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***An Examination of Differences in Intra-Personal Resources,
Self-Care Management, and Health Outcomes in Older and
Younger Adults with Sickle Cell Disease***

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ABSTRACT

Background: Sickle cell disease (SCD) and its manifestations often result in a lifetime of pain and hospitalizations. Although modern medicine has made advances in the diagnosis and treatment of SCD, these patients often receive inadequate health care and may lack the skills needed to improve self-care management, health status, and quality of life (QOL).

Purpose: To examine differences in intra-personal resources, self-care management, and health outcomes in older and younger adults with SCD.

Conceptual Framework: Theory of Self-Care Management for Vulnerable Populations

Design: Comparative descriptive

Sample and Setting: Sample of 57 older adults and 103 younger adults recruited from two southeastern United States SCD clinics

Measures: Simplified Rathus Assertiveness Schedule, Family Coping Project Coping Scale, Sickle Cell Self-Efficacy Scale, Medical Outcomes Study Social Support Survey, Jenerette Self-Care Assessment Tool, a brief Health Status Questionnaire, and the Chronic Illness QOL Scale.

Results: There were significant differences in assertiveness, spiritual activities and focusing on others' coping behaviors, and tangible and positive social interaction social support.

Conclusions: The data suggests that older and younger adults with SCD use different intra-personal resources to deal with SCD. Further studies need to be done to develop appropriate interventions for younger and older adults with SCD to enhance self-care management and improve health outcomes.

Key Words: *sickle cell disease, self-care management*

An Examination of Differences in Intra-Personal Resources, Self-Care Management, and Health Outcomes in Older and Younger Adults with Sickle Cell Disease

Introduction

Sickle cell disease (SCD) is an inherited, autosomal, recessive genetic disorder that is expressed as sickle cell anemia, sickle cell thalassemia disease, or sickle hemoglobin C disease.^{1,2} SCD is a chronic blood disorder that, in the United States, most often affects African Americans (Figure 1). In African Americans in the US, SCD is one of the most prevalent genetic disorders with a birth rates of 2.7 per 1000 for sickle cell anemia or Hb SS (homozygous disease), 1.2 per 1000 for Hb SC (heterozygous disease), 0.6 per 1000 for Hb S (beta-thalassemia) and 83.3 per 1000 for Hb AS (sickle cell trait).³ Globally, SCD is most common among people originating from sub-Saharan Africa, but it also affects people of Mediterranean, Caribbean, Middle Eastern, and Asian origin.⁴ SCD affects an estimated 1–2% (120,000) of newborns in Africa annually.⁵ Approximately 178 babies (2.8 per 10,000 conceptions) are affected by sickle cell disease in England annually,⁶ and 10,000 in the United Kingdom suffer from the disease.⁷ It is

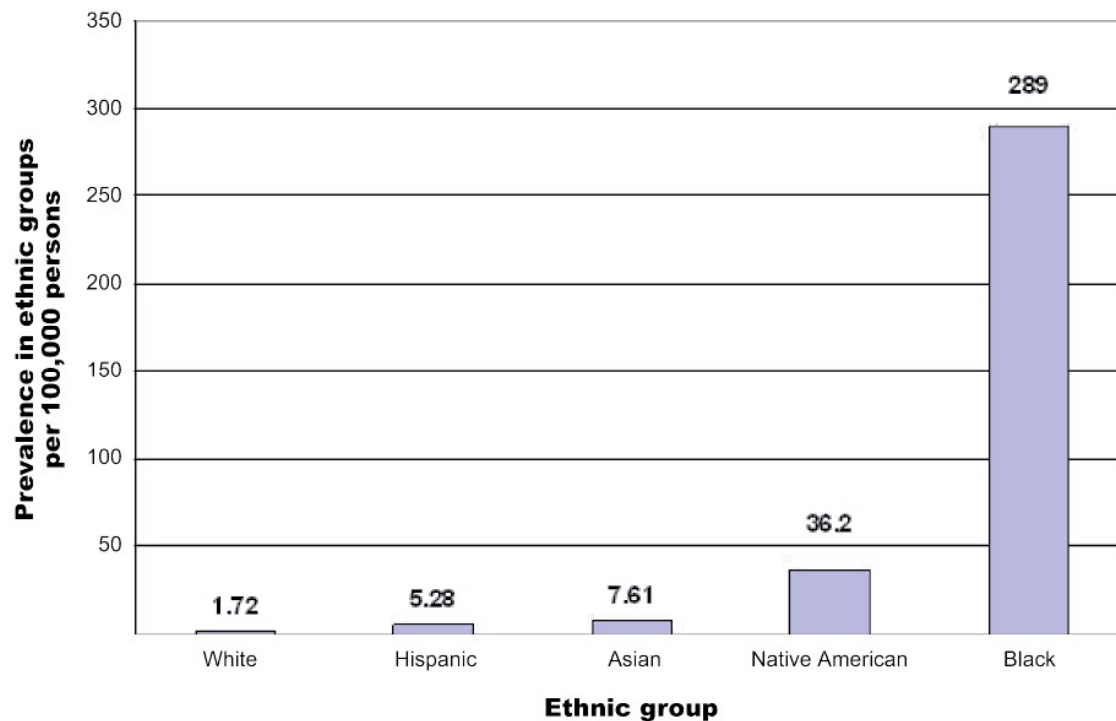
caused by a genetic mutation that produces defective hemoglobin.^{8,9} This mutation leads to the possibility of damage to every system in the body.¹⁰

Advancements in the detection and treatment of SCD have led to increased life expectancy.^{11,12} Thirty years ago, the median length of survival for SCD patients was 14 years.¹³ Because of advances in medical management, those affected with SCD are living much longer.^{14,15} In the US, the average lifespan of African Americans with sickle cell anemia, the most severe form of SCD, is 42 to 48 years,¹⁶ compared to healthy African Americans, who have an average lifespan of 67 to 75 years. Advances in the care of people affected with SCD include genetic counseling, neonatal screening, early initiation of prophylactic penicillin therapy, closer medical monitoring, newer medications such as hydroxyurea (the only treatment currently available that can reduce the severity and frequency of painful episodes), and early intervention to relieve painful symptoms.^{11,17} However, the only cure for SCD is bone marrow

transplantation, which is not an option for most people with SCD due to either a shortage of compatible donors or the

inherent risks posed by the drug regimen required before transplantation.^{11,17,18}

Figure 1
Prevalence of Sickle Cell Disease in the U.S., 1993³



SCD is a lifelong disorder characterized by recurrent and unpredictable episodes of pain, hemolytic anemia, anemic crises, stroke, infections, renal and pulmonary problems, and numerous complications related to organ dysfunction of varying severity.^{14,19} People with SCD may have high levels of emergency department use

and frequent hospitalizations.²⁰ Pain is the most frequent reason that adults with SCD seek health care. The intensity of an acute sickle cell crisis has been qualitatively compared to terminal bone cancer pain, but because pain is subjective and immeasurable, the patient, rather than a somatic origin, is often thought to be the problem.²¹

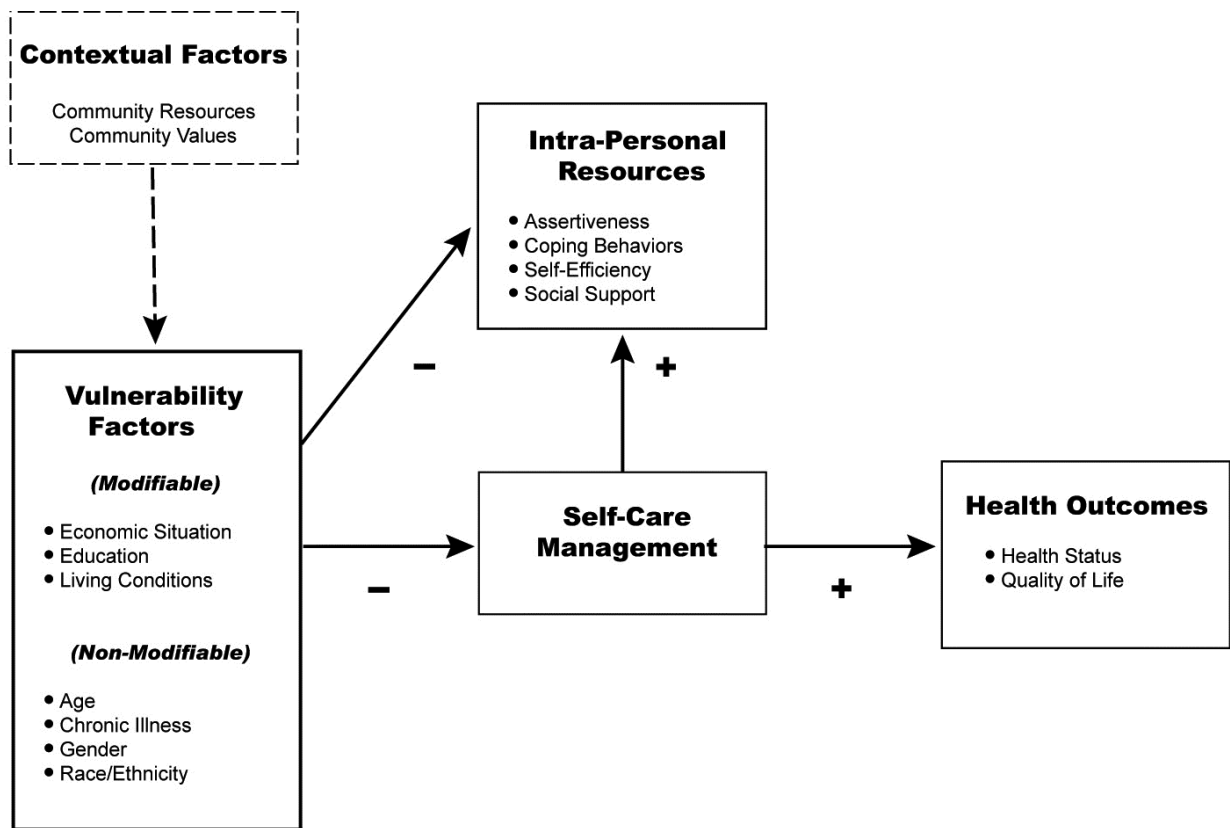
Because people with SCD are living longer, it imperative for health care providers to make sure that those affected with SCD get the best possible comprehensive care.²²

In order to develop comprehensive models of care, it is important to know the needs of adults with SCD so that their self-care management, health status, and quality of life can be enhanced. Moreover, it is important to understand differences in intra-personal resources, self-care management, and health outcomes of older and younger adults with SCD. The purpose of this research was to examine differences in intra-personal resources (coping behaviors, self-efficacy, and social support), self-care management, and health outcomes (health status and quality of life) in older and younger adults with SCD.

Theoretical Perspective. The Theory

of Self-Care Management for Vulnerable Populations (Figure 2) proposes an approach to identifying variables that influence self-care management, health status, and quality of life among populations who experience health disparities. Concepts include contextual factors (community resources, community values), vulnerability factors (age, complications, employment, father's education), intra-personal resources (assertiveness, coping behaviors, self-efficacy, social support), self-care management, health status, and quality of life. Vulnerability factors influence intra-personal resources, which in turn influence self-care management. Self-care management is theorized to directly predict both health status and quality of life. All hypothesized relationships in the model have been supported in prior published research.²³

Figure 2
Theory of Self-Care Management for Vulnerable Populations



Research Questions. This study addresses three research questions:

1. What are the differences in intra-personal resources (assertiveness, coping behaviors, self-efficacy, social support) between older and younger adults with SCD?
2. What are the differences in self-care management between older and younger adults with SCD?
3. What are the differences in health outcomes (health status and quality of life) between older and

younger adults with SCD?

Review of Literature. The literature review, guided by the conceptual framework, focuses on intra-personal resources (assertiveness, coping behaviors, self-efficacy, and social support), self-care management, and health outcomes (health status and quality of life) in adults with SCD and other chronic illnesses. Because life expectancy for individuals with the most severe type of SCD was less than 30 years and SCD was described as a

disease of childhood, there is a limited amount of research about intra-personal resources, self-care management, and health outcomes in adults with SCD.^{15,24} Moreover, the research most often does not differentiate between older and younger adults with SCD.

Assertiveness is defined as behavior that enables one to “stand up” for one’s rights without infringing on the rights of others.²⁵ This behavior may be useful to adults such as those with SCD who are facing a life-long struggle with a chronic illness. Few studies have described the role of assertiveness as an influential factor affecting an individual’s self-care management. In individuals with serious illnesses, assertiveness training is considered useful to increase an individual’s assertiveness, internal locus of control beliefs, and positive ways of coping with a serious illness.²⁶ Individuals who manage their pain at home express a strong sense of self-responsibility for their pain management and advocate self-education, assertiveness, and resistance to strategies toward hospital services.^{27,28} However, adults with SCD may have to enter the health care system when a SCD pain crisis cannot be managed at home. Assertiveness, or

taking charge of the situation, may be useful when patients with SCD are faced with inappropriate care by poorly informed nurses or medical staff.²⁹

In older adults with breast cancer, black women of lower socio-economic status were more likely to have full staging of their tumors when they made an assertive request. In fact, assertiveness led to more careful diagnostic testing for patients who were disadvantaged.³⁰ Similarly, research with a group of African American elders found that the individuals felt a need to advocate or stand up for themselves either with healthcare providers or significant others in order to have their needs met.³¹

Coping behaviors are cognitive and behavioral actions used to master conditions of harm, threat, or challenge when a normal or routine response is not available.³² Chronic illnesses such as SCD frequently leave the sufferer with feelings of powerlessness, and decreased self-esteem which may lead to the inability to use normal coping resources such as physical strength, psychological stamina, and positive self-esteem.³³ Brief training in cognitive coping skills has been shown to increase coping attempts, decreased negative thinking,

and lower tendency to report pain during a laboratory-induced noxious stimulation.³⁴ Coping strategies in adults with SCD have been shown to be stable over time.³⁵ Negative thinking, passive coping, and somatic awareness have been shown to be related to several measures of poor health in SCD. However, some relationships are better accounted for by general measures of negative affectivity.³⁶ In other studies, adults with SCD indicated that on pain days when they practiced coping strategies such as distraction, relaxation, or provided coping audio tapes, they sought less health care than on days that they did not use these strategies.^{37,38} In another study, cognitive behavioral therapy was immediately effective for management of SCD pain in terms of reducing the pain of psychological distress, as well as improving coping.³⁹

Self-efficacy refers to one's belief about the ability to achieve a desired health outcome.^{40,41} More specifically, self-efficacy focuses on individuals' convictions that they can exercise control over motivations, behaviors, and social environment.⁴² Although there has been little research related to self-efficacy in SCD, self-efficacy may be a determinant of adjustment to chronic

illness.⁴² In one study, self-efficacy among African American adults with SCD was inversely related to disease symptomatology and these relationships persisted over time.⁴³ In research that used case management to improve the transition of adolescents with SCD to adult care, patients who maintained follow-up appointments were more self-efficacious.¹⁴ Additionally, patients who reported higher scores on the Feeling Concerned and Worried subscale of the Chronic Illness Assessment Interview for SCD, an instrument based on a model of self-care for adult patients with chronic medical conditions, also reported increased visits to the emergency department, increased pain severity, and decreased levels of self-esteem, self-efficacy, and mastery.¹⁵

In elderly adults, self-efficacy may be protective against a decline in functional status by buffering diminished self-care capabilities related to diminished physical capacity.⁴⁴ A study found that individuals who have suffered cerebrovascular accidents (strokes) benefit from incorporating self-efficacy techniques in order to succeed in their self-care management after stroke.⁴⁵ Self-efficacy was the only variable found to be correlated with adherence in a

study of medication compliance in patients suffering from rheumatoid arthritis.⁴⁶

Social support is defined as one's internal perception that may influence interpersonal behaviors including expression of positive affect, affirmation of another's behaviors or views, or giving symbolic or material aid.⁴⁷ Self-esteem, social assertiveness, and use of social support were significant predictors of social functioning, mental health, health perceptions, total functioning score, and adherence in adolescents with SCD.⁴⁸ Research about the role social support plays in the health of adults with SCD is limited. Nash presented a review of studies related to the psychosocial aspects of SCD.⁴⁹ The major theme that permeates the review is the continuous need for social support. Support is needed from family and health care providers. Support from family, noted in studies of other chronic illnesses, may increase compliance and decrease depression, while support from health care providers may increase satisfaction with the healthcare delivery system and decrease the discrimination felt by some patients with SCD. In a study of older adults, it was also found that building a

partnership of care in which nurses and other health care professionals function in a supportive and educational role enhanced the older adult's lifelong self-care management and ability to stay in control of multiple chronic health conditions.⁵⁰ In studies pertaining to adherence to prescribed treatments, enlisting social support from family and friends improved adherence.⁵⁰⁻⁵²

Self-care management is defined as engaging in therapeutic behaviors and taking action to access resources to maintain and/or improve health status and quality of life.²³ For the adult with SCD priority self-care measures are adequate hydration, refraining from over-exercise, keeping medical appointments, adhering to health care provider's instructions, and making sure medical questions are answered.¹⁵ It was also found that individuals with SCD may employ strategies to take control of their lives in order to maintain a "normal" life. These self-care management strategies include coping behaviors which involves negotiation and engagement in both personal and structural factors.²⁹ Furthermore, it was found that one's ability to engage in self-care management is influenced by social

and material resources, life transitions, and the responses of society.²⁹

Another self-care management behavior for adults with SCD is religiosity. It was found that religious involvement played an important role in assisting some adults with SCD to manage their disease. In fact, attending church at least once per week is associated with fewer negative experiences with pain and lower levels of psychiatric disturbance for patients with SCD.⁵³ In a sample of African American elders living with chronic health conditions, reliance on God was found to an important strategy.³¹

Health status can be defined as one's subjective or self-assessment of physical, social, and mental well-being.⁵⁴ The health status of adults with SCD may be influenced by a clinical course that often worsens. Chronic organ damage may become evident, acute painful crises become harder to tolerate, and adults may face losses of productivity and psychological distress.¹⁷ Additionally, adults with SCD may experience organ damage that may result in stroke, pulmonary failure or hypertension, renal failure, congestive heart failure, leg ulcers, and osteonecrosis of the femoral or humeral head.¹⁶ Compared to

individuals with other chronic conditions, adults with SCD report lower general health and health-related quality of life.^{55,56} Haque and Telfair found that self-reported medical problems were higher for older adults with SCD.⁵⁷

Quality of life (QOL) is defined as a subjective sense of well-being with physical, psychological, and social dimensions of one's life.⁵⁸ SCD is a condition that has profound consequences for the QOL of individuals with SCD and their family members.⁵⁹ Individuals with SCD experience health-related QOL worse than the general population.⁵⁵ This reduced QOL may be due to the chronicity of the illness combined with frequent hospitalizations for pain or other complications, which can contribute to impaired psychosocial functioning.⁶⁰ Although increasing life expectancy is an important accomplishment, QOL is also important.⁶¹ Interventions in SCD should consider improvements in health-related QOL as an important outcome.^{55,56}

Methods

As a part of a larger cross-sectional descriptive study, a convenience sample of 232 adults with a diagnosis of SCD

was recruited from two SCD clinics located within academic medical centers in the southeastern United States. Using a comparative descriptive design, from the primary sample, 72 participants, ages 31-44 were excluded. This resulted in two more age distinct comparison groups; an older adult sample, adults with SCD age 45 years and above and the young adult sample, adults with SCD ages 18-30 years. Participant criteria included ability to read, write, or understand English, at least 18 years old, and have a diagnosis of SCD. In the original study, Institutional Review Board approval had been received from the two data collection sites and the principle investigator's academic institution. Participants were recruited and informed consent was obtained following the approved protocol. Data collection took place in a private area of each SCD clinic using paper and pencil. Participants completed the questionnaires during one clinic visit in an average of 30 to 60 minutes. Five participants requested assistance to complete the questionnaires. In these five cases, the investigator or nurse read the questions and recorded the responses. Upon completion of study instruments, each participant received

\$25 for the time required to participate in the study.

The questionnaire packet included a demographic data form and instruments that measured SCD knowledge, assertiveness, coping behaviors, SCD self-efficacy, social support, self-care, health status, and quality of life. All study instruments were developed or selected to encompass the range of variables relevant to the larger study in which the Theory of Self-Care Management for Vulnerable Populations was being tested.²³ The instruments relevant to examining differences in intra-personal resources (assertiveness, coping behaviors, self-efficacy, and social support), self-care management, and health outcomes (health status and quality of life) in older and younger adults with sickle cell disease are described below.

Assertiveness. Assertiveness was measured with the 30-item Simple Rathus Assertiveness Schedule (SRAS).⁶² An internal consistency reliability coefficient of 0.90 has been reported.⁶² Very little validity data have been published for the SRAS. However, since the SRAS is a parallel form of the Rathus Assertiveness Schedule (RAS),⁶³ much of the validity of the original RAS

applies to the SRAS. The RAS has established validity in terms of significant correlations with scales that measure impressions respondents make on other people ($r=0.33$ to $r=0.62$, $p < 0.01$) and indications of how people would behave in certain situations ($r=0.70$, $p < 0.01$).⁶² The SRAS correlates 0.90 with the original RAS. After reverse coding the necessary items, a total score is obtained by summing responses, with higher responses indicating higher levels of assertiveness. Cronbach's alpha reliability for the SRAS in the current study was 0.84.

Coping Behaviors. Coping behaviors were measured with the Family Coping Project Coping Scale (COP), a 54-item Likert-type instrument with five subscales (seeking/using social support, spiritual activities, avoidance, managing illness, and focusing on others). Subscale reliabilities range from 0.71 to 0.88 with a total scale reliability of 0.90. Construct validity was obtained using exploratory factor analysis. Total and subscale scores are obtained by summing responses, with higher responses indicating higher levels of the specific coping behavior.⁶⁴ Cronbach's alpha reliabilities for the coping subscales in the current study were

0.83, 0.84, 0.73, 0.72, and 0.51, respectively, and for the total scale 0.91.

Self-Efficacy. Self-efficacy was measured with the Sickle Cell Disease Self-Efficacy Scale (SCSES), a 9-item Likert-type scale measuring SCD disease-specific perceptions of self-efficacy. Internal consistency reliability has been reported to be 0.89.⁴² Convergent validity was estimated by significant correlations between self-efficacy and self-esteem (0.39), sense of mastery (0.45), and internal health locus of control (0.41). A significant negative correlation between the SCSES and reported pain severity supports the predictive validity of the instrument. Responses are summed, with higher scores indicating higher self-efficacy.⁴² Cronbach's alpha reliability for the SCSES in the current study was 0.87.

Social Support. Perceived availability of support was measured with the Medical Outcomes Study Social Support Survey (MOS-SSS), a 19-item Likert-type scale containing four subscales (emotional/informational, affectionate, tangible, and positive social interaction). Total scale and subscale internal consistency reliabilities have been reported to be above 0.91. Construct validity is supported by both

confirmatory and principal components factor analysis. Responses are summed, with higher scores indicating higher perceptions of available support.^{65,66} Cronbach's alpha reliabilities for the social support subscales in the current study were 0.92, 0.81, 0.82, and 0.89, respectively and for the total scale 0.95.

Self-Care Management. Self-care management was measured with the Jenerette Self-Care Assessment Tool (J-SAT), a 13-item scale that measures sickle cell specific self-care management actions. The internal consistency reliability of the J-SAT was 0.80 in a sample of 75 adults. Construct validity was estimated by a significant negative correlation ($r=-0.19$) with the Center for Epidemiological Studies Depression Scale (CESD), and significant positive correlation ($r=0.49$) with the Functional Status Questionnaire (FSQ) (unpublished study). Cronbach's alpha reliability for the J-SAT in the current study was 0.71.

Health Status. Health status was measured by a 5-item questionnaire adapted from Segovia, Bartlett, and Edwards' 49-item scale, which measures ten dimensions of health status.⁵⁴ In the five-item scale used in this study, health status was assessed by summing

responses, with a higher score indicating higher subjective health status.

Construct validity was supported with statistically significant correlations ranging from 0.31 to 0.40 between the five-item health status scale and self-reported health status and health care utilization. Cronbach's alpha for the health status measure in the current study was 0.77.

Quality of Life. The Chronic Illness Quality of Life Ladder (CIQOLL) was used to measure health-related quality of life (HRQOL) in relation to living with SCD. The ten-step ladder measures QOL at four time points: present, life without SCD (i.e., if the individual no longer had SCD), one year ago (past), and one year from now (future), where ten indicates the best possible quality of life and one indicates the worst possible quality of life. These four points in time form the four subscales of the CIQOLL. Internal consistency reliability has been reported to be greater than 0.90 for each subscale. Principal components factor analysis resulted in four meaningful factors corresponding to the four time periods, accounting for 87% of the variance. The CIQOLL also has demonstrated convergent validity, by high significant correlations with the

Life Purpose Scale (0.74) and divergent validity by high negative correlations with the CES-D (-.65).⁵⁸ Subscale scores are obtained for each time period: present, without SCD, past, and future, with higher scores indicating higher QOL. Cronbach's alpha reliabilities for the quality of life subscales in the current study were 0.89, 0.88, 0.88, and 0.91, respectively, and 0.96 for the total scale.

Data Analysis. Descriptive statistics were calculated to describe the demographic characteristics of the total sample of older and younger adults with SCD, older adults with SCD, and younger adults with SCD. Scale and subscale means, ranges, and standard deviations were calculated. T-tests were conducted to test for significant differences between older and younger adults with SCD in mean intra-personal resource scores, self-care management scores, and health outcomes scores. Chi-square tests were used to test for significance differences in categorical data (employment, marital status).

Results

The sample consisted of 105 (65.6%) women and 55 (34.4%) men. The

average participant was 34 years old with a high school education. The respondents had an average of two SCD crises per year. Almost two-thirds (63%) of the sample had never been married and almost three-quarters (73%) lived with their families. The majority were either not employed (29.4%), or were unemployed due to disability (41%). Using zip codes provided by participants, the average median household income was determined to be approximately \$36,000.⁶⁷ Responses from the older adults with SCD and the younger adults with SCD were examined for differences. Tables 1 and 2 depict demographic data for older and younger adults. There were significant differences between younger and older adults in the number of SCD crises per year, with younger adults reporting more crises per year (2.75 vs. 1.67, $p=.01$). There were also significant differences (Chi-square=10.23, $p=.02$) in employment between younger and older adults, with younger adults being more likely to have part-time employment (18% vs. 5.3%), more likely to be unemployed (35% vs. 19.3%), but less likely to be unemployed due to disability (33% vs. 56%). There were

significant differences (Chi-square= 83.01, $p < .01$) in marital status between younger and older adults, with younger

adults reporting higher rates of never being married (87% vs. 18%).

Table 1
Demographic Characteristics of Older and Younger Adults with SCD

	N	Mean (SD)	Range
Older Adults with SCD			
Age (years)	57	52.68 (6.05)	45-73
Education (years)	57	12.30 (2.60)	5-18
Median Household Income	53	\$36,284 (\$11,113)	\$17,843-\$57,755
Number of SCD Crises per year	52	*1.67 (1.78)	0-8
Younger Adults with SCD			
Age (years)	103	23.87 (3.40)	18-30
Education (years)	103	12.08 (1.47)	8-16
Median Household Income	100	\$35,724 (\$10,488)	\$17-843-\$65,375
Number of SCD Crises per year	99	*2.75 (2.82)	0-20

*Denotes significant difference in the Mean between older and younger adults with SCD. Sample size varies due to missing data.

Table 2
Demographic Characteristics of Older and Younger Adults with SCD

	Older N (%)	Younger N (%)
Gender		
Female	42 (73.7)	63 (61.2)
Male	15 (26.3)	40 (38.8)
Employment		
Full-time	11 (19.3)	19 (18.4)
*Part-time	3 (5.3)	14 (13.6)
Unemployed	11 (19.3)	36 (35)
Disabled	32 (56.1)	34 (33)
Marital Status		
*Never Married	10 (17.5)	90 (87.4)
Married	16 (28.1)	10 (9.7)
Divorced	13 (22.8)	1 (1)
Widowed	11 (19.3)	
Separated	7 (12.3)	1.9 (1.9)
Living Situation		
Alone	17 (29.8)	18 (17.5)
With Family	40 (70.2)	76 (73.8)
With Friends		9 (8.7)

* Denotes significant difference in N between older and younger adults with SCD.

Research Question 1: Are there statistically significant differences in intra-personal resources (assertiveness, coping behaviors, self-efficacy, social support) between older and younger adults with SCD? There were statistically significant differences in the intra-personal resource of assertiveness ($t=-3.34$, $p<.01$) (Table 3). Younger adults reported higher levels of assertiveness than older adults with SCD (116.50 vs. 105). In intra-personal resources coping behaviors subscales,

there were statistically significance differences between older and younger adults. Older adults reported use of more spiritual activities ($p<.05$, 16.7 vs. 13.8) and focusing on others ($p<.05$, 9.1 vs. 8.0). In the intra-personal resources social support subscales, there were statistically significant differences between older and younger adults with SCD. Older adults perceived less tangible social support ($p<.02$, 29.4 vs. 30.9) and perceived less positive social interactions ($p<.02$, 14.2 vs. 15.6).

Research question 2: Are there statistically significant differences in self-care management between older and younger adults with SCD? There

were no statistically significant differences in self-care management between older and younger adults with SCD.

Table 3
Intra-Personal Resources: Scale means and standard deviation

Intra-Personal Resources	Older		Younger	
	N	Mean (SD)	N	Mean (SD)
Assertiveness (SRAS)	48	105.0 (22.42)	89	116.49 (17.25)
Coping Behaviors (COP total)	35	104.09 (20.39)	62	97.76 (18.27)
Seeking Support	47	19.47 (7.03)	86	20.57 (6.35)
Avoidance	43	16.12 (6.25)	82	14.45 (5.17)
*Spiritual Activities	50	16.70 (4.11)	90	13.84 (4.12)
Managing the Illness	51	20.88 (3.90)	87	19.86 (4.06)
Focusing on Others	53	9.06 (2.05)	88	8.03 (20.5)
Self-Efficacy (SCSES)	55	30.42 (8.06)	97	31.84 (6.37)
Social Support (MOS-SSS total)	46	71.89 (17.01)	90	75.34 (15.75)
Emotional/Informational Support	50	29.40 (7.74)	95	30.88 (7.41)
Affectionate Support	53	11.47 (3.07)	100	12.15 (2.84)
*Tangible Support	56	14.59 (3.82)	102	16.09 (3.66)
*Positive Social Interaction Support	55	14.16 (4.12)	98	15.60 (3.63)

* Denotes significant difference in Mean between older and younger adults with SCD. Sample size varies due to missing data.

Research question 3: Are there statistically significant differences in health outcomes (health status and quality of life) between older and younger adults with SCD? There were no statistically significant differences in health outcomes between older and younger adults with SCD.

Limitations. There are several limitations that need to be

acknowledged. The self-selected convenience sample was recruited from two different clinic sites. In the original data analysis, there were significant differences in age, onset of first SCD crisis, and median household income between the two data collection sites. However, overall, the sites were more alike than different and were combined to achieve the required sample size

required for structural equation modeling, the data analysis technique used in the larger study.

Furthermore, there were missing data. Several factors may have resulted in missing data, including the multiple task responsibilities of the data collectors, which led to less than consistent follow-up for complete data from each participant. Also, the longest scale, 54 items, contained the most missing data. Changing the response format as well as decreasing the number of items may address this issue. T-tests confirmed that there were no significant differences in respondents with complete data and those with incomplete data.

Respondents were not asked to identify their specific type of SCD (e.g., Sickle Cell Anemia [SS], Sickle-Hemoglobin C Disease [SC], or Sickle-Thalassemia). Because the types of SCD have differing levels of severity, it will be important to obtain this information in future studies.

Conclusions

The data suggest that older adults use spiritual activities to cope with SCD. This result supports findings of other

studies that found that reliance on God and church attendance are important coping behaviors used by African Americans with chronic illnesses such as SCD.^{31,53} In addition to spiritual activities, older adults with SCD tend to focus on others rather than on themselves. In contrast to younger adults, older adults with SCD may have lost many of their friends to SCD or other illnesses and are unable to maintain employment. In order to cope with significant losses, African American older adults often 'engage in life' by using other activities to take their minds off challenges and to keep them focused on meaningful life activities such as visiting relatives in the nursing home or cleaning their church.³¹ Findings indicate that interventions to enhance self-care management in older adults with SCD should include some aspect of spirituality or religiosity and perhaps provide opportunities for them to focus on activities and persons other than themselves.

The data suggest that younger adults seek and use social support as a means to deal with SCD. Additionally, this younger cohort reports higher levels of tangible social support and positive

social interactions. This may be related to the life expectancy of individuals with SCD and the potential for numerous complications as the disease progresses. Compared to older adults with SCD, younger adults with SCD may be more physically able to obtain tangible support and participate in social activities. Younger adults report higher levels of assertiveness than older adults with SCD. This assertiveness may be perceived as aggressiveness or addiction when young adults enter the healthcare arena.^{68,69} Appropriate interventions for young adults with SCD should include self-care management strategies which enhance and use aspects of social support. Additionally, assertiveness training may be useful to insure that younger adults with SCD are better able to access and use the health care system.

Due to advances in medical care, adults with SCD are living much longer. Unfortunately, there has been little research on the intra-personal resources available to adults with SCD and the

self-care management activities that affect their health status and QOL. This study is an important step in developing tailored interventions to meet the needs of younger and older adults with SCD. Results suggest that older and younger adults with SCD use different coping behaviors and have different strengths in their battle to live with SCD. Although the Theory of Self-Care Management for Vulnerable Populations offers a useful framework, interventions for adults with SCD need to be tailored to meet the needs of both older and younger adults with SCD. Future studies should be done to further explore the needs of adults with SCD in order to develop interventions that will improve self-care management, health status, and quality of life among adults with SCD. Additionally, valuable information may also be gained by using a triangulated method wherein structured interviews could be used to identify factors that enhance self-care management and health outcomes in adults with SCD.

References

1. Godeau, B., Noel, V., Habibi, A., Schaeffer, A., Bachir, D., & Galacteros, F. (2001). Sick cell disease in adults: Which emergency care by the internists? *La Revue De Medecine Interne*, 22(5), 440-451.
2. Andrews, M. M., & Mooney, K. H. (1994). Alterations in hematologic function in children. In K. L. McCance, & S. E. Huether (Eds.), *Pathophysiology: The biologic basis for disease in children* (pp. 908-939). St. Louis: Mosby-Yearbook.
3. Sick Cell Disease Guideline Panel. (1993). *Sickle cell disease: Screening, diagnosis, management, and counseling in newborns and infants. Clinical practice guideline no. 6. AHCPR Pub. No. 93-0562*. Rockville, MD: Agency for Healthcare Policy and Research, Public Service, U.S. Department of Health and Human Services.
4. Serjeant, G. R. (1992). *Sickle cell disease* (2nd ed.). Oxford: Oxford University Press.
5. Ohene-Frempong, K., & Nkrumah, F. K. (1994). Sick cell disease in Africa. In S.H. Embury, R.P. Hebbel, N. Mohandes & M.H. Steinberg (Eds.), *Sickle cell disease: Basic principles and clinical practice* (pp. 423-435). New York: Lippincott Williams and Wilkins.
6. Hickman, M., Modell, B., Greengross, P., Chapman, C., Layton, M., & Falconer, S. et al. (1999). Mapping the prevalence of sickle cell and beta thalassaemia in England: Estimating and validating ethnic-specific rates. *British Journal of Haematology*, 104(4), 860-867.
7. Davies, S. C., & Oni, L. (1997). Management of patients with sickle cell disease. *British Medical Journal*, 315(7109), 656-660.
8. Yang, Y. M., Shah, A. K., Watson, M., & Mankad, V. N. (1995). Comparison of costs to the health sector of comprehensive and episodic health care for sickle cell disease patients. *Public Health Reports*, 110(1), 80-86.
9. Reed, W., & Vichinsky, E. P. (1998). New considerations in the treatment of sickle cell disease. *Annual Review of Medicine*, 49, 461-474.
10. Smith, W. R., Bovbjerg, V. E., Penberthy, L. T., McClish, D. K., Levenson, J. L., & Roberts, J. D. et al. (2005). Understanding pain and improving management of sickle cell disease: The PiSCES study. *Journal of the National Medical Association*, 97(2), 183-193.
11. Mayfield, E. (1996). New hope for people with sickle cell anemia. *Federal Drug Administration Consumer*, 30(4), 4.
12. McKerrell, T. D., Cohen, H. W., & Billett, H. H. (2004). The older sickle cell patient. *American Journal of Hematology*, 76(2), 101-106.
13. Diggs, L. M. (1973). Anatomic lesions in sickle cell disease. In H. Abramson, J. F. Bertles & D. L. Wethers (Eds.), *Sickle cell disease: Diagnosis, management, education, and research* (pp. 189-229). St. Louis: C.V. Mosby.
14. Wojciechowski, E. A., Hurtig, A., & Dorn, L. (2002). A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing*, 17(1), 18-27.
15. Lenoci, J. M., Telfair, J., Cecil, H., & Edwards, R. F. (2002). Self-care in adults with sickle cell disease. *Western Journal of Nursing Research*, 24(3), 228-245.

16. Platt, O. S., Brambilla, D. J., Rosse, W. F., Milner, P. F., Castro, O., & Steinberg, M. H. et al. (1994). Mortality in sickle cell disease, life expectancy, and risk factors for early death. *New England Journal of Medicine*, 330(23), 1639-1644.
17. Chakrabarti, S., & Bareford, D. (2004). Will developments in allogeneic transplantation influence treatment of adult patients with sickle cell disease? *Biology of Blood and Marrow Transplantation*, 10(1), 23-31.
18. BMT. (1998). BMT for sickle cell disease. *Blood and Marrow Transplant Newsletter*, 43(9), #3.
19. Ballas, S. K. (1999). Complications of sickle cell anemia in adults: Guidelines for effective management. *Cleveland Clinic Journal of Medicine*, 66(1), 48-58.
20. Mayer, M. L., Konrad, T. R., & Dvorak, C. C. (2003). Hospital resource utilization among patients with sickle cell disease. *Journal of Health Care for the Poor and Underserved*, 14(1), 122-135.
21. Rouse, C. M. (2004). Paradigms and politics: Shaping health care access for sickle cell patients through the discursive regimes of biomedicine. *Culture, Medicine and Psychiatry*, 28(3), 369-399.
22. Davies, S. C., & Gilmore, A. (2003). The role of hydroxyurea in the management of sickle cell disease. *Blood Reviews*, 17(2), 99-109.
23. Dorsey, C. J., & Murdaugh, C. L. (2003). The theory of self-care management for vulnerable populations. *Journal of Theory Construction and Testing*, 7(2), 43-49.
24. Onitilo, A. A., Lazarchick, J., Brunson, C. Y., Frei-Lahr, D., & Stuart, R. K. (2003). Autologous bone marrow transplant in a patient with sickle cell disease and diffuse large B-cell lymphoma. *Transplantation Proceedings*, 35(8), 3089-3092.
25. Gorman, L., Raines, M. L., & Sultan, D. F. (2002). *Psychosocial nursing for general patient care* (2nd ed.). Philadelphia: F.A. Davis.
26. Richardson, S.S. (2000). *The Effects of an Assertiveness Training Intervention on Clients' Level of Assertiveness, Locus of Control, and Ways of Coping with Serious Illness* (doctoral dissertation). New Orleans, LA: Louisiana State University Medical Center.
27. Maxwell, K., Streetly, A., & Bevan, D. (1999). Experiences of hospital care and treatment seeking for pain sickle cell disease: Qualitative study. *British Journal of Medicine*, 318, 1585-1590.
28. Maxwell, K. S., & Streetly, A. (1998). Living with sickle cell pain. *Nursing Standard*, 13(9), 33.
29. Atkin, K., & Ahmad, W. I. (2001). Living a "normal" life: Young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine*, 53(5), 615-626.
30. Krupat, E., Irish, J. T., Kasten, L. E., Freund, K. M., Burns, R. B., & Moskowitz, M. A. et al. (1999). Patient assertiveness and physician decision-making among older breast cancer patients. *Social Science & Medicine*, 49(4), 449-457.
31. Loeb, S. J. (2006). African American older adults coping with chronic health conditions. *Journal of Transcultural Nursing*, 17(2), 139-147.
32. Lazarus, R. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
33. Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N., & Bergman, W. et al. (1998). Illness perceptions, coping and functioning in patients

- with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, 44(5), 573-585.
34. Gil, K. M., Wilson, J. J., Edens, J. L., Webster, D. A., Abrams, M. A., & Orringer, E. et al. (1996). Effects of cognitive coping skills training on coping strategies and experimental pain sensitivity in African American adults with sickle cell disease. *Health Psychology*, 15(1), 3-10.
 35. Gil, K. M., Wilson, J. J., & Edens, J. L. (1997). The stability of pain coping strategies in young children adolescents, and adults with sickle cell disease over an 18-month period. *Clinical Journal of Pain*, 13(2), 110-115.
 36. McCrae, J. D., & Lumley, M. A. (1998). Health status in sickle cell disease: Examining the roles of pain coping strategies, somatic awareness, and negative affectivity. *Journal of Behavioral Medicine*, 21(1), 35-55.
 37. Gil, K. M., Carson, J. W., Porter, L. S., Scipio, C., Bediako, S. M., & Orringer, E. (2004). Daily mood and stress predict pain, health care use, and work activity in African American adults with sickle-cell disease. *Health Psychology*, 23(3), 267-274.
 38. Gil, K. M., Carson, J. W., Sedway, J. A., Porter, L. S., Schaeffer, J. J., & Orringer, E. (2000). Follow-up of coping skills training in adults with sickle cell disease: Analysis of daily pain and coping practice diaries. *Health Psychology*, 19(1), 85-90.
 39. Thomas, V. J., Gruen, R., & Shu, S. (2001). Cognitive-behavioural therapy for the management of sickle cell disease pain: Identification and assessment of costs. *Ethnicity & Health*, 6(1), 59-67.
 40. Bandura, A. (1997). Insights: Self-efficacy. *Harvard Mental Health Letter*, 13(9), 4-6.
 41. Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191-215.
 42. Edwards, R., Telfair, J., Cecil, H., & Lenoci, J. (2000). Reliability and validity of a self- efficacy instrument specific to sickle cell disease. *Behavior Research and Therapy*, 38(2000), 951-963.
 43. 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(5), 850-858.
 44. Mendes de Leon, C. F., Seeman, T. E., Baker, D. I., Richardson, E. D., & Tinetti, M. E. (1996). Self-efficacy, physical decline, and change in functioning in community-living elders: A prospective study. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences*, 51(4), S183-90.
 45. Robinson-Smith, G., & Pizzi, E. R. (2003). Maximizing stroke recovery using patient self-care self-efficacy. *Rehabilitation Nursing*, 28(2), 48-51.
 46. Brus, H., van de Laar, M., Taal, E., Rasker, J., & Wiegman, O. (1999). Determinants of compliance with medication in patients with rheumatoid arthritis: The importance of self-efficacy expectations. *Patient Education & Counseling*, 36(1), 57-64.
 47. Kahn, R. L. (1979). Aging and social support. In M. W. Riley (Ed.), *Aging from birth to death: Interdisciplinary perspectives* (pp. 77-91). Boulder, CO: Westview Press for American Association for the Advancement of Science.

48. Burlew, K., Telfair, J., Colangelo, L., & Wright, E. C. (2000). Factors that influence adolescent adaptation to sickle cell disease. *Journal of Pediatric Psychology, 25*(5), 287-299.
49. Nash, K. B. (1994). *Psychological aspects of sickle cell disease: Past, present, and future directions of research*. New York: Haworth.
50. Loeb, S. J., Penrod, J., Falkenstern, S., Gueldner, S. H., & Poon, L. W. (2003). Supporting older adults living with multiple chronic conditions. *Western Journal of Nursing Research, 25*(1), 8-23.
51. Cox, L. E. (2002). Social support, medication compliance and HIV/AIDS. *Social Work in Health Care, 35*(1-2), 425-460.
52. Haynes, R. B., McDonald, H. P., & Garg, A. X. (2002). Helping patients follow prescribed treatment: Clinical applications. *Journal of the American Medical Association, 288*(22), 2880-2883.
53. Harrison, M. O., Edwards, C. L., Koenig, H. G., Bosworth, H. B., Decastro, L., & Wood, M. (2005). Religiosity/spirituality and pain in patients with sickle cell disease. *Journal of Nervous & Mental Disease, 193*(4), 250-257.
54. Segovia, J., Bartlett, R. F., & Edwards, A. C. (1989). An empirical analysis of the dimensions of health status measures. *Social Science and Medicine, 29*(6), 761-768.
55. McClish, D. K., Penberthy, L. T., Bovbjerg, V. E., Roberts, J. D., Aisiku, I. P., & Levenson, J. L. et al. (2005). Health related quality of life in sickle cell patients: The PiSCES project. *Health & Quality of Life Outcomes, 3*(50). Retrieved Oct. 28, 2006 from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1253526>
56. Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology, 129*(6), 723-729.
57. Haque, A., & Telfair, J. (2000). Socioeconomic distress and health status: The urban-rural dichotomy of services utilization for people with sickle cell disorder in North Carolina. *The Journal of Rural Health, 16*(1), 43-55.
58. Murdaugh, C. (1997). Health-related quality of life as an outcome in organizational research. *Medical Care, 35*(11), NS41-NS48.
59. Strickland, O., Jackson, G., Gilead, M., McGuire, D. B., & Quarles, S. (2001). Use of focus groups for pain and quality of life assessment in adults with sickle cell disease. *Journal of the National Black Nurses Association, 12*(2), 36-43.
60. Edwards, C. L., Scales, M. T., Loughlin, C., Bennett, G. G., Harris-Peterson, S., & De Castro, L. M. et al. (2005). A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *International Journal of Behavioral Medicine, 12*(3), 171-179.
61. Dorman, K. (2005). Sickle cell crisis! Managing the pain. *RN, 68*(12), 33-6; quiz 37.
62. McCormick, I. (1984). A simple version of the Rathus Assertiveness Schedule. *Behavioral Assessment, 7*, 95-99.
63. Rathus, S. (1973). A 30-item schedule for assessing assertive behavior. *Behavior Therapy, 4*, 398-406.
64. Moneyham, L., Demi, A., Mizuno, Y., Sowell, R., Seals, B., & Guillory, J. (1997). Developing and testing of a contextually and culturally relevant measure of coping for use with women infected with HIV. *OMEGA- Journal of Death and Dying, 35*(4), 359-374.

65. Padilla, G. V., Frank-Stromberg, M., & Koresawa, S. (2004). Single instruments for measuring quality of life. In M. Frank-Stromborg, & S. Olsen (Eds.), *Instruments for clinical health-care research* (3rd ed.) (pp. 128-149). Boston: Jones & Bartlett.
66. Sherbourne, C. S., & Stewart, A. L. (1991). The MOS social support survey. *Social Science and Medicine*, 32(6), 705-714.
67. US Census Bureau. (2006). American fact finder. Retrieved October 2, 2006 from http://factfinder.census.gov/home/saff/main.html?_lang=en
68. Lusher, J., Elander, J., Bevan, D., Telfer, P., & Burton, B. (2006). Analgesic addiction and pseudoaddiction in painful chronic illness. *Clinical Journal of Pain*, 22(3), 316-324.
69. Yale, S., Nagib, N., & Guthrie, T. (2000). Approach to the vaso-occlusive crisis in adults with sickle cell disease. *American Family Physician*, 61(5), 1349-1356, 1363-1364.

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