Reliability and validity of a self-efficacy instrument specific to sickle cell disease

By: Robert Edwards, Joseph Telfair, Heather Cecil, Jennifer Lenoci

Edwards, R. R., Telfair, J., Cecil, H., and Lenoci, J., (2000). Reliability and validity of a Self-Efficacy Instrument Specific to Sickle Cell Disease. *Behaviour Research and Therapy* 38(2000): 951-963. DOI: 10.1016/S0005-7967(99)00140-0

Abstract:
The psychometric properties of a new, 9-item scale measuring disease-specific perceptions of self-efficacy were investigated in a community-based sample of adults (N = 83) with sickle cell disease (SCD). The Sickle Cell Self-Efficacy Scale (SCSES) was comprised of nine questions relating to participants' perceptions of their ability to function on a day-to-day basis and to manage SCD symptomatology (e.g. episodes of pain). The SCSES demonstrated good internal consistency, discriminant validity, and convergent and predictive validity, both with previously validated measures of related constructs as well as with reported SCD symptomatology. Overall, the instrument appears to be reliable and valid for assessing clients' self-efficacy for engaging successfully in day-to-day activities despite having SCD. Future investigators may wish to examine temporal and causal links between alterations in self-efficacy and changes in adjustment to sickle cell disease; the SCSES provides a psychometrically sound tool with which to investigate these phenomena.

Keywords: Sickle cell; Self-efficacy; Chronic illness; Instrument development; Psychometric properties

Article:
Sickle cell disease (SCD) is an inherited blood disorder affecting predominantly persons of African descent (Elander & Midence, 1996). Nationally, the incidence of SCD among African Americans is approximately 1 in every 400 live births; recent estimates of absolute numbers of SCD cases in the US range from 50-65,000 (Elander & Midence, 1996). Individuals with SCD are at risk for symptoms such as pain, stroke, anemia and major organ complications (Reed & Vichinsky, 1998). The most frequent intractable problem encountered by persons with SCD is painful tissue ischemia resulting from vaso-occlusion (Platt et al., 1991). Although SCD was previously characterized as a childhood disease (Platt, 1992), most adolescents with SCD now survive far into adulthood (Telfair, Myers & Drezner, 1994). Indeed, life expectancies for these individuals now approach those for the general population, with more than half surviving into their 60's (Platt et al., 1994). Thus, adult adjustment to SCD will likely be a growing health care concern in the coming decades. However, in most previous investigations of SCD impact, the focus has been almost exclusively on children and adolescents to the exclusion of adults (Telfair et al., 1994).

It is only in recent years that psychosocial factors relating to SCD adjustment have received rigorous study (Reece & Smith, 1997; Thompson, Gil, Abrams & Phillips, 1996). Emotional disturbances, social isolation, reductions in work and activity and frequent use of health care are more common in individuals with SCD than in individuals who do not suffer from a chronic illness (McCrae & Lumley, 1998; Reese et al., 1997; Thompson, Gustafson, Gil, Godfrey, & Murphy, 1998). In general, disease severity and related illness parameters tend to account for little of the variance in SCD adjustment (Gil, Abrams, Phillips & Keefe, 1989; Gil, Abrams, Phillips & Williams, 1992; Telfair, 1994; Thompson et al., 1996), suggesting that psychosocial variables may play a more influential role in determining adjustment to SCD (Telfair, 1994).

Collectively, previous research has tended to focus exclusively on the role of coping strategies in the prediction of children and adolescents' adjustment to SCD (Gil et al., 1989, 1992; Gil, Williams, Thompson

& Kinney, 1991). One variable potentially related to SCD adjustment which has received little attention is self-efficacy for coping with SCD. Self-efficacy, a component of social learning theory (Bandura, 1977a, 1977b), refers to personal judgments concerning one's capacity to perform specific actions which result in specific outcomes. In particular, self-efficacy focuses on individuals' convictions that they can exercise control over their motivations, behaviors and social environments. Typically, self-efficacy is conceptualized in a situation-specific manner rather than as a personality trait, indicating that efficacy beliefs may vary widely across environments and situations (Smith, 1989).

The construct of self-efficacy may be particularly important in predicting adjustment to chronic illness. The transactional stress and coping model (Thompson, Gil, Abrams & Phillips, 1992; Thompson, Gil, Burbach, Keith & Kinney, 1993) suggests that chronic illness is a stressor to which individuals gradually adapt. Adaptational processes such as development of efficacy beliefs may assist individuals in adjusting to symptoms of illness (e.g. periodic pain episodes). That is, individuals who believe that they have control over the symptomatology that they experience may cope more adaptively with their illness. Thus, high levels of self- efficacy in the presence of a chronic illness may act as a buffer for children, adolescents and adults (Patterson & Blum, 1996; Rutter, 1993).

Support for the potential utility of self-efficacy as a mediator of SCD coping is provided by research in the area of adjustment to chronic illness. Prior work has suggested that individuals' efficacy beliefs influence: the types of behaviors engaged in, the effort expended, the degree of behavioral persistence, the level of distress experienced and the cognitions associated with performed behaviors (Bandura, 1982; Dolce, 1987; Lin & Ward, 1996; Rutter, 1993), all of which affect adjustment to chronic illness (Thompson et al., 1996). Further, self-efficacy appears to play an important mediating role in the experience of chronically painful conditions such as: fibromyalgia (Buckelew, Murray, Hewett, Johnson & Huyser, 1995), arthritis (Barlow, Williams & Wright, 1996) and chronic low back pain (Lackner, Carosella & Feuerstein, 1996). A number of disease-specific efficacy measures have been developed and validated for such conditions as: diabetes (Grossman, Brink & Hauser, 1987), cystic fibrosis (Bartholemew, Parcel, Swank & Czyzewski, 1993), arthritis (Lorig, Chastain, Ung, Shoor & Holman, 1989), multiple sclerosis (Schwartz, Coulthard-Morris, Zeng & Retzlaff, 1996) and chronic obstructive pulmonary disease (Wigal, Creer & Kotses, 1991).

In summary, previous studies with diverse populations have demonstrated that self-efficacy bears an inverse relationship to such variables as pain behavior, pain severity, pain-coping strategies and pain-associated health-care utilization (Buescher et al., 1991; Kaplan, Wurtele & Gillis, 1996; Karoly & Ruehlmann, 1996; Weisenberg, 1998). Thus, one would anticipate self-efficacy to be of importance for SCD, a chronic, painful condition. To date, however, only one study has investigated the role of self-efficacy in psychosocial adjustment to SCD (Thompson et al., 1998). In this study, efficacy expectations were inversely associated with the degree of psychopathology in a sample of children with SCD. Currently, no published reports of the role of self-efficacy in adults' adjustment to SCD appear to exist.

In the present study, we investigated the psychometric properties of a disease-specific instrument assessing self-efficacy beliefs in adults with SCD. Responses to the 9 items comprising this instrument were used to assess individuals' confidence in their ability to manage SCD symptomatology and engage successfully in productive day-to-day activities. Globally, this instrument is based on the concept of `self-care agency' (Connelly, 1987; Gulick, 1986; Kearney & Fliescher, 1979), which incorporates individuals' perceptions of both their symptoms and their abilities to cope with or reduce those symptoms. This instrument is hereafter referred to as the Sickle Cell Self-Efficacy Scale (SCSES).

1. Method

1.1. Participants

Participants were 83 HbSS phenotype adult clients (46 female, 37 male) of a regional Sickle Cell Association in the Southeast United States. The majority (99%) of the sample reported their race as African-American; 1

subject identified herself as Asian. Participant ages ranged from 18 to 73 yr (M = 38.7; S.D. =12.8). Nearly half (47%) reported being employed in full- or part-time work; the majority of the remaining portion received Social Security Income benefits.

1.2. Procedure

Eligible participants were contacted by phone and informed of the nature of the study. The measures utilized in the present study comprised one portion of a full assessment survey battery; all measures were administered by phone in a 45 min interview. All telephone interviewers were research assistants trained by the second author.

All portions of the present research were approved by the University of North Carolina at Chapel Hill's Human Subjects Committee. The data presented in the present study constitute a single time point in the ongoing Sickle Cell Disease Association of the Piedmont longitudinal home health research project.

1.3. Measures

1.3.1. Self-efficacy

The Sickle Cell Self-Efficacy Scale (SCSES) is a 9-item scale developed specifically for this study to assess adults' 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'. As 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 scores were obtained by summing responses to all nine items, with higher scores indicating greater self-efficacy.

1.3.2. Self-esteem

Rosenberg's Self-Esteem Scale (SES) (Rosenberg, 1965) was utilized as an indication of global feelings of self-worth. Responses to each of the 10 Likert items range from `strongly disagree' to `strongly agree'. Total scores on the SES can range from 10 and 40, with higher scores representing greater levels of self-esteem. The SES has repeated demonstrated good psychometric properties among diverse samples, some of which include African-Americans (Blascovich & Tomaka, 1991; Demo, 1985).

1.3.3. Feelings of mastery

The 7-item Sense of Mastery Scale (SOM), developed by Pearlin and colleagues (Pearlin, Lieberman, Menaghan & Mullan, 1981), was used to assess respondents' general sense of life control and mastery. Scoring of the SOM is similar to that of the SES; higher scores indicate increasing perceptions of mastery. The SOM has been found to be psychometrically sound, demonstrating good reliability and convergent validity in diverse populations (Marshall & Lang, 1990; Walford-Kraemer & Light, 1984).

1.3.4. Locus of control

The Multidimensional Health Locus of Control Scale (MHLC) (Wallston, Wallston & DeVellis, 1978) assesses respondents' perceptions of the determinants of their health. The MHLC is an 18-item instrument assessing three dimensions of health-specific locus of control: internal health locus of control (IHLC) (the extent of perceived personal control over physical health), chance externality (CHLC) (the extent to which fate or chance is perceived to determine physical health) and powerful others externality (POHLC) (the extent to which external authorities determine physical health). Each subscale is comprised of 6 items, with response choices ranging from `strongly disagree' to `strongly agree'. Subscale scores range from 6 to 36, with higher total scores indicating greater internal, powerful others, or chance locus of control. The MHLC subscales have all demonstrated adequate internal consistency, test-retest reliability and convergent validity (Wallston & Wallston, 1983).

1.3.5. Sickle cell experience

Participants were queried about 2 aspects of adjustment to SCD: disease-specific symptomatology and health care utilization. Two variables were utilized as indices of SCD symptoms. First, participants rated the severity of their SCD-related pain in the past 30 days. Response choices ranged from 1 `no pain' to 10 `very severe pain.' Second, participants rated the frequency of 11 physical symptoms over the past 6 months: weakness, yellowing of skin or eyes, vomiting, nausea, pain, heart problems, gall stones, eye trouble, kidney problems, swelling of hands or feet, and shortness of breath. Ratings ranged from one `never or rarely (zero or one time)' to four `very often (six or more times)'; these ratings were then added to form a total physical symptom index (PSI). Cronbach's alpha for these 11 items was 0.79, suggesting an adequate level of internal consistency. These measures are similar to those utilized in previous studies (Gil et al., 1992; McRae & Lumley, 1998). Two separate variables were employed as indicators of health-care service utilization: number of emergency room (ER) visits in the past 12 months and number of physician visits in the past 12 months. Previous research with SCD patients has indicated that self-report of health care utilization is highly correlated with actual utilization as documented by medical record review: r = 0.68-0.76 (McRae & Lumley, 1998).

1.3.6. Demographics

The survey packet contained items measuring standard demographic information (i.e. gender, race, age, marital status and employment status).

1.3.7. Data analysis

Internal consistency of measures was estimated using Cronbach's alpha. Alpha values of.70 or greater generally indicate adequate internal consistency (Nunnally & Bernstein, 1994). Relationships between variables were assessed using Pearson product-moment correlation coefficients. Because a substantial number of analyses were performed, the level of statistical significance was set to $p < 0.01$ in order to reduce the likelihood of type I error. The significance of differences in the magnitude of correlation coefficients was assessed using the Z- transformation method of Edwards (1984).

2. Results

2.1. Descriptive data

Total scale scores for the entire sample, as well as by gender, are provided in Table 1. No gender differences were observed for any of these instruments.

2.2. Relationships with demographic variables

Pearson correlations between SCSES scores and demographic variables were computed. Collectively, SCSES scores were unrelated to the following variables: age, gender, marital status, employment status and socioeconomic status (all p's > 0.05).

2.3. Reliability

To determine internal consistency, Cronbach's alpha was computed for the SCSES as well as other utilized measures (Table 1). Alpha values of 0.70 or greater generally indicate adequate internal consistency (Nunnally & Bernstein, 1994). This analysis revealed adequate to good levels of internal consistency for each of the instruments. Cronbach's alpha for the SCSES was 0.89. Moreover, all item-total correlation coefficients for SCSES items exceeded 0.50 and no items adversely affected alpha values. That is, no items were identified whose deletion would elevate alpha for the total scale.

2.4. Convergent and predictive validity

Convergent and predictive validity was assessed with three sets of analyses in which the relationships of SCSES scores to related constructs, SCD symptoms and health care utilization were examined. First, we examined the intercorrelations between self-efficacy and the related constructs of self-esteem, sense of mastery and internal health locus of control (Table 2). As expected, all correlations between these measures (SES, SOM and IHLC) and SCSES scores were statistically significant positive correlations ($p < 0.01$).

Thus, greater SCSES total and subscale scores were associated with increased self-esteem, mastery and IHLC.

Predictive validity was assessed by computing correlations between SCSES scores and reported sickle cell pain severity in the previous 30 days as well as total SCD physical symptoms. Both of these variables were significantly negatively related to SCSES scores (see Table 2), indicating that higher self-efficacy was associated with decreased report of recent pain severity and lower reported levels of physical symptoms.

Table 1
Descriptive data for all scales (means with standard deviations in parentheses)[a]

Scale	Mean (S.D.)	Range	Alpha
SCSES	32.2 (7.0)	10–45	0.89
SES	40.2 (5.3)	23–48	0.85
SOM	21.3 (3.2)	13–28	0.77
IHLC	23.3 (5.0)	6–34	0.82
POHLC	24.4 (5.9)	10–36	0.73
CHLC	20.5 (5.2)	6–33	0.75

[a] SCSES = Sickle Cell Self-efficacy Scale; SES = Rosenberg Self-esteem Scale; SOM = Pearlin Sense of Mastery Scale; IHLC = Internal health locus of control subscale of the Multidimensional Health Locus of Control; POHLC = Powerful others subscale of the Multidimensional Health Locus of Control; CHLC = Chance subscale of the Multidimensional Health Locus of Control.

Table 2
Convergent and predictive validity of the SCSES: Pearson correlations with self-esteem, mastery, internal health locus of control, SCD symptomatology and health care utilization[a]

Measure	Correlation with SCSES	Significance
SES	0.39	$P < 0.01$
SOM	0.45	$P < 0.01$
IHLC	0.41	$P < 0.01$
Pain Severity	−0.30	$P < 0.01$
PSI	−0.44	$P < 0.01$
Physician Visits	−0.42	$P < 0.01$
ER Visits	−0.25	$P < 0.05$

[a] SCSES = Sickle Cell Self-Efficacy Scale; SES = Rosenberg Self-Esteem Scale; SOM = Pearlin Sense of Mastery Scale; IHLC = Internal Health Locus of Control subscale of the Multidimensional Health Locus of Control; Pain Severity = Reported severity of SCD pain in the past 30 days (0–10 scale); PSI = Physical Symptom Index (11 items); ER Visits = Number of visits to the emergency room in the past 12 months; Physician Visits = Number of visits to a physician in the past 12 months.

Finally, correlations between self-efficacy and reported health-care seeking behavior were assessed. The number of ER visits and the number of physician visits in the prior 12 months were utilized as measures of health-care seeking behavior. The correlation between the number of physician visits in the prior 12 months and SCSES scores was statistically significant in the expected (inverse) direction (Table 2). A similar, marginally significant ($p < 0.05$) relationship was noted between ER visits and SCSES scores.

2.5. Discriminant validity

To assess discriminant validity, we calculated Pearson correlation coefficients between SCSES scores and 2 subscales of the MHLOC, the chance (CHLC) and powerful others (POHLC) subscales. As predicted, no statistically significant correlations emerged between these subscales and SCSES scores (all p's > 0.1). Moreover, we tested the hypothesis that the magnitude of the correlation between the SCSES and the IHLC subscale of the MHLC ($r = 0.41$) was significantly larger than the magnitude of correlations between the

SCSES and the CHLC (r = -0.08) or POHLC (r = -0.14) subscales. The difference for the CHLC subscale was significant (Z = 2.3, $p < 0.01$), suggesting that the correlation between the SCSES and IHLC was larger than that between the SCSES and CHLC. A similar, marginally significant effect was noted for the POHLC subscale (Z = 1.9, $p < 0.05$).

3. Discussion

The present study evaluated the psychometric properties of a 9-item instrument assessing self-efficacy for managing sickle cell symptomatology and engaging productively in daily functional tasks. The SCSES is targeted for use in an adult SCD population. Overall, the SCSES appeared to exhibit good internal consistency, convergent and predictive validity, and discriminant validity. In the present investigation, adults with SCD who reported lower levels of self-efficacy tended to experience more frequent and severe pain and to seek greater access to health care than did those patients reporting relatively greater levels of self-efficacy. Thus, levels of SCD-specific efficacy beliefs related negatively to levels of SCD symptomatology. These findings are in agreement with previous investigations of self-efficacy beliefs in other chronic conditions: inverse relationships have been reported between efficacy beliefs and pain frequency (Karoly et al., 1996) and severity (Lin et al., 1996), health care utilization (Nicholas, Wilson & Goyen, 1992; O'Leary, 1985) and global adjustment (Patterson & Blum, 1996).

In addition, scores on the SCSES related positively to measures of self-esteem, mastery and internal locus of control. This finding supports previous research in which general measures of self-efficacy are positively correlated with self-esteem (Allgood-Merten & Stockard, 1991; Zimmerman, Sprecher, Langer & Holloway, 1995), mastery (Berry & West, 1993; Schunk & Hanson, 1985) and internal locus of control (Rokke, Absi, Lall & Oswald, 1991; Smith, 1989). However, the moderate magnitude of these correlations suggests that disease-specific efficacy beliefs do not overlap completely with individuals' general feelings of self-regard, mastery, or control. Thus, particular self-efficacy beliefs are likely to be unique additions to any model attempting to predict adjustment to chronic illness. This finding is in accordance with Bandura's conceptualization of self-efficacy as a situation-specific behavioral determinant, not a personality trait (Bandura, 1977a, 1977b).

Some evidence for discriminant validity of the SCSES was also obtained. In the present study, SCSES scores were uncorrelated with either the chance or powerful others subscales of the MHLC. Moreover, the magnitude of the correlation coefficient between the SCSES and IHLC was significantly greater than similar coefficients between the SCSES and either the CHLC or POHLC. Prior research has indicated that the IHLC subscale is not related to the CHLC or POHLC subscales (Robinson-Whelen & Storandt, 1992; Talbot, Nouwen & Gauthier, 1996; Wall, Hinrichsen & Pollack, 1989), suggesting that these latter variables should also be unrelated to SCSES scores. That is, since the constructs of self-efficacy and internal locus of control are conceptually (and empirically) related, one might anticipate the absence of a relationship between self-efficacy and constructs which are not related to internal locus of control.

Several limitations of the present study should be noted. First, participants were primarily middle-aged, urban-dwelling adults in the Southeastern US; future investigations may benefit from inclusion of individuals with more diverse backgrounds. Second, the present investigation relied upon participants' self-report. A substantial literature exists concerning the myriad potential problems of self-report data (Brown & Moskovitz, 1998; Turk, 1994). Of particular concerns herein are the issues of recall bias 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 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.). Third, we were unable to perform a factor analysis of the SCSES. Thus, it remains unclear whether SCD-specific self-efficacy beliefs are a uni- or multidimensional construct.

Overall, the SCSES demonstrated good reliability and validity and therefore appears suitable for use with adult SCD populations. Moreover, it appears to be the first available disease-specific efficacy measure utilized with a sickle cell population. This relatively brief instrument could be easily administered in a community health-care setting. Given the intimate ties between self-efficacy and behavior established in a number of studies across diverse populations, as well as the availability of interventions that have been demonstrated to enhance self-efficacy, identification of at-risk individuals low in self-efficacy may provide opportunities to reduce adverse SCD impact. Assessment of efficacy beliefs in this population might lead to interventions targeted toward those individuals who are at high risk for poor symptom management and decreased psychosocial adjustment as a consequence of low self-efficacy. Effective, relatively low-cost interventions such as psychoeducational groups, individual counseling, or group therapies (Smith, 1989) may facilitate increased efficacy beliefs and improved adjustment to SCD, thus increasing client and provider satisfaction.

Although we observed positive relationships between self-efficacy and SCD adjustment, adaptation to any chronic illness is a multidimensional construct with dynamically interacting facets. Self-efficacy beliefs constitute but one limited portion of this intricate whole. However, the results of the present study indicate that self-efficacy beliefs in a population of adults with SCD are measurable in a psychometrically sound manner. Furthermore, these data intimate that perceived efficacy may play a significant role in predicting adjustment to SCD. Such a conclusion awaits independent empirical verification, but the present study provides an adequate point of departure for such a program of research. Currently, follow-up longitudinal investigations at a community-based Sickle Cell Association are examining the temporal stability of the SCSES, the effects of a community-based psychoeducational intervention on SCSES scores and the feasibility of SCSES use in an adolescent population.

Acknowledgements
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, US department of human services grant MCJ9040. Thanks are expressed to the following individuals, without whose valuable assistance the present work would not have been possible: Kathy Norcott, Gladys Robinson, Marietto Douglas, Ernestine Bigelow and Maris Morris for project management and data gathering support. Special thanks to the study participants for volunteering their time to make this study possible. Finally, special thanks to Steven D. Pinkerton for his helpful comments on this manuscript.

References:

Allgood-Merten, B., & Stockard, J. (1991). Sex role identity and self-esteem: a comparison of children and adolescents. *Sex Roles*, 25, 129-139.

Bandura, A. (1977a). *Social learning theory*. Englewood Cliffs, NJ: Prentice-Hall.

Bandura, A. (1977b). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84, 191- 215.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 37, 122-147.

Barlow, J. H., Williams, B., & Wright, C. (1996). The generalized self-efficacy scale in people with arthritis. *Arthritis Care and Research*, 9, 189-196.

Bartholemew, L. K., Parcel, G. S., Swank, P. R., & Czyzewski, D. I. (1993). Measuring self-efficacy expectations for the self-management of cystic fibrosis. *Chest*, 103, 1524-1530.

Berry, J. M., & West, R. L. (1993). Cognitive self-efficacy in relation to personal mastery and goal setting across the life span. *International Journal of Behavioral Development*, 16, 351-379.

Blascovich, J., & Tomaka, J. (1991). Measures of self-esteem. In J. P. Robinson, P. R. Shaver, & L. S. Wrightsman, *Measures of personality and social psychological attitudes* (pp. 291-371). In *Measures of social psychological attitudes, Volume 1*. San Diego, CA: Academic Press.

Brown, K. W., & Moskovitz, D. S. (1998). It's a function of time: a review of the process approach to behavioral medicine research. *Annals of Behavioral Medicine*, 20, 109-117.

Buckelew, S. P., Murray, S. E., Hewett, J. E., Johnson, J., & Huyser, B. (1995). Self-efficacy, pain and physical activity among fibromyalgia subjects. *Arthritis Care and Research*, 8, 43-50.

Buescher, K. L., Johnston, J. A., Smarr, K. L., Buckelew, S. P., Anderson, S. K., & Walker, S. A. (1991). Relationship of self-efficacy to pain behavior. *Journal of Rheumatology*, 18, 968-972.

Connelly, C. E. (1987). Self-care and the chronically ill patient. Nursing Clinics of North America, 22, 621-629.

Demo, D. H. (1985). The measurement of self-esteem: refining our methods. *Journal of Personality and Social Psychology*, 48, 1490±1502.

Dolce, J. J. (1987). Self-efficacy and disability beliefs in behavioral treatment of pain. *Behavior Research and Therapy incorporating Behavioral Assessment*, 25, 289-299.

Edwards, A. L. (1984). *An introduction to linear regression and correlation*. New York: W.H. Freeman.

Elander, J., & Midence, K. (1996). A review of evidence about factors affecting quality of pain management in sickle cell disease. *Clinical Journal of Pain*, 12, 180-193.

Gil, K. M., Abrams, M. R., Phillips, G., & Keefe, F. J. (1989). Sickle cell disease pain: relation of coping strategies to adjustment. *Journal of Consulting and Clinical Psychology*, 57, 725-731.

Gil, K. M., Abrams, M. R., Phillips, G., & Williams, D. A. (1992). Sickle cell disease pain: 2. Predicting health care use and activity level at 9-month follow-up. *Journal of Consulting and Clinical Psychology*, 60, 267-273.

Gil, K. M., Williams, D. A., Thompson, R. J., & Kinney, T. (1991). Sickle cell disease in children and adolescents: the relation of child and parent pain coping strategies to adjustment. *Journal of Pediatric Psychology*, 16, 643- 663.

Grossman, H. Y., Brink, S., & Hauser, S. T. (1987). Self-efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care*, 10, 324-329.

Gulick, E. E. (1986). The self-assessment of health among the chronically ill. Topics in Clinical Nursing, 8, 74±82.

Kaplan, G. M., Wurtele, S. K., & Gillis, D. (1996). Maximal effort during functional capacity evaluation: an examination of psychological factors. *Archives of Physical and Medical Rehabilitation*, 77, 161-164.

Karoly, P., & Ruehlmann, L. (1996). Motivational implications of pain: chronicity, psychological distress and work goal construal in a national sample of adults. *Health Psychology*, 15, 383-390.

Kearney, B. J., & Fleisher, B. J. (1979). Development of an instrument to measure exercise of self-care agency. *Research in Nursing and Health*, 2, 25-34.

Lackner, J. M., Carosella, A. M., & Feuerstein, M. (1996). Pain expectancies, pain and functional self-efficacy expectancies as determinants of disability in patients with chronic low back disorders. *Journal of Consulting and Clinical Psychology*, 64, 212-220.

Lin, C. C., & Ward, S. E. (1996). Perceived self-efficacy and outcome expectancies in coping with chronic low back pain. *Research in Nursing and Health*, 19, 299-310.

Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis and Rheumatism*, 32, 37-44.

Marshall, G. N., & Lang, E. L. (1990). Optimism, self-mastery and symptoms of depression in women professionals. *Journal of Personality and Social Psychology*, 59, 132-139.

McCrae, J., & Lumley, M. (1998). Health status in sickle cell disease: examining the roles of pain coping strategies, somatic awareness and negative affectivity. *Journal of Behavioral Medicine*, 21, 35-55.

Nicholas, M. K., Wilson, P. H., & Goyen, J. (1992). Comparison of cognitive-behavioral group treatment and an alternative non-psychological treatment for chronic low back pain. *Pain*, 48, 339-347.

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York: McGraw-Hill.

O'Leary, A. (1985). Self-efficacy and health. *Behavioral Research and Therapy incorporating Behavioral Assessment*, 23, 437-451.

Patterson, J., & Blum, R. W. (1996). Risk and resilience among children and youth with disabilities. *Archives of Pediatric and Adolescent Medicine*, 150, 692-698.

Pearlin, L., Lieberman, M., Menaghan, E., & Mullan, J. (1981). The stress process. *Journal of Health and Social Behavior*, 22, 337-356.

Platt, O. S. (1992). *The natural history of sickle cell disease: life expectancy.* Paper presented at the Bone Marrow Transplantation for Hemoglobinopathies Workshop, May 1992, Bethesda, MD.

Platt, O. S., Brambilla, D. J., Rosse, W. F., Milner, P. F., Castro, O., Steinberg, M. H., & Klug, P. P. (1994). Mortality in sickle cell disease: life expectancy and risk factors for early death. *New England Journal of Medicine*, 330, 1639-1644.

Platt, O. S., Thorington, B. D., Brambilla, D. J., Milner, P. F., Rosse, W. F., Vichinsky, E., & Kinney, T. R. (1991). Pain in sickle cell disease: rates and risk factors. *New England Journal of Medicine*, 325, 11-16.

Reed, W., & Vichinsky, E. P. (1998). New considerations in the treatment of sickle cell disease. *Annual Review of Medicine*, 49, 461-474.

Reece, F. L., & Smith, W. R. (1997). Psychosocial determinants of health care utilization in sickle cell disease patients. *Annals of Behavioral Medicine*, 19, 171-178.

Robinson-Whelen, S., & Storandt, M. (1992). Factorial structure of two health belief measures among older adults. *Psychology and Aging*, 7, 209-213.

Rokke, P. D., Absi, M. A., Lall, R., & Oswald, K. (1991). When does a choice of coping strategies help? The interaction of choice and locus of control. *Journal of Behavioral medicine*, 14, 491-504.

Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press.
Rutter, M. (1993). Resilience: Some conceptual considerations. *Journal of Adolescent Health*, 14, 626-631.

Schunk, D. H., & Hanson, A. R. (1985). Peer models: influence on children's self-efficacy and achievement. *Journal of Educational Psychology*, 77, 313-322.

Schwartz, C. E., Coulthard-Morris, L., Zeng, Q., & Retzlaff, P. (1996). Measuring self-efficacy in people with multiple sclerosis: a validation study. *Archives of Physical and Medical Rehabilitation*, 77, 394-398.

Smith, R. E. (1989). Effects of coping skills training on generalized self-efficacy and locus of control. *Journal of Personality and Social Psychology*, 56, 228-233.

Talbot, F., Nouwen, A., & Gauthier, J. (1996). Is health locus of control a 3-factor or a 2-factor construct? *Journal of Clinical Psychology*, 52, 558-568.

Telfair, J. (1994). Factors in the long-term adjustment of children and adolescents with sickle cell disease: conceptualization and review of the literature. *Journal of Health and Social Policy*, 5, 69-96.

Telfair, J., Myers, J., & Drezner, S. (1994). Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult and parent perspectives. *Journal of Adolescent Health*, 15, 558-565.

Thompson, R., Gil, K., Abrams, M., & Phillips, G. (1992). Stress, coping and psychological adjustment of adults with sickle cell disease. *Journal of Consulting and Clinical Psychology*, 60, 433-440.

Thompson, R., Gil, K., Abrams, M., & Phillips, G. (1996). Psychological adjustment of adults with sickle cell anemia: Stability over 20 months, correlates and predictors. *Journal of Clinical Psychology*, 52, 253-261.

Thompson, R., Gil, K., Burbach, D., Keith, B., & Kinney, T. (1993). Role of child and maternal processes in the psychological adjustment of children with sickle cell disease. *Journal of Consulting and Clinical Psychology*, 61, 468-474.

Thompson, R., Gustafson, K., Gil, K., Godfrey, J., & Murphy, L. (1998). Illness specific patterns of psychological adjustment and cognitive adaptational processes in children with cystic fibrosis and sickle cell disease. *Journal of Clinical Psychology*, 54, 121-128.

Turk, D. C. (1994). Potentials of process measurement: motion picture versus snapshots. *Annals of Behavioral Medicine*, 16,198.

Walford-Kraemer, P., & Light, H. K. (1984). Depression and mastery in women: differences according to personal characteristics. *Psychological Reports*, 54, 710.

Wall, R. E., Hinrichsen, G. A., & Pollack, S. (1989). Psychometric characteristics of the multidimensional health locus of control scales among psychiatric patients. *Journal of Clinical Psychology*, 45, 94-98.

Wallston, K. A., & Wallston, B. S. (1983). Who is responsible for your health? The construct of health locus of control. In G. Saunders, & J. Suls, *Social psychology of health and illness* (pp. 77-95). Hillsdale, NJ: Erlbaum.

Wallston, K. A., Wallston, B. S., & DeVellis, R. (1978). Development of the Multidimensional Health Locus of Control (MHLC) scale. *Health Education Monographs*, 6, 161-171.

Weisenberg, M. (1998). Cognitive aspects of pain and pain control. *International Journal of Clinical and Experimental hypnosis*, 116, 44-61.

Wigal, J. K., Creer, T. L., & Kotses, H. (1991). The COPD self-efficacy scale. *Chest*, 99, 1193-1196.

Zimmerman, R. S., Sprecher, S., Langer, L. M., & Holloway, C. D. (1995). Adolescents' perceived ability to say `no' to unwanted sex. *Journal of Adolescent Research*, 10, 383-399.

Appendix A

The 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.

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