S. (2000). *Applied logistic regression* (2nd ed.). New York: John Wiley & Sons, Inc.

Iannotti, R., Schneider, S., Nansel, T., Haynie, D., Plotnick, L., Clark, L.,…Simons-Morton B. (2006). Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type I Diabetes. *Journal of Developmental and Behavioral Pediatrics, 27*, 98-105.

Jacob, E. (2001). The pain experience of patients with sickle cell anemia. *Pain Management Nursing,* 2, 74-83. doi: 10.1053/jpmn.2001.26119

Jenerette, C., Brewer, C., & Leak, A. (2011). Self-care recommendations of middle-aged and older adults with sickle cell disease. *Nursing Research and Practice, 2011*, 1-5. doi:10.1155/2011/270594

Jenerette, C. & Valrie, C. (2010). The influence of maternal behaviors during childhood on self-efficacy in individuals with sickle cell disease. *Journal of Family Nursing, 16*, 422-434. doi: 10.1177/1074840710385000

Jenerette, C. & Murdaugh, C. (2008). Testing the theory of self-care management for sickle cell disease. *Research in Nursing and Health*, *31*, 355-369. doi: 10.1002/nur.20261

Kaambwa, B., Bryan, S., & Billingham, L. (2012). Do the methods used to analyse missing data really matter? An examination of data from an observational study of intermediate care patients. *BMC Research Notes, 5*, 330-341. doi: 10.1186/1756-0500-5-330

Kauf, T., Coates, T., Huazhi, L., Mody-Patel, N., & Hartzema, A. (2009). The cost of health care for children and adults with sickle cell disease. *American Journal of Hematology, 84*, 323-327. doi:10.1002/ajh.21408

Kratz, A., Molton, I., Jensen, M., Ehde, D., & Nielson, W. (2011). Further evaluation of the motivational model of pain self-management: Coping with chronic pain in multiple sclerosis. *Annals of Behavioral Medicine, 41*, 391–400. doi:10.1007/s12160-010-9249-6

Laurence, B., George, D., & Woods, D. (2006). Association between elevated depressive symptoms and clinical disease severity in African-American adults with sickle cell disease. *The Journal of the National Medical Association, 98*, 365-369.

Lee, L., Askew, R., Walker, J., Stephen, J., & Robertson-Artwork, A. (2012). Adults with sickle cell disease: An interdisciplinary approach to home care and self-care management with a case study. *Home Healthcare Nurse, 30*, 172-183. doi:10.1097/NHH.0b013e318246d83d.

Levenson, J., McClish, D., Dahman, B., Bovbjerg, V., Citero, V., Penberthy, L.,…Smith, W. (2008). Depression and anxiety in adults with sickle cell disease: The PiSCES project. *Psychosomatic Medicine, 70*, 192-196. doi: 10.1097/PSY.0b013e31815ff5c5

Loeb, S., Penrod, J., Falkenstern, S., Gueldner, S., & Poon, L. (2003). Supporting older adults living with multiple chronic conditions. *Western Journal of Nursing Research, 25*, 8-23. doi: 10.1177/0193945902238830

Modi, A., Pai, A., Hommel, K., Hood, K., Cortina, S., Hilliard, M.,…Drotar D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics, 129*, e473–e485. doi:10.1542/peds.2011-1635

Mosher, C., DuHamel, K., Egert, J., & Smith, M. (2010). Self-efficacy for coping with cancer in a multiethnic sample of breast cancer patients: Associations with barriers to pain management and distress. *Clinical Journal of Pain, 26*, 227-234.

Nash, K. B. (1994). *Psychological aspects of sickle cell disease: Past, present, and future directions of research*. New York: Haworth.

Ngamvitroj, A., & Kang, D. (2007). Effects of self-efficacy, social support and knowledge on adherence to PEFR self-monitoring among adults with asthma: A prospective repeated measures study. *International Journal of Nursing Studies, 44*, 882-892.

Niscola, P., Sorrentino, F., Scaramucci, L., Fabritiis, P., & Cianciulli, P. (2009). Pain syndromes in sickle cell disease: An update. *Pain Medicine, 10*, 470-480. doi:10.1111/j.1526-4637.2009.00601.x

Olowoyeye, A. & Okwundu, C.I. (2010). Gene therapy for sickle cell disease (review). *Cochrane Database of Systematic Reviews*, Issue 8, 1-8. Art. no: CD007652. doi:10.1002/14651858.CD007652.pub2.

Orem, D.E. (1971). *Nursing: Concepts of practice*. New York: McGraw-Hill.

Pack-Mabien, A. & Haynes, J. (2009). A primary care provider's guide to preventive and acute care management of adults and children with sickle cell disease. *American Academy of Nurse Practitioners, 21*, 250-257. doi:10.1111/j.17457599.2009.00401.x

Palermo, T., Riley, C., & Mitchell, B. (2008). Daily functioning and quality of life in children with sickle cell disease pain: Relationship with family and neighborhood socioeconomic distress. *The Journal of Pain, 9*, 833-840. doi:10.1016/j.jpain.2008.04.002

Panepinto, J., & Bonner, M. (2012). Health-related quality of life in sickle cell disease: Past, present, and future. *Pediatric Blood & Cancer, 59*, 377–385. doi:10.1002/pbc.24176

Panepinto, J., Owens, P., Mosso, A., Steiner, C., & Brousseau, D. (2012). Concentration of hospital care for acute sickle cell disease-related visits. *Pediatric Blood & Cancer, 59*, 685-689. doi:10.1002/pbc.24028

Riegel, B., Jaarsma, T., & Stromberg, A. (2012). A middle-range theory of self-care of chronic illness. *Advances in Nursing Science, 35*, 194–204. doi:10.1097/ANS.0b013e318261b1ba

Ryan, P., & Sawin, K. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook, 57*, 217-225. doi:10.1016/j.outlook.2008.10.004

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R.,…Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 44*, 136–144. doi: 10.1111/j.1547-5069.2012.01444.x

Sherbourne, C.S. & Stewart, A.L. (1991). The MOS social support survey. *Social Science and Medicine, 32*, 705-714.

Sin, M., Kang, D., & Weaver, M. (2005). Relationships of asthma knowledge, self-management, and social support in African American adolescents with asthma. *International Journal of Nursing Studies, 42*, 307-313.

Smith, W., Penberthy, L., Bovbjerg, V., McClish, D., Roberts, J., Dahman, B.,…Roseff, S. (2008). Daily assessment of pain in adults with sickle cell disease. *Annals of Internal Medicine, 148*, 94-101.

Tabachnick, B., & Fidell, L. (2007). *Using multivariate statistics* (5th ed.). Boston, MA: Allyn & Bacon Inc.

Tanabe, P., Porter, J., Creary, M., Kirkwood, E., Miller, S., Ahmed-Williams, E. & Hassell, K. (2010). A qualitative analysis of best self-management practices: Sickle cell disease. *Journal of the National Medical Association, 102*, 1033-1041.

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education, 2*, 53-55. doi:10.5116/ijme.4dfb.8dfd

Taylor, L., Stotts, N., Humphreys, J., Treadwell, M. & Miaskowski, C. (2010). A review of the literature on the multiple dimensions of chronic pain in adults with sickle cell disease. *Journal of Pain and Symptom Management*, *40*, 416-435. doi:10.1016/j.jpainsymman.2009.12.027

U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute (2002). *The management of sickle cell disease* (NIH Publication No. 02-2117). Retrieved from http://www.nhlbi.nih.gov/health/prof/blood/sickle/sc_mngt.pdf

Velicer, W. (1978). Suppressor variables and the semipartial correlation coefficient. *Educational and Psychological Measurement, 38*, 953-958. doi: 10.1177/001316447803800415

Wetcher-Hendricks, D. (2006). Adjustments to the correction for attenuation. *Psychological Methods, 11*, 207-215. doi: 10.1037/1082-989X.11.2.207

Yusuf, H., Atrash, H., Grosse, S., Parker, C., & Grant, A. (2010). Emergency department visits made by patients with sickle cell disease: A descriptive study, 1999-2007. *American Journal of Preventive Medicine, 38*, S536–S541. doi: 10.1016/j.amepre.2010.01.001

Appendices

Appendix A

Demographic/Vulnerability/Knowledge Questionnaire

1. Age: _____

2. Gender

   1. Female 2. Male

3. What is the number of years of schooling completed? (Circle your response)

Elementary/Intermediate: 01 02 03 04 05 06 07 08 09
High School: 09 10 11 12
Technical College (Associate Degree): 13 14
4-Year College (Bachelor's Degree): 13 14 15 16
Graduate School (Master's Degree): 17 18
Doctorate: 19 20 21

4. What is the number of years of schooling completed <u>by your father?</u> (Circle your response)

Elementary/Intermediate: 01 02 03 04 05 06 07 08 09
High School: 09 10 11 12
Technical College (Associate Degree): 13 14
4-Year College (Bachelor's Degree): 13 14 15 16
Graduate School (Master's Degree): 17 18
Doctorate: 19 20 21

5. Are you currently working at a paying job? (Circle your response)

   1. Yes, full-time
   2. Yes, part-time
   3. No, not employed
   4. No, not employed (disabled)

6. What is your current marital status? (Circle your response)

   1. Single/never married
   2. Married
   3. Divorced
   4. Widowed
   5. Separated

7. Which best describes your current housing situation? (Circle your response)

    1. I rent
    2. I own

8. Which best describes your living situation? (Circle your response)

    1. I live alone
    2. I share housing with family
    3. I share housing with friends

9. What is your zip code? ___________

10. How old were you when you had your first Sickle Cell Disease Crisis?

    _______ years old

11. On average, how many Sickle Cell Disease Crises do you have per year that require being in the hospital?

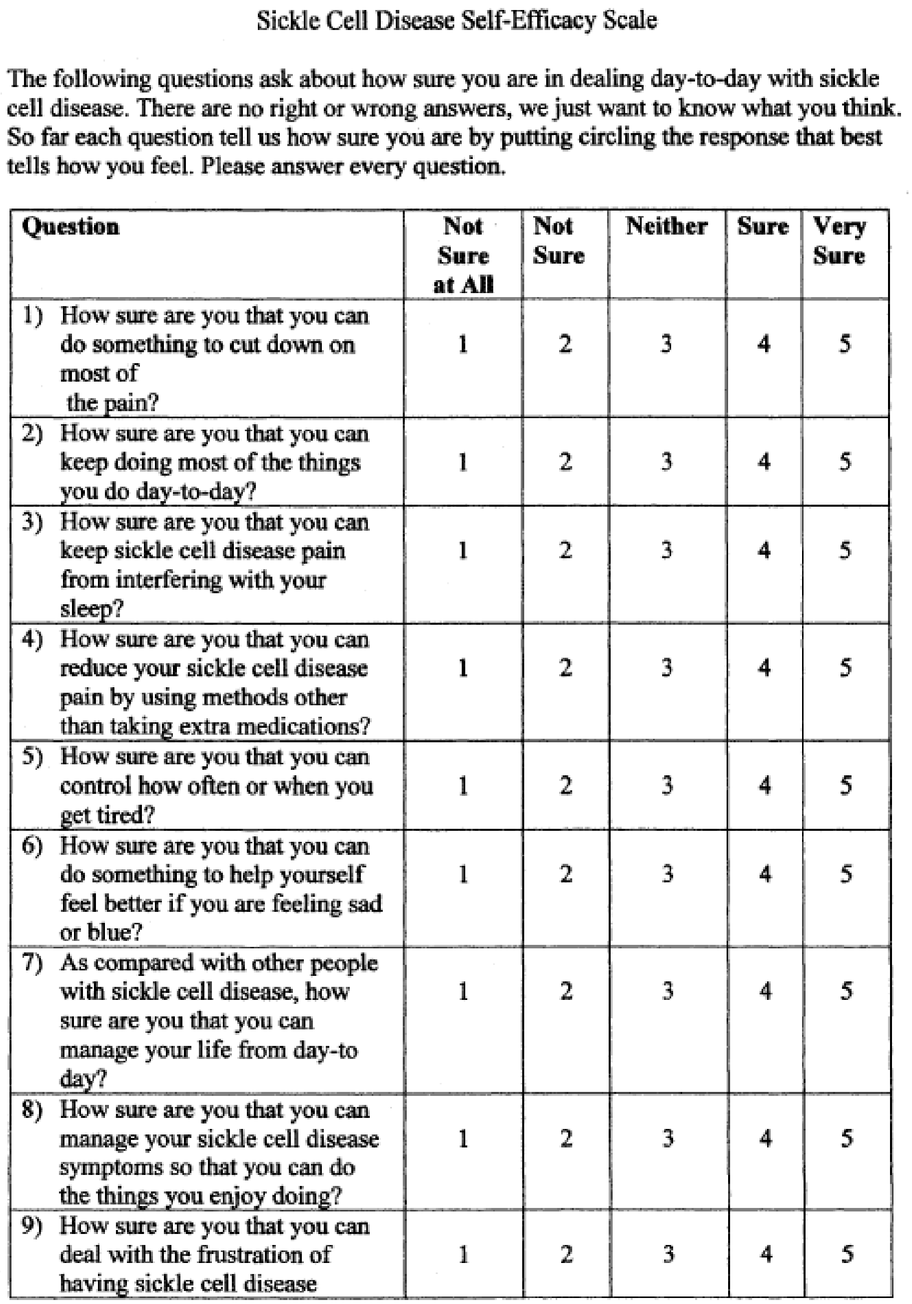
    ____

12. Circle **all** of the following conditions you have experienced because of having Sickle Cell Disease.

    1. Anemia
    2. Depression
    3. Drug dependency addiction
    4. Heart Failure
    5. Impotence/Priapism
    6. Kidney Problems
    7. Leg Ulcers
    8. Osteonecrosis (Hip/joint replacement/problems)
    9. Painful crises
    10. Vision problems
    11. Other ___________________________________

Unpublished; permission granted for use by the primary investigator of the parent study (Jenerette & Murdaugh, 2008).

Appendix B



Sickle Cell Disease Self-Efficacy Scale

The following questions ask about how sure you are in dealing day-to-day with sickle cell disease. There are no right or wrong answers, we just want to know what you think. So far each question tell us how sure you are by putting circling the response that best tells how you feel. Please answer every question.

Question	**Not Sure at All**	**Not Sure**	**Neither**	**Sure**	**Very Sure**
1) How sure are you that you can do something to cut down on most of the pain?	1	2	3	4	5
2) How sure are you that you can keep doing most of the things you do day-to-day?	1	2	3	4	5
3) How sure are you that you can keep sickle cell disease pain from interfering with your sleep?	1	2	3	4	5
4) How sure are you that you can reduce your sickle cell disease pain by using methods other than taking extra medications?	1	2	3	4	5
5) How sure are you that you can control how often or when you get tired?	1	2	3	4	5
6) How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?	1	2	3	4	5
7) As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to day?	1	2	3	4	5
8) How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?	1	2	3	4	5
9) How sure are you that you can deal with the frustration of having sickle cell disease	1	2	3	4	5

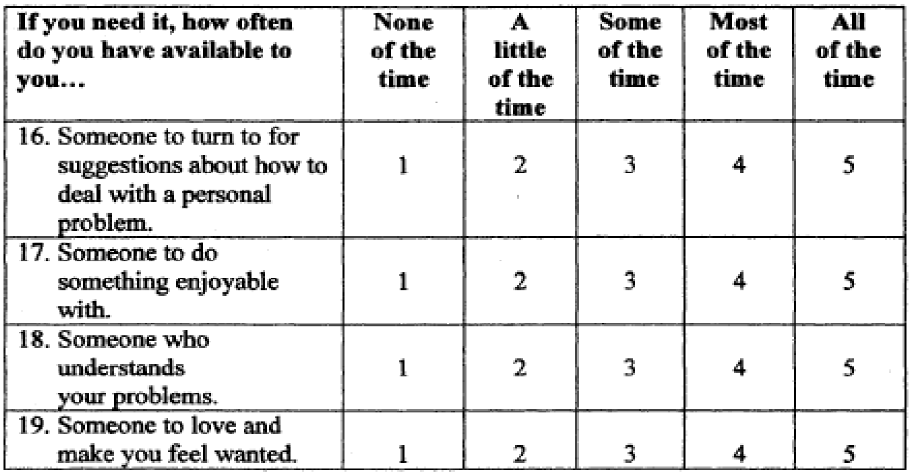
(Edwards, Telfair, Cecil & Lenoci, 2000).

Appendix C

Medical Outcomes Study Social Support Survey

People sometimes look to others for companionship, assistance or other types of support. Choose the answer that best describes how often each of the following types of support are available to you if you need it.

If you need it, how often do you have available to you…	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
1. Someone to help you if you were confined to bed.	1	2	3	4	5
2. Someone you can count on to listen when you need to talk.	1	2	3	4	5
3. Someone to give you good advice about a crisis.	1	2	3	4	5
4. Someone to take you to the doctor if you needed it.	1	2	3	4	5
5. Someone who shows you love and affection.	1	2	3	4	5
6. Someone to have a good time.	1	2	3	4	5
7. Someone to give you information to help you understand a situation.	1	2	3	4	5
8. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
9. Someone who hugs you.	1	2	3	4	5
10. Someone to get together with for relaxation.	1	2	3	4	5
11. Someone to prepare your meals if you were unable to do it for yourself.	1	2	3	4	5
12. Someone whose advice you really want.	1	2	3	4	5
13. Someone to do things with to help you get your mind off things.	1	2	3	4	5
14. Someone to help with daily chores if you were sick.	1	2	3	4	5
15. Someone to share your most private worries and fears with.	1	2	3	4	5



If you need it, how often do you have available to you…	None of the time	A little of the time	Some of the time	Most of the time	All of the time
16. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
17. Someone to do something enjoyable with.	1	2	3	4	5
18. Someone who understands your problems.	1	2	3	4	5
19. Someone to love and make you feel wanted.	1	2	3	4	5

(Sherbourne & Stewart, 1991)

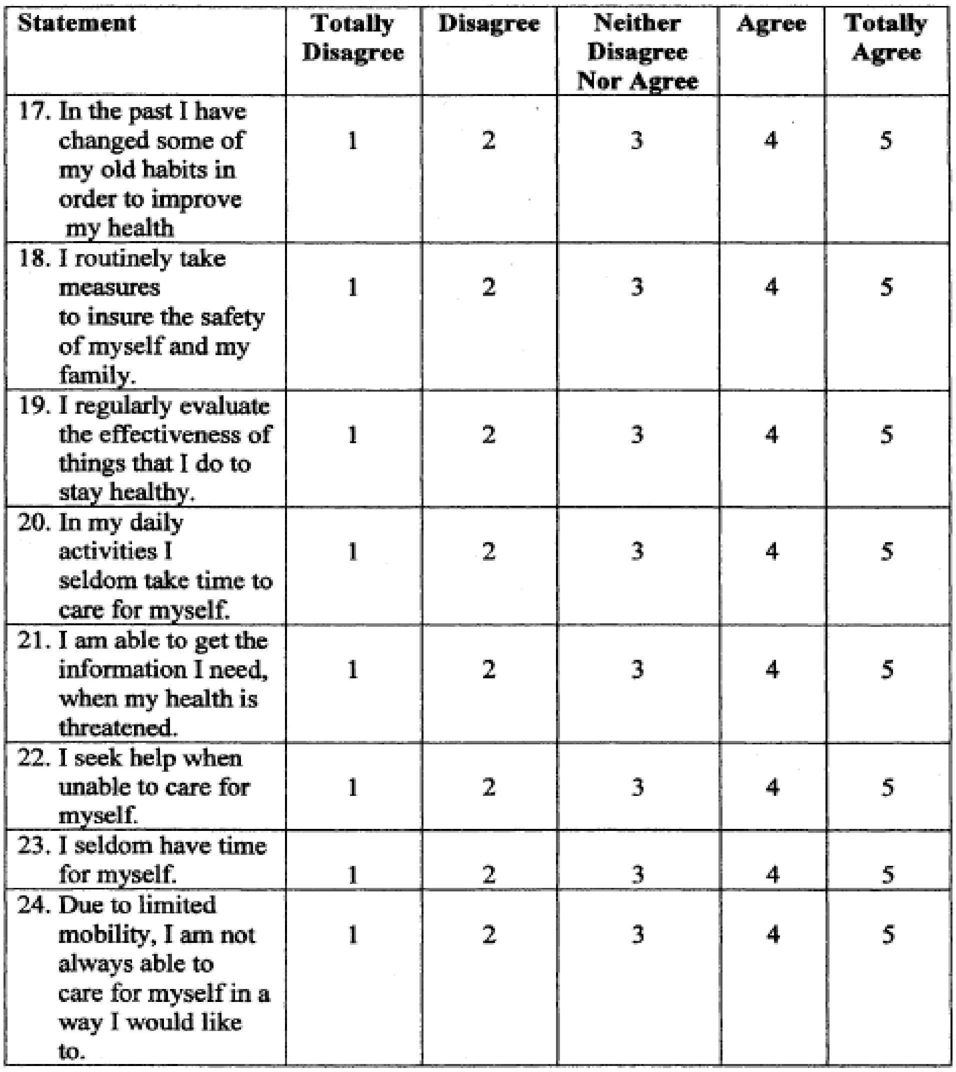
Appendix D

Appraisal of Self-Care Agency Scale (ASA)

A list of statements which people have used to describe themselves is given below. Please read each statement and then circle the appropriate number to the right of each statement to indicate how much you agree or disagree with the statement as a description of you. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to be most descriptive of you. You may skip over any questions that you choose not to answer.

Statement	**Totally Disagree**	**Disagree**	**Neither Disagree Nor Agree**	**Agree**	**Totally Agree**
1. As circumstances change, I make the needed adjustments to stay healthy.	1	2	3	4	5
2. I rarely check whether the measures I take to stay healthy are adequate	1	2	3	4	5
3. If my mobility is decreased, I make the needed adjustments.	1	2	3	4	5
4. I take measures to maintain sanitary conditions in my environment.	1	2	3	4	5
5. When needed, I set new priorities in the measures that I take to stay healthy.	1	2	3	4	5
6. I often lack the energy to care for myself in the way that I know I should.	1	2	3	4	5
7. I look for better ways to care for myself.	1	2	3	4	5
8. To maintain my hygiene, I adjust the frequency of bathing and showering to the circumstances.	1	2	3	4	5

Statement	**Totally Disagree**	**Disagree**	**Neither Disagree Nor Agree**	**Agree**	**Totally Agree**
9. I eat in a way that maintains my body weight at an appropriate level.	1	2	3	4	5
10. When needed, I manage to be by myself.	1	2	3	4	5
11. I often think about including a rogram of exercise and rest in my daily routine, but never get around to doing it.	1	2	3	4	5
12. Over the years I have developed a circle of friends that I can call upon when I need help.	1	2	3	4	5
13. I rarely get enough sleep to feel rested.	1	2	3	4	5
14. When receiving information regarding my health, I seldom ask for clarification of language that I do not understand.	1	2	3	4	5
15. I seldom examine my body to determine the presence of any changes	1	2	3	4	5
16. If I take a new medication, I obtain information about the side effects.	1	2	3	4	5



Statement	Totally Disagree	Disagree	Neither Disagree Nor Agree	Agree	Totally Agree
17. In the past I have changed some of my old habits in order to improve my health	1	2	3	4	5
18. I routinely take measures to insure the safety of myself and my family.	1	2	3	4	5
19. I regularly evaluate the effectiveness of things that I do to stay healthy.	1	2	3	4	5
20. In my daily activities I seldom take time to care for myself.	1	2	3	4	5
21. I am able to get the information I need, when my health is threatened.	1	2	3	4	5
22. I seek help when unable to care for myself.	1	2	3	4	5
23. I seldom have time for myself.	1	2	3	4	5
24. Due to limited mobility, I am not always able to care for myself in a way I would like to.	1	2	3	4	5

(Evers et al., 1986)

Appendix E

Jenerette Self-Care Assessment Tool (J-SAT)

Please choose the response that best reflects your agreement with each statement.

Statement	**Never**	**Rarely**	**Sometimes**	**Almost Always**
1. I take medications as prescribed.				
2. I keep my medical appointments.				
3. I understand (know why I am taking) my medications.				
4. I follow the diet recommended by my doctor/nurse.				
5. I know enough about my health.				
6. I drink plenty of fluids.				
7. I avoid stress whenever possible.				
8. I dress to stay warm.				

Unpublished; permission granted for use by the primary investigator of the parent study (Jenerette & Murdaugh, 2008).