Testing the Theory of Self-Care Management for Sickle Cell Disease

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Abstract: Factors predicting health outcomes in persons with sickle cell disease (SCD) were investigated within the framework of the theory of self-care management for SCD, which proposes that vulnerability factors negatively affect health care outcomes and self-care management resources and positively mediate the relationship between vulnerability factors and health care outcomes. A cross-sectional descriptive design was used to test the model with a sample of 232 African American adults with SCD. Results supported the negative effect of vulnerability factors on health outcomes. The overall model was supported, however, self-care management resources did not mediate the relationship between vulnerability and health care outcomes. The findings provide support for interventions to increase self-care management resources to improve health care outcomes. © 2008 Wiley Periodicals, Inc. Res Nurs Health 31:355–369, 2008

Keywords: vulnerable populations; sickle cell disease; self-care management; quality of life

Sickle cell disease (SCD) is an inherited autosomal recessive genetic disorder that affects 1 in 500 Blacks (Andrews & Mooney, 1994; Godeau et al., 2001; National Human Genome Research Institute, 2006). Life expectancy for persons with SCD has increased from 14 years in 1973 to the mid to late 40s in 2004, transforming SCD into a long-term chronic illness (Quinn, Rogers, & Buchanan, 2004). This chronic disorder may result in a lifetime of pain and frequent hospitalizations. Patients with SCD frequently report dissatisfaction with care they receive. Dissatisfaction is often related to inadequate pain relief, which in turn has a negative effect on health status and quality of life (Bolten, Kempel-Waibel, & Pförinner, 1998; Osman et al., 2000; Strickland, Jackson, Gilead, McGuire, & Quarles, 2001). Individuals may also lack adequate self-care management resources to be able to access...
and navigate the health care system. The purpose of this research was to describe factors that predict health outcomes in persons with SCD by testing a modification of a theory— the theory of self-care management for sickle cell disease (SCMSCD).

Medical interventions for SCD result in substantial costs. Self-care management is critical to decrease health care costs as well as improve the health status and quality of life for persons living with SCD. Once SCD has been diagnosed, individuals need to learn to manage symptoms and maintain control over the course of the disease to maintain an acceptable quality of life (Watkins et al., 2000).

The SCMSCD (Fig. 1) shows (a) vulnerability factors (socio-demographic and health-need factors) have a negative impact on both health outcomes (health status and quality of life) and self-care management resources (assertiveness, self-efficacy, coping behaviors, social support, self-care ability, self-care actions, and communication skills), and (b) self-care management resources positively mediate the relationship between vulnerability factors and health outcomes. The SCMSCD is based on the theory of self-care management for vulnerable populations, a middle range theory developed by one of the authors (CMJ) to describe variables that influence self-care management, health status, and quality of life among populations who experience or are at risk for health disparities. Model relationships have been supported in prior published research with individuals with SCD and other chronic illnesses (Dorsey, Phillips, & Williams, 2001).

Despite extensive research on vulnerable populations, there is no consensus as to what constitutes vulnerability. Broadly, vulnerability refers to the likelihood of experiencing poor health and is determined by a convergence of predisposing characteristics at both individual and ecological levels (Shi, 2001). These predisposing characteristics have been described previously (Aday, 1993) and are referred to as vulnerability factors in the SCMSCD. Vulnerability factors determine access to health care as well as health service use, which in turn influence health outcomes, including health status and quality of life (Shi).

In the SCMSCD vulnerability factors include socio-demographic characteristics (age, income, education, employment) and health need factors (complications and SCD crises). Examining multiple vulnerability factors is preferred to studying individual factors, as multiple factors capture reality and increase our understanding of characteristics that are related to health outcomes (Shi).

Age is a vulnerability factor in SCD. Painful sickle cell crises tend to increase in severity between ages 15 and 25 in males, progressively decrease after age 30, and may cease after age 40 (Serjeant, 1997). Pregnancy may increase the risk of crises for females (Miller et al., 2000). With age, the potential for pulmonary fibrosis and glomerular damage progressively increases.
Education was shown to be a significant predictor of poor adherence to self-monitoring, a required self-care component in persons with diabetes (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000). Adherence is enhanced by attributes related to education, such as the ability to comprehend the prescribed regimen and accommodate it into one’s lifestyle by making sound judgments (Goldman & Smith, 2002).

Employment also is considered a vulnerability factor in adults with SCD. Securing and maintaining employment may be very challenging, and it has important financial and social implications (V.J. Thomas & Taylor, 2002). Koshy and Dorn (1996) described three potential employment categories for adults with SCD: (a) individuals with illness-related disability, (b) individuals with job skills but unable to meet employer work requirements due to recurrent, unpredictable crises, and (c) individuals without job skills. In a study of beliefs and experiences of persons with genetic and other clinical conditions, 42% of respondents with SCD (n = 99) reported they were not hired for a job due to their medical condition (Kass et al., 2004). In one study an adult with SCD stated, “Once [an employer] finds out [about the SCD], they think you’re going to miss a lot of days, and they let you go” (Kass et al., p. 265). Individuals with chronic disorders are concerned about the prevalence of discrimination and fear the effects of discrimination on securing employment and health benefits (Johnson, Kass, & Natowicz, 2005; V.J. Thomas & Taylor). In studies of adults with SCD, unemployment and disability range from 26% to 70% (Gil et al., 2004; Kass et al.; Lenoci, Telfair, Cecil, & Edwards, 2002; Telfair, Haque, Etienne, Tang, & Strasser, 2003).

Race and ethnicity are also vulnerability factors. However, SCD is predominately a disease found in African Americans in the US. All of our study participants were Black, so race and ethnicity were not measured as vulnerability factors in this study.

Health-need vulnerability factors include the number of SCD complications and crises experienced annually. Frequent hospitalizations in individuals with SCD lead to early mortality. The majority of admissions are related to acute painful crises (Houston-Yu, Rana, Beyer, & Castro, 2003; Platt et al., 1994; Prasad, Hasan, Castro, Perlin, & Haque, Etienne, Tang, & Strasser, 2003). Researchers have demonstrated that adults with SCD who have three or more painful crises per year have more than a 27% mortality rate compared to 17% in those with fewer than three crises (Steinberg et al., 2003). Self-care management strategies that can mitigate complications and reduce acute painful crises may be helpful in decreasing hospitalizations.

Self-care management resources (assertiveness, self-efficacy, coping behaviors, social support, self-care ability, self-care actions, and communication skills) and health outcomes (health status and quality of life) included in the SCMSCD all have been supported in prior research (C. Edwards et al., 2006; Gil et al., 2000; Jenerette & Phillips, 2006; Lenoci et al., 2002; Strickland et al., 2001).

The purpose of this research was to describe socio-demographic and health need vulnerability factors and self-care management resources that are related to health status and quality of life in persons with SCD. Two hypotheses were tested:

1. Vulnerability factors will significantly negatively affect health outcomes in adults with SCD.
2. Self-care management resources will mediate the relationship between vulnerability and health outcomes.

METHODS

Sample and Setting

A convenience sample of 232 adults with a diagnosis of SCD was recruited for a cross-sectional descriptive study. Sample size was based on Kline’s (2005) structural equation modeling (SEM) guidelines, which indicate that a minimum sample of 225 subjects is required for stable parameter estimates of the model (approximately 15 model parameters). Kline defined sample sizes greater than 200 as large and suggested 10–20 observations per estimated parameter. Another recommendation for calculating sample size for SEM is 50 more than 8 times the number of variables or 15 cases per measured variable (Garson, n.d.). A calculated sample size based on the 15 variables measured in this study indicated that 210 participants (\(8 \times 15 + 50 = 170\)) were needed. In the literature, sample sizes for SEM are commonly 200–400 for 10–15 indicators (Garson, n.d.). When problems with missing data or non-normal distributions are not anticipated, a minimal sample size of 200 is recommended for any SEM (Weston & Gore, 2006).

Participants in the study had to be able to read, write, or understand English, be at least 18 years old, and have a diagnosis of SCD. Participants were recruited from two SCD clinics in the southeast United States between September 2003 and April 2004. The university’s Institutional Review Board and the SCD clinics approved the study prior to data collection. The PI and a registered nurse who had been trained recruited eligible patients and collected data. After giving written informed consent, participants completed a questionnaire packet during a clinic visit. A maximum of 60 minutes was needed to complete the questionnaires. Five participants needed assistance, and the PI or nurse read the questions aloud and recorded their responses. Participants received $25 for completing the study.

The sample is described in Table 1. Using zip codes provided by participants, the average median household income was approximately $36,039 ($10,125) ($17,843–$65,375).

Table 1. Demographic Description of Total Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>N(^a)</th>
<th>(M (SD))</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>231</td>
<td>34.91 (12.42)</td>
<td>18–73</td>
</tr>
<tr>
<td>Education (years)</td>
<td>232</td>
<td>12.36 (1.99)</td>
<td>5–21</td>
</tr>
<tr>
<td>1st SCD crisis (age in years)</td>
<td>212</td>
<td>6.47 (7.54)</td>
<td>1–55</td>
</tr>
<tr>
<td>Average SCD crises per year (number)</td>
<td>219</td>
<td>2.65 (3.08)</td>
<td>0–25</td>
</tr>
<tr>
<td>Median annual household income</td>
<td>221</td>
<td>$36,039 ($10,125)</td>
<td>$17,843–$65,375</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Categories</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Female</td>
<td>143 (61.60)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>89 (38.40)</td>
</tr>
<tr>
<td>Employment</td>
<td>Full-time</td>
<td>48 (20.70)</td>
</tr>
<tr>
<td></td>
<td>Part-time</td>
<td>24 (10.30)</td>
</tr>
<tr>
<td></td>
<td>Not-employed</td>
<td>64 (27.60)</td>
</tr>
<tr>
<td></td>
<td>Disabled</td>
<td>96 (41.40)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Never married</td>
<td>143 (61.60)</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>47 (20.30)</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>18 (7.80)</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>12 (5.20)</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>12 (5.20)</td>
</tr>
<tr>
<td>Living situation</td>
<td>Alone</td>
<td>42 (18.30)</td>
</tr>
<tr>
<td></td>
<td>With family</td>
<td>174 (75.70)</td>
</tr>
<tr>
<td></td>
<td>With friends</td>
<td>14 (6.10)</td>
</tr>
<tr>
<td>Environment</td>
<td>Rural</td>
<td>75 (32.90)</td>
</tr>
<tr>
<td></td>
<td>Urban</td>
<td>153 (67.10)</td>
</tr>
</tbody>
</table>

SCD, sickle cell disease.

\(^a\)Note: The sample size varies due to missing data.

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$36,000 (US Census Bureau, 2005). Zip code-based median income, a proxy for socio-economic position that often is more easily obtained than personal income data, has been shown to be a significant independent mortality predictor (A.J. Thomas, Eberly, Smith, & Neaton, 2006). The sample was examined by clinic site to assess any differences. Participants were an average of 4 years older at one site (33 vs. 37 years), reported earlier crisis onset (5 vs. 8 years), and had a higher average median household income ($40,000 vs. $34,000). No other significant differences were noted.

In addition to demographic information, participants were asked about their SCD complications. Anemia (69%) and painful crises (77%) were the most commonly reported complications in the total sample. Vision problems were also common (63%). Slightly more that one-fourth (26%) reported being depressed. Other complications reported were osteonecrosis (19%), kidney problems (15%), and leg ulcers (15%).

**Measures**

Cronbach’s alpha reliability coefficients for instruments used in this study are shown in Table 2. All instruments were assessed with the Flesch-Kincaid reading level assessment using Microsoft Word©. The measures were modified as needed to insure a reading level at the eighth grade or lower.

**Vulnerability**

Demographic data/health need vulnerability questionnaire. The 12-item questionnaire was developed by the authors to obtain age, sex, education, employment, and marital status. The two items to assess vulnerability factors were derived from the literature and supported by prior research so they were not pretested. The items were, “On average, how many sickle cell crises do you have per year that require being in the hospital?” and, “Circle all of the following complications you have experienced because of having SCD.” The total number of SCD crises per year and the total number of complications were the measures of health need characteristics of vulnerability.

**Self-Care Management Resources**

Assertiveness, or behavior that enables one to stand up for one’s rights without infringing on the rights of others, was measured with the 30-item Simple Rathus Assertiveness Schedule (SRAS) (McCormick, 1984). The SRAS is a parallel form of the Rathus Assertiveness Schedule (RAS; Rathus, 1973). The RAS has established construct validity in terms of significant correlations with scales that measure impressions respondents make on other people and indications of how people would behave in certain situations. McCormick reported an internal consistency reliability of .90. The SRAS correlates .94 with the original RAS. A total score is obtained by summing responses, with higher responses indicating higher levels of assertiveness.

Coping behaviors, cognitive and behavioral strategies used to master conditions of harm, threat, or challenge when a normal or routine response is not available, were measured with the Family Coping Project Coping Scale (COP; Demi, Moneyham, Sowell, & Cohen, 1997; Moneyham et al., 1997). The 54-item Likert-type instrument contains five subscales (seeking/using social support, spiritual activities, avoidance, managing illness, and focusing on others). Construct validity was demonstrated using exploratory factor analysis, and internal consistency reliabilities have ranged from .71 to .90. Subscale scores are obtained by summing responses, with higher responses indicating higher levels of the specific coping behavior.

Self-efficacy, belief about the ability to achieve a desired health outcome, was measured with the Sickle Cell Disease Self-Efficacy Scale (SCSES; Edwards, Telfair, Cecil, & Lenox, 2000). The nine-item Likert-type scale measures SCD disease-specific perceptions of self-efficacy. Convergent validity was estimated by significant correlations between self-efficacy and self-esteem (.39), sense of mastery (.45), and internal health locus of control (.41). An internal consistency reliability of .89 was reported. A total score is obtained by summing the responses, with higher scores indicating higher self-efficacy.

Social support, internal perception of interpersonal transactions, including expressions of positive affect, affirmation of another’s behaviors or views, or giving symbolic or material aid, was measured with the Medical Outcomes Study Social Support Survey (MOS-SSS; Sherbourne & Stewart, 1991). The 19-item Likert-type scale measures perceived availability of support with four subscales (emotional/informational, affectionate, tangible, and positive social interaction). Construct validity was supported by both confirmatory and principal components factor analysis. Both the total scale and subscales have internal consistency reliabilities above .91 (Sherbourne & Stewart). Responses are summed, with higher scores indicating higher perceptions of available support.
<table>
<thead>
<tr>
<th>Scale</th>
<th>Subscale</th>
<th>N</th>
<th>Actual range (potential range)</th>
<th>M (SD)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assertiveness (SRAS)</td>
<td></td>
<td>199</td>
<td>50–180 (30–180)</td>
<td>113.74 (20.11)</td>
<td>.85</td>
</tr>
<tr>
<td>Coping Behaviors (COP) total</td>
<td></td>
<td>141</td>
<td>56–156 (0–132)</td>
<td>101.34 (19.74)</td>
<td>.90</td>
</tr>
<tr>
<td></td>
<td>Seeking/using social support</td>
<td>195</td>
<td>3–36 (0–36)</td>
<td>20.42 (6.86)</td>
<td>.85</td>
</tr>
<tr>
<td></td>
<td>Avoidance</td>
<td>181</td>
<td>2–33 (0–36)</td>
<td>14.82 (5.49)</td>
<td>.83</td>
</tr>
<tr>
<td></td>
<td>Spiritual activities</td>
<td>208</td>
<td>2–21 (0–21)</td>
<td>15.23 (4.16)</td>
<td>.72</td>
</tr>
<tr>
<td></td>
<td>Managing the illness</td>
<td>203</td>
<td>8–27 (0–27)</td>
<td>20.34 (4.00)</td>
<td>.73</td>
</tr>
<tr>
<td></td>
<td>Focusing on others</td>
<td>207</td>
<td>3–12 (0–12)</td>
<td>8.34 (2.25)</td>
<td>.56</td>
</tr>
<tr>
<td>Self-Efficacy (SCSES) total</td>
<td></td>
<td>222</td>
<td>12–45 (9–45)</td>
<td>30.92 (7.16)</td>
<td>.87</td>
</tr>
<tr>
<td>Social Support (MOS-SSS) total</td>
<td></td>
<td>198</td>
<td>22–95 (19–95)</td>
<td>75.64 (15.12)</td>
<td>.95</td>
</tr>
<tr>
<td></td>
<td>Emotional/informational</td>
<td>212</td>
<td>9–40 (8–40)</td>
<td>31.00 (7.01)</td>
<td>.92</td>
</tr>
<tr>
<td></td>
<td>Affectionate</td>
<td>222</td>
<td>3–15 (3–15)</td>
<td>12.27 (2.82)</td>
<td>.82</td>
</tr>
<tr>
<td></td>
<td>Tangible</td>
<td>226</td>
<td>5–20 (4–20)</td>
<td>15.82 (3.58)</td>
<td>.80</td>
</tr>
<tr>
<td></td>
<td>Positive social interaction</td>
<td>221</td>
<td>4–20 (4–20)</td>
<td>15.37 (3.64)</td>
<td>.87</td>
</tr>
<tr>
<td>Self-Care Ability (ASA) total</td>
<td></td>
<td>192</td>
<td>24–120</td>
<td>87.85 (9.02)</td>
<td>.75</td>
</tr>
<tr>
<td>Self-Care Action (J-SAT)</td>
<td></td>
<td>225</td>
<td>14–22 (8–32)</td>
<td>28.22 (3.08)</td>
<td>.72</td>
</tr>
<tr>
<td>Communication Skills (BQ-C)</td>
<td></td>
<td>218</td>
<td>0–50 (0–50)</td>
<td>18.12 (10.19)</td>
<td>.82</td>
</tr>
<tr>
<td>Health status</td>
<td></td>
<td>224</td>
<td>5–22 (4–22)</td>
<td>12.85 (3.50)</td>
<td>.77</td>
</tr>
<tr>
<td>Quality of Life (CIQOLL) total</td>
<td></td>
<td>188</td>
<td>51–280 (70–280)</td>
<td>223.07 (33.72)</td>
<td>.95</td>
</tr>
<tr>
<td></td>
<td>Present</td>
<td>216</td>
<td>7–70 (7–70)</td>
<td>51.77 (10.90)</td>
<td>.87</td>
</tr>
<tr>
<td></td>
<td>Without sickle cell</td>
<td>214</td>
<td>7–70 (7–70)</td>
<td>61.13 (8.98)</td>
<td>.87</td>
</tr>
<tr>
<td></td>
<td>Past</td>
<td>202</td>
<td>13–70 (7–70)</td>
<td>49.67 (10.88)</td>
<td>.86</td>
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<tr>
<td></td>
<td>Future</td>
<td>200</td>
<td>14–70 (7–70)</td>
<td>58.37 (10.14)</td>
<td>.90</td>
</tr>
</tbody>
</table>

SRAS, Simple Rathus Assertiveness Schedule; ASA, Appraisal of Self-Care Agency; COP, Family Project Coping Scale; J-SAT, Jenerette Self-Care Assessment Tool; SCSES, Sickle Cell Self-Efficacy Scale; BQ-C, Barriers Questionnaire-Communication; MOS-SSS, Medical Outcomes Study Social Support Survey; CIQOLL, Chronic Illness Quality of Life Ladder.
Self-care ability, the capability to engage in therapeutic behaviors to maintain and/or improve health status and quality of life, was measured with the Appraisal of Self-Care Agency Scale (ASA; Evers et al., 1986). The 24-item scale has been used in healthy and ill adults from various ethnic groups across the lifespan. The ASA has established construct validity and a content validity index of .88 as well as internal consistency reliabilities ranging from .80 to .86. A total score is obtained by summing responses, with higher responses indicating higher levels of self-care ability.

Self-care action, defined as engaging in therapeutic activities and actively accessing resources to maintain or improve health status and quality of life, was measured with the eight-item Jenerette Self-Care Assessment Tool (J-SAT; unpublished). Construct validity was estimated by a significant negative correlation with the Centre for Epidemiological Studies Depression Scale (CESD; Radloff, 1977) and a significant positive correlation with the Functional Status Questionnaire (FSQ; Jette et al., 1986). The J-SAT had an internal consistency reliability of .80 in an initial test of the instrument. Higher summed scores indicate greater frequency of self-care actions.

Communication skills were defined as ones ability to share thoughts, feelings, or information. The Barriers Questionnaire Communication subscale (BQ-C) assesses one’s communication skills in pain treatment, as pain management is an essential component of self-care management in this population (Wells, Johnson, & Wujcik, 1998). Validity has been established in prior studies for the original instrument (Ward et al., 1993). The 10-item communication subscale has a reported internal consistency reliability of .78. The summed scores were reversed so that higher scores indicated higher communication skills and fewer communication barriers.

Health Outcomes

Health status, one’s perceived physical state, was measured with a 5-item questionnaire adapted from the 49-item Health Status scale (Segovia, Bartlett, & Edwards, 1989). Construct validity of the original scale has been supported by significant correlations with measures of health care utilization, but reliability data for the original scale was not reported. Higher total scores indicate higher perceived physical health status.

Quality of life, a subjective sense of well-being with physical, psychological, and social dimensions of one’s life, was measured with the Chronic Illness Quality of Life Ladder (CIQOLL; Murdaugh, Moneyham, Jackson, Phillips, & Tavakoli, 2006). The 28-item scale uses the concept of a self-anchoring striving scale (Cantril, 1965) based on the notion of a gap between one’s current situation and one’s goals and aspirations. The scale measures life satisfaction in seven domains: physical status, emotional status, financial status, family and friends, spiritual well-being, peace of mind, and overall satisfaction with life. The instrument uses a 10-step ladder response format (Cantril; Kilpatrick & Cantril, 1960). The top rung of the ladder (10) indicates the best possible quality of life and the bottom rung (1) indicates the worst possible QOL. Each of the above seven domains was measured for four time periods: present QOL; QOL without SCD (i.e., if the individual did not have a diagnosis of SCD); QOL 1-year ago; and anticipated future QOL (1 year from present circumstances). Each time period represents a subscale. The CIQOLL convergent validity was demonstrated by a significant correlation with the Functional Status Questionnaire (Jette et al., 1986) and divergent validity by a significant negative correlation with the CES-D (Radloff, 1977), and all internal consistency coefficients exceeded the criterion level of .80 with Cronbach’s α coefficients ranging from .91 to .95 for the four subscales (Murdaugh et al.). Higher summed scores indicate higher QOL. The total score was used in the current study.

Table 2 shows the descriptive data and reliability coefficients for measures of self-care management resources and health outcomes. The reliability of measures is an important factor in determining model fit (Jackson, 2003). All measures except one subscale had reliability coefficients greater than .70, an acceptable level (Nunnally & Bernstein, 1994).

Data Analysis

The SPSS (version 12.0) program was used for construction of the covariance matrix to be used in SEM analysis and to check the multivariate normality of the data. All data were examined both visually and with the Shapiro–Wilk statistical test for normality. Transformations were performed on the data to improve normal distributions. Not all data, after being transformed, met the normality assumption via Shapiro–Wilk. Variables with data that did not meet the assumption of normality either visually or with Shapiro–Wilk were excluded from the SEM analyses. These included self-care action, coping behaviors
subscases (5), QOL subscales (4), and social support subscales (4), for a total of one scale and 13 subscales.

SEM analytical techniques were used to assess the proposed relationships in the hypothesized model. Missing data varied across measures (see Table 2). The AMOS Graphics 4.0 SEM program uses a procedure known as Full Information Maximum Likelihood to handle missing data. This program assumes that data are missing at random (Byrne, 2001). In order to meet this assumption, all scales with more than 5% missing data were evaluated with t-tests to test for significant differences between participants with complete data and those with missing data. No statistically significant differences were found. Therefore, the assumption that data were missing at random was met.

First, the measurement models (the mapping of measures onto theoretical constructs) were assessed to describe the measurement properties of latent variables. Next the structural equation model (the theorized links between the variables), which specifies direct and indirect relationships among the latent variables, was obtained to describe the amount of variance explained by the model (Kenny, Kashy, & Bolger, 1998). The chi-square statistic was used to test model fit. However, because chi-square has no upper bound, it cannot be standardized, and it is very sensitive to sample size. For this reason, the chi-square was divided by the degrees of freedom (χ^2/df). An acceptable χ^2/df ratio is less than 3 (Byrne, 2001; Kline, 2005).

The model’s overall fit also was assessed using the following goodness of fit statistics: comparative fit index (CFI), a chi-square estimate using a maximum likelihood solution, >.90; normed fit index (NFI), >.90; and the root mean square error of approximation (RMSEA), <.10. Data were analyzed using SPSS and AMOS software.

The latent variables (vulnerability, self-care management resources, and health outcomes) along with their respective indicators were correlated to assess relationships among the latent variables and the strength of loadings of indicators on respective latent variables. Higher loadings indicate a stronger relationship between the indicator and the latent variable (Kline, 2005; Pedhazur & Schmelkin, 1991). Indicators were deleted if standardized loadings were less than .40. Deleting these indicators improved convergent validity among each factor’s indicators and discriminant validity among the latent variables (Kline).

RESULTS

In the first model (Fig. 2), the three measurement models were correlated, and theorized indicators of each latent variable were included. In the vulnerability measurement model, only the health need vulnerability factor indicators were included because the socio-demographic vulnerability factor indicators were controlled for when the final measurement model was determined. In the self-care management resources model measures included assertiveness, self-efficacy, coping behaviors, social support, self-care ability, and communication skills. Two self-care management measures that had standardized loadings below .40, (a) coping behaviors (.31) and (b) the communications subscale (.33), were deleted, resulting in Model 2 (Fig. 3). In Model 2, all standardized loadings were greater than .40 and correlations among latent variables were less than .85, so the measurement models were considered adequate (Kline, 2005). The structural model was then evaluated to test the two study hypotheses.

Determining the Structural Model

The initial structural model was analyzed to test the hypothesized relationships among the latent variables by evaluating the χ^2/df (< 3), the CFI (> .90), NFI (> .90), and the RMSEA (< .10). Figure 4 depicts the initial structural model. The fit statistics were: χ^2/df: 3.3, CFI: .99, NFI: .99, and RMSEA: .10.

In the final structural model, Figure 5, the socio-demographic vulnerability factors (age, income, education, and employment) were controlled. The fit statistics were: χ^2/df: 3.12, NFI: .98, and RMSEA: .096. When the socio-demographic factors were controlled, the theorized relationships in the SCMSCD did not change. Furthermore, the direction of the relationships between latent variables, statistical significance, and magnitude were either unchanged or improved. For example, when controlling for socio-demographic vulnerability factors, vulnerability accounted for 32% of the variance in self-care management resources, an increase from 13%. The fit statistics improved slightly from the initial to the final structural model.

Testing Hypotheses

Once the final structural model was determined, study hypotheses were addressed. Hypothesis 1 stated that vulnerability factors would significantly
negatively affect health outcomes in adults with SCD. While controlling for socio-demographic vulnerability factors, the health need vulnerability factors negatively affected health outcomes (path coefficient $-0.55$, $p < 0.05$), so the hypothesis was supported.

Hypothesis 2 stated that self-care management resources would mediate the relationship between vulnerability and health outcomes in adults with SCD. Using Preacher's (2006) interactive tool to test for mediation, results indicated a Sobel test statistic of $1.90$ ($p = 0.057$). Therefore, self-care management resources did not mediate the relationship between vulnerability and health outcomes. Hypothesis 2 was not supported.

Factor loadings provide important information about how well an observed variable is able to measure a latent variable. The factor loadings are the regression of the factor on indicators. Therefore, by squaring the factor loadings, one has the percent of variance that is explained by the latent variable. Self-care management resources explained 36% of the variance in social support. Forty-five percent of the variance in self-efficacy was explained by self-care management resources. Self-care management resources accounted for 38% of the variance in self-care ability. Self-care resources also accounted for 25% of the variance in assertiveness. Finally, 87% of the variance in health outcomes was accounted for by self-care management resources.

**DISCUSSION**

The theoretical modeling tested factors expected to predict health status and quality of life for persons with SCD. The hypothesis of mediation was not supported. However, results of model testing substantiate prior research on other chronic diseases that has described the benefit of self-care management resources, such as assertiveness, social support (Cox, 2002; Dorsey & Murdaugh, 2003; Smith et al., 2005), self-efficacy (R. Edwards, Telfair, Cecil, & Lenoci, 2001; Farrell, Wicks, & Martin, 2004; Robinson-Smith & Pizzi,
FIGURE 3. Correlations among measurement models with standardized loadings less than .40 deleted.

FIGURE 4. Initial structural model.
2003), and self-care ability (Dorsey & Murdaugh; Greene, Yedidia, & The Take Care to Learn Evaluation Collaborative, 2005; Lenoci et al., 2002) to health outcomes.

Individuals need to be capable of self-care, be confident in their self-care abilities, and have social support in order to enhance their health outcomes. Results suggest that a combination of self-care ability, self-efficacy, assertiveness, and social support, all self-care management resources, may assist individuals with SCD to manage the day to day activities required to cope with a lifelong illness and access needed health care resources.

Assertiveness training is a potential self-care management resource strategy for persons with a chronic illness, such as SCD, who must frequently access and navigate the healthcare system. Previous research also has identified the role of assertiveness training as a resource in chronic illness (Andersen, Abullarade, & Urban, 2005; Krupat et al., 1999; Richardson, 2000).

Finding support the critical role of self-care management resources for improving health status and quality of life in chronic illness. These resources are amenable to interventions, as interventions can target assertiveness, self-efficacy, social support, and self care ability. Self-care management resources enable persons to gain and or maintain control over their disease, and to improve their health status and quality of life.

In future research, the vulnerability predisposing characteristics need to be expanded to include additional individual factors and ecological factors. As mentioned earlier, although vulnerability is extensively mentioned in the literature, measurement is less well described. In addition, no published measures of the vulnerability predisposing factors for SCD are available. In the health care utilization framework, Aday (1993) addressed characteristics that determine an individual’s ability to use health services, including demographic variables, social structure variables, beliefs, enabling characteristics, need characteristics, and attributes of the community. Both socio-demographic and need factors were included in this study. However, additional relevant vulnerability factors, such as ecological...

FIGURE 5. Final structural model controlling for socio-demographic factors.
vulnerability factors need to be explored for their potential contribution, including residence, social capital (family structure, religious organizations, neighborhood connections), availability and accessibility of health care, and community health indicators. Last, for racial and ethnic minorities with SCD, additional vulnerability factors not previously considered may need to be included, such as stress due to racial discrimination (Lightsey & Barnes, 2007). The limited attention in the literature to the measurement of vulnerability as a multidimensional concept, as well as a lack of reliable and valid measures of this concept, suggest the need for further research prior to retesting the model.

**Limitations**

The results provide important insight about the needs of adults who live with SCD. However, several limitations need to be acknowledged. Although significant differences were noted in age, onset of first SCD crisis, and median household income between the two recruitment sites, the sites were combined to achieve the sample size required for SEM.

The socio-demographic vulnerability factor, employment, was measured categorically and had to be excluded from the initial analysis, as continuous measures were necessary to apply the powerful statistical functions of the SEM program used, AMOS 4.0. However, categorical variables can be controlled for in using AMOS 4.0, as they were in this study.

Missing data were also a potential issue. The AMOS Graphics 4.0 SEM program fits models to incomplete raw data within a single sample without the need for case deletion or imputation of missing values (Kline, 2005). Although SEM with AMOS can accommodate incomplete data, missing data may have been an issue in testing the model.

Missing data, although apparently missing at random, may have resulted from response burden, an important consideration in research for persons with a chronic illness such as SCD (Shadish, Cook, & Campbell, 2002). Respondents completed 11 questionnaires ranging in length from 5 to 54 items each. A balance is needed between longer instruments that have higher reliability and require smaller sample sizes, yet increase response burden, and shorter instruments that require larger sample sizes but impose less response burden.

Use of self-report data is considered a limitation by some authors. However, self-report data are essential to behavioral and healthcare research and practice (Baldwin, 2000). For this reason self report measures and data collection procedures need to be as robust as possible, as they are influenced by wording, format, and context (Schwartz & Oyserman, 2001). Strategies to decrease potential issues were implemented. All of the measures had sound psychometric properties, and measures were at the appropriate level and in a language the participants understood. The data collectors, both African American, established rapport with the participant prior to administering the measures.

A potential validity issue was that all of the model concepts were measured with one method. An individual’s score is a component of both the concept (trait) measured by the scale items, as well as the method used to measure the items. Because only one measurement method (self report) was used, it is not possible to measure the effect of methods variance on the path coefficients in the model. This issue can be addressed in future research by using multiple, independent methods to measure each concept or trait to be able to demonstrate convergence, a minimal requirement in testing for methods versus trait variance (Campbell & Fiske, 1959).

The goodness of fit criterion of a \( \chi^2/df \) less than 3 (Kline, 2005) was not met. This may cast some doubt on the parameter estimates of the final model, although the final model is plausible. There is a lack of agreement on the appropriate value of \( \chi^2/df \). Some researchers allow \( \chi^2/df \) values as high as 5 to consider a model adequate fit, while others insist on a ratio of 2 or less (Bollen, 1989; Garson, 2007).

Finally, to meet the assumptions of normality as well as criteria for retaining variables for the SEM analysis, several theorized self-care management resource variables (coping behaviors and self-care activities) were deleted. In order to have confidence in the final structural model, the analysis needs to be repeated with another sample and including the full set of theorized variables.

**CONCLUSIONS**

The Theory of Self Management for SCD was tested using SEM. In this first test of the model, results indicate that almost all theorized relationships were supported. Additional research is needed to expand the vulnerability factors (predisposing characteristics). The model can then be retested to examine further the hypothesized mediation effects. In spite of lack of support
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