5-28-2009

Pain, Quality of Life, and Coping in Pediatric Sickle Cell Disease

Crystal Marie Stack Lim
Georgia State University

PAIN, QUALITY OF LIFE, AND COPING IN PEDIATRIC SICKLE CELL DISEASE

by

CRYSTAL MARIE STACK LIM

Under the Direction of Lindsey L. Cohen, Ph.D.

ABSTRACT

Introduction: Sickle cell disease (SCD) affects predominately African Americans and is one of the most prevalent diseases in the United States (Schecter, 1999). Research has not sufficiently examined whether pain associated with SCD impacts quality of life or whether coping impacts this relation. The purpose of this study was to examine the relation between pain and quality of life in children with SCD and to determine whether coping moderates the relation. A secondary aim was to examine associations between age and pain, quality of life, and coping. A final exploratory aim was to examine the relation between racial identity and study variables. *Method:* 104 children (M = 12.93 years, SD = 3.17 years) with SCD and their parents participated during a regularly scheduled SCD-related medical visit. Parents completed a demographic form. Children completed the Pediatric Pain Questionnaire (PPQ), the Pain Coping Questionnaire (PCQ), the Pediatric Quality of Life Inventory (PedsQL), Sickle Cell Disease Quality of Life (SCD-QoL), and the Multidimensional Inventory of Black Identity (MIBI).

Results: After controlling for site and gender, regression analyses revealed that pain ($\beta = -0.37$) and emotion-focused avoidance coping ($\beta = -0.39$) were significant predictors of overall generic quality of life (PedsQL Total Score), *total* $R^2 = 0.44$, $F(5, 93) = 13.88$, $p < 0.001$. There was no significant pain x coping interactions found for overall generic quality of life. Child age was not associated with study variables. Exploratory analyses revealed the MIBI Centrality Scale was associated with PCQ Approach Coping, $r(80) = -0.24$, $p < 0.05$, and the MIBI Regard Scale was correlated with PCQ Problem-Focused Avoidance Coping, $r(84) = 0.30$, $p < 0.01$.

Discussion: This study found that pain and emotion-focused avoidance coping were inversely associated with quality of life in children with SCD. Coping was not found to moderate the relation between pain and overall quality of life. The associations between racial identity and coping demonstrate the importance of further examining cultural factors in children with SCD. In addition, there continues to be a need for future research to focus on the psychosocial functioning of children with SCD.

INDEX WORDS: Sickle cell disease, Children, Pain, Quality of life, Coping, Racial identity

PAIN, QUALITY OF LIFE, AND COPING IN PEDIATRIC SICKLE CELL DISEASE

by

CRYSTAL MARIE STACK LIM

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2009

PAIN, QUALITY OF LIFE, AND COPING IN PEDIATRIC SICKLE CELL DISEASE

by

CRYSTAL MARIE STACK LIM

Committee Chair: Lindsey L. Cohen, Ph.D.

Committee: Lisa Armistead, Ph.D.
Leslie L. Jackson, Ph.D.
Erin McClure Tone, Ph.D.

Electronic Version Approved:

Office of Graduate Studies
College of Arts and Sciences
Georgia State University
August 2009

I would like to dedicate this work to children with sickle cell disease and their families, whose participation in and support of this research would not be possible. Their courage and strength is an inspiration to us all.

ACKNOWLEDGEMENTS

First, I would like to thank my mentor, Lindsey L. Cohen, Ph.D., for his endless dedication, support, and assistance throughout the years. Without his patience and encouragement this project and manuscript would not have been possible. I would also like to thank my committee members, Lisa Armistead, Ph.D., Leslie Jackson, Ph.D., and Erin McClure Tone, Ph.D. for their thoughtful suggestions and comments. In addition, I would like to thank the doctors and nurses at Children's Healthcare of Atlanta and the Comprehensive Sickle Cell Disease Center for their collaboration on this project. I would also like to express my gratitude to the research assistants who helped with data collection and data entry. Specifically, I would like to thank Josie Welkom, Chloe Peacock, Niusha Ghazban, Katherine Rhodes, and Diane Sykes for their assistance and dedication to this project.

Finally, I would like to thank my husband, Kek "Kevin" Lim, for his endless amount of unwavering encouragement and support. I would also like to thank our immediate and extended family for providing me with the foundation to accomplish my dreams, as well as for their tireless support and dedication. Thank you also to all of my colleagues and friends at GSU and UF, whose advice and support has been invaluable during this journey.

This project was supported by Grant Number 1F31HL091728 from the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) through a pre-doctoral NRSA fellowship to Crystal S. Lim, M.A. The content is solely the responsibility of the author and does not necessarily represent the official views of the NHLBI or the NIH. I wish to thank the NHLBI and NIH for the financial support to further my research and clinical training and to conduct this project under the guidance of Lindsey L. Cohen, Ph.D.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Sickle cell disease (SCD) is one of the most common genetic diseases in the United States (Schecter, 1999), primarily found in people of African descent. SCD affects approximately 1 in 400 African Americans (Brown, Mulhern, & Simonian, 2002), and more than 70,000 children and adults are living with the disease in the United States (Sickle Cell Disease Association of America [SCDAA], 2005). Currently, about 1,000 infants born in the United States are diagnosed with SCD each year (SCDAA, 2005). Despite the high prevalence of SCD, research with this population is relatively sparse compared with other chronic pediatric health conditions (Lemanek, Ranalli, Green, Biega, & Lupia, 2003).

SCD is a group of genetic disorders that is characterized by the presence of abnormal hemoglobin, specifically the protein hemoglobin S, in the red blood cells (Thompson & Gustafson, 1996). The most common types of SCD are sickle cell anemia (SS), sickle-hemoglobin C disease (SC), sickle beta-plus thalassemia, and sickle beta-zero thalassemia (SCDAA, 2005). The presence of abnormal hemoglobin S results in the irregular synthesis of hemoglobin, which causes red blood cells to become rigid and crescent shaped (i.e., sickled). When large numbers of sickled red blood cells collect, they hinder blood flow, which results in vaso-occlusive pain episodes. In addition to pain episodes, decreased oxygenation and blood flow are associated with pulmonary and cardiac complications; strokes; infection; skeletal, growth, and puberty complications; and liver and kidney dysfunction. However, for pediatric

patients with SCD, the most common and debilitating symptom reported by children and their parents is pain (Lemanek et al., 2003).

Pain

Pain associated with SCD is considered both acute and chronic. Vaso-occlusive acute pain episodes occur in children with SCD about five to seven times a year and may last from one to three days (Lemanek et al., 2003). These pain episodes are relatively unpredictable and vary in frequency and severity (Thompson & Gustafson, 1996). Treatment of acute pain episodes most often occurs at the patient's home but may be severe enough to require hospitalization (Shapiro et al., 1995). The locations of acute pain episodes are also variable, although past research has indicated that the arms, legs, abdomen, chest, and back are the most common sites of pain reported by children with SCD and their parents (Graumlich et al., 2001; Lemanek et al., 2003; Schecter, 1999). Pain associated with SCD is described by children as aching, tiring, and uncomfortable (Walco & Dampier, 1990). Vaso-occlusive episodes are thought to be triggered by various environmental and psychological states, such as high altitudes, extreme temperatures, infection, dehydration, stress, and fatigue (Schecter, 1999). Painful episodes experienced by children with SCD often interfere with academic functioning, such as attending school and completing homework; social activities, such as participating in activities with family members and peers; and the quality and quantity of sleep (Gil et al., 2000; Shapiro et al., 1995).

Besides acute pain episodes, SCD is also associated with chronic pain. Chronic pain due to SCD is more common in adults than in children and more common in adolescents than in young children (Schecter, 1999); however, chronic pain in pediatric SCD has only been recently discussed on a limited basis. Aseptic necrosis, or bone death due to poor blood oxygenation, is thought to cause chronic pain in limbs and joints (Ballas, 1998; Schecter, 1999). In addition,

shrinking of the vertebrae is thought to be the source of chronic back pain in children with SCD. Another source of chronic pain associated with the disease is poor circulation, which can lead to leg ulcers. As chronic pain increases in frequency and severity, a cycle of inadequate coping skills, poor relationships, and worsening pain may develop in children with SCD (Shapiro, 1993). Thus, there is a need for researchers to better understand the influence of acute and chronic pain on the health and functioning of children with SCD, as well as to identify possible correlates and predictors of health and functioning (Palermo, Schwartz, Drotar, & McGowan, 2002).

Developmental issues. Understanding how developmental factors interact with pain in children with SCD is important. In healthy children, there is evidence to suggest that symptoms of recurrent pain increase as children get older (Petersen, Brulin, & Bergstrom, 2006). Mechanisms through which this may occur could be related to increased exposure and sensitization to painful experiences or a decreasing ability to manage pain due to a variety of developmental factors. However, little is known about how developmental factors may relate to acute and chronic pain in children with chronic medical conditions, such as SCD.

Given that SCD is a progressive chronic illness, it is likely that children with SCD experience an increase in acute and chronic pain symptoms as they progress through childhood and adolescence. However, there is limited empirical information about how age is related to acute and chronic pain in this population. Therefore, there is a need for researchers to examine how acute and chronic pain is experienced across developmental stages.

Quality of Life

Significant advances in the diagnosis and treatment of SCD have led to increases in the life span of patients. Compared to the early 1970s, when median life expectancy for patients with

SCD was about 14 years of age, life expectancy in the 1990s was about 45 years of age (Platt et al., 1994). Much of the increase in life expectancy can be attributed to advances in medical treatments for SCD (Eiser & Morse, 2001). Such increases in life expectancy and the development of new treatments have prompted researchers to focus on ways to measure and improve the quality of life of patients with SCD.

Quality of life is important to measure in children with SCD for three main reasons. First, it can be used to describe the health profile and functional status of children living with the disease (Palermo et al., 2002). There is a lack of descriptive studies in the literature about quality of life in children and adults with SCD, as well the effects of pain on patients with SCD (Shapiro, 1993). Thus, a study on quality of life in this population could add important information about the impact of the illness. Second, information about this construct can be helpful when evaluating the effects of new medical procedures (i.e., transfusion therapy, bone marrow transplants) or the impact of new medications on the daily functioning of children with SCD (Palermo et al., 2002; Stegenga, Ward-Smith, Hinds, Routhieaux, & Woods, 2004). For example, physicians may prescribe one medication over another due to the impact of potential side effects on a pediatric patient's quality of life. Third, information about quality of life can be utilized by physicians and psychologists to evaluate the needs of children with SCD and their families. Interventions can then be implemented to target areas of functioning where there is decreased quality of life (Palermo et al., 2002). Despite the importance of assessing quality of life in patients with SCD, there is a paucity of research examining quality of life in children with SCD.

Quality of life has been widely accepted as a multi-dimensional, patient-centered construct that includes several domains, such as physical functioning and symptoms,

psychological and emotional states, social functioning, the performance of daily activities, and disease-related symptoms (Coons & Kaplan, 1992; Panepinto, O'Mahar, DeBaun, Loberiza, & Scott, 2005; Quittner, 1998). Quality of life in adults and children with SCD has been previously examined, although the amount of work in this area is limited.

Qualitative work with adolescents and adults with SCD provides information about the disease's impact on areas of quality of life. Thomas and Taylor (2002) conducted focus groups with patients with SCD ranging in age from 15 to 35. All patients who attended the focus groups (n = 17) identified six areas where they felt SCD impacted their quality of life. These areas included: growing up with SCD, education, the recurrent nature of the disease, employment, relationships, and hospitalization.

Stegenga et al. (2004) also qualitatively examined quality of life in 10 children, ages 6 to 12, with SCD who were receiving transfusion therapy for stroke. Transfusion therapy has been shown to reduce the amount of HbS in the blood, which improves blood flow and reduces the risk of additional strokes. However, transfusions are rigorous and time intensive for children and their families (Stegenga et al., 2004). Results of the study revealed five themes that emerged as concerns across participants. These included pain (physical and psychological), school issues (i.e., attendance and being treated differently by teachers and peers), disease knowledge, transfusion therapy, and having a stroke. However, it is important to note that children in the study did not discriminate between quality of life related to transfusion therapy and quality of life related to the impact of having SCD. In addition, a small sample size with a limited age range was utilized, so these findings may not be applicable to older children, those who have not experienced a stroke, or those who have not received transfusion therapy. In addition to these

qualitative studies, some researchers have used quantitative quality of life measures to examine the construct in adults and children with the SCD.

Quality of life has traditionally been measured in two ways: a) generic measures, and b) disease-specific measures. These measures are completed by the patient, or by a proxy respondent (e.g., parent) in the case of younger children. The advantages and disadvantages of these types of quality of life measure will be discussed.

Generic measures. Generic quality of life measures, or health profiles, are instruments designed for application across a wide range of diseases, necessitating items that are general and applicable to a variety of diseases. Examples of generic measures used with adolescent and adult SCD populations include the Short-Form Health Survey (SF-36) (Ware & Sherbourne, 1992), the Child Health Questionnaire (CHQ) (Landgraf, Abetz, & Ware, 1996), and the Pediatric Quality of Life Inventory (PedsQL) (Varni, Seid, & Kurtin, 2001). The benefits of using generic quality of life instruments include their assessment of multiple domains of functioning and their ability to compare quality of life scores across diseases (Quittner, Davis, & Modi, 2003).

Some research examining quality of life in adults with SCD has utilized generic measures to examine differences between patients with SCD and healthy samples. In the United Kingdom, Anie, Steptoe, and Bevan (2002) found that adults with SCD reported significantly poorer quality of life when compared to the general population on all subscales on the SF-36. However, it is not clear what the racial or ethnic make-up was of the healthy comparison sample. It is possible that some factors resulting in poorer quality of life in the SCD sample could be the result of potential cultural or socioeconomic differences that were not accounted for.

A more recent study conducted in the United States by McClish et al. (2005) found that patients with SCD between the ages of 16 and 64 had significantly poorer quality of life across

all domains of the SF-36 when compared to national norms for healthy adults, with the exception of the mental health subscale, which assesses symptoms of anxiety and depression. However, the racial and socioeconomic characteristics of the comparison group are not clear. Taken together, past quantitative and qualitative studies demonstrate that in children and adults, SCD has a significant impact on quality of life.

One study by Palermo et al. (2002) compared quality of life in children, ages 5 to 18, with SCD to the quality of life of healthy controls on the CHQ. Results from this study revealed that children with SCD have poorer physical, psychological, and social functioning compared to healthy African American children. In addition, this study assessed SCD related complications and found that the number of disease-related complications was associated with decreased quality of life. To measure disease complications, a review of the patient's medical chart was utilized over a two year period. Given that children with SCD are most often treated at home for painful episodes (Conner-Warren, 1996; Shapiro et al., 1995), the generalizability of these findings are limited to more severe disease complications (e.g., hospitalizations, stroke). Examining these relations in different SCD-related complications, such as vaso-occlusive acute pain episodes and chronic pain, is warranted.

Another study (Barakat, Lutz, Nicolaou, & Lash, 2005) examined quality of life in children, newborn to 11 years of age, with SCD hospitalized for pain or fever by utilizing the Miami Pediatric Quality of Life Questionnaire (MPQOL). When compared to a clinic sample of children with leukemia, children with SCD had significantly lower total quality of life, social competence, and self-competence. However, they had significantly higher emotional stability. This study also calls into question the use of the comparison group who likely differed from children with SCD on racial and socioeconomic characteristics. In addition, both the Palermo et

al. (2002) and Barakat et al. (2005) studies utilized parent-proxy reports of quality of life. Research with SCD and other pediatric populations suggest that children and parents offer unique perspectives about the impact chronic illnesses may have on quality of life (Eiser & Morse, 2001; Panepinto et al., 2005). For example, Panepinto et al. (2005) found that parents of children with SCD rated their child's quality of life lower in most domains examined (with the exception of mental health and family activities) on the CHQ when compared to children's report. Thus, child report of quality of life offers unique information about their every day functioning and continuing to examine it in children with SCD is needed.

Generic quality of life measures have been criticized for their inability to assess relevant domains of functioning for specific diseases. For example, a generic measure such as the SF-36 does not assess specific symptoms associated with SCD, such as disease-related pain. In addition, generic measures also tend to be less sensitive to small, but meaningful changes that occur as a result of clinical interventions (Juniper et al., 1996). Finally, most generic measures have not been validated with specific disease populations, but instead have been normed primarily on healthy populations, limiting their reliability and validity for use in chronic disease populations (Abbott, Webb, & Dodd, 1997; Quittner et al., 2003). To reduce these problems and to provide more sensitive, comprehensive evaluations of quality of life, researchers have recently developed disease-specific measures that include core quality of life dimensions (e.g., physical functioning, social functioning), as well as disease-specific dimensions (e.g., pain).

Disease-specific measures. Over the past decade, disease-specific measures have been developed in order to detect and quantify changes in quality of life in patients with particular diseases. For example, disease-specific measures have been developed for children with diabetes (Diabetes Quality of Life for Youths; Ingersoll & Marero, 1991) and asthma (Paediatric Asthma

Quality of Life Questionnaire; Juniper et al., 1996). The advantages of using disease-specific quality of life measures include the information they provide about specific domains of functioning and their greater sensitivity to the effects of interventions for target populations (Juniper et al., 1996). The major disadvantage of using disease-specific measures is that they do not allow for comparisons across different diseases (Quittner et al., 2003). Currently, no disease-specific quality of life measure has been developed for adults or children with SCD. In the current study, both a generic and a new disease-specific measure were utilized to evaluate quality of life in children with SCD.

Developmental issues. When examining quality of life in children it is also important for researchers to recognize that development may play an important role. Given the positive relation between age and cognitive ability, it is possible that a similar relation might exist between age and perceptions of quality of life (Annett, 2001). Specifically, it is thought that due to their stable, self-focused cognitions younger children may not realize that their health may change over time, which may lead them to misperceive the cause of their illness (Quittner et al., 2003). Thus, these cognitions and misperceptions may impact their report of their own quality of life. For example, due to egocentricism younger children may think that their physical limitations are due to something they did wrong while older children may perceive health related limitations due to their medical condition, as well as compare their functioning to that of other children.

In children with SCD, there is some evidence to suggest that older age is related to decreased quality of life. Specifically, Palermo et al. (2002) found that age was inversely related to quality of life on the physical functioning domain of the CHQ; however this result was not found on the psychosocial functioning domain and the study relied on a parent proxy report of quality of life. It should be noted that this is the only study to date that has specifically examined

the impact of age on children's report of quality of life in SCD. Clearly there is a need to better understand how children of different ages with SCD perceive their quality of life.

Pain and Quality of Life

Although pain and quality of life have been studied separately in patients with SCD, only two studies have examined both of these constructs in SCD. Anie, Steptoe, and Bevan (2002) found that higher pain was significantly related to four areas of quality of life in adult patients with SCD: poorer physical functioning, greater role limitations, lower social functioning, and more negative health perceptions. A study conducted by Fuggle, Shand, Gill, and Davies (1996) found that pain impacted quality of life in children with SCD more than it did in control children. In this study quality of life was measured via four questions related to an inability to perform everyday activities (e.g., did not go to school, school work not completed, missed sports, and missed favorite activities). This measure did not assess physical, social, or emotional functioning. Thus, this measure is not consistent with quality of life being defined as a multidimensional construct. Whether these findings apply to other areas of quality of life in children with SCD is unclear. Given that pain only accounts for a portion of the variance in quality of life and that pain can be challenging to treat in SCD, it is important to study factors that might influence the relation between pain and quality of life.

Given the paucity of research on pain and quality of life and the lack of examination of moderators of this relation in pediatric SCD, studies of pain and quality of life in children *without* SCD might shed light on what moderators may be important to consider. Parental factors, such as parenting stress (Guntlett-Gilbert & Eccelston, 2007), parental response to pain (Peterson & Palermo, 2004), and parental attention to pain (Van Slyke & Walker, 2006) have been found to impact pain and functioning in children. Despite the importance of parents,

parental factors do not account for all of the variance in predicting children's functioning. In addition, there is a need to study individual child factors in order to create and implement child-focused interventions to improve quality of life in pediatric patients experiencing chronic pain. Some studies have focused on emotional symptoms and found that depression impacts both pain and every day functioning in children with chronic pain (Claar & Walker, 2006; Guntlett-Gilbert & Eccelston, 2007). Additional studies have found that coping impacts functioning (Kashikar-Zuck et al., 2002); however, there is a need for researchers to continue to examine coping in children with chronic illnesses and there are few studies that focus on coping in children with SCD.

Coping

One concept that may be important to consider when examining pain and quality of life in children with SCD is coping. Coping is defined by Lazarus and Folkman (1984) as cognitive and behavioral efforts that constantly change in order to manage external and internal demands that are taxing or exceeding available resources. In addition, Compas et al. (2001) define coping as conscious, purposeful efforts to regulate emotion, cognition, behavior, physiology, and environment in response to stress. Coping has been linked to health status and is viewed as a central factor related to the well being of children with chronic illnesses (Compas, Worsham, & Ey, 1992). Folkman, Lazarus, Gruen, and DeLongis (1986) described three ways in which coping may influence health status. First, coping may influence the frequency, intensity, and pattern of physiological responses, such as neural firing that result from experiencing pain. Second, coping can affect health when it involves excessive use of dangerous substances or participation in dangerous situations. Third, certain forms of coping can impede adaptive health or illness-related behavior. In addition, studying coping in children who experience pain, such as

in SCD, is important because how children cope likely influences how they cope and adjust to pain as adults (Gil, Williams, Thompson, & Kinney, 1991). For these reasons, examining coping in children with SCD is warranted.

A commonly used measure to examine coping in adults and children with SCD is the Coping Strategies Questionnaire for Sickle Cell Disease (CSQ-SCD), developed by Gil and colleagues (Gil, Abrams, Phillips, & Keefe, 1989; Gil et al., 1997; Gil et al., 1991). The measure has demonstrated good internal consistency in adults and children (Gil et al., 1989; Gil et al., 1991) and consists of three factors: coping attempts, negative thinking, and passive adherence. Coping attempts refers to coping with pain actively by utilizing cognitive and behavioral strategies, such as distraction and increased activity (Anie, 2005). Negative thinking is related to engaging in negative thinking patterns, such as catastrophizing, fear and anger, and isolation. Passive adherence refers to utilizing coping strategies recommended by health care professionals to reduce pain, such as rest and fluid intake (Anie, 2005).

In one of the first studies of coping in pediatric SCD, Gil et al. (1991) found that some coping strategies children and adolescents engage in are related to psychosocial and functional impairment. Specifically, children using more passive adherence strategies, such as rest and drinking fluids, had more emergency room visits and less activity while in pain, whereas children high on coping attempts, such as distraction and increased activity, had less frequent emergency room visits and were more active during painful events. In addition, children with high levels of negative thinking, such as fear and anxiety, were found to be less active and more psychologically distressed. However, in this study parents provided ratings of child pain but children reported on the coping strategies they utilize. It is possible that different results may have been discovered if children provided their own pain ratings. In fact, Barakat, Simon,

Schwartz, and Radcliffe (2008) found that pain ratings by adolescents with SCD and their parents were only moderately consistent. This finding indicates the importance of assessing coping and pain from the child's perspective in pediatric research.

Another study examined coping strategies in 8- to 17-year-old children with SCD during a laboratory pain task (e.g., cold pressor task; Gil et al., 1997). This study found that children who reported the use of more cognitive and behavioral pain coping strategies reported lower pain levels than those who reported the use of fewer coping strategies. However, pain in laboratory tasks is predictable, whereas acute pain associated with SCD is relatively unpredictable. In addition, the impact of laboratory pain and pain associated with a chronic illness are qualitatively and quantitatively different. Pain that is the result of a chronic illness has the potential to disrupt a child's lifestyle (e.g., not attending school) and may cause emotional distress for the child and their family which may impact pain coping strategies.

An additional study examining coping in children with SCD was conducted in the United Kingdom. Anie, Steptoe, Ball, Dick, and Samlling (2002) found that child report of passive adherence coping strategies was associated with more intense pain, which was reported by parents. However, it is unknown whether this relation would have been found if child report of pain was included. There is a need for future coping research to evaluate pain and coping from the perspective of children with the disease.

The studies examining coping in children with SCD have utilized mostly the CSQ-SCD. However, there are some limitations to using the CSQ-SCD. One is that the measure is time intensive. The measure consists of 80 items, which may not be practical for use in clinical settings, such as during regularly scheduled SCD-related medical visits. Second, the CSQ was a measure originally created for use with adults experiencing pain. Thus, some of the items may

not be developmentally appropriate for children. Utilizing coping measures with fewer items and items that are developmentally appropriate for children is warranted.

A third drawback to the CSQ-SCD is that it does not tap common coping constructs discussed and examined in the pediatric psychology literature, such as problem- and emotion-focused coping (Folkman et al., 1986; Lazarus & Folkman, 1984) and approach and avoidance coping (Bernard, Cohen, McClellan, & MacLaren, 2004; Rudolph, Dennig, & Weisz, 1995). Lazarus and Folkman (1984) posited that coping consists of two main types: problem-focused and emotion-focused. Problem-focused coping refers to efforts made to change some aspect of the situation by eliminating or altering it. Emotion-focused coping is described as strategies that are used to regulate the negative emotions associated with the situation. Another common dimension of coping is approach and avoidance. Approach coping refers to efforts to focus on or confront a stressful event (e.g., vaso-occlusive SCD pain episode), whereas avoidance coping refers to attempts to avoid or ignore a stressful event (Bernard et al., 2004; Rudolph et al., 1995). Continuing to examine coping in children with SCD is recommended, but the use of additional coping measures might continue to shed light on how children with SCD handle pain associated with the disease.

Developmental issues. Similar to pain and quality of life, the literature examining children's coping has revealed important developmental patterns. In a review of the literature, Compas et al. (1992) found that specific types of coping, especially emotion-focused coping, increases as children get older. In children with SCD, Gil et al. (1991) found that passive adherence, which is associated with maladaptive adjustment, was positively correlated with child age. Therefore, as child age increased so did the use of a negative coping strategy. However, later studies have not found a significant relation between coping and children's age in pediatric

SCD (Gil, Wilson, & Edens, 1997). Given the inconsistent findings between coping and age in children with SCD further research in this area is needed.

Pain, Quality of Life, and Coping

To date, only one study has examined pain, quality of life, and coping in children with SCD. Fuggle et al. (1996) found that SCD related pain impaired daily activities in children 6 to 16 years of age when compared to healthy control children. In addition, the most common way children in the study coped with pain was by talking to parents. However, this study had numerous limitations. One was the lack of a multidimensional assessment of quality of life. Important areas of quality of life, such as emotional and social functioning, were not examined. Another limitation was that coping was assessed utilizing diaries in which children reported how they handled their pain. This strategy may have overlooked important coping strategies, such as problem- and emotion-focused strategies. A third limitation is that the relations among all three variables were not examined. For example, it is possible that coping might have moderated the relation between pain and quality of life, as has been found in a study of adolescents with non-specific chronic pain (Merlijn et al., 2005).

The purpose of the current study was to investigate relations among pain, quality of life, and coping in children with SCD. More specifically, this study sought to explore the potential moderating impact of coping styles on the relation between pain and quality of life (Specific Aim #1). Although previous studies have investigated pain in children and adolescents with SCD, limited information about quality of life is available in this population. In addition, there is limited research examining coping in children with SCD. Taking these factors into consideration, the results of this study will not only provide valuable information about pain, quality of life, and coping in children with SCD, but may help lay the necessary groundwork leading to the

development and implementation of theoretically derived interventions that have the potential to improve the lives of children with SCD and their families.

It was hypothesized that coping would moderate the relation between pain and quality of life (See Figure 1). Specifically, coping would act as a protective factor in the relation between pain and quality of life, with children who experience high pain and utilize more approach coping strategies having higher quality of life compared to children with high pain who utilize less approach coping strategies. In addition, it is unclear how children's age may influence pain, quality of life, and coping in children with SCD. Thus, this study will attempt to explore how age influences these constructs (Specific Aim #2). Cultural factors are also important to consider in research with children who have SCD.

Cultural Factors

SCD is a disease that affects primarily people of African descent, and there may be unique cultural factors relevant to the adjustment of patients with SCD (Barbarin & Christian, 1999) that have been overlooked in prior research. Gurung (2006) stated, "The experience of illness is shaped by *cultural factors* that influence how it is perceived, labeled, and explained and how the experience is valued" (p. 297; italics added). Since SCD is a chronic medical condition that affects primarily a minority group (i.e., African Americans or those of African descent), examining cultural variables is important (Kaslow, Collins, Loundy, Brown, Hollins, & Eckman, 1997; Kaslow et al., 2000) and unfortunately has been overlooked in most of the current body of pediatric psychology research. In fact, a recent review of empirically supported treatments in pediatric psychology found that 27% of pediatric studies included information about participants' race or ethnicity, whereas even fewer (e.g., 6%) identified possible moderating cultural variables (Clay, Mordhorst, & Lehn, 2002). Thus, there is a need for researchers to

examine cultural variables in this pediatric population. In addition, examining cultural factors may prove valuable in understanding this population and the possible impacts cultural factors may have on children with SCD.

Racial identity. One important cultural factor that has been defined in the literature is racial identity. Despite racial identity being what Sellers, Smith, Shelton, Rowley, and Chavous (1998) described as "one of the most heavily researched areas that focuses on the psychological experiences of African Americans" (pg. 19), it has been significantly understudied in adult and pediatric patients with SCD.

Racial identity has been conceptualized as a person's group or collective identity based on perceptions that they share a common heritage with a specific racial group (Chavez & Guido-DiBrito, 1999; Helms, 1993). The Multidimensional Model of Racial Identity (MMRI; Sellers, Rowley, Chavous, Shelton, & Smith, 1997; Sellers et al., 1998) provides a framework for researchers to investigate the impact of racial identity on a variety of outcomes.

The MMRI posits that racial identity in African Americans is the significance and meaning people place on their membership within the Black racial group that is incorporated into their self-concept (Sellers et al., 1998). Sellers and colleagues (1997, 1998) hypothesized that racial identity is composed of four dimensions: salience, centrality, regard, and ideology. Salience refers to how relevant one's race is to one's self-concept during a particular time or situation. Centrality is the degree to which race is an important component of a person's self-concept or identity. In MMRI, regard refers to positive or negative feelings about being Black. Ideology consists of beliefs, opinions, and attitudes about how members of the race should act. Aspects of the MMRI have been examined in adults with SCD. Bediako, Lavender, and Yasin (2007) found that one aspect of the model, racial centrality, was negatively associated with pain

severity ratings in adults 18 to 64 years old with SCD. These results suggest that patients who reported being Black as a large part of their self-concept also reported less severe pain episodes, which may indicate that positive racial identity may act as a buffer in patients with SCD. However, whether positive racial identity may be related to better pain outcomes in children with SCD is unknown.

In fact, one study by Barbarin (1999) examined the impact of parent's racial identity on the psychological functioning of children with SCD. Racial identity, where racial attributions were used to explain the condition of African Americans in the United States, was found to significantly predict children's psychological functioning; specifically more positive racial identity in parents was related to better functioning in their children. However, very little research has focused on children's racial identity. In addition, very little research has examined racial identity in the context of a pediatric chronic illness. This study examined the associations between racial identity and pain, quality of life, and coping in children with SCD and to date is the only study to do so.

Pain. The perception and experience of pain has been recognized as being influenced by various social and cultural factors (Craig & Riddell, 2003; Gurung, 2006). The impact of cultural beliefs on the experience of pain has been recognized in cancer research with adults. Specifically, Lasch (2000) posits that cultural factors may influence the expression of pain, the language used to describe pain, the context of pain related suffering, social roles and expectations, holistic treatments for pain, and perceptions of the health care system. Despite the obvious potential importance of cultural factors on the pain experience related to SCD there is little mention of them in the SCD research focusing on adults.

The cultural experience of African Americans in the U.S. may also impact the frequency and intensity of pain related to SCD. Racism, "beliefs, attitudes, institutional arrangements, and acts that tend to denigrate individuals or groups because of phenotypic characteristics or ethnic group affiliation" (Clark, Anderson, Clark, & Williams, 1999, p. 805), is considered a significant stressor for African Americans and has been found to impact both psychological and physiological health (Clark et al., 1999). Given that acute pain episodes in SCD are thought to be in part triggered by psychological states (Schecter, 1999); it is possible that racism experienced by adults and children with SCD could exacerbate pain related symptoms.

However, there is little mention of cultural factors as they relate to pain in children with SCD in the current literature. Thus, it is unclear what role cultural factors may play in the expression of both acute and chronic pain in children with SCD. There is a need for researchers to begin to incorporate cultural variables in pediatric research (Clay et al., 2002) and this study is one of the first to attempt to do so.

Quality of life. Similar to pain, little is known about how racial identity may impact quality of life in children with SCD. Research on this variable in adults is even lacking. However, Bediako et al. (2007) indicated that positive racial identity in African Americans may be health enhancing. Thus, it may be likely that positive racial identity would be positively correlated with quality of life. However, research is needed to examine whether this is true in children with SCD.

Coping. How children with a chronic illness cope is likely influenced by various social and cultural factors. In addition, specific types of coping may be valued over others in specific cultures. In fact, research focusing on health behaviors in adults, such as mammogram screening (Kudadjie-Gyamfi & Magai, 2008) and prostate screening (Kudadjie-Gyamfi, Consedine, &

Magai, 2006), has revealed significant cultural differences in coping styles. In addition, some coping differences have been found between racial groups in adults with chronic pain. Two recent studies found that African Americans significantly differed from Caucasians on the use of praying/hoping as a coping strategy (Edwards, Moric, Husfeldt, Buvanendran, & Ivenkovich, 2005; Tan, Jensen, Thornby, & Anderson, 2005). Another study also found that African Americans reported using diverting attention, prayer, and hoping pain coping strategies more often than Caucasians (Cano, Mayo, & Ventimiglia, 2006). However, in these studies these few coping strategies were the only significant differences found between racial groups. Given the amount of analyses conducted these results indicate few ethnic differences in pain coping strategies in adults experiencing chronic pain. However, the relation between racial identity and coping strategies have not been examined in children with chronic pain. It is likely that racial identity may be a key cultural factor that impacts how children with SCD cope with disease-related pain. This project will be the first to explore the relation between racial identity and coping in children with SCD.

Since there is limited information about racial identity in children with SCD, this aim was exploratory in nature. This was the first pediatric psychology study to examine the role of racial identity on pain, quality of life, and coping in children with SCD (Specific Aim #3). Including racial identity in this study is important, as it could lead to the identification of protective cultural factors which could be used to develop culturally appropriate interventions that reduce pain, increase quality of life, and improve coping in children with SCD.

Specific Aims

Aim 1. Examine coping as a moderator in the relation between pain and quality of life in children with SCD.

It was hypothesized that approach coping would moderate the relationship between pain and overall quality of life.

Aim 2. Explore the relation between child age and pain, quality of life, and coping.

It was expected that child age would be associated with pain, quality of life, and coping. Specifically, that as child age increases pain increases, quality of life decreases, and approach coping increases.

Aim 3. Conduct exploratory analyses to examine associations between racial identity and pain, quality of life, and coping.

It was expected that racial identity would be associated with pain, quality of life, and coping where more positive racial identity would be associated with lower pain, higher quality of life, and more approach coping.

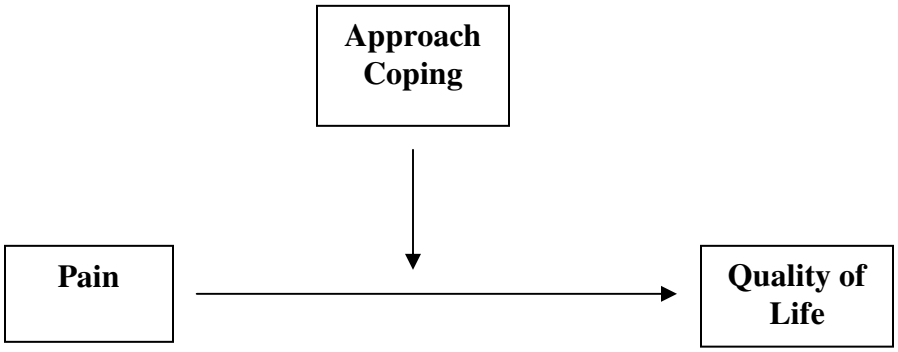


Figure 1. Hypothesized relation between pain, quality of life, and coping. Hypothesized relation between pain, quality of life, and coping, with approach coping moderating the relation between pain and quality of life in children with SCD.

CHAPTER 2

METHOD

Participants

Participants included 104 children diagnosed with SCD who ranged in age from 8 to 18 years of age (*M* = 12.93 years, *SD* = 3.17 years) and who were receiving SCD-related care at two children's medical facilities from March 2008 to July 2008 and their caregivers (See Table 1). Both clinics were located in an urban city in the southeastern United States and both had Caucasian and African American health care providers. Fifty-five children were female (52.9%) and 100 were African American (96.2%). In terms of SCD type, caregivers reported that 72 (69.2%) children had SS, the most severe subtype, 13 (12.5%) had SC, 6 (5.8%) had Beta Thalassemia, and 13 (12.5%) did not specify their child's type of SCD.

Most children were accompanied by a female caregiver (90 children, 86.5%), 88 (84.6%) of which were mothers (See Table 2). Caregivers ranged in age from 28 to 68 years (*M* = 40.84, *SD* = 7.92) and 100 (96.2%) self-identified as African American. Ninety-five caregivers (91.3%) reported their annual family income. Median family income in the sample was $40,001 to $50,000. Caregivers' average years of education was 13.9 (*SD* = 2.1 years). Fifty-nine caregivers (56.7%) were married, 25 (24.0%) were single, 16 (15.4%) were divorced, 3 (2.9%) were separated, and 1 (1.0%) failed to report their marital status.

115 children and their families were approached to participate in this study. Nine families (7.8%) did not wish to participate. The reasons for non-participation included not being interested in participating in research (7) and not having enough time to complete the measures (2). Therefore, 106 participants were enrolled in the study. However, 2 children (1.9%) did not

complete the main outcome measures due to time constraints, so they were removed from analyses. Therefore, the final sample consisted of 104 children with SCD and their parents.

Measures

Background information. Caregivers who accompanied participants for their SCD-related medical visit completed a background history form. Questions included child and caregiver age, child and caregiver races/ethnicities and genders, family income, and child's current disease and medication status (Appendix A).

Pain. The Pediatric Pain Questionnaire (PPQ; Varni & Thompson, 1985) was used to assess pain from the child's perspective. The PPQ is a structured interview that allows for children to be interviewed individually and consists of different methods of assessing pain (Appendix B). Specifically, the PPQ consists of visual analogue scales (VAS) and open-ended questions. VASs are widely used in pediatric pain studies because they usually have good reliability and validity and do not result in the clustering of scores as is common with likert-type scales (Cohen et al., 2008; McGrath, 1990; Varni, Walco, & Wilcox, 1990). The VAS included in the PPQ is a 100 mm horizontal line that measures present pain and worst pain in the past week. The VAS questions are anchored at each end of the line with developmentally appropriate pain descriptions (e.g., No pain) and happy and sad faces. Scores on the PPQ range from 0 to 100, with higher scores representing more pain. The open ended questions on the PPQ ask children to provide words that describe their pain and identify locations on their body where they are experiencing pain. The PPQ has demonstrated adequate reliability and validity in children with juvenile rheumatoid arthritis (Varni, Thompson, & Hanson, 1987) and demonstrated validity in a sample of children with SCD and their parents (Walco & Dampier, 1990). The PPQ has been deemed a "well-established" instrument for assessing children's pain (Cohen et al.,

2008). The internal consistency coefficient of the two PPQ VAS questions in this sample was 0.59. An additional three items were added to the PPQ in order to assess chronic pain associated with SCD and children's perceptions of pain. Cronbach's alpha for these items was 0.65. A PPQ Total Pain score was calculated by averaging the three main pain scores obtained from the PPQ and additional items (e.g., Current Pain, Worst Pain, and Chronic Pain), which was used in the main analyses.

Quality of life. The Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Kurtin, 2001) was completed by children to assess their quality of life (Appendix C). The PedsQL is a 23-item generic quality of life measure designed for children and adolescents between 2 and 18 years of age. In the current study, the PedsQL Child Report (ages 8-12) and the PedsQL Teen Report (ages 13-18), were utilized. Although the contents of the items are similar, the language for each version is developmentally appropriate for the specified age ranges. The PedsQL assesses several domains of functioning, including Physical (8 items), Emotional (5 items), Social (5 items), and School (5 items) and utilizes a 5-point likert scale (0 = never a problem to 4 = almost always a problem). Scores on the PedsQL were reverse scored and transformed to scores ranging from 0 to 100, with higher scores representing higher quality of life. In addition to having specific scaled scores, the items on the PedsQL are averaged to create a Total Scale Score and two summary scores, the Physical Health Summary Score and the Psychosocial Health Summary Score. The PedsQL has been found to be valid and reliable for the Child and Teen Reports (Cronbach's alphas ranged from 0.68 to 0.88) (Varni, Seid, & Kurtin, 2001) and is considered a "well-established" instrument (Palermo, Long, Lewandowski, Drotar, Quittner, & Walker, 2008). In a sample of children with SCD, Cronbach's alpha ranged from 0.56 (School) to 0.79 (Physical) and the Total Score was 0.89 (McClellan, Schatz, Sanchez, & Roberts, 2008).

In this sample, Cronbach's alpha for the PedsQL Total Score was 0.90. The internal consistency of the scales, measured by Cronbach's alpha, ranged from 0.69 (School) to 0.86 (Physical). For the purposes of this study the PedsQL Total Score was used in primary analyses.

To date there is no disease-specific measure of quality of life available for adults or children with SCD. Thus, the Sickle Cell Disease Quality of Life (SCD-QoL) measure was created for use in this study. Items included in the measure were selected based on previous qualitative research conducted in patients with SCD (Stegenga et al., 2004; Thomas & Taylor, 2002), as well as with discussions with doctors and psychologists who work with pediatric patients with SCD. In addition, other disease-specific quality of life measures created for children with other chronic illnesses were examined to determine the appropriate formats and scales. The SCD-QoL consists of 28 items and scores ranged from (1 = Always to 4 = Never), with higher scores representing higher quality of life (Appendix D). The scores were transformed to a 0 to 100 scale, which is common in quality of life measures. Internal consistency for the entire measure was 0.92. The items were divided into four subscales, which included Physical, Emotional, Social, and School. Internal consistency for the different subscales ranged from 0.58 (Social) to 0.81 (Physical). Concurrent validity of the SCD-QoL was examined via bivariate correlations with the PedsQL (See Table 3). Results revealed medium to large correlations between subscales of the SCD-QoL and the subscales of the PedsQL, suggesting adequate concurrent validity.

Coping. To assess children's pain coping strategies, the Pain Coping Questionnaire (PCQ; Reid, Gilbert, & McGrath, 1998) was utilized. The PCQ is a 39-item measure that consists of eight subscales, which were identified based on previous coping research conducted with adults and children (Appendix E). The subscales include: information seeking, problem

solving, seeking social support, positive self-statements, behavioral distraction, cognitive distraction, externalizing, and internalizing/catastrophizing. Higher-order factor analyses of the PCQ with healthy children and children with recurrent pain revealed three composites: approach, problem-focused avoidance, and emotion-focused avoidance (Reid et al., 1998). The approach scale assesses direct attempts to deal with pain and the use of active methods to regulate feelings when in pain. The approach scale is comprised of the information seeking, problem solving, seeking social support, and positive self-statements subscales. The problem-focused avoidance scale measures attempts to separate or disengage from the pain and consists of the positive self-statements, behavioral distraction, and cognitive distraction subscales. The emotion-focused avoidance scale assesses strategies where emotions are freely expressed and reflect a lack of effort to regulate feelings when in pain. The emotion-focused avoidance composite consists of the externalizing and internalizing/catastrophizing subscales. Thus, the PCQ examines two of the most common coping dimensions utilized in pediatric research: problem-/emotion-focused and approach/avoidance. Children answered questions based on how often they engage in a particular coping strategy by using a 5-point likert scale (1 = never to 5 = very often). The PCQ was created for use with children 8 to 18 years of age and has a third grade reading level (Reid et al., 1998). The measure has good internal consistency with Cronbach's alphas for the subscales ranging from 0.78 to 0.86 and for the factors from 0.85 to 0.89. The measure also has shown high internal consistency in a large sample of adolescents (n = 631) experiencing chronic pain with no known etiology (Cronbach's alphas for higher-order scales: 0.78 to 0.89; Merlijn et al., 2003). In a review of coping measures, the PCQ was recognized as a "well-established" measure (Blount et al., 2008). In this sample, internal consistency ranged from 0.73 (Externalizing) to

0.82 (Behavioral Distraction) for the subscales and 0.78 (Emotion-Focused Avoidance) to 0.83 (Approach) for the factors. The three PCQ factor scores were utilized in primary analyses.

Racial identity. To assess children's racial identity, the Multidimensional Inventory of Black Identity (MIBI; Sellers et al., 1997) was used (Appendix F). From this measure, two scales, Centrality (8 items) and Regard (12 items) were utilized. The Centrality scale examines the degree to which being African American is central to a person's self-concept. The Regard scale consists of Private Regard and Public Regard. Private regard refers to whether individuals feel positively or negatively toward African Americans and their membership in that group (Sellers et al., 1997). Public regard refers to the extent to which individuals feel that others view African Americans positively or negatively (Sellers et al., 1997). A total of 20 MIBI items were administered to children in this study. Children rated how strongly they agreed or disagreed with each item on a likert scale with scores ranging from 1 to 7 (1 = Strongly disagree to 7 = Strongly agree). Higher scores indicated the belief that the child and others hold more positive attitudes towards African Americans. The MIBI has been found to be a valid and reliable measure of racial identity in a sample of African American college students, Cronbach's alpha for the public regard scale was 0.78 and for the private regard scale was 0.78 (Sellers et al., 1997). In a study examining public regard and private regard in a sample of African American high school students Cronbach's alphas were 0.75 for public regard and 0.76 for private regard (Rowley, Sellers, Chavous, & Smith, 1998). The MIBI was originally developed for adults. Therefore, some items were modified to help children in this study better understand the meaning of the items. In this sample, internal consistency of the Centrality Scale was 0.56 and the Regard Scale was 0.76 (Public Regard = 0.55 and Private Regard = 0.78).

Procedures

Children scheduled to receive SCD-related medical care at two urban children's hospitals in the metro Atlanta area and their parents were informed of the study by clinic personnel and directed to receive additional information from a researcher. The trained research assistant further explained the study and obtained parent consent and child assent if the family was interested in participating. Before meeting with physicians, the child and caregiver completed measures in a quiet room in the clinic. Children completed the PPQ, PedsQL, SCD-QoL, PCQ, and MIBI. Parents completed the Background Information Form.

Data Analyses Overview

First, preliminary analyses consisting of descriptive statistics (e.g., means, standard deviations, frequencies) were used to characterize the sample. Specifically, demographic characteristics (e.g., age, gender) and study data (i.e., pain, quality of life, coping, racial identity) were detailed (See Table 3). In addition, preliminary analyses were conducted to examine the internal consistency of the study measures (e.g., PPQ, PedsQL, SCD-QoL, PCQ, and MIBI) with the obtained sample. Internal consistency was examined with Cronbach's alpha. Finally, participant demographics (e.g., site of data collection, gender) were examined with respect to the study variables to examine if any covariates would be used in moderation analyses (Tables 5 and 6).

Primary analyses were conducted to determine whether coping (PCQ Approach Score) moderates the relation between pain (PPQ Total Score; independent variable) and quality of life (PedsQL Total Score; dependent variable) (Specific Aim #1). The variables (PPQ Total Pain and PCQ Approach Score) were first centered before main analyses were conducted to reduce multicollinearity. To test for moderation, three hierarchical regression equations were used, the

first of which included potential covariates. The second equation examined the main effects of pain and coping, and the final equation examined the variable representing the interaction between pain and coping. It was hypothesized that coping style would act as a protective factor in the relation between pain and quality of life, specifically that children experiencing high pain who utilize more approach coping strategies would have higher quality of life compared to children with high pain who utilize fewer approach coping strategies (See Figure 1). Additional regression analyses were also conducted to examine whether other types of coping (e.g., problem-focused avoidance, emotion-focused avoidance) moderated the relation between pain and quality of life. In addition, the SCD-QoL Total Score and subscales of both the PedsQL and the SCD-QoL were examined as dependent variables.

To examine the impact of age on pain, quality of life, and coping (Specific Aim #2) correlations were utilized. These analyses were conducted in an exploratory nature due to the limited information available in the literature. However, it was hypothesized that age would be significantly associated with pain, as children with SCD are thought to experience more acute and chronic pain as they get older, report lower quality of life, and use more approach coping strategies.

To evaluate the impact of racial identity on pain, quality of life, and coping (Specific Aim #3) correlations were also used. These analyses were also exploratory in nature yet it was hypothesized that more positive racial identity would be associated with lower pain, higher quality of life, and more approach coping.

Due to time limitations in the clinical setting, unwillingness to complete some questions, or inadvertently skipping some questions, some participants did not complete all items on the questionnaires and therefore did not have complete quality of life or coping data. For the main

study outcome variables, 6 participants were missing the PedsQL Total Score and 13 were missing the PCQ Approach Score. These data were left as missing points in analyses and other compensatory actions (e.g., inserting a mean value) were not taken.

Table 1

Child Demographic Information (N = 104)

	M (SD)
Age	12.93 (3.17)
	N (%)
Gender	
Female	55 (52.9)
Male	49 (47.1)
Race/Ethnicity	
African American	100 (96.1)
Asian	1 (1.0)
Not Reported	3 (2.9)
SCD Type	
HbSS	72 (69.2)
HbSC	13 (12.5)
Beta Thalassemia	6 (5.8)
Type not Specified	13 (12.5)

Table 2

Parent Demographic Information (N = 104)

	M (SD)
Age	40.84 (7.92)
	N (%)
Gender	
Female	90 (86.5)
Male	14 (13.5)
Relationship to Child	
Mother	88 (84.6)
Father	9 (8.7)
Grandmother	3 (2.9)
Grandfather	2 (1.9)
Stepfather	2 (1.9)
Race/Ethnicity	
African American	100 (96.1)
Native Hawaiian or Pacific Islander	1 (1.0)
Missing	3 (2.9)
Marital Status	
Married/Partnered	59 (56.7)
Single	25 (24.0)
Divorced	16 (15.4)
Separated	3 (2.9)

Missing	1 (1.0)
Education Level (*M (SD)* in years)	13.8 (2.1)
Family Income	
Up to $10,000	6 (5.8)
10,001- 20,000	10 (9.6)
20,001 – 30,000	12 (11.5)
30,001 – 40,000	14 (13.5)
40,001 – 50,000	11 (10.6)
50,001 – 60,000	10 (9.6)
60,001 – 70,000	6 (5.8)
70,001 – 80,000	7 (6.7)
80,001 – 90,000	3 (2.9)
90,001 and above	16 (15.1)
Not Reported	10 (9.6)

Table 3

Concurrent Validity between the SCD-QoL and the PedsQL

PedsQL Subscales	SCD-QoL Subscales				
	Physical	Emotional	Social	School	Total
Physical	**0.72*** **	0.61***	0.57***	0.65***	0.76***
Emotional	0.59***	**0.61*** **	0.46***	0.49***	0.63***
Social	0.48***	0.47***	**0.54*** **	0.60***	0.59***
School	0.43***	0.41***	0.32**	**0.59*** **	0.50***
Total	0.71***	0.64***	0.60***	0.72***	**0.78*** **

Note. ** $p < 0.01$, *** $p < 0.001$

CHAPTER 3

RESULTS

Preliminary Analyses

First, descriptive statistics (e.g., means, standard deviations, frequencies) were utilized to characterize the sample on demographic variables (see Tables 1 and 2). Second, means and standard deviations of the study data (i.e., pain, quality of life, coping, racial identity) were obtained (See Table 4). Third, analyses were conducted to determine whether there were any differences between the two clinics where data was collected, with a focus on demographic characteristics and main outcome variables. Chi-square analyses indicated no site differences on child gender and type of SCD, as well as parent relation to child (See Table 5). Analyses with *t*-tests revealed no significant differences between sites on child age, parent education level, and annual family income. However, results indicated a significant difference between sites on parent age, $t\ (99) = -3.46$, $p < 0.001$, where parents from the second site were older than parents from the first site. These results can be accounted for by the difference in the number of grandparents accompanying participating children across the different sites. One grandparent participated in the first site, while four participated in the second site. However, chi-square analyses did not reveal any significant differences between parent relation to child between the two sites. In addition, parent age was not found to be related to the main study outcomes so it was not controlled for in primary analyses.

In regards to the main outcome variables, *t*-tests revealed no site differences on PPQ Total Pain and PCQ Approach Score. Yet, there was a site difference on the PedsQL Total Score,

where children from the second site reported significantly lower overall quality of life compared to children from the first site, t (96) = 2.38, p = 0.02 (See Table 5). In addition, there was a significant site difference on the SCD-QoL Total Score, where children from the second site reported lower quality of life compared to the first site, t (96) = 2.00, p = 0.05. A possible reason for the difference in quality of life between the two sites is likely due to the differences in the number of participants from each site that were recruited during an SCD specialty clinic. In the clinics where data collection occurred, children attended specialty SCD clinics if they experienced additional medical complications associated with SCD; and likely more impact on their quality of life. More children (n = 23) from the second site were attending a pulmonary SCD clinic compared to children from the first site (n = 13). In addition, four children from the second site were recruited while attending a SCD pain specialty clinic, while no children from the first site were recruited while attending a SCD pain specialty clinic. Due to the site differences on quality of life, site of participation was entered as a covariate in the main analyses.

Fourth, potential gender differences were examined. Analyses with t-tests revealed that males and females reported significantly different overall generic quality of life on the PedsQL, t (96) = 1.99, $p < 0.05$, and overall disease-specific quality of life on the SCD-QoL, t (96) = 2.61, $p < 0.05$, with males reporting higher quality of life (See Table 6). In addition, there was a gender difference approaching significance on PCQ Approach Coping, with females reporting more approach coping than males, t (90) = -1.88, p = 0.06. Due to these findings, gender was also entered as a covariate in primary analyses.

Primary Analyses

The primary goal of this study was to examine whether coping moderates the relation between pain and quality of life (Specific Aim #1). To examine this aim, hierarchical regression

analyses were conducted. To control for potential site differences and child gender differences (see preliminary analyses above), site and gender were entered as covariates in the first step of the regression. Then, the centered pain and coping variables were entered in the second step. Next, the pain x coping interaction term was entered in the third step. The dependent variable for the regression analysis was quality of life (e.g., PedsQL Total Score).

Results from the regression analysis examining approach coping revealed that the main effect of pain was a significant predictor of overall generic quality of life, $\beta = -0.49$, $t\ (80) = -4.94$, $p < 0.001$ (See Table 7). Thus, children who reported higher pain (PPQ Total) also reported lower overall generic quality of life (PedsQL Total). There was no significant main effect of approach coping or significant pain x approach coping interaction for overall generic quality of life.

As further exploratory tests of the primary aim, other indices of coping were examined. Regression analyses were conducted to determine whether problem-focused avoidance coping was a significant moderator between pain and quality of life. The main effect of pain was a significant predictor of overall generic quality of life (PedsQL Total), $\beta = -0.48$, $t\ (88) = -5.16$, $p < 0.001$ (See Table 7). There was no significant main effect of problem-focused avoidance coping or significant pain x problem-focused avoidance coping interaction for overall generic quality of life. An additional analysis was conducted to examine whether emotion-focused avoidance coping was a significant moderator of the pain and quality of life relation. The main effects of pain ($\beta = -0.37$, $t\ (87) = -4.26$, $p < 0.001$) and emotion-focused avoidance coping ($\beta = -0.39$, $t\ (87) = -4.64$, $p < 0.001$) were significant predictors of overall generic quality of life (PedsQL Total; See Table 7), where higher pain was associated with lower overall generic

quality of life and higher emotion-focused avoidance coping was associated with lower quality of life. There was not a significant pain x emotion-focused avoidance coping interaction.

The various subscales of the PedsQL were also entered in regression analyses as dependent variables to further examine the main purpose of this study. Results examining the PedsQL Physical Scale, PedsQL Emotion Scale, PedsQL Social Scale, and PedsQL School Scale as the dependent variables revealed similar results as above, where pain and emotion-focused avoidance coping were significant predictors of quality of life and there were no significant pain x coping interactions (See Tables 8 to 11).

Disease-specific quality of life, the SCD-QoL Total Score, was also examined as the dependent variable in regression analyses to further examine whether coping moderates the relation between pain and quality of life. Results were similar to those found using the PedsQL Total Score as the dependent variable, where pain and emotion-focused avoidance coping were significant predictors of overall disease-specific quality of life (See Table 12) and no significant interaction between pain and coping styles were found.

Additional regression analyses were conducted with subscales of the SCD-QoL entered as dependent variables to further examine the main aim of the study. Results of these analyses revealed significant main effects of pain and emotion-focused avoidance coping, similar to previous results (see Tables 13 to 16); with the exception of the SCD-QoL Social Score as pain was not a significant predictor of quality of life. In addition, these analyses revealed a significant interaction between pain and approach coping on the SCD-QoL Emotion Scale, $\beta = 0.28$, $t\ (84) = 2.85$, $p < 0.01$ (See Table 14). Post hoc probing of this significant interaction was conducted, as recommended by Aiken and West (1991) and Holmbeck (2002).

Post-hoc probing of the significant interaction involved creating high (1 SD above the mean) and low (1 SD below the mean) approach coping moderator variables and two interaction terms, pain x high approach coping and pain x low approach coping. Two separate post-hoc regressions were then conducted to determine whether the high and low slopes were significant. In addition, these equations provided a regression equation to plot high (1 SD above the mean) and low (1 SD below the mean) pain scores. Post-hoc probing of the significant pain x approach coping interaction on SCD-QoL Emotion Scale revealed that at high approach coping, pain did not significantly predict quality of life. However, at low approach coping, pain was significantly inversely related to quality of life (See Figure 2).

To further explore gender differences, hierarchical regression analyses were conducted separately for males and females (See Appendix G). These analyses revealed similar results as above for both males and females, where pain and emotion-focused avoidance coping were significant predictors of both generic and disease-specific quality of life. In addition, for males, approach coping was a significant predictor of SCD-QoL School Score, $\beta = -0.42$, t (37) = -2.48, $p < 0.05$ (See Appendix G, Table 10). There was also a main effect approaching significance for approach coping predicting SCD-QoL Total Score, $\beta = -0.28$, t (36) = -1.80, $p = 0.08$ (See Appendix G, Table 6). For females, there was also a significant main effect of approach coping on SCD-QoL School Score, $\beta = 0.30$, t (40) = 2.12, $p < 0.05$ (See Appendix G, Table 10) and an approaching significance main effect of problem-focused avoidance coping on SCD-QoL Social Score, $\beta = 0.27$, t (46) = 1.82, $p = 0.08$ (See Appendix G, Table 9). An interaction approached significance between pain and approach coping for both the PedsQL Emotion Score $\beta = 0.32$, t (41) = 1.95, $p = 0.06$ (See Appendix G, Table 3) and the SCD-QoL Emotion Score, $\beta = 0.33$, t (42) = 1.88, $p = 0.07$ (See Appendix G, Table 8).

Exploratory Analyses

To examine the association between child age and the study variables (Specific Aim #2), bivariate correlational analyses were conducted (See Table 17). No significant correlations were found. To examine the possible relation between racial identity and the outcome variables (Specific Aim #3), bivariate correlational analyses were also conducted (See Table 18). Results of these analyses revealed that the MIBI Centrality Scale was negatively correlated with PCQ Approach Coping, r (80) = -0.24, $p < 0.05$, with higher racial centrality associated with lower approach coping. The MIBI Centrality Scale was also significantly positively correlated with the SCD-QoL Total Score, r (88) = 0.29, $p < 0.01$, with higher racial centrality associated with higher disease-specific quality of life. The MIBI Regard Scale was significantly positively correlated with PCQ Problem-Focused Avoidance Coping, r (84) = 0.30, $p < 0.01$ and with SCD-QoL Total Score, r (82) = 0.27, $p < 0.05$, with higher regard associated with higher problem-focused avoidance coping and higher disease-specific quality of life. In terms of regard type, the MIBI Private Regard Scale was significantly positively correlated with PCQ Problem-Focused Avoidance Coping, r (88) = 0.28, $p < 0.01$, with higher public regard associated with higher problem-focused avoidance coping. The MIBI Public Regard Scale was positively correlated with PedsQL Total Score, r (86) = 0.22, $p < 0.05$, with SCD-QoL Total Score, r (85) = 0.29, $p < 0.01$, with PCQ Problem-Focused Avoidance Coping, r (88) = 0.22, $p < 0.01$, with higher public regard associated with higher generic overall quality of life, higher disease-specific quality of life, and higher problem-focused avoidance coping. In addition, the correlation between the MIBI Public Regard Scale and PCQ Emotion-Focused Avoidance Coping approached significance, r (85) = -0.20, $p = 0.072$.

Table 4

Means and Standard Deviations of Study Variables

Measures	*M (SD)*
Pediatric Pain Question (PPQ) [a]	
Current Pain	12.70 (22.81)
Worst Pain	29.46 (34.57)
Chronic Pain	21.12 (28.86)
Total Pain	21.09 (24.48)
Pediatric Quality of Life Inventory (PedsQL) [b]	
Physical Score	69.09 (21.18)
Emotional Score	71.32 (20.67)
Social Score	80.29 (18.95)
School Score	62.07 (19.34)
Total Score	70.61 (16.33)
Sickle Cell Disease Quality of Life (SCD-QoL) [c]	
Physical Score	75.22 (15.82)
Emotional Score	80.74 (15.36)
Social Score	78.98 (15.09)
School Score	81.66 (14.38)
Overall Score	78.74 (13.46)
Pain Coping Questionnaire (PCQ) [d]	
Approach Coping	3.04 (0.60)
Problem-Focused Avoidance Coping	2.79 (0.80)

Emotion-Focused Avoidance Coping	1.85 (0.63)
Multidimensional Inventory of Black Identity (MIBI) [e]	
Centrality	4.65 (1.06)
Regard	5.34 (0.85)
Private Regard	6.18 (1.07)
Public Regard	4.48 (0.93)

Note. [a] Scores on the PPQ range from 0 to 100, with higher scores representing more pain. [b] Scores on the PedsQL range from 0 to 100, with higher scores representing higher quality of life. [c] On the SCD-QoL scores range from 0 to 100, with higher scores representing higher quality of life. [d] Scores on the PCQ range from 1 to 5, with higher scores representing more frequent use of the coping strategy. [e] On the MIBI scores range from 1 to 7, with higher scores indicating a more positive perception of African-Americans.

Table 5

Examination of Site Differences

	Site		
Variables	Site 1 (n = 54)	Site 2 (n = 50)	Chi square
Child Gender (% Female)	55.6	50.0	X^2 (1) = 0.32
Type of SCD (% SS)	77.6	77.3	X^2 (3) = 2.71
Parent Relation to Child (% Mothers)	90.7	78.0	X^2 (3) = 4.90
Variables	*M (SD)*	*M (SD)*	*t*-tests
Child Age	12.66 (3.17)	13.23 (3.18)	t (102) = -0.93
Parent Age	38.33 (5.98)	43.51 (8.87)	t (99) = -3.46***
Parent Education Level (in years)	13.81 (2.37)	13.91 (1.77)	t (100) = -0.26
Annual Family Income [a]	5.00 (2.67)	5.94 (3.02)	t (93) = -1.60
PPQ Total Pain	20.05 (26.18)	22.22 (22.72)	t (102) = -0.45
PedsQL Total Score	74.37 (14.47)	66.69 (17.36)	t (96) = 2.38*
SCD-QoL Total Score	81.30 (12.82)	75.95 (13.71)	t (96) = 2.00*
PCQ Approach Coping	3.00 (0.67)	3.07 (0.53)	t (89) = -0.56
PCQ Problem-Focused Avoidance Coping	2.74 (0.82)	2.85 (0.79)	t (98) = -0.96
PCQ Emotion-Focused Avoidance Coping	1.81 (0.64)	1.89 (0.62)	t (96) = -0.63

Note. [a] Family income ranged from 1 = Up to $10,000 to 10 = $90,000 and above. * $p < 0.05$, *** $p < 0.001$.

Table 6

Examination of Gender Differences

	Gender		
	Males (n = 49)	Females (n = 55)	
Variables	*M (SD)*	*M (SD)*	*t*-tests
PPQ Total Pain	17.02 (21.77)	24.72 (26.34)	t (102) = -1.61
PedsQL Total Score	73.91 (16.81)	67.43 (15.35)	t (96) = 1.99*
SCD-QoL Total Score	82.40 (12.70)	75.50 (13.39)	t (96) = 2.61*
PCQ Approach Coping	2.91 (0.57)	3.15 (0.62)	t (90) = -1.88†
PCQ Problem-Focused Avoidance Coping	2.82 (0.83)	2.76 (0.78)	t (98) = 0.36
PCQ Emotion-Focused Avoidance Coping	1.78 (0.65)	1.91 (0.61)	t (96) = -1.02

Note. † $p < 0.10$, * $p < 0.05$

Table 7

Regressions of Pain and Coping Types on Generic Overall Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 86)				
Step 1		0.075	0.075	3.387*
Site	-0.184†			
Gender	-0.100			
Step 2		0.299	0.224	13.130***
Total Pain	-0.493***			
Approach Coping	-0.036			
Step 3		0.302	0.003	0.293
Total Pain x Approach Coping	0.054			
Problem-Focused Avoidance Coping (N = 94)				
Step 1		0.107	0.107	5.512**
Site	-0.227*			
Gender	-0.124			
Step 2		0.326	0.219	14.627***
Total Pain	-0.476***			
Problem-Focused Avoidance (PFA)	0.073			
Step 3		0.326	0.000	0.006
Total Pain x PFA Coping	-0.007			
Emotion-Focused Avoidance Coping (N = 93)				
Step 1		0.101	0.101	5.089**
Site	-0.217**			
Gender	-0.102			
Step 2		0.440	0.340	27.024***
Total Pain	-0.372***			
Emotion-Focused Avoidance (EFA)	-0.391***			
Step 3		0.441	0.001	0.085
Total Pain x EFA Coping	0.025			

Note. Dependent variable = PedsQL Total Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 8

Regressions of Pain and Coping Types on Generic Physical Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 87)				
Step 1		0.075	0.075	3.453*
Site	-0.185*			
Gender	-0.096			
Step 2		0.301	0.226	13.403***
Total Pain	-0.475***			
Approach Coping	-0.050			
Step 3		0.301	0.000	0.000
Total Pain x Approach Coping	0.000			
Problem-Focused Avoidance Coping (N = 95)				
Step 1		0.113	0.113	5.930**
Site	-0.235**			
Gender	-0.121			
Step 2		0.329	0.216	14.620***
Total Pain	-0.452***			
Problem-Focused Avoidance (PFA)	0.074			
Step 3		0.334	0.006	0.750
Total Pain x PFA Coping	-0.080			
Emotion-Focused Avoidance Coping (N = 94)				
Step 1		0.104	0.104	5.316**
Site	-0.231**			
Gender	-0.125			
Step 2		0.329	0.225	15.087***
Total Pain	-0.397***			
Emotion-Focused Avoidance (EFA)	-0.204*			
Step 3		0.329	0.000	0.015
Total Pain x EFA Coping	0.012			

Note. Dependent variable is PedsQL Physical Score. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 9

Regressions of Pain and Coping Types on Generic Emotional Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 89)				
Step 1		0.083	0.083	3.913*
Site	-0.134			
Gender	-0.189†			
Step 2		0.208	0.126	6.746**
Total Pain	-0.375***			
Approach Coping	-0.078			
Step 3		0.222	0.014	1.527
Total Pain x Approach Coping	0.127			
Problem-Focused Avoidance Coping (N = 98)				
Step 1		0.070	0.070	3.630*
Site	-0.147			
Gender	-0.165†			
Step 2		0.197	0.127	7.420**
Total Pain	-0.374***			
Problem-Focused Avoidance (PFA)	0.142			
Step 3		0.204	0.007	0.766
Total Pain x PFA Coping	0.087			
Emotion-Focused Avoidance Coping (N = 96)				
Step 1		0.065	0.065	3.286*
Site	-0.113			
Gender	-0.129			
Step 2		0.398	0.333	25.447***
Total Pain	-0.221*			
Emotion-Focused Avoidance (EFA)	-0.486***			
Step 3		0.398	0.000	0.013
Total Pain x EFA Coping	-0.010			

Note. Dependent variable is PedsQL Emotion Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 10

Regressions of Pain and Coping Types on Generic Social Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 90)				
Step 1		0.026	0.026	1.152
Site	-0.127			
Gender	-0.041			
Step 2		0.133	0.107	5.327**
Total Pain	-0.356***			
Approach Coping	0.045			
Step 3		0.137	0.004	0.405
Total Pain x Approach Coping	0.068			
Problem-Focused Avoidance Coping (N = 99)				
Step 1		0.048	0.048	2.434†
Site	-0.152			
Gender	-0.095			
Step 2		0.143	0.095	5.252**
Total Pain	-0.323**			
Problem-Focused Avoidance (PFA)	0.004			
Step 3		0.144	0.002	0.187
Total Pain x PFA Coping	0.045			
Emotion-Focused Avoidance Coping (N =97)				
Step 1		0.056	0.056	2.840†
Site	-0.177			
Gender	-0.039			
Step 2		0.309	0.253	17.015***
Total Pain	-0.264**			
Emotion-Focused Avoidance (EFA)	-0.417***			
Step 3		0.317	0.008	1.103
Total Pain x EFA Coping	0.099			

Note. Dependent variable is PedsQL Social Score. [a] Site and Child Gender were originally entered in Step 1 but were not retained as covariates. † $p < 0.10$, ** $p < 0.01$, *** $p < 0.001$

Table 11

Regressions of Pain and Coping Types on Generic School Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 90)				
Step 1		0.025	0.025	1.149
Site	-0.133			
Gender	0.015			
Step 2		0.155	0.130	6.612**
Total Pain	-0.362***			
Approach Coping	-0.050			
Step 3		0.156	0.001	0.056
Total Pain x Approach Coping	0.025			
Problem-Focused Avoidance Coping (N = 99)				
Step 1		0.046	0.046	2.341
Site	-0.172†			
Gender	-0.020			
Step 2		0.178	0.132	7.638***
Total Pain	-0.361***			
Problem-Focused Avoidance (PFA)	0.016			
Step 3		0.180	0.002	0.189
Total Pain x PFA Coping	-0.044			
Emotion-Focused Avoidance Coping (N = 97)				
Step 1		0.045	0.045	2.239
Site	-0.176†			
Gender	0.005			
Step 2		0.232	0.187	11.301
Total Pain	-0.295**			
Emotion-Focused Avoidance (EFA)	-0.270**			
Step 3		0.232	0.000	0.025
Total Pain x EFA Coping	0.016			

Note. Dependent variable is PedsQL School Score. † $p < 0.10$, ** $p < 0.01$, *** $p < 0.001$.

Table 12

Regressions of Pain and Coping Types on Disease-specific Overall Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 86)				
Step 1		0.114	0.114	5.431**
Site	-0.167†			
Gender	-0.224*			
Step 2		0.306	0.192	11.346***
Total Pain	-0.454***			
Approach Coping	-0.038			
Step 3		0.316	0.009	1.076
Total Pain x Approach Coping	0.099			
Problem-Focused Avoidance Coping (N = 94)				
Step 1		0.117	0.117	6.097**
Site	-0.179*			
Gender	-0.203*			
Step 2		0.313	0.196	12.848***
Total Pain	-0.435***			
Problem-Focused Avoidance (PFA)	0.086			
Step 3		0.316	0.003	0.331
Total Pain x PFA Coping	-0.055			
Emotion-Focused Avoidance Coping (N = 91)				
Step 1		0.106	0.106	5.304**
Site	-0.178*			
Gender	-0.166*			
Step 2		0.449	0.342	26.991***
Total Pain	-0.325***			
Emotion-Focused Avoidance (EFA)	-0.439***			
Step 3		0.451	0.003	0.436
Total Pain x EFA Coping	0.062			

Note. Dependent variable is SCD-QoL Total Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 13

Regressions of Pain and Coping Types on Disease-specific Physical Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 88)				
Step 1		0.073	0.073	3.374*
Site	-0.123			
Gender	-0.127			
Step 2		0.349	0.276	17.823***
Total Pain	-0.514***			
Approach Coping	-0.127			
Step 3		0.353	0.004	0.571
Total Pain x Approach Coping	0.069			
Problem-Focused Avoidance Coping (N = 96)				
Step 1		0.072	0.072	3.673*
Site	-0.147†			
Gender	-0.109			
Step 2		0.341	0.269	18.747***
Total Pain	-0.514***			
Problem-Focused Avoidance (PFA)	0.080			
Step 3		0.344	0.003	0.392
Total Pain x PFA Coping	-0.058			
Emotion-Focused Avoidance Coping (N = 93)				
Step 1		0.060	0.060	2.920†
Site	-0.140†			
Gender	-0.079			
Step 2		0.436	0.375	29.594***
Total Pain	-0.402***			
Emotion-Focused Avoidance (EFA)	-0.392***			
Step 3		0.437	0.001	0.201
Total Pain x EFA Coping	0.042			

Note. Dependent variable is SCD-QoL Physical Score. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 14

Regressions of Pain and Coping Types on Disease-specific Emotional Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 90)				
Step 1		0.098	0.098	4.778*
Site	-0.151			
Gender	-0.242*			
Step 2		0.212	0.114	6.221**
Total Pain	-0.423***			
Approach Coping	0.001			
Step 3		0.281	0.069	8.134**
Total Pain x Approach Coping	0.280**			
Problem-Focused Avoidance Coping (N = 99)				
Step 1		0.069	0.069	3.613*
Site	-0.144			
Gender	-0.157			
Step 2		0.186	0.116	6.783**
Total Pain	-0.331***			
Problem-Focused Avoidance (PFA)	0.130			
Step 3		0.186	0.000	0.008
Total Pain x PFA Coping	-0.009			
Emotion-Focused Avoidance Coping (N = 97)				
Step 1		0.068	0.068	3.465*
Site	-0.118			
Gender	-0.140			
Step 2		0.364	0.296	21.650***
Total Pain	-0.218*			
Emotion-Focused Avoidance (EFA)	-0.446***			
Step 3		0.365	0.001	0.119
Total Pain x EFA Coping	-0.031			

Note. Dependent variable is SCD-QoL Emotion Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 15

Regressions of Pain and Coping Types on Disease-specific Social Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 89)				
Step 1		0.060	0.060	2.783†
Site	-0.172			
Gender	-0.167			
Step 2		0.099	0.039	1.858
Total Pain	-0.216†			
Approach Coping	0.050			
Step 3		0.101	0.002	0.161
Total Pain x Approach Coping	0.044			
Problem-Focused Avoidance Coping (N = 98)				
Step 1		0.083	0.083	4.364
Site	-0.192*			
Gender	-0.193†			
Step 2		0.142	0.059	3.234
Total Pain	-0.212*			
Problem-Focused Avoidance (PFA)	0.167†			
Step 3		0.143	0.001	0.096
Total Pain x PFA Coping	0.032			
Emotion-Focused Avoidance Coping (N = 96)				
Step 1		0.085	0.085	4.340*
Site	-0.196*			
Gender	-0.142			
Step 2		0.267	0.182	11.418***
Total Pain	-0.102			
Emotion-Focused Avoidance (EFA)	-0.425***			
Step 3		0.275	0.008	1.042
Total Pain x EFA Coping	0.100			

Note. Dependent variable is SCD-QoL Social Score. † $p < 0.10$, * $p < 0.05$, *** $p < 0.001$.

Table 16

Regressions of Pain and Coping Types on Disease-specific School Quality of Life

Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 88)				
Step 1		0.141	0.141	7.058***
Site	-0.225*			
Gender	-0.272**			
Step 2		0.257	0.116	6.551**
Total Pain	-0.384***			
Approach Coping	0.042			
Step 3		0.269	0.012	1.346
Total Pain x Approach Coping	0.116			
Problem-Focused Avoidance Coping (N = 97)				
Step 1		0.160	0.160	9.015
Site	-0.233*			
Gender	-0.275**			
Step 2		0.263	0.104	6.531
Total Pain	-0.339***			
Problem-Focused Avoidance (PFA)	0.017			
Step 3		0.265	0.002	0.243
Total Pain x PFA Coping	0.048			
Emotion-Focused Avoidance Coping (N = 95)				
Step 1		0.141	0.141	7.661***
Site	-0.225*			
Gender	-0.234*			
Step 2		0.297	0.155	10.063***
Total Pain	-0.242*			
Emotion-Focused Avoidance (EFA)	-0.286**			
Step 3		0.298	0.001	0.173
Total Pain x EFA Coping	0.040			

Note. Dependent variable is SCD-QoL School Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 17

Associations between Age and Main Study Variables

Variables	Child Age
PPQ Total Pain	0.12
PedsQL Total Score	0.03
SCD-QoL Total Score	-0.04
PCQ Approach Coping	-0.03
PCQ Problem-Focused Avoidance Coping	-0.16
PCQ Emotion-Focused Avoidance Coping	0.01

Note. No significant correlations found.

Table 18

Associations between Racial Identity and Main Study Variables

	MIBI Scales			
Variables	Centrality	Regard	Private Regard	Public Regard
PPQ Total Pain	-0.09	-0.08	0.02	-0.16
PedsQL Total	0.09	0.14	0.06	0.22*
SCD-QoL Total	0.29**	0.27*	0.18†	0.29**
PCQ Approach Coping	-0.24*	0.13	0.12	0.10
PCQ Problem-Focused Avoidance Coping	0.05	0.30**	0.28**	0.22*
PCQ Emotion-Focused Avoidance Coping	-0.03	-0.18	-0.15	-0.20†

Note. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$

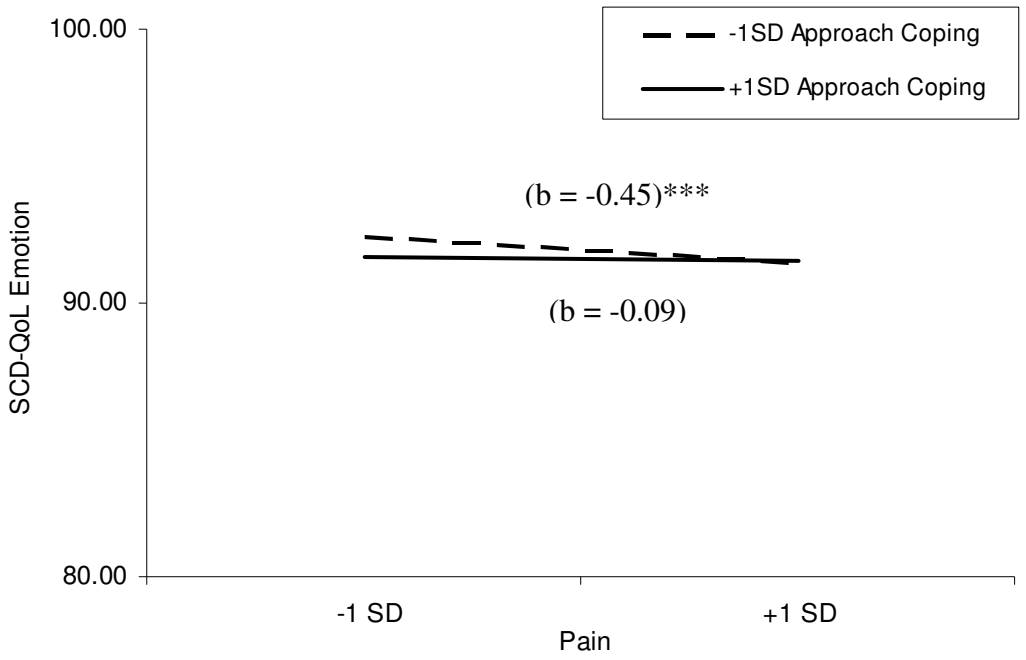


Figure 2. Post-hoc Probing of Interaction between Pain and Approach Coping on SCD-QoL Emotion Score. SCD-QoL Emotional Functioning as a function of Pain and Approach Coping 1 standard deviation above and 1 standard deviation below the mean in children with SCD.

Note. *** $p < 0.001$

CHAPTER 4

DISCUSSION

This study examined whether coping moderates the relation between pain and quality of life in children with sickle cell disease (SCD). In addition, the potential roles of development and racial identity were investigated.

Relation between Pain, Quality of Life, and Coping

This is one of the first studies to examine the relation between pain and quality of life in children with SCD. Results revealed that children's pain significantly predicted their quality of life, where higher pain was associated with lower quality of life. This finding is consistent with prior research conducted with adolescents with chronic pain (Merlijn et al., 2003), adults with SCD (Anie et al., 2002), and children with SCD when a non-standardized measure of quality of life (i.e., four questions about daily activities) was utilized (Fuggle et al., 1996).

The link between pain and quality of life can be explained in numerous ways. It is likely that acute and chronic pain influence various areas of quality of life. For example, acute pain episodes are associated with significant physical symptoms that have been found to interfere with school attendance and interactions with peers (Gil et al., 2000; Shapiro et al., 1995), which may lead to decreased quality of life in the physical, social, and/or academic domains. Pain experiences may also lead to children with SCD viewing their everyday functioning more negatively, thus impacting their self-reported quality of life. However, due to the correlational nature of this study causality cannot be determined, and other explanations must be considered. It may be that children with lower quality of life who experience acute and chronic pain may

experience additional negative impacts on their daily functioning, which thus negatively impacts quality of life. Lower quality of life in children with SCD may lead to negative perceptions about painful experiences, which may lead to higher ratings of pain. This study found that pain and quality of life are associated; however, the mechanisms through which this occurs are unclear and further research is warranted.

Previous studies have relied on medical chart reviews to determine disease related factors, including pain, that impact quality of life in children with SCD. One study found that disease status was related to physical functioning on a parent-report quality of life measure (e.g., CHQ; Panepinto et al., 2005). In addition, a recent study by McClellan et al. (2008) found that children with SCD who had a history of pain episodes reported significantly lower quality of life on most scales of the PedsQL, with the exception of the Emotional Scale, compared to children without a significant pain history. However, pain history in their study was determined by a retrospective two-year medical chart review and child or parent report of pain was not obtained. The current study is one of the first to examine the relation between pain and quality of life in children with SCD by utilizing children's self-report of both constructs. The findings from this study suggest that prospective child-report of pain and quality of life are important to consider. In addition, it suggests that children's report of these measures should be included in pediatric intervention research involving children with SCD if changes in these constructs are of interest.

The central hypothesis of this study, that coping would moderate the relation between pain and quality of life, was not supported. Specifically, approach coping, problem-focused avoidance coping, and emotion-focused avoidance coping were not found to influence the relation between pain and overall quality of life in this sample of children with SCD. Thus, results from this study do not support the model linking pain, quality of life, and coping as

proposed by Merlijn et al. (2005). There are numerous reasons why the results from this study are inconsistent with past research. First, Merlijn and colleagues' (2003, 2005, 2006) model of pain, quality of life, and coping was based on research conducted with Dutch adolescents with non-specific chronic pain, such as headache, back pain, limb pain, and abdominal pain. Thus, participants in these studies differed in numerous ways. For example, participants in the current study experienced pain in the context of a chronic illness, whereas participants in the Merlijn et al. studies did not have a chronic illness. Also participants in the current study included children and adolescents ranging in age from 8 to 18 who predominately African American. Merlijn et al. targeted Dutch adolescents who were 12 to 18 years of age. Thus, developmental, racial/ethnic, and cultural differences might explain differences in findings between the studies. Second, measurement differences could have also contributed to the inconsistent findings. Merlijn and colleagues utilized a chronic pain specific quality of life measure, whereas this study utilized generic and disease-specific pediatric quality of life measures. In addition, the measures of pain between the studies also differed. This study utilized the PPQ (Varni & Thompson, 1985), whereas Merlijn et al. utilized a measure created by Perquin et al. (2000), but pain was assessed in similar ways across both measures (e.g., visual analogue scales). Yet, the same coping measure, the Pain Coping Questionnaire, was utilized in both studies, although it was translated into Dutch in the Merlijn and colleagues' studies.

However, when the relations between pain, specific domains of quality of life, and coping were further examined, results revealed a significant interaction between pain and approach coping on the SCD-specific emotional quality of life subscale. This finding suggests that approach coping moderates the relation between pain and SCD-specific emotional functioning and is consistent with the model proposed by Merlijn and colleagues. On the other hand, no other

significant interactions between pain and coping were found in this study, and this finding may be an artifact due to the high number of analyses conducted.

Significant relations between quality of life and emotion-focused avoidance coping, but not approach or problem-focused avoidance coping, were found in this study, with higher emotion-focused avoidance coping associated with lower quality of life. For example, children in this study who endorsed coping efforts that were ineffective at regulating their feelings when in pain also endorsed lower every day functioning. Thus, this finding suggests that emotion-focused avoidance coping in children with SCD is associated with poorer functioning.

This result is consistent with prior research conducted with adult patients with SCD. Anie et al. (2002) found that affective coping on the CSQ-SCD was associated with poorer quality of life on physical, social, and emotional domains of functioning; however, other types of coping, such as active coping and passive adherence were not associated with quality of life. Associations between quality of life and coping have also been found in adults with other chronic illnesses (e.g., cystic fibrosis; Abbott, Hart, Morton, Gee, & Conway, 2008). In adolescents with chronic pain, Merlijn et al. (2006) found that coping was associated with quality of life. Specifically, emotion-focused avoidance coping was negatively associated with psychological functioning and satisfaction with health, which were subscales on the chronic pain specific quality of life measure utilized. Results from this study were similar to the findings in the current study. Another study examined quality of life and coping in children with chronic illnesses (e.g., asthma, diabetes, and arthritis) and found associations between quality of life and types of coping (wishful thinking and distance on the Coping with a Disease measure; Petersen, Schmidt, Bullinger, & the DISABKIDS Group, 2006). Possible reasons for some of the contradictory findings are likely due to differences in participants and measures utilized in the

current and past studies. The lack of consistent definitions of coping and the multiple types of coping examined also further complicate efforts to compare findings specific to coping across studies. However, the current findings emphasize the importance of examining emotion-focused avoidance coping in children with SCD. Given the complexity of coping and the complex literature focusing on it, continued examination of pain, quality of life, and coping in children with SCD is warranted.

Gender Differences

Preliminary results from this study found that there were significant differences in quality of life between males and females with SCD. Specifically, males reported higher overall generic and disease-specific quality of life compared to females. This finding is consistent with a past study, which found that female gender predicted lower parent proxy report of quality of life in children with SCD (Palermo et al., 2002). A reason for the finding in the Palermo et al. (2002) study could be related to parents' differing perceptions between the everyday functioning of males and females with SCD. However, child report was examined in this study. Additionally, females in this study endorsed more pain compared to males. Although this difference was not statistically significant it is possible that the difference in quality of life may be accounted for by differences in pain. Given the gender differences in quality of life, primary analyses were also run separately in order to examine specific main effects of pain and coping, as well as the interaction between pain and coping for both genders.

Pain and emotion-focused avoidance coping were found to be important predictors of quality of life in both males and females. In addition, approach coping was a significant predictor of disease-specific school quality of life in both males and females. However, the directions of the relations were different; approach coping was negatively associated with quality of life in

boys but positively associated with quality of life in girls. For example, in boys with SCD asking questions about their disease-related pain and talking with others about their pain may be related to decreased school functioning but for girls these strategies are related to better school functioning. Therefore, approach coping might serve a protective function for girls but not boys in academic settings.

Potential reasons for this finding are numerous. However, gender socialization related to coping with painful experiences seems important to consider. Boys are typically taught that crying or reporting that they are in pain is not socially acceptable, whereas it is often more acceptable for girls to express pain via crying or talking with others. Gender differences in coping and social support have been found in adults (Gurung, 2006). Research with adults suggests that females are more likely to mobilize social support and are more engaged in social networks compared to males (Gurung, 2006). In addition, it has been suggested that girls may be more sensitive than boys to pain-reinforcing social contingencies (Dahlquist & Switkin, 2003), which could impact pain coping strategies, especially related to seeking support and talking about painful experiences. However, it is interesting that gender differences were found for approach coping and not problem- or emotion-focused avoidance in this sample of children with SCD. It is likely that important developmental and cultural factors are also playing a role in the coping strategies endorsed by children in this study. If similar gender differences in coping are found across studies, there may be implications for the design and implementation of coping interventions, where specific coping skills may be more appropriate to teach girls with SCD than boys with SCD.

Developmental Issues

A secondary aim of this study was to examine the relation between child age and the main outcome variables (e.g., pain, quality of life, coping). Contrary to expectations, age was not related to pain, quality of life, or coping in this study. This is inconsistent with the hypothesis that SCD pain-related complications are progressive in nature. In addition, it is not consistent with past research in healthy children, which suggests that symptoms of recurrent pain increase as children get older (Petersen, Brulin, & Bergstrom, 2006). However, the lack of correlations between age and pain may be explained by children with SCD becoming familiar with experiencing acute and chronic pain associated with the disease. For example, older children may not rate their pain experience as being as intense as younger children due to the number of pain episodes and disease complications they may have experienced. It may be that the perception of disease-related pain changes over time, which impacts the level of pain endorsement and accounts for the lack of age-related associations.

The lack of associations between child age and quality of life is also inconsistent with a prior study, which found that age and the physical functioning domain of quality of life in SCD were inversely related; however, this result was not found on the psychosocial functioning domain (Palermo et al., 2002). Finer grained analyses of age and domains of quality of life in SCD might be in order. Examining specific domains of quality of life (e.g., social, emotional, etc.) via longitudinal research studies would allow for more in-depth analyses of developmental changes. In addition, quality of life in the Palermo et al. (2002) study was based on parent report, whereas this study focused on child report of quality of life. Difference in reporters might also explain discrepancies between the two investigations.

The lack of associations between child age and coping is inconsistent with some findings but consistent with others. One study found that types of coping, such as emotion-focused coping, increase as children get older (Compas et al., 1992). In addition, Gil et al. (1991) found that in children with SCD passive adherence was positively correlated with child age. However, other studies have not found a significant relation between coping strategies and child age in pediatric SCD (Gil et al., 1997), which is similar to findings from this study. Continuing to examine the relation between coping strategies and child age is warranted. In addition, longitudinal research examining prospective changes in pain, quality of life, and coping is in order due to the progressive nature of SCD and the inconsistent findings from this and prior studies.

Racial Identity

This was one of the first studies to examine racial identity in children with SCD. Racial identity was found to be associated with overall quality of life and coping. Public regard, the extent to which a person feels others positively view African Americans (Sellers et al., 1997), was positively associated with higher generic and disease-specific overall quality of life in children with SCD. This finding is consistent with Bediako et al. (2007), which posited that positive racial identity in African American adults with SCD may be related to improved health. Thus, it appears that public regard may act as a protective factor for quality of life in children with SCD.

Centrality, whether race makes up an important part of an individual's self-concept (Sellers et al., 1997), was found to positively correlate with SCD-specific overall quality of life, where higher racial centrality was associated with higher quality of life. In addition, centrality was found to negatively correlate with approach coping. Thus, higher centrality, or race being a

more central part of one's self-concept, was associated with lower approach coping. Therefore, decreased information seeking, problem solving, seeking social support, and positive self-statements were associated with higher centrality. In addition, regard, or positive feelings about being Black, was positively associated with problem-focused avoidance coping. These findings suggest that racial identity may influence the strategies that children with SCD utilize to cope with disease-related pain.

This is one of the first studies to examine pain, quality of life, coping, and racial identity in children with SCD; thus, caution should be taken when interpreting findings. One study with adults with SCD found that higher centrality was associated with lower pain ratings (Bediako et al., 2007). The experiences of African Americans, such as experiencing racism and prejudice, could be a possible reason for the association between pain and racial identity. However, significant associations between racial identity and pain were not found in this study of children with SCD. This was one of the first attempts to examine cultural factors in children with SCD and has laid the initial groundwork to suggest that examining racial identity in this population is important. This study is also unique in that it examines racial identity in the context of a pediatric chronic illness. For example, having SCD, which primarily affects African Americans in the U.S., may impact the development of a child's racial identity. However, further research comparing racial identity in African American children with and without SCD may provide more information about the impact of SCD on racial identity. In addition, the environment in which children reported their racial identity is also important to consider. All children in this study were attending SCD clinics associated with a children's hospital in an urban city in the southeastern U.S. Health care providers at both clinics were both Caucasian and African American. It is possible that the medical clinic setting and/or the race or ethnicity of the primary health care

provider may have impacted children's report of racial identity. However, the racial identity findings from this study suggest that future research is needed to continue to investigate the relation between cultural factors and pain, quality of life, and coping, as well as other constructs, in pediatric patients with SCD.

Limitations

Despite the significant contributions of this study, caveats should be taken into account when interpreting results. First, the generalizability of the findings from this study is limited. Children in this study were attending a routine SCD-related medical visit; thus, these findings likely do not apply to children attending non-routine medical visits or those children experiencing acute pain crises. In fact, children participating in this study reported relatively low pain ratings. However, it is possible that different pain measures, such as pain diaries, may have been more sensitive. In addition, assessing pain on more than one occasion and following children for a specific period of time after their clinic visit may have revealed greater variability in pain ratings.

Second, this study found a significant association between pain and quality of life; however, the results are correlational in nature and a causal relation cannot be determined. It may be possible that pain experiences lead to decreased quality of life but it also possible that quality of life may impact pain experiences. For example, decreased physical functioning may make it more likely that children with SCD experience increased acute and chronic pain. Examining potential causal relations between pain and quality of life via longitudinal studies would be important and might lead to additional avenues of intervention. In addition, due to the correlational nature of this study it is possible that there may be an unaccounted variable (e.g., response bias, method variance, etc.) that may be influencing the constructs examined.

Third, no parent report measures of pain, quality of life, and coping were utilized in this study, which is a limitation. Given that parents are responsible for most medical decisions, such as administering pain medications or taking a child with SCD to the emergency room during an acute pain episode, it is clinically important to include parent report in pediatric research. In addition, obtaining parent report could increase our understanding of parent perceptions of the impact of pediatric SCD, as well as the relation between child and parent report of pain, quality of life, and coping. Future studies focusing on pediatric SCD would benefit from using multiple informants (e.g., child, parent, health care providers, etc.).

Fourth, to examine the main purpose of this study numerous hierarchical regression analyses were performed examining different types of coping, as well as examining different measures and domains of quality of life as the dependent variable. The number of analyses run in this study likely increased the chances of type I error, or finding a statistical difference when there is really not one. However, due to the paucity of research in the areas under investigation the number of analyses conducted seemed warranted.

Future Directions

To date, this is the first study to examine whether coping moderates the relation between pain and quality of life in children with SCD. Research focusing on the relation between pain and quality of life in children with SCD should continue to examine possible moderators impacting the relation. This study did not incorporate measures of spiritual or religious coping, which has been found to be important in African Americans with other types of chronic medical conditions (Christian & Barbarin, 2001). It would be important for future research to utilize these measures of coping in order to incorporate culturally sensitive measures of coping in research focusing on children with SCD. Future research is also needed to continue to identify effective

pain coping strategies so that interventions can be created to teach patients and their parents' strategies that have empirical evidence for reducing disease-related pain and increasing quality of life. For example, results from this study suggest that emotion-focused avoidance coping is inversely associated with quality of life. Therefore, teaching coping strategies that reduce the reliance on this type of coping strategy may lead to improvements in quality of life. However, there is a need for future research to confirm and expand the findings from this study.

Given that patients with SCD experience both acute and chronic pain, future research may benefit from examining the relation between quality of life and different types of pain separately. For example, it is possible that for children with SCD attending regularly scheduled clinic visits, chronic pain may be more likely to impact their quality of life, or everyday functioning. However, if a child is experiencing an acute pain episode and presenting to the emergency room it is likely that the impact of chronic pain is overshadowed by the impact of the acute pain episode. Assessing different types of pain longitudinally would also be valuable, as it could shed further light on the progressive nature of both acute and chronic pain in children with SCD.

Similar to examining other types of coping and specific types of pain, future research should continue to examine specific domains of quality of life in children with SCD. It is likely that acute and chronic pain differentially impact domains of quality of life. For example, acute pain episodes may negatively impact physical functioning in children with SCD but may not significantly impact other areas, such as social functioning. It is not clear how acute and chronic pain in children with SCD may predict different domains of quality of life or whether specific coping strategies may moderate the relation. Continuing to examine additional ways to measure quality of life in children with SCD is also warranted. Results from this study suggest adequate

reliability and concurrent validity of the SCD-QoL, a SCD-specific measure of quality of life. Continuing to examine its psychometric properties, as well as its associations with other constructs is warranted.

Future research should also continue to examine potential gender differences in pain, quality of life, and coping in children with SCD. This is especially important given findings from this study that there may be differential gender effects of coping types on quality of life. In addition, although age was not found to be associated with main variables in this study, continuing to examine developmental issues in this population is warranted, especially given the continued increase in life expectancy. Assessing pain, quality of life, and coping longitudinally in children with SCD would also be important. Longitudinal designs could provide further evidence for the causal relations between pain, quality of life, and coping and could provide important information about the progressive nature of SCD. Specifically, changes in pain, quality of life, and coping could be examined throughout the development of children with SCD, which could help physicians and psychologists better understand potential developmental issues patients experience, as well allow them to address developmental needs of children with SCD and their families. In addition, future research could examine the interaction between age and gender. For example, it would be interesting to investigate pain, quality of life, coping and racial identity in adolescent females. Adolescence would especially be an important age for further research due to the physical, cognitive, and emotional changes that occur during puberty. Also it may be likely that the pain experiences of adolescent females with SCD are qualitatively and quantitatively different compared to adolescent males with SCD due to menstruation and other physiological changes that accompany puberty.

Future studies focusing on children with SCD should continue to conduct culturally sensitive research and include cultural factors into their study designs (Clay et al., 2002; Kaslow et al., 1997; Kaslow et al., 2000); especially given findings from this study that indicate that racial identity is associated with quality of life and coping. Including racial identity and other cultural factors in future SCD-focused research can provide valuable information about this population (Bediako et al., 2007), which is an area that has largely been overlooked in both adult and pediatric SCD research. Further examining the racial experiences of adults and children with SCD would also be important. For example, there is little information about how perceived racism and prejudice may impact stress and pain-related symptoms in patients with SCD despite data suggesting that racism impacts the psychological and physical health of African Americans (Clark et al., 1999). It would also be interesting to examine whether the race or ethnicity of the health care provider may be related to cultural factors, as well as psychosocial functioning in children with SCD. In addition, researchers can begin to empirically identify cultural factors that may be important to include in culturally sensitive interventions (Clay et al., 2002; Kaslow et al., 1997; Kaslow et al., 2000; Schwartz, Radcliffe, & Barakat, 2007). Another area of future research could also investigate how cultural variables, such as racial identity, may influence health beliefs and health behaviors, such as adherence, in children with SCD and their parents.

Given that the cultural context of SCD is important to consider, future researchers should also consider the family context in children with SCD (Kazak, 2008). This can be accomplished by including parent report about child pain, coping, and quality of life, as well as focusing on what impact having a child with SCD places on the parental and family systems. In fact, one recent study found that coping and family functioning were positively associated (Mitchell, Lemanek, Palermo, Crosby, Nichols, & Powers, 2007). Continuing to examine family

functioning, as well as parenting stress, and the quality of the parent-child relationship would further our knowledge about the context of pediatric SCD. Studying cultural factors in families of children with SCD is also important, as racial identity is likely modeled by parents, making African American families a primary source of racial socialization for children (Radcliffe, Barakat, & Boyd, 2006). In addition, given that SCD primarily affects African Americans and runs in families it would be important to consider how cultural factors influence perceptions of SCD by patients, families, and health care providers.

An additional area of future research is the inclusion of qualitative research methods in studies focusing on children with SCD. Qualitative research could further evaluate pain, quality of life, and coping, as well as allow for the qualitative examination of gender, cultural, and family factors. For example, research examining coping in other pediatric chronic illnesses has utilized vignettes where children and parents describe how they would handle specific generic and disease-specific problem situations (Quittner, Tolbert, Regoli, Orenstein, Hollingsworth, & Eigen, 1996). Answers provided by children and parents can then be qualitatively evaluated for content and effectiveness. However, quantitative measures of coping using this strategy have also been developed (Quittner et al., 1996) but have not been created or used in research focusing on children with SCD. To qualitatively examine family functioning, family narratives may be interesting to pursue in families with a child with SCD. Family narratives are a form of story telling which can facilitate children's understanding and evaluation of their personal and family past and have been found to be related to sense of self in adolescents (Bohanek, Marin, Fivush, & Duke, 2006). Therefore, there are numerous qualitative methods that may be helpful in continuing to examine the psychosocial functioning of children with SCD and their families.

In conclusion, this study examined pain, quality of life, and coping in children with SCD. In addition, developmental and cultural factors were examined. This study revealed that pain and emotion-focused avoidance coping were inversely associated with quality of life, but in general did not find that coping moderated the relation between pain and quality of life. Also, racial identity was found to be associated with both quality of life and coping. Results from this study highlight a number of future endeavors in the study of the psychosocial functioning of children with SCD.

REFERENCES

Abbott, J., Hart, A., Morton, A., Gee, L., & Conway, S. (2008). Health-related quality of life in adults with cystic fibrosis: The role of coping. *Journal of Psychosomatic Research, 64,* 149-157.

Abbott, J., Webb, K., & Dodd, M. (1997). Quality of life in cystic fibrosis. *Journal of the Royal Society of Medicine, 90,* 37-42.

Aiken, L. S. & West, S. G. (1991). *Multiple Regression: Testing and Interpreting Interactions.* Thousand Oaks, CA: Sage Publications.

Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology, 129,* 723-729.

Anie, K. A., Steptoe, A., Ball, S., Dick, M., & Samlling, B. M. (2002). Coping and health service utilization in a UK study of paediatric sickle cell pain. *Archives of Disease in Childhood, 86,* 325-329.

Anie, K. A., Steptoe, A., & Bevan, D. H. (2002). Sickle cell disease: Pain, coping and quality of life in a study of adults in the UK. *British Journal of Health Psychology, 7,* 331-344.

Annett, R. D. (2001). Assessment of health status and quality of life outcomes for children with asthma. *Journal of Allergy and Clinical Immunology, 107,* S473-S481.

Ballas, S. K. (1998). *Progress in Pain Research and Management, Vol. 11 Sickle Cell Pain.* Seattle, WA: IASP Press.

Barakat, L. P., Lutz, M. J., Nicolaou, D. C., & Lash, L. A. (2005). Parental locus of control and family functioning in the quality of life of children with sickle cell disease. *Journal of Clinical Psychology in Medical Settings, 12,* 323-331.

Barakat, L. P., Simon, K., Schwartz, L. A., and Radcliffe, J. (2008). Correlates of pain-rating concordance for adolescents with sickle cell disease and their caregivers. *Clinical Journal of Pain, 24,* 438-446.

Barbarin, O. A. (1999). Do parental coping, involvement, religiosity, and racial identity mediate children's psychological adjustment to sickle cell disease? *Journal of Black Psychology, 25,* 391-426.

Barbarin, O. A. & Christian, M. (1999). The social and cultural context of coping with sickle cell disease: I. A review of biomedical and psychosocial issues. *Journal of Black Psychology, 25,* 277-293.

Bediako, S. M., Lavender, A. R., & Yasin, Z. (2007). Racial centrality and health care use among African American adults with sickle cell disease. *Journal of Black Psychology, 33,* 422-438.

Bernard, R. S., Cohen, L. L., McClellan, C. B., & MacLaren, J. E. (2004). Pediatric procedural approach-avoidance coping and distress: A multitrait-multimethod analysis. *Journal of Pediatric Psychology, 29,* 131-141.

Blount, R. L., Simons, L. E., Devine, K. A., Jaaniste, T., Cohen, L. L., Chambers, C. T. et al. (2008). Evidence-based assessment of coping and stress in pediatric psychology. *Journal of Pediatric Psychology, 33,* 1021-1045.

Bohanek, J. G., Marin, K. A., Fivush, R., & Duke, M. P. (2006). Family narrative interaction and children's sense of self. *Family Process, 45,* 39-54.

Brown, R. T., Mulhern, R. K., & Simonian, S. (2002). Diseases of the blood and blood-forming organs. In T. J. Boll (Ed.-in-chief) & S. B. Johnson, N. W. Perry, Jr., & R. H. Rozensky (Volume Eds.), *Handbook of Clinical Health Psychology, Vol. 1 Medical Disorders and Behavioral Applications* (pp. 101-141). Washington, D.C.: American Psychological Association.

Cano, A., Mayo, A., & Ventimiglia, M. (2006). Coping, pain severity, interference, and disability: The potential mediating and moderating roles of race and education. *The Journal of Pain, 7,* 459-468.

Chavez, A. F., & Guido-DiBrito, F. (1999). Racial and ethnic identity and development. *New Directions for Adult and Continuing Education, 84,* 39-47.

Christian, M. D., & Barbarin, O. A. (2001). Cultural resources and psychological adjustment of African American children: Effects of spirituality and racial attribution. *Journal of Black Psychology, 27,* 43-63.

Claar, R. L., & Walker, L. S. (2006). Functional assessment of pediatric pain patients: Psychometric properties of the functional disability inventory. *Pain, 121,* 77-84.

Clark, R., Anderson, N. B., Clark, V. R., & Williams, D. R. (1999). Racism as a stressor for African Americans. *American Psychologist, 54,* 805-816.

Clay, D. L., Mordhorst, M. J., & Lehn, L. (2002). Empirically supported treatments in pediatric psychology: Where is the diversity? *Journal of Pediatric Psychology, 27,* 325-337.

Cohen, L. L., Lemanek, K., Blount, R. L., Dahlquist, L. M., Lim, C. S., Palermo, T. M. et al. (2008). Evidence-based assessment of pediatric pain. *Journal of Pediatric Psychology, 33,* 939-955.

Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H., & Wadsworth, M. E. (2001). Coping with stress during childhood and adolescence: Problems, progress, and potential in theory and research. *Psychological Bulletin, 27,* 87-217.

Compas, B. E., Worsham, N. L., & Ey, S. (1992). Conceptual and developmental issues in children's coping with stress. In A. M. LaGreca, L. J. Siegel, J. L. Wallander, & C. E. Walker (Eds.), *Stress and Coping in Child Health* (pp. 7-24). New York: Guilford.

Conner-Warren, R. L. (1996). Pain intensity and home pain management of children with sickle cell disease. *Issues in Comprehensive Pediatric Nursing, 19,* 183-195.

Coons, S. J., & Kaplan, R. M. (1992). Assessing health-related quality of life: Application to drug therapy. *Clinical Therapeutics, 14,* 850-858.

Craig, K. D., & Riddell R. P. (2003). Social influences, culture and ethnicity. In G. A. Finley & P. J. McGrath (Eds.), *Pediatric pain: Biological and social context* (pp. 159-182). Seattle: IASP Press.

Dahlquist, L. M., & Switkin, M. C. (2003). Chronic and recurrent pain. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology* (pp. 198-215). New York: Guilford Press.

Edwards, R. R., Moric, M., Husfeldt, B., Buvanendran, A., & Ivenkovich, O. (2005). Ethnic similarities and differences in the chronic pain experience: A comparison of African American, Hispanic, and White Patients. *Pain Medicine, 6,* 88-98.

Eiser, C. & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research*, 10, 347-357.

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology, 30,* 571-579.

Fuggle, P., Shand, P. A., Gill, J. L., & Davies, S. C. (1996). Pain, quality of life, and coping in sickle cell disease. *Archives of Disease in Childhood, 75,* 199-203.

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

Gil, K. M., Edens, J. L., Wilson, J. J., Raezer, L. B., Kinney, T. R., Schultz, W. H., et al. (1997). Coping strategies and laboratory pain in children with sickle cell disease. *Annals of Behavioral Medicine, 19,* 22-29.

Gil, K. M., Porter, L., Ready, J., Workman, E., Sedway, J., & Anthony, K. K. (2000). Pain in children and adolescents with sickle cell disease: An analysis of daily pain diaries. *Children's Health Care, 29,* 225-241.

Gil, K. M., Williams, D. A., Thompson, R. J., & Kinney, T. R. (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.

Gil, K. M., Wilson, J. J., & Edens, J. L. (1997). The stability of pain coping strategies in young children, adolescents, and adults with sickle cell disease over an 18-month period. *The Clinical Journal of Pain, 13,* 110-115.

Graumlich, S. E., Powers, S. W., Byars, K. C., Schwarber, L. A., Mitchell, M. J. & Kalinyak, K. A. (2001). Multidimensional assessment of pain in pediatric sickle cell disease. *Journal of Pediatric Psychology, 26*, 203-214.

Guntlett-Gilbert, J., & Eccleston, C. (2007). Disability in adolescents with chronic pain: Patterns and predictors across different domains of functioning. *Pain, 131,* 132-141.

Gurung, R. A. (2006). *Health psychology: A cultural approach*. Belmont, CA: Thomson Wadsworth.

Helms, J. E. (1993). Introduction: Review of racial identity terminology. In J. E. Helms (Ed.) *Black and White Racial Identity: Theory, Research and Practice* (pp. 3-9). Westport, CT: Praeger.

Holmbeck, G. N. (2002). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27,* 87-96.

Ingersoll, G. M. & Marrero, D. G. (1991). A modified quality-of-life measure for youths: Psychometric properties. *The Diabetes Educator, 17 (2),* 114-118.

Juniper, E. F., Guyatt, G. H., Feeny, D. H., Ferrie, P. J., Griffith, L. E. & Townsend, M. (1996). Measuring quality of life in children with asthma. *Quality of Life Research, 5,* 35-46.

Kashikar-Zuck, S., Vaught, M. H., Goldschneider, K. R., Graham, T. B., & Miller, J. C. (2002). Depression, coping, and functional disability in juvenile primary fibromyalgia syndrome. *The Journal of Pain, 3,* 412-419.

Kaslow, N. J., Collins, M. H., Loundy, M. R. Brown, F., Hollins, L. D., & Eckman, J. (1997). Empirically validated family interventions for pediatric psychology: Sickle cell disease as an exemplar. *Journal of Pediatric Psychology, 22,* 213-227.

Kaslow, N. J., Collins, M. H., Rashid, F. L., Baskin, M. L., Griffith, J. R., Hollins, L., et al. (2000). The efficacy of a pilot family psychoeducational intervention for pediatric sickle cell disease. *Families, Systems & Health, 18,* 381-404.

Kazak, A. E. (2008). Commentary: Progress and challenges in evidence-based family assessment in pediatric psychology. *Journal of Pediatric Psychology, 33,* 1062-1064.

Kudadjie-Gyamfi, E., Consedine, N. A., & Magai, C. (2006). On the importance of being ethnic: Coping with the threat of prostate cancer in relation to prostate cancer screening. *Cultural Diversity and Ethnic Minority Psychology, 12,* 509 –526.

Kudadjie-Gyamfi, E. & Magai, C. (2008). The influence of coping styles on mammography screening in a multiethnic sample. *Cultural Diversity and Ethnic Minority Psychology, 14,* 183–192.

Landgraf, J. M., Abetz, L., & Ware, J. E. (1996). Child health questionnaire (CHQ): A user's manual (1st Ed.). Boston, M.A.: The Health Institute, New England Medical Center.

Lasch, K. E. (2000). Culture, pain, and culturally sensitive pain care. *Pain Management Nursing, 1,* 16-22.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Lemanek, K. L., Ranalli, M. A., Green, K., Biega, C., & Lupia, C. (2003). Diseases of the Blood: Sickle Cell Disease and Hemophilia. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology,* 3rd edition, (pp. 321-341). New York: Guilford Press.

McClellan, C. B., Schatz, J., Sanchez, C., & Roberts, C. W. (2008). Validity of the pediatric quality of life inventory for youth with sickle cell disease. *Journal of Pediatric Psychology, 33,* 1153-1162.

McClish, D. K., Penberthy, L. T., Bovbjerg, V. E., Roberts, J. D., Aisiku, I. P., Levenson, J. L. et al. (2005). Health related quality of life in sickle cell patients: The PiSCES project. *Health and Quality of Life Outcomes, 3,* 50-56.

McGrath, P. A. (1990). *Pain in children: Nature, assessment, and treatment.* New York: Guilford.

Merlijn, V. P., Hunfield, J. A., van der Wouden, J. C., Hazenbroek-Kampscheur, A. A., Koes, B. W., & Passchier, J. (2003). Psychosocial factors associated with chronic pain in adolescents. *Pain, 101*, 33-43.

Merlijn, V. P., Hunfeld, J. A., van der Wouden, J. C., Hazebroek-Kampschreur, A. A., van Suijlekom-Smit, L. W., Koes, B. W. et al. (2005). A cognitive behavioural program for adolescents with chronic pain – A pilot study. *Patient Education and Counseling, 59,* 126-134.

Merlijn, V. P., Hunfield, J. A., van der Wouden, J. C., Hazenbroek-Kampscheur, A. A., Passchier, J., & Koes, B. W. (2006). Factors related to the quality of life in adolescents with acute pain. *Clinical Journal of Pain, 22,* 306-315.

Mitchell, M. J., Lemanek, K., Palermo, T. M., Crosby, L. E., Nichols, A., & Powers, S. W. (2007). Parent perspectives on pain management, coping, and family functioning in pediatric sickle cell disease. *Clinical Pediatrics, 46,* 311-319.

Palermo, T. M., Long, A. C., Lewandowski, A. S., Drotar, D., Quittner, A. L., & Walker, L. S. (2008). Evidence-based assessment of health-related quality of life and functional impairment in pediatric psychology. *Journal of Pediatric Psychology, 33,* 983-996.

Palermo, T. M., Schwartz, L., Drotar, D., & McGowan, K. (2002). Parental report of health-related quality of life in children with sickle cell disease. *Journal of Behavioral Medicine, 25*, 269-283.

Panepinto, J. A., O'Mahar, K. M., DeBaun, M. R., Loberiza, F. R., & Scott, J. P. (2005). Health-related quality of life in children with sickle cell disease: Child and parent perception. *British Journal of Haematology, 130*, 437-444.

Perquin, C. W., Hazebroek-Kampschreur, A. A., Hunfeld, J. A., Bohnen, A. M., van Suijlekom-

Smit, L. W., Passchier, J. et al. (2000). Pain in children and adolescents: A common experience. *Pain, 87,* 51-58.

Petersen, C., Schmidt, S., Bullinger, M., & the DISABKIDS Group. (2006). Coping with a pediatric health condition and health-related quality of life. *European Psychologist, 11,* 50-56.

Petersen, S., Brulin, C., & Bergstrom, E. (2006). Recurrent pain symptoms in young school children are often multiple. *Pain, 121*, 145-150.

Peterson, C. C. & Palermo, T. M. (2004). Parental reinforcement of recurrent pain: The moderating impact of child depression and anxiety on functional disability. *Journal of Pediatric Psychology, 29,* 331-341.

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

Quittner, A. L. (1998). Measurement of quality of life in cystic fibrosis. *Current Opinion in Pulmonary Medicine, 4,* 326-331.

Quittner, A. L., Davis, M. A., & Modi, A. C. (2003). Health-related quality of life in pediatric populations. In M. Roberts (Ed.), *Handbook of Pediatric Psychology,* (pp. 696-709). New York: Guilford Publications.

Quittner, A. L., Tolbert, V. E., Regoli, M. J., Orenstein, D. M., Hollingsworth, J. L., & Eigen, H. (1996). Development of the role-play inventory of situations and coping strategies for parents of children with cystic fibrosis. *Journal of Pediatric Psychology, 21,* 209-235.

Radcliffe, J., Barakat, L. P., & Boyd, R. C. (2006). Family systems issues in pediatric sickle cell disease. In R. T. Brown (Ed.), *Comprehensive handbook of childhood cancer and sickle*

cell disease: A biopsychosocial approach, (pp. 496-513). New York: Oxford University Press.

Reid, G. J., Gilbert, C. A., & McGrath, P. J. (1998). The Pain Coping Questionnaire: Preliminary validation. *Pain, 76,* 83-96.

Rowley, S. J., Sellers, R. M., Chavous, T. M., & Smith, M. A. (1998). The relationship between racial identity and self-esteem in African American college and high school students. *Journal of Personality & Social Psychology, 1998,* 715-724.

Rudolph, K. D., Dennig, M. D., & Weisz, J. R. (1995). Determinants and consequences of children's coping in the medical setting: Conceptualization, review, and critique. *Psychological Bulletin, 118,* 328-357.

Schecter, N. L. (1999). The management of pain in sickle cell disease. In P. J. McGrath and G. A. Finley (Eds.) *Chronic and Recurrent Pain in Children and Adolescents*, Vol. 13, pp. 99-114. Seattle: IASP Press.

Schwartz, L. A., Radcliffe, J., & Barakat, L. P. (2007). The development of a culturally sensitive pediatric pain management intervention for African American adolescents with sickle cell disease. *Children's Healthcare, 36,* 267-283.

Sellers, R. M., Rowley, S. A. J., Chavous, T. M., Shelton, J. N., & Smith, M. A. (1997). Multidimensional Inventory of Black Identity: A preliminary investigation of reliability and construct validity. *Journal of Personality and Social Psychology, 73*, 805-815.

Sellers, R. M., Smith, M. A., Shelton, J. N., Rowley, S. A. J., & Chavous, T. M. (1998). Multidimensional Model of Racial Identity: A reconceptualization of African American racial identity. *Personality and Social Psychology Review, 2,* 18-39.

Shapiro, B. S. (1993). Management of painful episodes in sickle cell disease. In N. L. Schechter, C. B. Berde, & M. Yester (Eds.), *Pain in infants, children, and adolescents* (pp. 385-410). Baltimore, MD: Williams & Wilkins.

Shapiro, B. S., Dinges, D. F., Orne, E. C., Bauer, N., Reilly, L. B., Whitehouse, W. G. et al. (1995). Home management of sickle cell-related pain in children and adolescents: Natural history and impact on school attendance. *Pain, 61,* 139-144.

Sickle Cell Disease Association of America. Frequently Asked Questions. (2005). Retrieved September 18, 2005, from http://www.sicklecelldisease.org/about_scd/faqs.phtml

Stegenga, K. A., Ward-Smith, P., Hinds, P. S., Routhieaux, J. A., & Woods, G. M. (2004). Quality of life among children with sickle cell disease receiving chronic transfusion therapy. *Journal of Pediatric Oncology Nursing, 21,* 207-213.

Tan, G., Jensen, M. P., Thornby, J., & Anderson, K. O. (2005). Ethnicity, control appraisal, coping, and adjustment to chronic pain among black and white Americans. *Pain Medicine, 6,* 18-28.

Thomas, V. J., & Taylor, L. M. (2002). The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups. *British Journal of Health Psychology, 7,* 345-363.

Thompson, R. J. & Gustafson, K. E. (1996). *Adaptation to childhood chronic illness*. Washington, D.C.: American Psychological Association.

Van Slyke, D. A. & Walker, L. S. (2006). Mothers' responses to children's pain. *Clinical Journal of Pain, 22,* 387-391.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the

pediatric quality of life inventory™ version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39,* 800-812.

Varni, J., & Thompson, K. (1985). *The Varni/Thompson Pediatric Pain Questionnaire.* Unpublished manuscript.

Varni, J., Thompson, K., & Hanson, V. (1987). The Varni/Thompson Pediatric Pain Questionnaire. I. Chronic musculoskeletal pain in juvenile rheumatoid arthritis. *Pain,* 28, 27-38.

Varni, J. W., Walco, G. A., & Wilcox, K. T. (1990). Cognitive-biobehavioral assessment and treatment of pediatric pain. In A. M. Gross & R. S. Drabman (Eds.), *Handbook of clinical behavioral pediatrics*, pp. 83-97. New York: Plenum Press.

Walco, G., & Dampier, C. (1990). Chronic pain in adolescent patients. *Journal of Pediatric Psychology, 12,* 215-225.

Ware, J. E., & Sherbourne, C. (1992). The MOS 36 item short-form health survey (SF-36) 1: Conceptual framework and item selection. *Medical Care, 30*, 473–483.

APPENDIX A

Background Information Form

Sickle Cell Disease (SCD) Background Information

Questions about the Family

1. Your Relation to Child: ___Mother ___Father ___Grandparent If other, describe: _____

2. Your Gender: ___Male ___Female

3. Your Age: ____

4. Your Ethnicity: ___Hispanic or Latino ___Not Hispanic or Latino

5. Your Race: ___American Indian or Alaska Native ___Asian ___Black or African American ___Native Hawaiian or Other Pacific Islander ___White

6. The highest education level you completed (Please write a number. For example, 8 = completed middle school, 10 = completed sophomore year of high school, 12 = graduated high school, 13 = completed freshman year of college, 16 = graduated college): _____

7. Please describe your occupation: _____

8. Your Marital Status: ___Single ___Married/Partnered ___Separated ___Divorced ___Widowed If other, please describe: _____

9. The highest education level your spouse/partner completed (Please write a number. For example, 10 = completed sophomore year of high school, 12 = graduated high school, 13 = completed freshman year of college, 16 = graduated college): ___

10. Please describe your spouse/partner's occupation: _____

11. Please circle your approximate total family income per year:
    a. Up to $10,000
    b. $10,001 – 20,000
    c. $20,001 – 30,000
    d. $30,001 – 40,000
    e. $40,001 – 50,000
    f. $50,001 – 60,000
    g. $60,001 – 70,000
    h. $70,001 – 80,000
    i. $80,001 – 90,000
    j. $90,000 and above

12. Do you have a chronic medical condition (e.g., asthma, SCD, diabetes, etc.)? YES NO
    If so, what kind(s) _____

13. Does your spouse/partner have a chronic medical condition? YES NO
    If so, what kind(s) _____

14. Have you been diagnosed with a psychological disorder (i.e., anxiety, depression, etc.)?
YES NO
If so, what _____

15. Has your spouse/partner been diagnosed with a psychological disorder? YES NO
If so, what _____

Questions about the Child

16. Child's Gender: ___Male ___Female

17. Child's Age: ____ yrs. ____ mos.

18. Child's Ethnicity: ___Hispanic or Latino ___Not Hispanic or Latino

19. Child's Race: ___American Indian or Alaska Native ___Asian ___Black or African American ___Native Hawaiian or Other Pacific Islander ___White

20. How many *other children* live in the home? ___ What are their ages? _____
How many children in the home have SCD? _____ How many do not have SCD? _____

21. How many *other adults* live in the home? _____ What are their ages? _____

22. What type of SCD does your child have? _____

23. Does your child have a chronic illness or medical condition besides SCD (e.g., asthma, diabetes)?
YES NO If so, what? _____

24. Has your child been diagnosed with a psychological disorder (i.e., anxiety, depression, etc.)?
YES NO If so, what _____

25. What medication(s) is your child prescribed?
_____

26. Who is responsible for making sure your child takes their medication (i.e., you, child)?
_____

27. When was your child's last SCD related clinic visit? _____

28. When was your child's last SCD related hospitalization? _____

29. How many SCD related pain crises does your child usually experience in one year?
_____

30. What major complications has your child experienced related to SCD (i.e., strokes, etc.)?
    _____

31. How many days of school has your child missed due to SCD symptoms in the past school year? _____

32. How many days of work have you missed due to your child's SCD symptoms in the past year? _____

33. Would you be willing to allow us to keep you and your child's contact information for follow-up or future research projects? YES NO
    If YES, please provide your contact information below:

    Your Name: _____ Phone #: _____

    Address: _____

    _____

APPENDIX B

Pediatric Pain Questionnaire (PPQ)

PedsQL™

Pediatric Pain Questionnaire™

Child Form (**8-12** years of age)

Name: _____

Date: _____ **Record Number:** _____

What words would you use to describe your pain or hurt?

_____

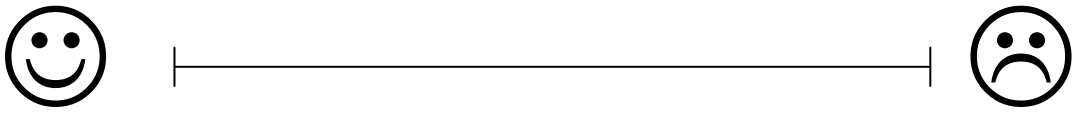
_____

1. Put a mark on the line that best shows **how you feel now.** If you have no pain or hurt, you would put a mark at the end of the line by the happy face. If you have some pain or hurt, you would put a mark near the middle of the line. If you have a whole lot of pain or hurt, you would put a mark by the sad face.

Not hurting
No discomfort
No pain

Hurting a whole lot
Very uncomfortable
Severe Pain

2. Put a mark on the line that best shows what was the **worst pain you had this week.** If you had no pain or hurt this week, you would put a mark at the end of the line by the happy face. If you had some pain or hurt, you would put a mark by the middle of the line. If the worse pain you had was a whole lot of pain, you would put a mark by the sad face.

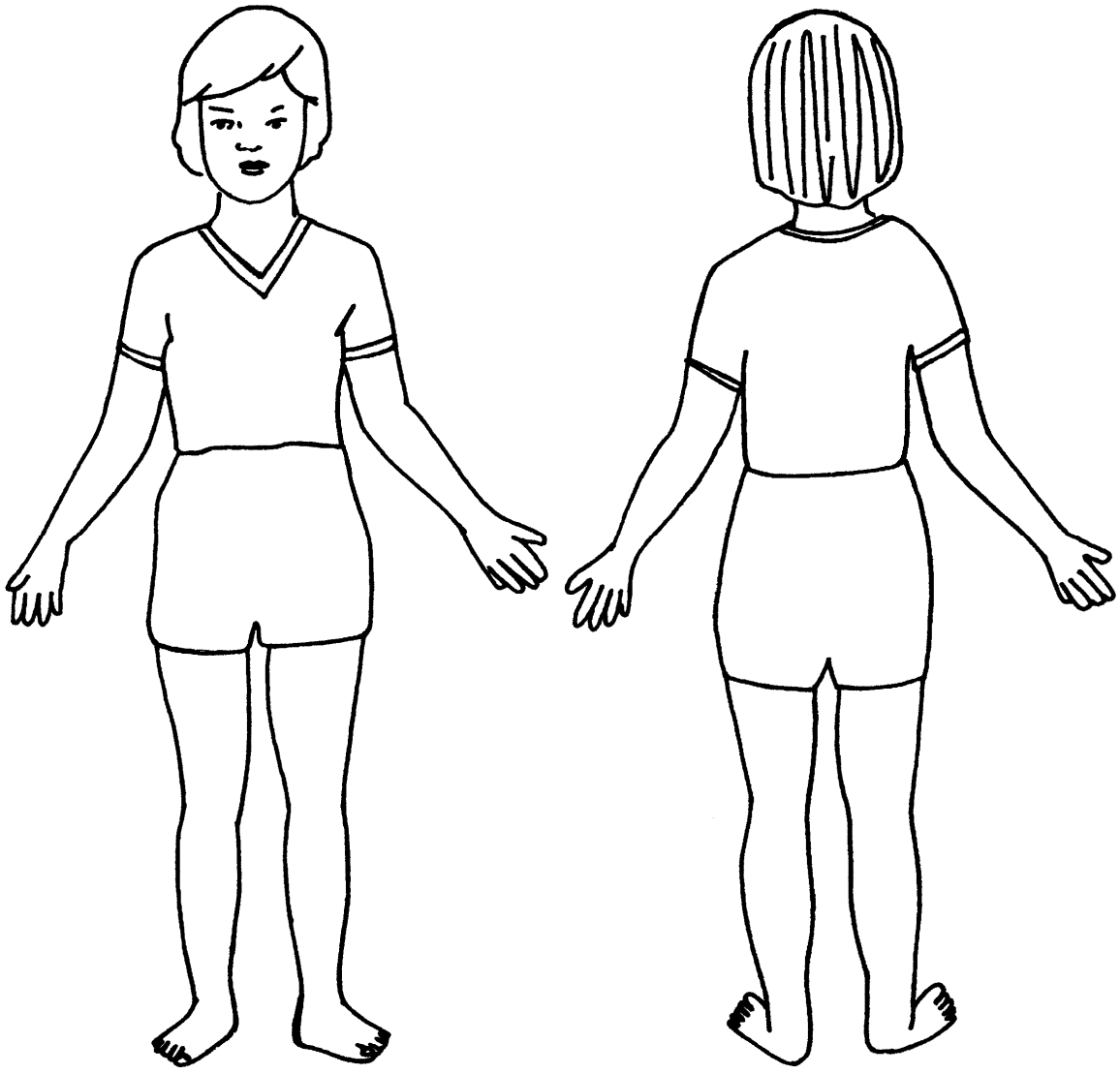


Not hurting
No discomfort
No pain

Hurting a whole lot
Very uncomfortable
Severe Pain

Pick the colors that mean **No hurt, A little hurt, More hurt,** and **A lot of hurt** to you and color in the boxes. Now, using these colors, color in the body to show how you feel. Where you have no hurt, use the **No hurt** color to color in your body. If you have hurt or pain, use the color that tells how much hurt you have.

No pain No hurt	Mild pain A little hurt	Moderate pain More hurt	Severe pain A lot of hurt



Front Back

PedsQL™

Pediatric Pain Questionnaire™

Teen Form (**13-18** years of age)

Name: _____

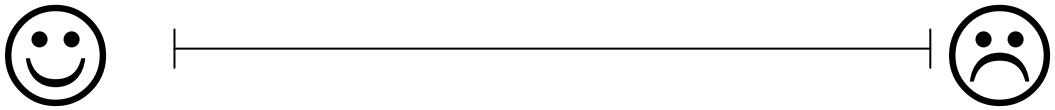
Date: _____ **Record Number:** _____

What words would you use to describe your pain or hurt?

_____

_____

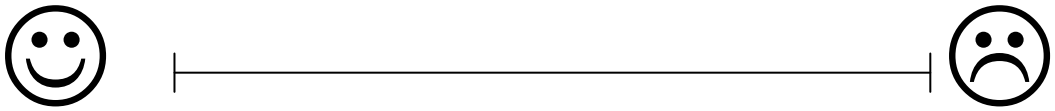
1. Put a mark on the line that best shows **how you feel now.** If you have no pain or hurt, you would put a mark at the end of the line by the happy face. If you have some pain or hurt, you would put a mark near the middle of the line. If you have a whole lot of pain or hurt, you would put a mark by the sad face.



Not hurting
No discomfort
No pain

Hurting a whole lot
Very uncomfortable
Severe Pain

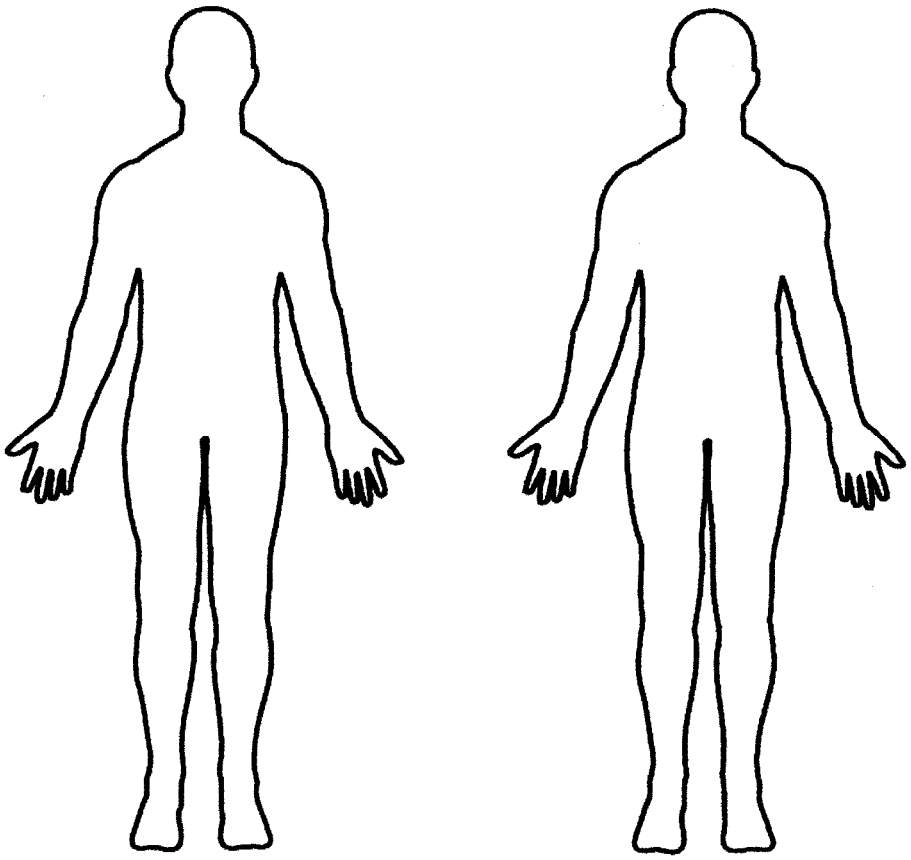
2. Put a mark on the line that best shows what was the **worst pain you had this week.** If you had no pain or hurt this week, you would put a mark at the end of the line by the happy face. If you had some pain or hurt, you would put a mark by the middle of the line. If the worse pain you had was a whole lot of pain, you would put a mark by the sad face.



Not hurting
No discomfort
No pain

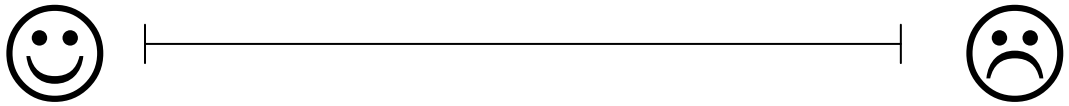
Hurting a whole lot
Very uncomfortable
Severe Pain

Please mark an **X** on the **exact** place where you are having pain now. If there is more than one painful place, mark them ‘1’, ‘2’, ‘3’, etc., starting with the most painful place as ‘1’.



Sickle Cell Pain

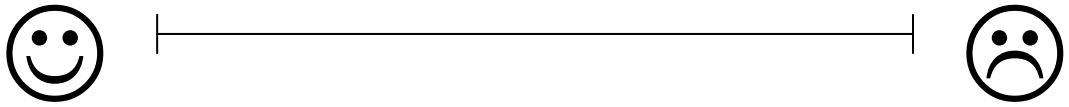
1. What was the **general or normal pain you had this week**?



No hurting
No discomfort
No pain

Hurting a whole lot
Very uncomfortable
Severe Pain

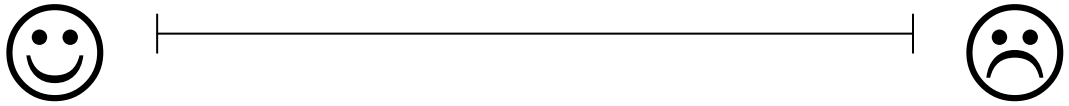
2. Compared to **other kids with sickle cell**, my pain is usually:



Better

Worse

3. Compared to **other kids without sickle cell**, my pain is usually:



Better

Worse

4. About how many pain crises do you usually have in a month? _____

APPENDIX C

Pediatric Quality of Life Inventory (PedsQL)

ID# _____

Date:_____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

CHILD REPORT (ages **8-12**)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

About My Health and Activities (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

About My Feelings (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I Get Along with Others (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

About School (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

ID# _____

Date:_____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

TEEN REPORT (ages **13-18**)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

About My Health and Activities (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

About My Feelings (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I Get Along with Others (PROBLEMS WITH)	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

About School (PROBLEMS WITH…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

APPENDIX D

Sickle Cell Disease Quality of Life (SCD-QoL)

Sickle Cell Disease Quality of Life (SCD-QoL)

These questions are for children like you who have sickle cell disease. Your answers will help us understand what this disease is like and how your treatments help you. Answering these questions will help you and others like you in the future.

There are no right or wrong answers! If you are not sure how to answer, choose the response that seems closest to you.

During the past two weeks:

	Always	**Often**	**Some-times**	**Never**
1. I felt a sharp pain ……	☐	☐	☐	☐
2. I felt uncomfortable ……	☐	☐	☐	☐
3. I had trouble listening in class …….....	☐	☐	☐	☐
4. I felt out of control ……	☐	☐	☐	☐
5. I had difficulty controlling my pain	☐	☐	☐	☐
6. I was able to engage in normal activities with friends ……	☐	☐	☐	☐
7. I took all of my medication ……	☐	☐	☐	☐
8. I felt tired ……	☐	☐	☐	☐
9. I had low energy …….....	☐	☐	☐	☐
10. I could not play when I wanted to …….....	☐	☐	☐	☐
11. I was able to run and jump …….	☐	☐	☐	☐
12. I felt stressed ……..	☐	☐	☐	☐

	Always	Often	Some-times	Never
13. I spent time with friends ……	☐	☐	☐	☐
14. I felt sad …….	☐	☐	☐	☐
15. I felt a dull, soft pain ……..	☐	☐	☐	☐
16. I felt worried ……..	☐	☐	☐	☐
17. I felt mad ……...	☐	☐	☐	☐
18. I felt good about myself …….....	☐	☐	☐	☐
19. I had trouble falling asleep ……	☐	☐	☐	☐
20. I was treated differently by my teachers …..	☐	☐	☐	☐
21. I felt happy ……	☐	☐	☐	☐
22. I was teased by other kids …….	☐	☐	☐	☐
23. I missed school ……..	☐	☐	☐	☐
24. I thought I was physically different from others my age …….....	☐	☐	☐	☐
25. I couldn't keep up with my school work …..	☐	☐	☐	☐
26. I felt pressure from my friends ……..	☐	☐	☐	☐
27. I was sent home early or missed school because I was sick or in pain……..	☐	☐	☐	☐
28. I was able to participate in sports I like	☐	☐	☐	☐

THANK YOU FOR YOUR TIME!!

APPENDIX E

Pain Coping Questionnaire (PCQ)

Age (*in years*) _____ Sex (*circle*): Male Female Grade _____

COPING WITH PAIN (PCQ)

Everyone has had a time when they have been hurt or in pain for a few hours or longer. For example, you might have had a headache, a stomach ache, a bad muscle pull, pain in your joints (elbow, knee), back pain, an earache, or, for women, menstrual pain, etc. Below are some things that people might say, do, or think when they are hurt or in pain. We are interested in the things you do when you are in pain for a few hours or days.

Circle one number for each question to show how often you do each thing listed:

1=never, 2=hardly ever, 3=sometimes, 4=often, or 5=very often.

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...	*Never*	*Hardly ever*	*Sometimes*	*Often*	*Very often*
1) Ask questions about the pain.	1	2	3	4	5
2) Focus on the pain and see how I can make it better.	1	2	3	4	5
3) Talk to a friend about how I feel.	1	2	3	4	5
4) Tell myself, don't worry everything will be ok.	1	2	3	4	5
5) Go and play.	1	2	3	4	5
6) Forget the whole thing.	1	2	3	4	5
7) Say mean things to people.	1	2	3	4	5
8) Worry that I will always be in pain.	1	2	3	4	5
9) Ask a nurse or doctor questions.	1	2	3	4	5
WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...					
10) Think about what needs to be done to make the pain better	1	2	3	4	5
11) Talk to someone about how I am feeling.	1	2	3	4	5
12) Say to myself, be strong.	1	2	3	4	5
13) Do something fun.	1	2	3	4	5
14) Ignore the pain.	1	2	3	4	5
15) Argue or fight.	1	2	3	4	5
16) Keep thinking about how much it hurts.	1	2	3	4	5
17) Find out more information.	1	2	3	4	5
18) Think of different ways to deal with the pain.	1	2	3	4	5

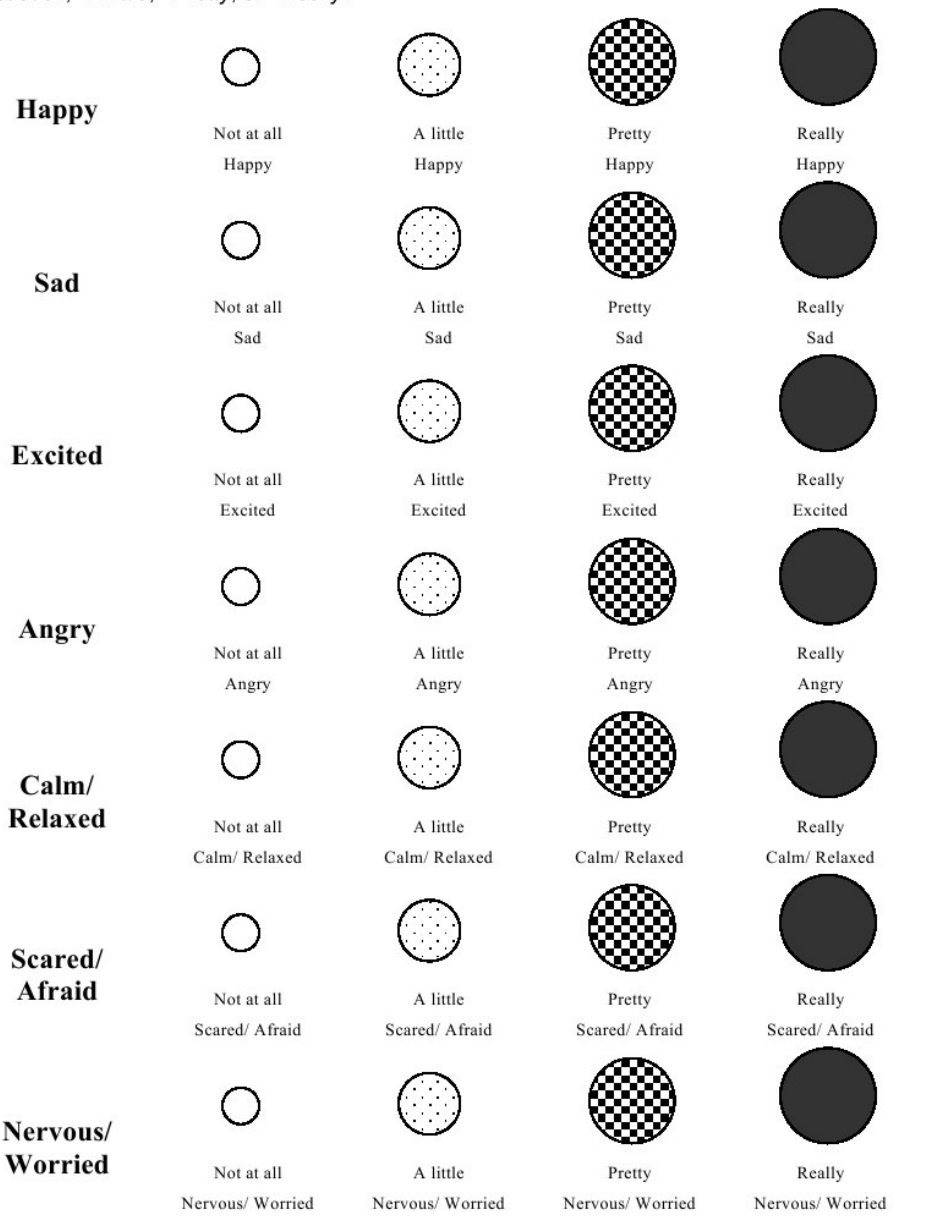
ID#: SCD_____ Date: _____

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...	Never	Hardly ever	Sometimes	Often	Very often
19) Tell someone how I feel.	1	2	3	4	5
20) Tell myself, it's not so bad.	1	2	3	4	5
21) Do something I enjoy.	1	2	3	4	5
22) Try to forget it.	1	2	3	4	5
23) Yell to let off steam.	1	2	3	4	5
24) Think that nothing helps.	1	2	3	4	5
25) Learn more about how my body works.	1	2	3	4	5
26) Figure out what I can do about the pain.	1	2	3	4	5
27) Talk to a family member about how I feel.	1	2	3	4	5
28) Say to myself, things will be ok.	1	2	3	4	5
29) Do something active.	1	2	3	4	5
WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...					
30) Put the pain out of my mind.	1	2	3	4	5
31) Get mad and throw or hit something.	1	2	3	4	5
32) Think that the pain will never stop.	1	2	3	4	5
33) Try different ways to make the pain better until I find one that works.	1	2	3	4	5
34) Let my feelings out to a friend.	1	2	3	4	5
35) Tell myself, I can handle anything that happens.	1	2	3	4	5
36) Do something to take my mind off the pain.	1	2	3	4	5
37) Don't think about the pain.	1	2	3	4	5
38) Curse or swear out loud.	1	2	3	4	5
39) Worry too much about the pain.	1	2	3	4	5

ID#: SCD_____ Date: _____

PCQ 2

People have different feelings when they are hurt or in pain. For **each** of the 7 feelings listed below, circle the one response that shows how you feel when you are hurt or in pain for a few hours or days. In other words, circle one of the following for each question:
Not at all, *A little*, *Pretty*, or *Really*.



ID#: SCD_____ Date: _____

Dealing with Pain

1) When you are hurt or in pain for a few hours or a few days, how often do you think you can do something to change it?

Never Hardly Ever Sometimes Often Very Often

2) Being hurt or in pain can be hard or easy to deal with. How hard or easy is it for you to deal with being in pain?

Really Easy | Kind of Easy | Kind of Easy/ Kind of Hard | Kind of Hard | Really Hard

3) How often do you think you can do something to change your moods or feelings when you are hurt or in pain?

Never Hardly Ever Sometimes Often Very Often

Please answer the next seven questions in terms of how your problems with pain turned out or how you felt about being in pain after it was over. *How your problems with hurt/ pain turned out*: In terms of when you have been hurt or in pain for a few hours or a few days, how much do you agree with the following statements.

1 = I strongly disagree with the statement
2 = I sort of disagree with the statement
3 = I agree and disagree with the statement
4 = I sort of agree with the statement
5 = I strongly agree with the statement

	Strongly Disagree	*Sort of Disagree*	*Agree/ Disagree*	*Sort of Agree*	*Strongly Agree*
1) I handled the pain well.	1	2	3	4	5
2) I learned from this problem.	1	2	3	4	5
3) I felt better about myself	1	2	3	4	5
4) I handled my feelings well in dealing with the pain.	1	2	3	4	5
5) I did a good job of solving the problems that came up.	1	2	3	4	5
6) I became a stronger person	1	2	3	4	5
7) The things that I did when I was in pain were helpful.	1	2	3	4	5

Pain Experiences

Which of the following different kinds of hurt or pain were you thinking about while answering the questions above? Circle as many of the different types of pain you were thinking about.

a) headache b) stomach ache c) muscle paind) joint pain (e.g., elbow, knee)

e) back pain f) earache g) (for women) menstrual pain

h) other_____

ID#: SCD_____ Date: _____

APPENDIX F

Multidimensional Inventory of Black Identity (MIBI)

Child Multidimensional Inventory of Black Identity (MIBI)

Please indicate below how strongly you disagree or agree with the statements by circling the number that applies most to you.

	Strongly Disagree			Neutral			Strongly Agree
1. Overall, being Black has very little to do with how I feel about myself.	1	2	3	4	5	6	7
2. I feel good about Black people.	1	2	3	4	5	6	7
3. Overall, Blacks are considered good by others.	1	2	3	4	5	6	7
4. In general, being Black is an important part of my self image (e.g., how I see myself).	1	2	3	4	5	6	7
5. I am happy that I am Black.	1	2	3	4	5	6	7
6. I feel that Blacks have made major accomplishments and advancements (e.g., successes, achievements).	1	2	3	4	5	6	7
7. My destiny (e.g., fate) is tied to the destiny of other Black people.	1	2	3	4	5	6	7
8. Being Black is unimportant to my sense of what kind of person I am.	1	2	3	4	5	6	7
9. In general, others respect Black people.	1	2	3	4	5	6	7
10. Most people consider Blacks, on average to be more ineffective (e.g., unproductive) than other racial groups.	1	2	3	4	5	6	7
11. I have a strong sense of belonging (e.g., fitting in) with Black people.	1	2	3	4	5	6	7
12. I often regret (e.g., feel sorry) that I am Black.	1	2	3	4	5	6	7
13. I have a strong attachment to other Black people.	1	2	3	4	5	6	7
14. Being Black is an important reflection of who I am.	1	2	3	4	5	6	7
15. Being Black is not a major factor in my social relationships.	1	2	3	4	5	6	7
16. Blacks are not respected by the broader society.	1	2	3	4	5	6	7
17. In general, other groups view Blacks in a positive manner.	1	2	3	4	5	6	7
18. I am proud to be Black.	1	2	3	4	5	6	7
19. I feel that the Black community has made valuable contributions to this society.	1	2	3	4	5	6	7
20. Society views Black people as an asset (e.g., benefit).	1	2	3	4	5	6	7

APPENDIX G

Gender Specific Regression Analyses

Table 19

Gender Specific Regression Analyses of Pain and Coping Types on Generic Overall Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.021	0.021	0.879
Site	-0.090			
Step 2		0.286	0.265	7.226**
Total Pain	-0.557***			
Approach Coping	-0.211			
Step 3		0.296	0.011	0.573
Total Pain x Approach Coping	-0.136			
Problem-Focused Avoidance Coping (N = 45)				
Step 1		0.035	0.035	1.619
Site	-0.097			
Step 2		0.298	0.263	7.860***
Total Pain	-0.458***			
Problem-Focused Avoidance (PFA)	0.112			
Step 3		0.311	0.013	0.791
Total Pain x PFA Coping	-0.130			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.048	0.048	2.240
Site	-0.181			
Step 2		0.513	0.464	20.023***
Total Pain	-0.261†			
Emotion-Focused Avoidance (EFA)	-0.534***			
Step 3		0.513	0.000	0.000
Total Pain x EFA Coping	0.000			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 43)				
Step 1		0.065	0.065	2.934†
Site	-0.286*			
Step 2		0.306	0.240	6.918**
Total Pain	-0.522**			
Approach Coping	0.025			
Step 3		0.307	0.001	0.064
Total Pain x Approach Coping	0.042			
Problem-Focused Avoidance Coping (N = 48)				
Step 1		0.102	0.102	5.310*
Site	-0.329*			
Step 2		0.330	0.229	7.690***

Total Pain	-0.508***			
Problem-Focused Avoidance (PFA)	0.025			
Step 3		0.340	0.009	0.621
Total Pain x PFA Coping	0.100			
Emotion-Focused Avoidance Coping (N = 47)				
Step 1		0.083	0.083	4.170*
Site	-0.286*			
Step 2		0.354	0.271	9.239***
Total Pain	-0.432***			
Emotion-Focused Avoidance (EFA)	-0.244†			
Step 3		0.355	0.001	0.017
Total Pain x EFA Coping	-0.017			

Note. Dependent variable = PedsQL Total Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 20

Gender Specific Regression Analyses of Pain and Coping Types on Generic Physical Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.038	0.038	1.621
Site	-0.137			
Step 2		0.333	0.295	8.614***
Total Pain	-0.586***			
Approach Coping	-0.221			
Step 3		0.344	0.011	0.631
Total Pain x Approach Coping	-0.138			
Problem-Focused Avoidance Coping (N = 45)				
Step 1		0.069	0.069	3.264†
Site	-0.179			
Step 2		0.342	0.273	8.772***
Total Pain	-0.479***			
Problem-Focused Avoidance (PFA)	0.045			
Step 3		0.362	0.020	1.300
Total Pain x PFA Coping	-0.161			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.096	0.096	4.649*
Site	-0.255*			
Step 2		0.400	0.304	10.632***
Total Pain	-0.373*			
Emotion-Focused Avoidance (EFA)	-0.258†			
Step 3		0.401	0.001	0.078
Total Pain x EFA Coping	-0.043			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 44)				
Step 1		0.042	0.042	1.878
Site	-0.223			
Step 2		0.250	0.208	5.685**
Total Pain	-0.409*			
Approach Coping	0.026			
Step 3		0.255	0.005	0.288
Total Pain x Approach Coping	-0.093			
Problem-Focused Avoidance Coping (N = 49)				
Step 1		0.072	0.072	3.719†
Site	-0.290*			
Step 2		0.269	0.197	6.191**

Total Pain	-0.447**			
Problem-Focused Avoidance (PFA)	0.084			
Step 3		0.270	0.001	0.060
Total Pain x PFA Coping	-0.032			
Emotion-Focused Avoidance Coping (N = 48)				
Step 1		0.042	0.042	2.079
Site	-0.220			
Step 2		0.215	0.172	4.939*
Total Pain	-0.386**			
Emotion-Focused Avoidance (EFA)	-0.161			
Step 3		0.218	0.003	0.174
Total Pain x EFA Coping	0.061			

Note. Dependent variable is PedsQL Physical Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 21

Gender Specific Regression Analyses of Pain and Coping Styles on Generic Emotional Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.007	0.007	0.270
Site	-0.045			
Step 2		0.149	0.143	3.276*
Total Pain	-0.438*			
Approach Coping	-0.220			
Step 3		0.170	0.021	0.939
Total Pain x Approach Coping	-0.189			
Problem-Focused Avoidance Coping (N = 46)				
Step 1		0.002	0.002	0.106
Site	0.019			
Step 2		0.125	0.122	3.004†
Total Pain	-0.299†			
Problem-Focused Avoidance (PFA)	0.119			
Step 3		0.129	0.005	0.219
Total Pain x PFA Coping	-0.076			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.004	0.004	0.193
Site	-0.054			
Step 2		0.460	0.455	17.694***
Total Pain	-0.059			
Emotion-Focused Avoidance (EFA)	-0.652***			
Step 3		0.460	0.000	0.014
Total Pain x EFA Coping	0.017			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 46)				
Step 1		0.060	0.060	2.895†
Site	-0.233†			
Step 2		0.141	0.137	3.664*
Total Pain	-0.508**			
Approach Coping	-0.122			
Step 3		0.264	0.067	3.799†
Total Pain x Approach Coping	0.320†			
Problem-Focused Avoidance Coping (N = 51)				
Step 1		0.073	0.073	3.920†
Site	-0.316*			
Step 2		0.241	0.168	5.307**

Total Pain	-0.464***			
Problem-Focused Avoidance (PFA)	0.213			
Step 3		0.278	0.037	2.436
Total Pain x PFA Coping	0.200			
Emotion-Focused Avoidance Coping (N = 50)				
Step 1		0.063	0.063	3.312†
Site	-0.193			
Step 2		0.348	0.285	10.266***
Total Pain	-0.326**			
Emotion-Focused Avoidance (EFA)	-0.342**			
Step 3		0.362	0.014	0.976
Total Pain x EFA Coping	-0.126			

Note. Dependent variable is PedsQL Emotion Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 22

Gender Specific Regression Analyses of Pain and Coping Styles on Generic Social Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.007	0.007	0.298
Site	-0.035			
Step 2		0.157	0.150	3.472*
Total Pain	-0.374*			
Approach Coping	-0.109			
Step 3		0.157	0.000	0.006
Total Pain x Approach Coping	0.015			
Problem-Focused Avoidance Coping (N = 46)				
Step 1		0.008	0.008	0.349
Site	-0.021			
Step 2		0.155	0.147	3.754*
Total Pain	-0.332*			
Problem-Focused Avoidance (PFA)	0.047			
Step 3		0.177	0.022	1.123
Total Pain x PFA Coping	-0.168			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.019	0.019	0.864
Site	-0.115			
Step 2		0.377	0.357	12.044***
Total Pain	-0.161			
Emotion-Focused Avoidance (EFA)	-0.523***			
Step 3		0.377	0.000	0.029
Total Pain x EFA Coping	0.027			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 47)				
Step 1		0.038	0.038	1.796
Site	-0.198			
Step 2		0.151	0.114	2.950†
Total Pain	-0.350*			
Approach Coping	0.160			
Step 3		0.151	0.000	0.000
Total Pain x Approach Coping	0.002			
Problem-Focused Avoidance Coping (N = 52)				
Step 1		0.062	0.062	3.368†
Site	-0.210			
Step 2		0.145	0.083	2.390

Total Pain	-0.306*			
Problem-Focused Avoidance (PFA)	-0.059			
Step 2		0.177	0.032	1.857
Total Pain x PFA Coping	0.185			
Emotion-Focused Avoidance Coping (N = 51)				
Step 1		0.071	0.071	3.796†
Site	-0.245†			
Step 2		0.262	0.191	6.209**
Total Pain	-0.296*			
Emotion-Focused Avoidance (EFA)	-0.348*			
Step 3		0.274	0.012	0.786
Total Pain x EFA Coping	0.119			

Note. Dependent variable is PedsQL Social Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 23

Gender Specific Regression Analyses of Pain and Coping Styles on Generic School Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.009	0.009	0.356
Site	-0.055			
Step 2		0.169	0.160	3.760*
Total Pain	-0.455**			
Approach Coping	-0.142			
Step 3		0.178	0.009	0.401
Total Pain x Approach Coping	-0.123			
Problem-Focused Avoidance Coping (N = 46)				
Step 1		0.019	0.019	0.878
Site	-0.052			
Step 2		0.208	0.189	5.136**
Total Pain	-0.377*			
Problem-Focused Avoidance (PFA)	0.200			
Step 3		0.208	0.000	0.009
Total Pain x PFA Coping	-0.014			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.024	0.024	1.076
Site	-0.127			
Step 2		0.387	0.363	12.417***
Total Pain	-0.193			
Emotion-Focused Avoidance (EFA)	-0.506***			
Step 3		0.387	0.000	0.026
Total Pain x EFA Coping	0.025			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 47)				
Step 1		0.050	0.050	2.413
Site	-0.218			
Step 2		0.171	0.121	3.222*
Total Pain	-0.325†			
Approach Coping	-0.067			
Step 3		0.171	0.000	0.001
Total Pain x Approach Coping	0.005			
Problem-Focused Avoidance Coping (N = 52)				
Step 1		0.073	0.073	3.999†
Site	-0.195			
Step 2		0.230	0.157	5.000*

Total Pain	-0.310*			
Problem-Focused Avoidance (PFA)	-0.188			
Step 3		0.231	0.001	0.066
Total Pain x PFA Coping	-0.034			
Emotion-Focused Avoidance Coping (N = 51)				
Step 1		0.069	0.069	3.707†
Site	-0.259†			
Step 2		0.180	0.111	3.234*
Total Pain	-0.322*			
Emotion-Focused Avoidance (EFA)	0.017			
Step 3		0.186	0.006	0.366
Total Pain x EFA Coping	-0.086			

Note. Dependent variable is PedsQL School Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 24

Gender Specific Regression Analyses of Pain and Coping Styles on Disease-specific Overall Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 41)				
Step 1		0.035	0.035	1.462
Site	-0.114			
Step 2		0.398	0.363	11.450***
Total Pain	-0.617***			
Approach Coping	-0.283†			
Step 3		0.405	0.007	0.426
Total Pain x Approach Coping	-0.109			
Problem-Focused Avoidance Coping (N = 44)				
Step 1		0.029	0.029	1.292
Site	-0.106			
Step 2		0.314	0.285	8.523***
Total Pain	-0.506***			
Problem-Focused Avoidance (PFA)	0.039			
Step 3		0.323	0.009	0.502
Total Pain x PFA Coping	-0.105			
Emotion-Focused Avoidance Coping (N = 42)				
Step 1		0.034	0.034	1.456
Site	-0.147			
Step 2		0.552	0.517	22.514***
Total Pain	-0.249			
Emotion-Focused Avoidance (EFA)	-0.554***			
Step 3		0.555	0.003	0.253
Total Pain x EFA Coping	-0.072			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 44)				
Step 1		0.050	0.050	2.257
Site	-0.226			
Step 2		0.193	0.143	3.646*
Total Pain	-0.433*			
Approach Coping	0.061			
Step 3		0.199	0.006	0.294
Total Pain x Approach Coping	0.090			
Problem-Focused Avoidance Coping (N = 49)				
Step 1		0.069	0.069	3.568†
Site	-0.289*			
Step 2		0.244	0.175	5.336**

Total Pain	-0.416**			
Problem-Focused Avoidance (PFA)	0.168			
Step 3		0.245	0.000	0.005
Total Pain x PFA Coping	-0.010			
Emotion-Focused Avoidance Coping (N = 48)				
Step 1		0.060	0.060	3.003†
Site	-0.226†			
Step 2		0.310	0.250	8.142***
Total Pain	-0.353*			
Emotion-Focused Avoidance (EFA)	-0.389**			
Step 3		0.330	0.30	1.306
Total Pain x EFA Coping	0.159			

Note. Dependent variable is SCD-QoL Total Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 25

Gender Specific Regression Analyses of Pain and Coping Types on Disease-specific Physical Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 41)				
Step 1		0.030	0.030	1.256
Site	-0.100			
Step 2		0.463	0.433	15.306***
Total Pain	-0.682***			
Approach Coping	-0.253†			
Step 3		0.472	0.009	0.619
Total Pain x Approach Coping	-0.124			
Problem-Focused Avoidance Coping (N = 44)				
Step 1		0.026	0.026	1.135
Site	-0.102			
Step 2		0.390	0.362	12.239***
Total Pain	-0.607***			
Problem-Focused Avoidance (PFA)	0.022			
Step 3		0.390	0.000	0.008
Total Pain x PFA Coping	0.013			
Emotion-Focused Avoidance Coping (N = 42)				
Step 1		0.030	0.030	1.258
Site	-0.121			
Step 2		0.546	0.516	22.195***
Total Pain	-0.336*			
Emotion-Focused Avoidance (EFA)	-0.454***			
Step 3		0.555	0.009	0.746
Total Pain x EFA Coping	-0.123			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 46)				
Step 1		0.032	0.032	1.501
Site	-0.149			
Step 2		0.237	0.205	5.763**
Total Pain	-0.425**			
Approach Coping	-0.142			
Step 3		0.239	0.002	0.098
Total Pain x Approach Coping	0.049			
Problem-Focused Avoidance Coping (N = 51)				
Step 1		0.053	0.053	2.808†
Site	-0.240†			
Step 2		0.294	0.240	8.166***

Total Pain	-0.476***			
Problem-Focused Avoidance (PFA)	0.176			
Step 3		0.304	0.011	0.714
Total Pain x PFA Coping	-0.106			
Emotion-Focused Avoidance Coping (N = 50)				
Step 1		0.038	0.038	1.954
Site	-0.169			
Step 2		0.313	0.274	9.382***
Total Pain	-0.419**			
Emotion-Focused Avoidance (EFA)	-0.372**			
Step 3		0.343	0.030	2.128
Total Pain x EFA Coping	0.194			

Note. Dependent variable is SCD-QoL Physical Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 26

Gender Specific Regression Analyses of Pain and Coping Styles on Disease-specific Emotional Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.027	0.027	1.124
Site	-0.088			
Step 2		0.342	0.315	9.333***
Total Pain	-0.523***			
Approach Coping	-0.119			
Step 3		0.345	0.003	0.199
Total Pain x Approach Coping	0.077			
Problem-Focused Avoidance Coping (N = 46)				
Step 1		0.009	0.009	0.423
Site	-0.022			
Step 2		0.227	0.218	6.060**
Total Pain	-0.418**			
Problem-Focused Avoidance (PFA)	0.012			
Step 3		0.259	0.032	1.819
Total Pain x PFA Coping	-0.202			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.009	0.009	0.421
Site	-0.063			
Step 2		0.483	0.474	19.245
Total Pain	-0.167			
Emotion-Focused Avoidance (EFA)	-0.572***			
Step 3		0.490	0.007	0.529
Total Pain x EFA Coping	-0.104			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 47)				
Step 1		0.049	0.049	2.394
Site	-0.211			
Step 2		0.106	0.056	1.384
Total Pain	-0.416*			
Approach Coping	0.016			
Step 3		0.174	0.068	3.541†
Total Pain x Approach Coping	0.325†			
Problem-Focused Avoidance Coping (N = 52)				
Step 1		0.049	0.049	2.627
Site	-0.275†			
Step 2		0.141	0.092	2.627†

Total Pain	-0.304*			
Problem-Focused Avoidance (PFA)	0.223			
Step 3		0.149	0.008	0.449
Total Pain x PFA Coping	0.092			
Emotion-Focused Avoidance Coping (N = 51)				
Step 1		0.051	0.051	2.698
Site	-0.182			
Step 2		0.240	0.189	5.965**
Total Pain	-0.221†			
Emotion-Focused Avoidance (EFA)	-0.358*			
Step 3		0.240	0.000	0.000
Total Pain x EFA Coping	0.001			

Note. Dependent variable is SCD-QoL Emotion Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 27

Gender Specific Regression Analyses of Pain and Coping Styles on Disease-specific Social Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.015	0.015	0.613
Site	-0.098			
Step 2		0.090	0.076	1.622
Total Pain	-0.337†			
Approach Coping	-0.262			
Step 3		0.123	0.032	1.391
Total Pain x Approach Coping	-0.236			
Problem-Focused Avoidance Coping (N = 46)				
Step 1		0.012	0.012	0.529
Site	-0.047			
Step 2		0.095	0.083	1.981
Total Pain	-0.203			
Problem-Focused Avoidance (PFA)	0.082			
Step 3		0.122	0.027	1.300
Total Pain x PFA Coping	-0.186			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.028	0.028	1.264
Site	-0.153			
Step 2		0.192	0.164	4.275*
Total Pain	-0.115			
Emotion-Focused Avoidance (EFA)	-0.361*			
Step 3		0.194	0.002	0.098
Total Pain x EFA Coping	0.056			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 46)				
Step 1		0.056	0.056	2.681
Site	-0.252†			
Step 2		0.122	0.066	1.613
Total Pain	-0.262			
Approach Coping	0.197			
Step 3		0.124	0.002	0.100
Total Pain x Approach Coping	0.057			
Problem-Focused Avoidance Coping (N = 51)				
Step 1		0.077	0.077	4.147*
Site	-0.350*			
Step 2		0.150	0.074	2.082

Total Pain	-0.254†			
Problem-Focused Avoidance (PFA)	0.265†			
Step 3		0.175	0.025	1.398
Total Pain x PFA Coping	0.162			
Emotion-Focused Avoidance Coping (N = 50)				
Step 1		0.073	0.073	3.873†
Site	-0.233†			
Step 2		0.285	0.212	6.973**
Total Pain	-0.111			
Emotion-Focused Avoidance (EFA)	-0.501***			
Step 3		0.311	0.026	1.712
Total Pain x EFA Coping	0.173			

Note. Dependent variable is SCD-QoL Social Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 28

Gender Specific Regression Analyses of Pain and Coping Styles on Disease-specific School Quality of Life

Males				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 42)				
Step 1		0.046	0.046	1.977
Site	-0.152			
Step 2		0.284	0.238	6.472**
Total Pain	-0.454**			
Approach Coping	-0.416*			
Step 3		0.301	0.017	0.921
Total Pain x Approach Coping	-0.171			
Problem-Focused Avoidance Coping (N = 46)				
Step 1		0.046	0.046	2.185
Site	-0.158			
Step 2		0.163	0.117	2.995†
Total Pain	-0.329*			
Problem-Focused Avoidance (PFA)	0.087			
Step 3		0.163	0.000	0.000
Total Pain x PFA Coping	-0.019			
Emotion-Focused Avoidance Coping (N = 45)				
Step 1		0.051	0.051	2.384
Site	-0.205			
Step 2		0.338	0.286	9.075***
Total Pain	-0.135			
Emotion-Focused Avoidance (EFA)	-0.466**			
Step 3		0.338	0.000	0.000
Total Pain x EFA Coping	0.000			
Females				
Variables	β	R^2	R^2 Change	F Change
Approach Coping (N = 45)				
Step 1		0.079	0.079	3.758†
Site	-0.305*			
Step 2		0.292	0.214	6.338**
Total Pain	-0.514**			
Approach Coping	0.297*			
Step 3		0.303	0.010	0.607
Total Pain x Approach Coping	0.128			
Problem-Focused Avoidance Coping (N = 50)				
Step 1		0.094	0.094	5.061*
Site	-0.293*			
Step 2		0.215	0.121	3.628*

Total Pain	-0.368*			
Problem-Focused Avoidance (PFA)	-0.001			
Step 3		0.222	0.007	0.441
Total Pain x PFA Coping	0.090			
Emotion-Focused Avoidance Coping (N = 49)				
Step 1		0.080	0.080	4.158*
Site	-0.275*			
Step 2		0.199	0.119	3.414*
Total Pain	-0.283*			
Emotion-Focused Avoidance (EFA)	-0.184			
Step 3		0.199	0.000	0.013
Total Pain x EFA Coping	0.017			

Note. Dependent variable is SCD-QoL School Score. † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.