

## Development and Testing of a Tool to Assess Self-Care Agency in Adults with Sickle Cell Disease.<sup>1</sup>

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Lenoci, J., [Telfair, J.](#), Cecil, H. and Edwards, R.R.,(2002). Development and Testing of a Tool to Assess Self-Care Agency in Adults with Sickle Cell Disease. *Western Journal of Nursing Research*. 24(3): 228-245. DOI: 10.1177/01939450222045879

Made available courtesy of SAGE Publications: <http://dx.doi.org/10.1177/01939450222045879>

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### **Abstract:**

This article summarizes the psychometric evaluation of the Chronic Illness Assessment Interview for Sickle Cell Disease (CIAI-SCD), an instrument based on a model of self-care for adult patients with chronic medical conditions. The CIAI-SCD was administered to 104 adults with sickle cell disease. A factor analysis identified three factors that reflected the psychological constructs of Personal Satisfaction and Perceived Control (Factor 1), Feeling Concerned and Worried (Factor 2), and Feeling Supported (Factor 3). Preliminary evidence for the internal consistency, test-retest reliability, content validity, and construct validity of the CIAI-SCD was obtained. After further refinement and validation, the CIAI-SCD may be a useful tool for assessing factors related to self-care skills among adults with sickle cell disease.

### **Article:**

Sickle cell disease (SCD) is a chronic illness characterized by a variety of complications associated with malformations of red blood cells (Reed & Vichinsky, 1998). The most common consequences of SCD are pain and organ damage arising from vaso-occlusive episodes (Reese & Smith, 1997). Whereas SCD was formerly characterized primarily as a childhood illness, advances in treatment have led to expanding survival rates, making adult adjustment to SCD an important health concern (Edwards, Telfair, Cecil, & Lenoci, in press). Interestingly, disease severity accounts for little of the variance in SCD adjustment (Telfair, 1994), suggesting that psychosocial and behavioral factors may play an influential role. In particular, adequate management of such chronic conditions as SCD may require improving self-care to promote optimal health and functioning (Reed & Vichinsky, 1998; Reese & Smith, 1997).

Promoting self-care has become a central component of nursing interventions for patients with chronic illnesses (Carter, 1998; Coates & Boore, 1995; Craddock, Adams, Usui, & Mitchell, 1999; Cutler, 2001). Individuals diagnosed with a chronic disease such as SCD have to deal with a complex array of tasks in order to manage their illness and prevent SCD-related complications. Modifications of diet and activity are typically recommended as a means of reducing these symptoms. Actions such as these, which the individual undertakes to improve health and limit disease, are termed self-care and are an important factor in the prognosis for chronic illness (Horsburgh, 1999; Lee, 1999). Self-care refers to the process wherein patients take an active role in their health and well-being, a process that encompasses the skills, attitudes, and abilities needed to master the settings in which individuals with a chronic illness function. (Carter, 1998; Connelly, 1987; Orem, 1995; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

Researchers and health professionals have become increasingly interested in self-care because of the growing evidence of its benefits for patients with a chronic disease. Improved self-care practices are related to enhanced quality of life (QOL) and improved health status in medical populations and the general public (Acton & Malathum, 2000; Testa & Simonson, 1996; Von Korff et al., 1997). For example, a retrospective case-controlled study of a self-management education program for asthmatics found significant benefits for those receiving self-care training (Boulet, Boutin, Cote, Leblanc, & Laviolette, 1995). One year after the intervention, the 42 asthma patients showed increased QOL and reductions in emergency department (ED) visits when compared with the control group. Moore, Von Korff, Cherkin, Saunders, and Lorig (2000)

prospectively studied 226 patients with chronic low back pain assigned to either usual care or to a self-care promotion group consisting of two 2-hour sessions that included informational materials related to self-management of low back pain. At the 3- and 6-month follow-up periods, participants in the self-care promotion group had significantly less pain and physical disability. Finally, another recent study noted diminished costs and improved health status as a function of increased self-care practices among a national sample of older adults (Stearns et al., 2000). Although this study did not include an intervention, the researchers did find significant relationships between reported self-care practices and self-reported health status and health care utilization within a very large sample of elderly adults.

In spite of these clear benefits associated with improving self-care, relatively little is known about the variables that might affect self-care practices. A number of factors are presumed to underlie the capacity and willingness to engage in effective self-care behavior (McDonald-Miszczak, Wister, & Gutman, 2001). Some time ago, Catherine Connelly (1987) proposed a model of the process of self-care in chronic illness. She described this model as a modification and extension of the health belief model (HBM) (Rosenstock, 1974), which posits that health behaviors (e.g., self-care) are determined within an expectancy-value framework by comparison of the costs of health behaviors with the value of these actions for reducing the likelihood or severity of an illness. Connelly's model of self-care practices suggests that the process of self-care is affected by predisposing and enabling factors that she classified to represent a total of seven constructs (i.e., self-concept, psychological status, health motivation, characteristics of the health regimen, social support, cues to action, and characteristics of the health care system). Self-concept refers to the general sense of one's own functioning and well-being. Psychological status refers to the typical mood and habitual levels of anxiety and distress of an individual. Health motivation describes a person's perceptions of the importance of health and an individual's willingness to perform health care behaviors. Characteristics of the health regimen refers to an individual's level of involvement in health care planning and the costs and benefits of performing health behaviors. Social support refers to the perceived degree and adequacy of assistance received from others. Cues to action represents perceived manifestations of illness that motivate an individual to act. Finally, characteristics of the health care system includes satisfaction with health care, personal contact with medical care personnel, and accessibility of health services. Each of these factors is presumed to influence the performance of self-care activities. Connelly incorporated these factors into a Chronic Illness Assessment Interview (CIAI), which she suggested could be used as a means of assessing constructs related to self-care practices in a variety of medical conditions. The CIAI was designed as a tool to be used in nursing for the evaluation of personal and environmental characteristics, as perceived by the individual with a chronic illness, that may play a role in shaping self-care practices. The original report by Connelly (1987) was a theoretical paper intended to guide research in the domain of self-care. To date, no psychometric evaluations of the CIAI have appeared in the literature. The purpose of this study was to examine the structure, reliability, and validity of this self-care instrument for adults with SCD. Only by using instruments with demonstrated validity and reliability can relationships between constructs be conclusively demonstrated (Janda, 1998).

In summary, self-care training benefits patients and providers by reducing symptoms and costs among individuals with chronic illnesses. Self-care practices in individuals with SCD, however, have rarely been investigated, and we know relatively little about the factors that may play important roles in influencing self-care. The CIAI (Connelly, 1987) is an instrument designed to measure constructs such as self-concept, health motivation, psychological status, social support, cues to action, and perceived characteristics of the self-care regimen and health care delivery system that are presumed to underlie self-care practices, providing a foundation on which the self-care process rests.

The purpose of this study was to investigate the reliability and validity of the CIAI in a sample of adults with SCD. Because self-care is an important aspect of managing SCD symptoms (Reese & Smith, 1997), validation of an assessment instrument for individuals with this condition would be a potentially important step in SCD management. In fact, some recent research has indicated that self-care behaviors and the factors that influence them may vary across chronic illnesses (McDonald-Miszczak et al., 2001). In this study,

disease symptoms and illness beliefs predicted self-care behavior among adults with arthritis, whereas perceptions of self-efficacy and general well-being predicted self-care behavior among adults with hypertension. Thus, it may be important to use disease-specific measures when assessing the self-care process in chronic illness. This study is a psychometric evaluation of a modified CIAI, adapted for use with individuals with SCD, henceforth referred to as the CIAI-SCD.

A series of hypotheses guided the statistical analyses in this study. First, we hypothesized that the CIAI-SCD would be reliable as measured by estimates of internal consistency and test-retest reliability over the course of 6 months. Second, we hypothesized that the instrument would be content valid as determined by a panel of individuals with expertise in the field of SCD. Third, we hypothesized that factor analysis would show the CIAI-SCD to be composed of factors roughly corresponding to those identified by Connelly (1987). Fourth, regarding construct validity, we hypothesized that the factors of the CIAI-SCD would be related to previously validated measures of related constructs. We utilized measures of self-esteem, self-efficacy, sense of mastery, health-care utilization, pain severity, and satisfaction with medical care in order to assess construct validity. In addition, we hypothesized that CIAI-SCD scores would be related to measures of reported self-care behavior among individuals with SCD as predicted by Connelly's model.

## **METHOD AND RESULTS**

### **Sample**

A sample comprising clients from the Sickle Cell Disease Association of the Piedmont (SCDAP) in Greensboro, North Carolina was recruited. In total, 104 patients with SCD participated in the study and completed a comprehensive interview. Eighty-four members of the sample were reassessed at a 6-month follow-up time point. Respondents were interviewed in person at the agency or in their homes by one of three research nurses with specialized training in SCD. Consent to participate in the project was a part of the routine intake process of the SCDAP and was approved by the SCDAP oversight board.

Descriptive data for the sample are provided in Table 1. The mean age of participants was 37.7 ( $SD = 12.8$ ). Almost all (99%) reported their ethnic background as African American. Genetic information was not available for members of this sample. However, of the total SCDAP clientele, 51% have the hemoglobin SS (homozygous) form of SCD, 33% have hemoglobin SC, and 16% have hemoglobin beta-thalassemia. The majority of the sample were single and reported annual incomes below \$20,000. Over half (54%) of the sample reported being employed in full- or part-time work; the majority of the remaining portion received social security income benefits. Sixty-two percent of the participants reported that one or more of their family members also had received a diagnosis of SCD. Members of the sample reported an average of three physician visits and 10 days spent in the hospital for SCD-related complications over the previous 12 months.

### **Measures Assessed at Baseline**

#### *CIAI-SCD*

The CIAI-SCD was adapted from a model of the self-care process developed by Connelly (1987). In the present investigation, 32 items were utilized as a measure of the constructs presumed to underlie the willingness and ability to engage in effective self-care behavior. Connelly identified these constructs as self-concept, health motivation, psychological status, social support, cues to action, and perceived characteristics of the self-care regimen and health-care delivery system. The CIAI-SCD is a paper-and-pencil inventory with items presented in a 5-point Likert-type format where response choices range from never to very often (see appendix). The CIAI-SCD was administered both at baseline and 6-month follow-up.

#### *Self-Care*

Information was collected on six basic practices important for routine self-care in SCD. To our knowledge, no instruments designed to measure self-care activities in individuals with SCD have yet been reported in the literature, although there are specific self-care behaviors that are recommended in order to prevent symptom exacerbation. Thus, we used a self-report measure of individuals' perceptions of how frequently they

engaged in these behaviors. Participants were asked about the frequency with which they drank enough liquids, refrained from overexercise, kept clinic appointments, took medications as prescribed, followed the doctor's instructions, and made sure medical questions were answered. Response options ranged from *never* to *very often*. The six responses were added, forming a composite score, with higher scores representing more frequent self-care practices.

**TABLE 1: Sample Characteristics (N = 104)**

<i>Variable</i>	<i>Frequency</i>	<i>Percentage</i>
<b>Age (<i>M</i> ± <i>SD</i>: 37.7 ± 12.8)</b>		
18-30	26	25
31-40	46	44
41-50	21	20
> 60	11	11
<b>Gender</b>		
Male	46	44
Female	58	56
<b>Employment</b>		
Employed full- or part-time	56	54
Unemployed	48	46
<b>Annual income</b>		
< \$5,000	25	24
\$5,000-\$9,999	35	33
\$10,000-\$19,999	27	26
\$20,000-\$30,000	7	7
> \$30,000	10	10
<b>Ethnicity</b>		
African American	103	99
Asian	1	1
<b>Marital status</b>		
Single	60	58
Married	23	22
Divorced or widowed	21	20

### *SCD Experience*

Participants reported several aspects of adjustment to SCD. Participants rated their pain severity in the last 30 days on a 1 to 10 scale. In addition, health care utilization was assessed by recording the number of ED and physician visits in the past 12 months. We, and others, have utilized similar measures of pain and health care utilization as an index of SCD adjustment in prior studies (Edwards et al., in press; Edwards, Telfair, Cecil, & Lenoci, 2000; Reese & Smith, 1997).

### **Measures Assessed at 6-Month Follow-up**

#### *Self-Esteem*

Rosenberg's (1965) Self-Esteem Scale (SES) was utilized as an indicator of global feelings of self-worth. The range of possible total scale scores on the SES was between 10 and 40, with higher scores representing greater levels of self-esteem. The internal consistency of the SES, as assessed by Cronbach's alpha, was .85.

#### *Mastery*

The seven-item Sense of Mastery Scale (SOM) (Pearlin, Lieberman, Menaghan, & Mullan, 1981) was used to assess respondents' general sense of life control. Scoring of the SOM is similar to that of the SES. The SOM has demonstrated good reliability and convergent validity; alpha for the SOM in this study was .77.

#### *Self-Efficacy*

Self-efficacy for coping with SCD was measured with the nine-item Sickle Cell Self-Efficacy Scale (SCSES) (Edwards et al., 2000). Higher scores represent greater perceived efficacy for coping with SCD. Alpha for the SCSES was .88.

### *Satisfaction With Providers*

Satisfaction with health care providers was assessed with two questions: (1) How satisfied are you with the overall care and services you receive here? (*not at all satisfied to very satisfied*) and (2) It is easy for me to talk with my doctor (*strongly disagree to strongly agree*).

### **Content Validity**

Content validity refers to the degree of adequacy and representativeness of the items on a measure. It is often assessed by allowing groups of experts to evaluate the items on a measure (Janda, 1998). In this study, five research nurses with extensive clinical experience in the field of SCD and 10 adults with SCD assessed content validity. These individuals were given a standardized explanation of the content domain of self-care based on Connelly's (1987) work, after which they judged the content validity of each item. The criterion for adequate content validity was approval by at least 80% of the judges (Lynn, 1986). All 32 items, as well as the overall scale, received ratings of adequate content validity from at least 80% of the judges.

### **Item Analysis and Factor Analysis**

We performed an item analysis on the 32 items making up the CIAISCD; the criterion for item retention was a decrease in the scale alpha value if the item was dropped (Ferketich, 1991). The remaining items were analyzed using exploratory principal components analysis (PCA) with promax rotation. To attain the best fitting structure, the criteria used were the scree test (Tabachnick & Fidell, 1996) and factor loadings higher than .40.

Five items did not meet the criterion for item retention and were not included in subsequent analyses, reducing the CIAI-SCD to 27 items. Using the scree test, the PCA revealed a three-factor solution accounting for 47% of the variance. Four of the 27 items did not load primarily on any of the three factors identified by the PCA. To confirm the structure of the CIAISCD, these four items were eliminated from the item pool and the remaining 23 items were subjected to a PCA with a forced three-factor structure. Results of this analysis confirmed the previously identified structure of the CIAI-SCD. Factor loadings appear in Table 2. The first factor (13 items, eigenvalue = 5.6) accounted for 23% of the variance and is labeled Personal Satisfaction and Perceived Control. The second factor (7 items, eigenvalue = 4.1) accounted for 17% of the variance and is labeled Feeling Concerned and Worried. The third factor (3 items, eigenvalue = 1.9) accounted for 7% of the variance and is labeled Feeling Supported. All subscale scores were calculated as the sum of responses to items loading on those subscales.

### **Internal Consistency**

Internal consistency refers to the degree to which the items composing a measure are interrelated; it is presumed that highly related sets of items are all measuring roughly the same construct (Janda, 1998). In this study, internal consistency was determined using Cronbach's alpha. Values of .70 or above indicate good levels of reliability (Nunnally & Bernstein, 1994).

Cronbach's alpha was calculated for each of the three CIAI-SCD sub-scales. This resulted in an alpha of .86 for the Personal Satisfaction and Perceived Control subscale, .80 for the Feeling Concerned and Worried subscale, and .66 for the Feeling Supported subscale. An analysis of the interscale correlations indicated that the subscales were marginally interrelated, though none of the relationships achieved statistical significance. Factor 1 and Factor 2 tended to be negatively related ( $r = -.18, p < .08$ ), whereas small positive correlations between Factors 2 and 3 ( $r = .17, p < .09$ ) as well as between Factors 1 and 3 ( $r = .19, p < .06$ ) were observed.

### **Test-Retest Reliability**

A measure of test-retest reliability provides an indication of the stability of test scores over time. Because most scales are intended to measure relatively stable characteristics, moderate to high relationships between scores across time are expected (Janda, 1998). Correlations were computed between CIAI-SCD factor scores at baseline and 6-month follow-up, when 84 of the original 104 participants (82%) were reassessed. The 6-

month test- retest reliability for each subscale was as follows:  $r = .55$  for the Personal Satisfaction and Perceived Control subscale ( $p < .001$ ),  $r = .48$  for the Feeling Concerned and Worried subscale ( $p < .001$ ), and  $r = .45$  for the Feeling Supported subscale ( $p < .001$ ).

**TABLE 2: Structure Coefficients for Oblique Rotation Factor Solution for Chronic Illness Assessment Interview for Sickle Cell Disease (CIAI-SCD)**

Item (Item No.)	CIAI-SCD Subscale		
	Factor 1	Factor 2	Factor 3
Can follow advice (19)	<b>.76</b>	-.02	.20
Understand advice (18)	<b>.69</b>	-.02	.22
Able to do things (2)	<b>.68</b>	-.25	-.24
Feeling well (3)	<b>.65</b>	-.36	-.22
Emotionally stable (8)	<b>.62</b>	-.48	-.17
Say in health care (17)	<b>.60</b>	-.11	.04
Plan is possible (21)	<b>.60</b>	.14	.29
Felt in control (7)	<b>.59</b>	-.37	.02
Satisfied with care (28)	<b>.59</b>	.14	.40
Plan helps (22)	<b>.58</b>	-.08	.17
Do follow advice (20)	<b>.51</b>	-.05	.37
Satisfied with self (1)	<b>.51</b>	-.32	.09
Happy and satisfied (4)	<b>.51</b>	-.50	.14
Been anxious (11)	-.04	<b>.80</b>	.23
Felt downhearted (6)	-.13	<b>.74</b>	-.02
Been under stress (10)	-.07	<b>.70</b>	.11
Bothered by nerves (9)	-.22	<b>.67</b>	.21
Worry about health (12)	-.15	<b>.57</b>	.13
Other problems (16)	-.04	<b>.54</b>	.24
Condition serious (15)	-.07	<b>.51</b>	.32
Someone to tell (30)	.20	.17	<b>.72</b>
Someone to contact (31)	.09	.09	<b>.72</b>
Staff suggestions (26)	.13	.14	<b>.70</b>

NOTE: Boldface indicates primary factor loading; Factor 1 = Personal Satisfaction and Perceived Control; Factor 2 = Feeling Concerned and Worried; Factor 3 = Feeling Supported.

### Construct Validity

Construct validity refers to relationships between scores on a measure and scores on measures of theoretically related constructs (Janda, 1998). To examine the relationship between identified CIAI-SCD factors and self-care practices reported by the sample, we performed a multiple regression analysis using CIAI-SCD scores to predict the self-care composite variable. Factors 1 (i.e., Personal Satisfaction and Perceived Control) and 2 (Feeling Concerned and Worried) were both significant predictors of the self-care composite variable (see Table 3). The positive nature of the relationships indicated that individuals with higher scores on these CIAI-SCD subscales tended to engage more frequently in self-care behaviors. The multiple regression analysis revealed that 29% of the variance in the self-care composite variable was accounted for by CIAI-SCD subscale scores.

We also examined the intercorrelations between CIAI-SCD subscale scores and the SCD experience variables (i.e., pain and health care utilization), self-esteem, sense of mastery, self-efficacy, and satisfaction with providers (see Table 4). Scores on the Personal Satisfaction and Perceived Control subscale were inversely related to health care-seeking behavior and pain severity and were positively related to self-efficacy, self-esteem, and sense of mastery. Scores on the Feeling Concerned and Worried scale were positively related to health care-seeking behavior and pain severity and were negatively related to self-efficacy, self-esteem, and sense of mastery. Finally, scores on the Feeling Supported scale were related only to overall satisfaction with services and ease of interactions with physicians. Higher scores on the Feeling Supported subscale were associated with greater satisfaction with services and with greater ease of physician-client interactions (see Table 4).

**TABLE 3: Results of Multiple Regression Equation Predicting Self-Care Composite Scores From Chronic Illness Assessment Interview for Sickle Cell Disease (CIAI-SCD) Subscale Scores**

<i>CIAI Subscale</i>	<i>Standardized <math>\beta</math></i>	<i>t</i>	<i>Significance</i>
Factor 1	.51	5.8	.001
Factor 2	.24	2.7	.007
Factor 3	.06	0.6	.54

NOTE: Factor 1 = Personal Satisfaction and Perceived Control; Factor 2 = Feeling Concerned and Worried; Factor 3 = Feeling Supported.

## DISCUSSION

The results of this study into the psychometric properties of the CIAISCD, an instrument assessing constructs related to self-care in the SCD population, are preliminary but promising. The content validity of the instrument, which was reviewed by an expert panel, seems sufficiently high. At least 80% of our panel of 15 judges rated each of the items making up the CIAI-SCD as relevant to the domain of self-care in the context of SCD. Item and factor analysis revealed three subscales of the CIAI-SCD. The following three subscales emerged from the analyses: Personal Satisfaction and Perceived Control (Factor 1), Feeling Concerned and Worried (Factor 2), and Feeling Supported (Factor 3). These three domains correspond to many of the CIAI assessment dimensions originally proposed by Connelly (1987). The Personal Satisfaction and Perceived Control factor of the CIAI-SCD incorporates elements of self-concept, health motivation, and perceived characteristics of the health regimen. The second factor, Feeling Concerned and Worried, corresponds to Connelly's construct of psychological status. Finally, the third subscale, Feeling Supported, corresponds to the social support factor proposed by Connelly.

**TABLE 4: Correlations of Chronic Illness Assessment Interview for Sickle Cell Disease (CIAI-SCD) With Construct Validity Variables: Health Care Utilization and SCD Adjustment**

<i>Variable</i>	<i>Factor 1</i>	<i>Factor 2</i>	<i>Factor 3</i>
ED visits	-.26**	.21*	.02
Physician visits	-.21**	.18	-.06
Pain severity	-.26**	.35***	.14
SES	.49***	-.26*	.11
SOM	.37**	-.30**	.01
SCSES	.46***	-.44***	-.03
Satisfied with services	.08	.15	.33**
Talk to physician	.06	-.03	.35**

NOTE: Factor 1 = Personal Satisfaction and Perceived Control; Factor 2 = Feeling Concerned and Worried; Factor 3 = Feeling Supported; ED visits = Number of visits to the emergency department in the past 12 months; Physician visits = Number of visits to a physician in the past 12 months; Pain severity = Reported severity of SCD pain in the past 30 days (0-10 scale); SES = Total score on the Rosenberg Self-Esteem Scale; SOM = Total score on the Pearlin Sense of Mastery Scale; SCSES = Total score on the Sickle Cell Self-Efficacy Scale; Satisfied with services = Overall satisfaction with services (1-4 scale); Talk to physician = Reported ease of communication with SCD physician (1-5 scale).

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

It had been expected that an adequate or better level of internal consistency would be obtained for Cronbach's alpha as evidence of the reliability of the CIAI-SCD. In this study, alpha values for the Personal Satisfaction and Perceived Control and Feeling Concerned and Worried subscales were at least .80, indicating good levels of internal consistency (Nunnally & Bernstein, 1994). The estimated alpha for the Feeling Supported subscale was well below the desired .80, probably because of the limited number of items. In addition, we anticipated significant correlations between subscale scores on the CIAI-SCD administered at two different time points. The results of the test-retest reliability analyses show adequate stability of this instrument, measured with a time interval of approximately 6 months, with test-retest correlations ranging from .45 to .55. Given that perceptions of health and self in the context of a chronic illness are generally

presumed to be rather dynamic (Connelly, 1987), the moderate but significant magnitude of these estimates of temporal stability appears appropriate.

Construct validity refers to relationships between scores on a measure and scores on measures of theoretically related constructs (Janda, 1998). The construct validity analyses revealed significant relationships between two of the CIAI-SCD subscales and reported self-care behaviors (indexed by the self-care composite variables). The Personal Satisfaction and Perceived Control subscale and the Feeling Concerned and Worried sub-scale were both positive predictors of the reported frequency of self-care behaviors. That is, greater perceived satisfaction with one's health, increased levels of perceived control, higher levels of general anxiety, and more concern about health were associated with more frequent use of self-care behaviors. These findings are consistent with a number of prior studies of factors affecting self-care behaviors. Gillis (1993) reviewed several dozen studies indicating that higher levels of perceived control in the domain of health and higher perceived satisfaction with health were associated with more frequent performance of self-care activities. More recent studies have verified that individuals who report more satisfaction with their health and greater perceived control also display more self-care behavior (Acton & Malathum, 2000; McDonald-Miszczak et al., 2001). These two factors appear to be the most frequently reported determinants of self-care; in this study of the CIAI-SCD, both constructs are represented in the Personal Satisfaction and Perceived Control subscale of the instrument. Health-related anxiety has also been shown to be a positive predictor of self-care behavior in prior studies. Studies of individuals with cancer (Dodd, 1988; Dodd & Dibble, 1993), end-stage renal disease (Horsburgh, 1999), and pregnant women (Hart & Foster, 1998) have all revealed positive relationships between health-related anxiety and the performance of self-care behaviors. Several prior investigations have also reported relationships between social support and self-care behavior (Dodd & Dibble, 1993; Hanucharunkul, 1989). In this study, however, no such relationship was observed. It may be the case that the internal consistency of the Feeling Supported subscale of the CIAI-SCD was inadequate and that the construct of social support was not properly represented.

In our additional analyses of construct validity, adults with SCD who attained high scores on the Perceived Satisfaction and Control subscale of the CIAI-SCD reported fewer physician and ED visits and decreased levels of SCD-related pain. Moreover, high scores on this CIAI-SCD subscale were associated with greater levels of self-esteem, self-efficacy, and mastery. Thus, this subscale of the CIAI-SCD does appear to measure perceptions of control and well-being in the arena of health and to be positively related to SCD adjustment. These findings are commensurate with previous investigations reporting significant relationships between general perceptions of health satisfaction and well-being and adjustment to chronic illness (Acton & Malathum, 2000; Bobak, Pikhart, Hertzman, Rose, & Marmot, 1998; Chang & Mackenzie, 1998; McDonald-Miszczak et al., 2001; Rijken, Komproe, Ros, Winnubst, & Van Heesch, 1995). In contrast, participants with higher scores on the Feeling Concerned and Worried subscale reported increased ED visits, increased pain severity, and decreased levels of self-esteem, self-efficacy, and mastery. The Feeling Supported subscale was unrelated to health care-seeking behavior or self-perception variables (i.e., efficacy, esteem, and mastery) but was related to satisfaction with services received from staff and physicians, as expected.

Collectively, these findings accord well with Connelly's (1987) conceptualization of self-care as a multidimensional construct that emphasizes perceptions and values of health. In general, the four hypotheses identified in the introduction were supported. The CIAI-SCD appears to be reliable, as indexed by the estimates of Cronbach's alpha and the significant test-retest correlation coefficients. In addition, the CIAI-SCD appeared to demonstrate adequate content validity as judged by a panel of experts. Factor and item analyses revealed that the seven content domains originally proposed by Connelly could be reduced to three domains: Personal Satisfaction and Perceived Control, Feeling Concerned and Worried, and Feeling Supported. Finally, CIAI-SCD subscale scores were significantly related to measures of conceptually relevant constructs and also related to measures of reported self-care behavior, as predicted by Connelly's model. These results suggest that the Personal Satisfaction and Perceived Control as well as the Feeling Concerned and Worried subscales of the CIAI-SCD are positively associated with performance of self-care behaviors. That is, individuals with SCD who report more perceived control over their health, more

satisfaction with their health, and more concern regarding their future health are more likely to appropriately engage in self-care.

Nursing services can benefit from using psychometrically validated assessment instruments to provide improved care and more focused training to the numerous clients that suffer from chronic illnesses. Use of a psychometrically sound assessment measure permits nurses to more accurately and reliably assess variables and behaviors of interest. By using well-validated instruments, reliable identification of attitudes that pose a potential risk for self-care deficits is possible. Although individualized training in self-care skills may be time-consuming, prior studies have demonstrated such clear benefits as reduced pain, decreased use of the health care system, and improved QOL (Boulet et al., 1995; Moore et al., 2000; Testa & Simonson, 1996). These results using the CIAI-SCD are preliminary in nature, but they may suggest that interventions designed to raise individuals' perceptions of self-efficacy, as well as their awareness of disease consequences, may enhance performance of self-care behaviors.

A number of limitations necessitate caution in interpreting the results of this study. First, the data were based entirely on participant self-report, which is subject to recall bias and social desirability factors. Second, we had less than 200 respondents, the recommended number for performing a factor analysis (Tabachnick & Fidell, 1996). When replicating or extending this study, larger sample sizes will be necessary. Third, the Feeling Supported subscale of the CIAI-SCD may have contained an inadequate number of items and did not demonstrate an acceptable level of internal consistency. Future research with the CIAI-SCD should include a more thorough assessment of this subscale. Fourth, the 6-month test-retest interval is longer than typically recommended (Janda, 1998). Future studies utilizing this instrument may benefit from assessment of CIAI-SCD test-retest reliability over a shorter time period. Finally, the direct clinical relevance of this new instrument is unclear at present; future research will be required to determine whether or not interventions targeted toward altering the constructs assessed by the CIAI-SCD are effective in changing self-care behaviors and improving adjustment to SCD. Collectively, in light of these limitations, this study can be considered a preliminary investigation of a new self-care agency instrument applied to adults with SCD. In this early stage of scale development, the CIAI-SCD can be tentatively recommended for nurses working with individuals with SCD.

**Note:**

1. This work was supported by funds to the second author by the Sickle Cell Disease Association of the Piedmont and the Maternal and Child Health Bureau, U.S. Department of Human Services grant MCJ9040. Thanks are expressed to the following individuals, without whose valuable assistance this work would not have been possible: Marietto Douglas, Ernestine Bigelow, and Maris Morris for project management and data gathering support. Special thanks go to the study participants for volunteering their time to make this study possible. Finally, thanks to Joan S. Grant for her helpful comments on this manuscript.

## APPENDIX

### The Chronic Illness Assessment Interview for Sickle Cell Disease (CIAI-SCD)

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Below are statements about the things persons with sickle cell disease think about or have to deal with from day to day. In the box next to the statement, please check how often you think about or have to deal with these things. PLEASE ANSWER EVERY QUESTION.

(1) Never    (2) Rarely    (3) Sometimes    (4) Often    (5) Very Often

1. Are you satisfied with yourself?
2. Do you feel able to do things as well as other people?
3. Have you been feeling well in general?
4. Have you been happy and satisfied with your personal life?
5. Have you felt sad, discouraged, or helpless, or wondered if anything was worthwhile?\*
6. Have you felt downhearted or blue?
7. Have you felt in control of your behavior, thoughts, and feelings?
8. Do you feel emotionally stable and sure of yourself?
  
9. Have you been bothered by nervousness or your "nerves"?
10. Have you been under stress, strain, or pressure?
11. Have you been anxious, worried, or upset?
12. Do you worry about your health?
13. Do you think that your medical check-ups are important to your health?\*
14. Do you think your lifestyle affects your health?\*
15. Do you rate your condition as serious?
16. Do you think your condition could cause other health problems?
17. Do you think you have had any say in planning your own health care?
18. Do you understand the things you have been advised to do for your health care?
19. Do you know how to do the things you have been advised to do for your health care?
20. Do you do the things you have been advised to do for your health care?
21. Do you think it is possible to follow the plan for your health care?
22. Do you think following the plan of health care helps you?
23. Do you think it is hard for you to follow the plan for your health care?\*
24. Do you have any discomfort as a result of following the plan of care?\*
25. Does following the plan of health care cost you much or anything in additional expenses?\*
26. Does someone on the staff make suggestions or give advice that helps you follow your plan of health care?
27. Do those at home help you or make suggestions that help you follow your plan of care?\*
28. Are you satisfied with the health care you received here?
29. Can you usually tell when something is wrong with your health?\*
30. Is there someone here you can tell when you are having a problem?
31. Can you contact someone here when you are having a problem?
32. Do you run into problems when you try to get help after 5 pm?\*

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\*Identifies items subsequently deleted following item analysis or factor analysis.

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