Evaluation of a Disease-Specific Self-Efficacy Instrument in Adolescents with Sickle Cell Disease and its Relationship to Adjustment

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Abstract:
The psychometric properties of a disease-specific instrument used to assess self-efficacy in adolescents with sickle cell disease, the Sickle Cell Self-Efficacy Scale, were evaluated in a sample of 131 adolescents ranging from 11 to 19 years of age. This nine-item instrument was associated with a one-item, general self-efficacy question and an item of self-control. After controlling for age, gender, highest grade of education completed, and the number of individuals in the household, high levels of self-efficacy were related to fewer physical, psychological, and total symptoms. Using the stress process framework to examine the relationship between self-efficacy and self-reported symptoms in adolescents may lead to the initiation of effective intervention programs capable of increasing levels of self-efficacy in adolescents. These interventions could lead to better outcomes for adolescents with sickle cell disease. Additional longitudinal investigations are needed to evaluate the ability of self-efficacy to predict adolescent adjustment over time.

Keywords: Sickle cell disease; self-efficacy; adolescent health; health promotion; youth health; adjustment

Article:

Introduction

Sickle cell disease (SCD) comprises a group of genetic hemoglobin disorders. The predominant symptom associated with SCD is pain resulting from “vasoocclusion” of small blood vessels by abnormally “sickle-shaped” red blood cells. There are other complications including chronic organ damage (Serjeant, 2001), however severity is variable. Current treatments include transfusion for severe complications (Reed & Vichinsky, 1998), and hydroxyurea, which raises fetal hemoglobin level, rehydrates the red blood cells, and reduces vasoocclusion (Charache et al., 1995). Bone marrow transplantation may also be considered in cases with extreme disease severity (Hoppe & Walters, 2001).

SCD is found in people originating from Africa, the Mediterranean, the Middle East, and Asia. The United States affected population is about 75,000 (National Heart, Lung & Blood Institute, 2002) and mostly African American. Medical advances over the past few decades have lead to improved life expectancy for people with SCD (Platt et al., 1991). Nonetheless, as children grow into adulthood they are faced with new challenges of social and institutional barriers, such as access to health care, social services, and employment (Telfair, 1994; Telfair, Myers, & Drezner, 1994). Many young people with SCD have to deal with health professionals' and the public's lack of knowledge and understanding of their condition, the stereotype of being socially dysfunctional, and the stigmatization of their condition (Telfair & Nash, 1996). This is partly because SCD is characterized as a “black” disease (Tapper, 1999).

The emergence of chronic conditions like SCD as a problem for health care systems to address is becoming more obvious, and research indicates that adolescents with chronic conditions have opinions and expectations about their future health care and health management (Court, 1993; Tapper, 1999). Their recurring health care needs put them at an increased risk of chronic dependency, low self-esteem, high levels of stress, ineffective coping skills, psychological difficulties (e.g., increased anxiety, depression and decreased self-efficacy), and

functional failure within their families and in adult social and health care systems (Burlew, Telfair, Colangelo, & Wright, 2000; McAnarney, 1985; Streetley, Maxwell, & Meija, 1997; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Hurtig, Koepke, & Park, 1989; Hurtig & White, 1986; Thompson et al., 1994). Adolescents with difficulties adjusting to their illness are especially vulnerable for poor longitudinal outcome and are identifiable by low scores on questionnaires that assess current self-efficacy, self-esteem, and social competence. Difficulties in adjustment could be related to neurocognitive dysfunction either through damage by the disease to the neurologic structures that regulate emotional and social behaviors or through the difficulties involved in performing certain tasks. Additional longitudinal investigations are needed in this area that utilize techniques such as computerized tomography (CT) and positron emission tomography (PET) to determine the nature of the these relationships (Brown, Armstrong, & Eckman, 1993).

The increasing number of adolescents with SCD surviving into adulthood and ready for transfer from pediatric to adult care has made transition a critical issue (Telfair, Myers, & Drezner, 1994). Given the chronicity of SCD, this transition encompasses both medical and life transition and is defined as the process involved in the movement of adolescents from a focus on pediatric life skill issues to adult life skill issues, including transfer from pediatric or child-centered care to adult health care services (Telfair, Myers, & Drezner, 1994). Transition from pediatric to adult health care is identified as "the most difficult and potentially traumatic passage faced by adolescents with SCD" (Kinney & Ware, 1996; Hauser & Dorn, 1999) and many adolescents and young adults with chronic conditions, such as diabetes (Crosnier & Tubiana-Rufi, 1998), cystic fibrosis (Landau, 1995), spina bifida (Sawyer et al. 1998), congenital heart disease (Dore, de Guise, Mercier, 2002), and chronic arthritis (Ansell & Chamberlain, 1998), lack the self-advocacy, independent living and vocational skills, and sense of self-efficacy that would allow them to smoothly transition into adult care (Wagner, 1992).

The changing delivery of health care services presents additional challenges such as availability of and coordination between primary and specialty care, competing health care plans and administrative bureaucracies, managed care "gate-keeping," financing and reimbursement systems, and quality of care (Committee on Child Health Financing, 1995; Jessop & Stein, 1994; Ballas, 1998; Palfrey, Samuels, Haynie, & Cammisa, 1994). Similarly, adolescents with SCD may be unwilling to seek out the services of an adult provider since they may have developed a strong relationship with, and reliance upon, their pediatrician (Betz, 1998; Callahan, Feinstein, & Keenan, 2001). For this and other reasons, many who reach late adolescence and young adulthood still remain in pediatric medical care systems or "find themselves adrift in search of appropriate fulfillment of their care needs" (Scal, Evans, Blozis, Okinow, & Blum, 1999; Chamberlain & Rooney, 1996; Maternal & Child Health Bureau, 1992; Blum et al., 1993). The rapid advancements in the treatment and care of persons affected by SCD has not been matched by development of effective programs focusing on the acquisition of needed personal, interpersonal and social life skills, self-advocacy, medical self-management and system negotiation, educational skills, and vocational readiness for young people (Reinholt & Oberg, 1993). Improved longitudinal outcomes for young people with chronic diseases are associated with participation in appropriate child to adult care transition programs, though there is little evidence to suggest that this is happening at a rate commensurate with clinical requirements (Sawyer, Blair, & Bowes, 1997) or that comparable to adolescents without such conditions. Adolescents with chronic conditions like SCD need guidance, support, and information about available services to help meet daily challenges (Court, 1993).

Previous research on psychosocial aspects of SCD has examined the extent of its impact on children, adolescents, and adults, the ways in which the affected families function, and the resultant psychological adjustment. Some of these studies have demonstrated that SCD is a risk factor for maladjustment (psychosocial functioning) in children and adolescents (Brown, Kaslow et al., 1993; Kliewer & Lewis, 1995; Gil, Wilson, & Edens, 1997; Thompson et al., 1999). Understanding the needs of adolescents is necessary to help them through behavioral and emotional difficulties of living with a chronic genetic disorder like SCD. Moreover, it is acknowledged that guidelines for clinical practice should be based on good evidence of effective recommended interventions (Garrison & McQuiston, 1989). However, in the context of moving through the health care system and life for adolescents with SCD there is hardly any empirical evidence available about appropriate interventions.

One potentially modifiable construct that may be important to adolescent adjustment is self-efficacy. Self-efficacy, a component of Social Learning Theory, refers to the extent to which individuals feel they have control over the events that affect their lives. In addition, the actions they take in response to a situation are expected to lead to a certain outcome (Bandura, 1977a, 1977b). An individual's level of motivation, actions, and affective states are not only based on what is objectively true but also on what the individual believes to be true (Bandura, 1997). This sometimes leads to self-efficacy being a better predictor of behavior and functioning than an individual's knowledge and skills. Bandura (1986) warns that measures of self-efficacy and self-perception must be relevant to the domain of functioning in question in order to avoid examining ambiguous relationships. Therefore, a valid, disease-specific measure of self-efficacy is necessary to examine the relationship between self-efficacy and adolescent outcome. The Sickle Cell Self-Efficacy Scale (SCSES) serves as the first validated instrument designed to assess self-efficacy in adolescents with SCD.

Previous studies have examined the relationship between disease-specific self-efficacy and adolescent outcome. For example, Caplain and associates (2002) developed and evaluated a Seizure Self-Efficacy Scale for Children (SSES-C). This scale consisted of 15 items that loaded on a single factor, and the internal consistency as assessed by Cronbach's alpha coefficient was 0.93. High levels of seizure-specific self-efficacy were found to be associated with a more positive attitude toward the illness, a positive self-concept, less worry, and fewer depressive symptoms. Additionally, disease specific self-efficacy in adolescents has been shown to be modifiable by interventions. A 23-item questionnaire was used to assess asthma-specific self-efficacy in urban dwelling adolescents. This instrument was tested on a larger sample of 171 children with asthma and revealed an internal consistency of 0.77 (Bartholomew et al., 2000). A computer-assisted educational program designed to teach asthma self-management skills was shown to increase self-efficacy over a 3-week period (Shegog et al., 2001).

In this investigation, a stress process model (Lazarus & Folkman, 1984; Haley, Levine, Brown, & Bartolucci, 1987) was used to examine adolescents' adjustment to SCD. The stress process was originally divided into four multiple component domains, which can be used to examine adolescents' adjustment to SCD. First, the background and contexts of the stressful event or situation must be considered. Demographics such as age, education, and gender must be examined to determine if some adolescents with SCD are members of groups with unequal distributions of rewards, privileges, opportunities, or responsibilities, if so these variables must be controlled for when examining individual differences in adjustment. For this study, we did not examine the second domain of the stress process: primary, secondary, and extrinsic stressors (Pearlin, Mullan, Semple, & Skaff, 1990). Stressors such as pain that arise directly as a consequence of SCD would be labeled primary stressors. The stress associated with living with SCD has additional negative consequences, or secondary stressors, that affect the lives of adolescents. These may include missing days from school for sickle-cell-related illness or medical appointments and potentially limited opportunities for leisure activities or recreation. Extrinsic stressors include life events such as being involved in a car accident that are unrelated to the having SCD.

The third domain of the stress process model involves the mediation of stress and explaining individual differences in adjustment to SCD. Investigations examining both child and adult samples have shown that self-efficacy, social support, and appraisals of the stress involved in living with SCD explain some but not all individual differences on participant adherence to treatment and adjustment (Dalton & Pakenham, 2002; Ott, Greening, Palardy, Holderby, & DeBell, 2000; Haley et al., 1996). The stress process model would be incomplete if we had no way to measure the effects of stress on the everyday life of the adolescent. Individual outcomes, physical and psychological symptoms in this investigation, are the final domain of the model.

The purpose of this investigation was first to evaluate use of a disease-specific instrument, the SCSES, in assessing self-efficacy in adolescents with SCD, then to examine the relationships between demographic factors, self-efficacy, and physical and psychological symptoms in these adolescents. It is hypothesized that (a) the SCSES will have excellent psychometric properties when utilized in an adolescent sample as it did when used with adults (Edwards, Telfair, Cecil, & Lenoci, 2000), (b) background or demographic measures will not

be significantly associated with self-efficacy, (c) the SCSES will correlate with questions that assess related constructs such as self-care, and (d) after controlling for demographics, self-efficacy will be associated with the number of psychological symptoms, physical symptoms, and total symptoms reported by adolescents.

METHODS

Recruitment and Inclusion Criteria

The current study is a "substudy" of the Multi-site Study of Transition to Adult Care for Adolescents with SCD (Telfair et al., 1994; Anie, Telfair, & the Sickle Cell Disease Transition Study Group, 2005; Telfair, Ehiri, Loosier, & Baskin, 2004). The study was a cross-sectional survey of a volunteer international sample of individuals with SCD, who were still receiving care in pediatric community-based and medical center sickle cell disease programs. The purpose of the larger study was to present the "voice" of the adolescent with SCD as part of the discussion of transition issues and to assess the adolescent's readiness for transition to adult care and life (Anie et al., 2005). Respondents came from community-based and medical center sickle cell programs from 18 centers in the United States. In addition, participants from one site in London were also included in the sample examined for this manuscript.

Data gathering for the larger study was conducted between June 1998 and December 2002 to allow for the continuous enrollment of sites who wished to volunteer their participation. Each site collected data for an average of six months. This allowed for a larger sample to be gathered and for each site to exhaust their eligible participant base. Given the low prevalence of SCD, it was rare for a center to have more than 40 individuals who met the inclusion criteria on its active patient list: those that have been seen by providers at least once in the previous year. Individuals were not excluded because of disease severity or other reasons. The total number of individuals in the centers that met the inclusion criteria was 264 and each was invited to participate in the study. One hundred and seventy-two of these consented, giving a response rate of 65%. The list of participating sites is included in the acknowledgements.

Procedures

The measures described in this investigation were included in the adolescent sickle cell transfer questionnaire (A-SCTQ) designed to elicit demographics, adolescent-expressed demonstration of transition behaviors, expectations of transition, opinions regarding the need for a systematic transition program, and self-reports of personal health care, self-efficacy, and psychological and physical symptoms (Telfair et al., 1994; Telfair et al., 2004). Human subjects' approval was obtained from the Institutional Review Boards at the relevant agencies before commencement of the study. Signed consent was sought from the parent(s) or legal guardian(s) and the assent of the eligible adolescent was obtained. Parents/guardians and adolescents were informed by mail about the purpose and procedures of the study. They were told participation in the project was completely voluntary and they could refuse to participate, to discontinue participation at any point, or to refuse to answer questions they did not feel comfortable answering. Participants were reassured that if they chose not to participate in the study, they would not lose any benefits from their health care providers. Thus, participation in the study was voluntary and no incentive was provided to respondents. A stamped postcard was included for parents and adolescents to sign and return if they did not want to participate in the study.

Measures

Demographics. The sociodemographic characteristics of the respondents, including hemoglobinopathy status, race, gender, marital status, employment, health insurance status, geographic location, highest grade in school completed, household size, and type of care program received, were all collected.

Self-efficacy. The Sickle Cell Self-Efficacy Scale (SCSES) is a nine-item scale developed specifically to assess adults and adolescent's self-appraisals of their ability to engage in daily functional activities despite having SCD (see appendix A). Response choices ranged from "not at all sure" to "very sure." In the earlier study on the reliability and validity of the SCSES in adults (Edwards, et al., 2000), we noted that the items comprising the SCSES were relatively few (nine), queried efficacy beliefs in rather general terms, and were based on responses from fewer than 100 study participants, we elected not to factor-analyze the scale. Thus, total self-efficacy

scores were obtained by summing responses to all nine items, with higher scores indicative of greater self-efficacy. Adolescents answered the same items that were used with the adult sample.

Personal health care. Individuals were asked to rate whether they performed certain activities as a part of their health care on a four-point Likert scale (1 = rarely or never, 2 = not very often, 3 = often, and 4 = very often). The activities included: drinking enough liquids, not overexercising, taking medications as told, making sure the doctor's instructions were understood, and making sure that all medical questions were answered. For these items, higher scores were better.

Physical symptoms. A modified version of the National SCD Adult Self-Help (NSCDSH) study's Sickle Cell Disease Problem Scale (SCDPS) was employed to assess the presence and the extent of physical symptoms experienced by participants in the last 30 days (Nash, 1991a). Modifications involved simplifying the language of the items to make them more understandable for adolescents. Eleven items assessing how often the participant experienced physical symptoms common in SCD (e.g., pain, shortness of breath, threw up/vomited, etc…) were measured using a four-point Likert scale (1 = "rarely or none of the time", 2 = "not very often", 3 = "often", 4 = "very often"). A composite score was computed by summing the responses with higher scores indicating that the member experienced higher number of physical symptoms or problems. Cronbach's alpha for these eleven items was = 0.80.

Psychological symptoms. The Sickle Cell Disease Psychological Symptoms (SCDPYS) subscale of the NSCDSH study questionnaire (Nash, 1991b) was employed. The SCDPYS is an eight-item, four-point scale, also rated from 1 (rarely or never) to 4 (very often), that assesses adolescents' experiences of psychological symptoms specific to SCD in the preceding six months (e.g. was low, sad, or blue, was tense and nervous, had problems coping, etc…). Higher scores on this subscale indicate more psychological symptoms, hence more distress. Internal consistency of this subscale in this study sample was also quite high $\boldsymbol{\alpha} = 0.86$.

Total symptoms. This was the sum of the 19 physical and psychological symptoms items.

Analyses

All analyses were conducted using SAS Version 9 (SAS, 2002). An exploratory factor analysis was conducted to determine the number of factors that should be extracted from the nine-item SCSES. After using the principal components extraction method, an examination of the scree plot and eigenvalues were used to determine the number of factors to be retained. Cronbach's alpha was computed to examine the internal consistency of the factor(s). Pearson's product-moment correlations were used to examine the relationships between self-efficacy, demographics, adolescent outcome, and other study variables. Finally, multiple regression analysis was used to determine if self-efficacy was associated with adolescent outcome after controlling for demographics.

RESULTS

Participants

Of the 172 participants who gave informed consent and enrolled in the study, 148 were administered and completed the SCSES. There were no systematic differences between the individuals who completed the SCSES and those who did not on demographics, self-efficacy, or symptoms. Seventeen (17) individuals over the age of 19 who were still receiving care in pediatric community-based and medical center sickle cell disease programs were excluded from the current investigation. The 131 adolescents who are the focus of this manuscript ranged from 11 to 19 years of age and 60.31% were female. Ninety-seven (97) percent of the participants reported being of African American race/ethnicity. The majority of the participants reported a SS hemoglobin type (61.07%), followed by Hb SC (18.32%), and Hb S/beta thalassemia (7.63%). The remaining 17 participants (12.98%) reported not knowing their hemoglobin type or another type of hemoglobin. Descriptive statistics for the main study variables are included in Table 1. Additional *t*-tests were conducted using all measures from Table 1 to determine if the 16 (12.21%) adolescents from the United Kingdom differed from the adolescents residing in the United States. The results of these *t*-tests were all nonsignificant, *p*'s > .17. Also, equality of variance tests were conducted to determine if the variances of the measures were equal for the

United Kingdom adolescents and adolescents from the United States. The results of these tests were also nonsignificant, *p*'s > .12, specifying that the variances of the groups were not statistically different from each other and validating the decision to analyze all data as if it were from the same population.

Table 1 Descriptive Statistics for Study Variables.

Variable	Mean	Standard Deviation	Minimum	Maximum
Age	15.68	1.88	11	19
Education	9.06	1.95	4	13
Number in Household	4.04	1.82	1	10
Self-efficacy	29.73	8.31	9	45
Physical Symptoms	17.46	5.41	11	36
Psychological Symptoms	13.34	5.31	8	30
Total Symptoms	30.80	9.90	19	62

Psychometric Properties of Scale

Factor Analysis suggested the existence of a single self-efficacy factor that accounted for 49.78% of the total variance. There was no need to rotate the factor pattern due to the evidence of only one factor (Tabachnick & Fidell, 1996). A Cronbach's alpha of .87 was computed for the nine items. Alpha values of .70 or greater generally indicate adequate internal consistency (Nunnally & Bernstein, 1994). George and Mallery (2003) categorized Cronbach alpha scores as follows: 1.00 - .90 = Excellent, .89 - .80 = Good, .79 - .70 = Acceptable, .69 - .60 = Questionable, .59 - .50 = Poor, and < .50 = Unacceptable. Gliem and Gliem (2003) suggest that an alpha = .80 is a reasonable goal when focused on scale development. Moreover, all item-total correlation coefficients between the SCSES individual items and the SCSES total exceeded .49 and no items adversely affected alpha values. That is, no items were identified whose deletion would elevate the alpha for the total scale. This high level of internal consistency replicated the results of the factor analysis and is consistent with findings in an adult population with sickle cell (Edwards et al., 2000).

Relationship Between Adolescent Demographics and Self-efficacy

The participant's age, gender, level of education, and the number of members in the adolescent's household were not significantly associated to self-efficacy when bivariate relationships were examined (see Table 2). These variables were controlled for in the multiple regressions that assessed the relationship between self-efficacy and adolescent outcome.

Table 2 Pearson's Product-Moment Correlations Between Demographics and Self-Efficacy.

	Age	Gender	Education	# in household	Self-efficacy
Age	1.00				
Gender	−.11 (.21)	1.00			
Education	.75 (<.0001)	−.11 (.23)	1.00		
# in household	.18 (.04)	.03 (.77)	.09 (.33)	1.00	
Self-efficacy	−.05 (.61)	.10 (.27)	.08 (.36)	−.12 (.19)	1.00

Note. *P*-values are in parentheses ( ).

Association Between Self-Efficacy and Other Related Constructs

An individual item was incorporated into the protocol to serve as a one-item measure of self-efficacy. Individuals were asked, "Do you think there are things you can do to reduce the number of problems you have related to your SCD?" This item was significantly associated with the total score from the SCSES ($r = .23$, $p < .01$). Self-efficacy was also significantly related to one of the ratings of an individual's personal health care, adolescent's report of drinking enough liquids ($r = .18$, $p = .04$). The associations between self-efficacy and the adolescents' ratings of not overexercising, having all medical questions answered, taking medications as told, and making sure to understand the doctor's instructions were all nonsignificant, *p*'s > .10.

Association Between Self-efficacy and Adolescent Outcome

After controlling for age, gender, education, and the number of members in the household, self-efficacy was negatively associated with the adolescent outcomes of physical symptoms, psychological symptoms, and total symptoms (see Table 3). Higher levels of self-efficacy were associated with fewer self-reported symptoms. There were concerns of multicolinearity due to the significant bivariate associations between age and education and between age and the number of members in the household. Separate multivariate models were conducted without age as a predictor to examine the strength of the relationships between education and symptoms and the number of members of the household and symptoms that did not adjust for age. The adolescent's highest level of education completed was positively associated with adolescent outcome in all three models when age was not included as a predictor, *p*'s < .03. Number of people in the household was related to adolescent outcome for all models whether age was included as a predictor or not, *p*-values ranged from $p = .04$ to $p = .07$. The total variance accounted for in each model was also examined, and age, gender, education, number of individuals in the household, and self-efficacy accounted for 13% of the total variance in psychological symptoms, 17% in physical symptoms, and 17% in total symptoms.

Table 3 Multivariate Models of Association Between Self-Efficacy and Adolescent Outcome After Controlling for Demographics.

Predictors	B	*SE* B	β	*p*-value
Physical Symptoms				
Age	−.19 (–)	.36 (–)	−.07 (–)	.59 (–)
Gender	−.91 (−.89)	.91 (.91)	−.08(−.08)	.32 (.33)
Education	.71 (.58)	.35 (.23)	.26 (.21)	.04* (.01*)
Number in Household	.47 (.45)	.25 (.24)	.16 (.15)	.06 (.07)
Self-efficacy	−.19 (−.19)	.05 (.05)	−.29(−.29)	<.01** (<.01**)
Psychological Symptoms				
Age	−.19 (–)	.36 (–)	−.07 (–)	.60 (–)
Gender	−.59 (−.61)	.91 (.91)	−.05(−.06)	.52 (.50)
Education	.40 (.53)	.35 (.23)	.15 (.20)	.26 (.02*)
Number in Household	.47 (.49)	.25 (.25)	.16 (.17)	.07 (.05)
Self-efficacy	−.14 (−.14)	.05 (.05)	−.21(−.22)	.01* (.01*)
Total Symptoms				
Age	−.005 (–)	.66 (–)	−.001 (–)	.99 (–)
Gender	−1.50 (−1.50)	1.66 (1.65)	−.07(−.07)	.37 (.37)
Education	1.11 (1.11)	.63 (.42)	.22 (.22)	.08 (<.01**)
Number in Household	.94 (.94)	.46 (.45)	.17 (.17)	.04* (.04*)
Self-efficacy	−.33 (−.33)	.10 (.10)	−.27(−.27)	<.01** (<.01**)

Note. B = unstandardized regression coefficient; *SE* = standard error; β = the standardized beta estimate. *p < .05, **p < .01. Statistics in parentheses ( ) represent values after age was removed from the model.

DISCUSSION

The first purpose of this investigation was achieved. The SCSES demonstrated good psychometric properties, results similar to those in the earlier adult study (Edwards et al., 2000) and therefore appears suitable for use with adolescents with SCD. As with the adult scale, it would be the first available disease-specific efficacy measure utilized in this population. It is brief compared to other disease-specific self-efficacy measures discussed earlier, but has similar internal consistency. Secondly, self-efficacy was significantly related to the self-care item of drinking enough liquids. In addition to the relationship with self-efficacy, it is clinically well known that in children with chronic conditions, especially those with SCD, self-care practices are strongly related to parental support and a good understanding of how one's disease effects one personally (Kliewer & Lewis, 1995; Atkin & Ahmad, 1999; Logan, Radcliffe, & Smith-Whitley, 2002). Given the need for clinically useful tools, the brevity of the SCSES makes its use very practical in the identification of at-risk adolescents with low self-efficacy. The identification of these adolescents would provide clinicians with the opportunity to implement focused efforts such as individual counseling, psycho-educational groups, and family-centered education. Preventive efforts targeted towards adolescents who have the potential for poor symptom management, poor medical adherence, poor psychological and social adjustment as a consequence of their condition, and low self-efficacy can be effective in terms of cost and in increasing efficacy beliefs.

The final purpose was an examination of the relationship between adolescent sickle cell self-efficacy and self-reports of physical and psychological well-being. There was a significant association between sickle cell self-efficacy in adolescents and the report of symptoms after controlling for age, gender, highest grade completed in school, and the number of individuals in the household. Increased levels of SCD-specific efficacy beliefs were related to lower levels of SCD symptomatology. These findings are in agreement with the earlier adult SCD self-efficacy study (Edwards et al., 2000) and previous investigations of self-efficacy beliefs in other chronic conditions: inverse relationships have been reported between efficacy beliefs and pain frequency (Karoly & Ruehlman, 1996), and severity (Lin & Ward, 1996), health care utilization (Nicholas, Wilson, & Goyen, 1992; O'Leary, 1985), and global adjustment (Patterson & Blum, 1996).

The stress process model attempts to explain individual differences in adaptation to a stressful situation or event using mediators such as self-efficacy. Results of this investigation suggest that high levels of self-efficacy among adolescents may serve as a buffer, allowing them to find ways to adapt to the psychological and physical stressors of their condition, while those with low self-efficacy tended to be more symptomatic. This is supported by previous findings where a transactional stress and coping model revealed that adjustment to SCD for adults was related to higher efficacy expectations suggesting that chronic illness is a stressor to which individuals can successfully adapt (Thompson, Gil, Abrams, & Phillips, 1992). Additional longitudinal studies are needed to truly determine if higher levels of self-efficacy lead to better adjustment or if successful adjustment to SCD leads to higher levels of self-efficacy, but initial work has been undertaken using an adult sample. The results of a one-year investigation revealed that baseline levels of self-efficacy along with temporal changes in self-efficacy were uniquely associated with changes in SCD symptomatology. Multiple regression models revealed that higher baseline self-efficacy was predictive of declines in pain severity and physical symptoms. In addition, increases in self-efficacy were associated with declines in symptomatology (Edwards, Telfair, Cecil, & Lenoci, 2001).

The highest grade completed in school by the adolescent was positively associated with self-reported symptoms. Adolescents with more education may be better able to identify their problems. Another reason for this association could be the age of onset of symptoms. It has been shown that SCD-related symptoms may first appear as early as the first few months or as late as after puberty (Hurtig & White, 1986). The association between the number of individuals in the household and symptoms is a novel finding for this adolescent sample that requires further investigation.

Several limitations of the present study should be noted. Participation was voluntary and adolescents with parents/guardians who were active in their treatment and who rarely missed appointments may have been more likely to be enrolled. Second, the cross-sectional design makes it impossible to examine the causal sequence. This problem is further compounded by the lack of longitudinal data from the parent study. Although data from the present investigation suggest that perceived efficacy plays a significant role in predicting adjustment to SCD, as was demonstrated in adults with SCD (Edwards et al., 2001), further study is needed. Third, participants were primarily urban-dwelling adolescents, throughout the United States. Future investigations may benefit from inclusion of individuals with more diverse backgrounds, such as those in rural areas. Finally, the present investigation relied upon participants' self-report. While this is true of many studies of this kind, a substantial literature exists concerning the myriad potential problems of self-report data (Brown & Moskovitz, 1998; Turk, 1994). Of particular concern herein are the issues of recall bias for retrospective symptoms reported and social desirability bias, which may have affected the nature or magnitude of the results. Moreover, recall of events over the preceding 12 months (e.g., physician and ER visits) is likely to be somewhat inaccurate. Future investigations of the SCSES with adolescents may benefit from direct measurement of social desirability bias, as well as from inclusion of multiple data sources (e.g., behavioral observations, report of family members, medical chart review, etc…).

The SCSES serves as one of the first psychometrically sound, population-based tools that can be used by clinicians and researchers as part of a quality-of-life (QOL) battery. Unlike standard measures of QOL, the

SCSES was not designed as a measure of participant well-being but serves as a screening instrument to identify adolescents who may be at risk for negative psychosocial and/or physical outcomes as a result of having SCD. Measuring and understanding the adolescent's confidence in their own ability to function in spite of their condition will allow clinicians and researchers to make predictions concerning the adolescent in critical areas such as adherence with prescribed regimens, appropriate levels of interaction with family and friends, school functioning, and personal/self health care. The tool can also serve as an adjunctive measure in a neuropsychological assessment of adolescents with SCD given its development and standardization on the population for which such an assessment is aimed and support from previous findings that show that low levels of self-efficacy on a disease-specific measure are related to an increased number of depressive symptoms in children and adolescents (Caplin, Austin, Dunn, Shen, & Perkins, 2002). This study was a first step in obtaining evidence that the promotion of efforts to bolster condition specific self-efficacy in adolescents may be a critical component in the planning of future interventions.

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Appendix A: Sickle Cell Self-Efficacy Scale:

The following questions ask about HOW SURE YOU ARE in dealing day-to-day with sickle cell disease. There are no right or wrong answers, we just want to know what you think. So for each question tell us **HOW SURE YOU ARE** by putting a check (✓) in the box that best tells us how you feel. **PLEASE ANSWER EVERY QUESTION**.

	NOT AT ALL SURE	NOT SURE	NEITHER	SURE	VERY SURE
A. **HOW SURE ARE YOU** THAT YOU CAN DO SOMETHING TO CUT DOWN ON MOST OF THE PAIN YOU HAVE WHEN HAVING A PAIN EPISODE?	☐	☐	☐	☐	☐
B. **HOW SURE ARE YOU** THAT YOU CAN KEEP DOING MOST OF THE THINGS YOU DO DAY-TO-DAY?	☐	☐	☐	☐	☐
C. **HOW SURE ARE YOU** THAT YOU CAN KEEP SICKLE CELL DISEASE PAIN FROM INTERFERING WITH YOUR SLEEP?	☐	☐	☐	☐	☐
D. **HOW SURE ARE YOU** THAT YOU CAN REDUCE YOUR SICKLE CELL DISEASE PAIN BY USING METHODS OTHER THAN TAKING EXTRA MEDICATION?	☐	☐	☐	☐	☐
E. **HOW SURE ARE YOU** THAT YOU CAN CONTROL HOW OFTEN OR WHEN YOU GET TIRED?	☐	☐	☐	☐	☐
F. **HOW SURE ARE YOU** THAT YOU CAN DO SOMETHING TO HELP YOURSELF FEEL BETTER IF YOUR ARE FEELING SAD OR BLUE?	☐	☐	☐	☐	☐
G. AS COMPARED WITH OTHER PEOPLE WITH SICKLE CELL DISEASE, **HOW SURE ARE YOU** THAT YOU CAN MANAGE YOUR LIFE FROM DAY-TO-DAY?	☐	☐	☐	☐	☐
H. **HOW SURE ARE YOU** THAT YOU CAN MANAGE YOUR SICKLE CELL DISEASE SYMPTOMS SO THAT YOU CAN DO THE THINGS YOU ENJOY DOING?	☐	☐	☐	☐	☐
I. **HOW SURE ARE YOU** THAT YOU CAN DEAL WITH THE FRUSTRATION OF HAVING SICKLE CELL DISEASE?	☐	☐	☐	☐	☐