Georgia State University
Digital Archive @ GSU

Psychology Theses | Department of Psychology

12-1-2009

An Examination of the Influence of Stress and Coping on Psychosocial Functioning in Caregivers of Children with Sickle Cell Disease

Josie S. Welkom
Georgia State University, jwelkom1@student.gsu.edu

Follow this and additional works at: http://digitalarchive.gsu.edu/psych_theses

Recommended Citation
Welkom, Josie S., "An Examination of the Influence of Stress and Coping on Psychosocial Functioning in Caregivers of Children with Sickle Cell Disease" (2009). *Psychology Theses.* Paper 65.

This Thesis is brought to you for free and open access by the Department of Psychology at Digital Archive @ GSU. It has been accepted for inclusion in Psychology Theses by an authorized administrator of Digital Archive @ GSU. For more information, please contact digitalarchive@gsu.edu.

AN EXAMINATION OF THE INFLUENCE OF STRESS AND COPING ON PSYCHOSOCIAL FUNCTIONING IN CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE

by

JOSIE S. WELKOM

Under the Direction of Dr. Lindsey Cohen

ABSTRACT

Sickle Cell Disease (SCD) is a genetic disorder that affects approximately 1 out of every 600 African-American newborns (NHLBI, 2006). Research suggests that caregivers of children with SCD are at risk for maladjustment. The purpose of this current study was to build upon previous research regarding stress and coping of parents of children with SCD. Additionally, novel information regarding the effects of racial identity was explored. Participants included 103 caregivers (*M* = 41.1 years old, *SD* = 8.04 years) of children with SCD. Parents completed a demographic form, the Brief Symptom Inventory-18, Pediatric Inventory for Parents, Coping Health Inventory for Parents, and the Multidimensional Inventory of Black Identity. Results revealed that increases in caregiver stress associated with parenting a chronically ill child were accompanied by increases in caregiver psychosocial maladjustment. Caregiver coping did not significantly predict functioning nor moderate the stress-adjustment relation. Exploratory analysis revealed significant associations between parents' racial identity and parenting stress.

INDEX WORDS: Sickle Cell Disease, Caregivers, Parents, Stress, Coping, Racial identity, African Americans

AN EXAMINATION OF THE INFLUENCE OF STRESS AND COPING ON PSYCHOSOCIAL FUNCTIONING IN CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE

by

JOSIE S. WELKOM

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

Master of Arts

in the College of Arts and Sciences

Georgia State University

2009

Copyright by
Josie Sibongile Welkom

2009

AN EXAMINATION OF THE INFLUENCE OF STRESS AND COPING ON PSYCHOSOCIAL FUNCTIONING IN CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE

by

JOSIE S. WELKOM

Committee Chair: Lindsey Cohen

Committee: Frank Floyd

Leslie Jackson

Electronic Version Approved:

Office of Graduate Studies

College of Arts and Sciences

Georgia State University

December 2009

DEDICATION

I would like to dedicate this work to my mother, Lorna D. Welkom, and my father, Harris A. Welkom, for their endless support and unconditional love. As a testament to the sacrifices they have made and their devotion to our family, I am forever grateful.

ACKNOWLEDGEMENTS

First, I would like to thank my mentor, teacher, and friend, Lindsey L. Cohen, Ph.D. for his unyielding support. Without Dr. Cohen's guidance, I would not have developed into the researcher I am today and I look forward to the many years of collaboration to come. In addition, I would like to thank my committee members, Frank Floyd, Ph.D. and Leslie Jackson, Ph.D. for always being available to share their knowledge and insights. I would also like to express my gratitude to Bradley Marino, M.D. for introducing me to the world of pediatric research and never failing to impress me with his drive and perseverance.

I am extremely grateful to the families of Children's Healthcare of Atlanta (CHOA) and the Comprehensive Sickle Cell Disease Center for sharing their stories with me and the doctors and nurses of CHOA for their collaboration on this project. Moreover, this project would not have been possible without the assistance of some very special colleagues including Crystal Lim, Ph.D., Niusha Ghazban, Chloe Peacock, Katherine Rhodes, and Diane Sykes.

Finally, I would like to thank my family especially my aunt, Bernie Titus, my little sister, Yentl Vertuin, and my boyfriend, Robert Wells. No journey traveled alone is worth traveling, and I never could have made this journey without your love and support. Additionally, I would like to thank my lab mates and peers at GSU for their friendship.

This project was supported by Grant Number 1F31HL094120-01A1 from the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) through a pre-doctoral NRSA fellowship. The content is solely the responsibility of the author and does not necessarily represent the official views of the NHLBI or NIH. I wish to thank the NHLBI and NIH for the financial support to further my research and clinical training and to conduct this study under the guidance of my sponsors, Dr. Lindsey Cohen and Dr. Lisa Armistead.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS v
INTRODUCTION 1
1.1 Caregiver Psychosocial Functioning 3
1.2 Caregiver Stress 4
1.3 Caregiver Coping 6
1.4 African-American Racial Identity 8
1.5 Study Purpose and Hypotheses 11
METHOD 13
2.1 Participants 13
2.2 Measures 14
2.3 Procedures 17
RESULTS 19
3.1 Data Analyses Overview 19
3.2 Preliminary Analyses 19
3.3 Primary Analyses 20
3.4 Secondary Analyses 21
DISCUSSION 23
REFERENCE 32
Appendix A: Table 1 Parent Demographic Information 40
Appendix B: Table 2 Child Demographic Information 43
Appendix C: Table 3 Means and Standard Deviations of Study Variables 45
Appendix D: Table 4 Associations among Main Study Variables 48
Appendix E: Table 5 Regression Analysis 50
Appendix F: Table 6 Associations among Racial Identity and Study Variables 53
Appendix G: SCD Background Information Form 55
Appendix H: The Brief Symptom Inventory-18 59
Appendix I: The Pediatric Inventory for Parents 61
Appendix J: The Coping Health Inventory for Parents 64
Appendix K: The Multidimensional Inventory of Black Identity 67

CHAPTER 1

INTRODUCTION

Sickle Cell Disease (SCD) is a genetic disorder affecting primarily people of African descent. In the United States, 1 out of every 600 African-American newborns is born with SCD and approximately 72,000 people are currently living with the disease (National Heart, Lung, and Blood Institute [NHLBI], 2006). Related to advances in medical care, the mortality rates of children with sickle cell disease have decreased by approximately 53% over the past four decades (Davis, Schoendorf, Gergen, and Moore, 1997). Davis et al. reported that the mortality rate of children with sickle cell disease accounted for between 3.5% and 4.8% of deaths of children between 1 and 14 years of age. For one to inherit sickle cell anemia, two copies of the sickle cell gene, one from each parent, must be transmitted to the offspring. Children whose parents each carry the trait will have a 25% chance of inheriting the disease (NHLBI). SCD is a blood disorder that is characterized by an abnormal type of hemoglobin. The red blood cells become rigid and crescent or sickle shaped, which causes complications in blood flow. The red blood cells can stick and block the flow of blood to the limbs and organs resulting in pain, organ damage, and a low blood count (NHLBI).

The most common symptom of SCD is pain. Vaso-occlusive pain episodes are the result of "sickling" of the blood vessels leading to a lack of flexibility. Pain most often occurs in the extremities but also occur in the back, chest, and abdomen. The frequency of these pain episodes ranges from fewer than once a year to multiple times a day. Although there is no cure for SCD pain, treatment of SCD pain symptoms typically includes vigorous hydration, analgesia use, and blood transfusions (Lemanek, Buckloh, Woods, and Butler, 1995). Common psychosocial treatments include coping skills training, biofeedback, and relaxation techniques.

Other symptoms of SCD include hand-foot syndrome (small blood vessels in the hands and feet become blocked causing pain and swelling), eye problems (the retina does not receive sufficient blood), decreased ability to fight infections, acute chest syndrome (an illness similar to pneumonia), delayed growth and puberty (due to decreased red blood cells), sores similar to ulcers, stroke (the blood cells stick to the walls of the blood vessels in the brain), gallstones (due to an increased production of billirubin, which is made through the breakdown of red blood cells), and priapism (unwanted and painful erections due to the lack of blood flow in the penis).

Individuals with SCD, especially children during the first decade of life, are at risk for the development of cognitive and learning problems (Brown et al., 1993; Chapar, 1988; Daly, Kral, & Brown, 2008; Fowler, Johnson, & Atkinson, 1985; Fowler et al., 1988; Swift et al., 1989). Given that approximately 5-8% of children are at risk for overt strokes or cerebrovascular impairments (Balkaran et al., 1992; Ohene-Frempong et al., 1998) and 20-30% are at risk for silent strokes also defined as changes in brain imaging despite the lack of apparent of neurological symptoms (Kinney et al., 1999), neurocognitive deficits are likely. Resulting impairments include decrements in overall intellectual functioning, language and verbal abilities, visual-motor and visual-spatial processing, memory, sustained attention, executive functions, and academic achievement (for review see Kral, Brown, & Hynd, 2001)

Caregivers of children with SCD are burdened with missed work, increased family stress, and increased disease care demands, which is in part due to the unpredictability of crises care in SCD (Moskowitz et al., 2007). Thus the tasks associated with managing their child's care, such as encouraging their child to engage in preventative behaviors, managing the pain episodes, teaching coping skills and providing adequate nutrition, may cause these caregivers to experience heightened levels of stress.

1.1 Caregiver Psychosocial Functioning

Caregivers of children with SCD have alarmingly high rates of maladjustment. For example, previous research has consistently found that approximately 24% of parents of young children with SCD report clinically significant levels of psychological distress; similar to that of adolescents with SCD (Thompson, Gustafson, Bonner & Ware, 2002). In tandem, Brown et al., (2000) found that 35% of the primary caregivers in the sample met criteria for clinically significant levels of poor adjustment and 65% were at risk. The rates of psychosocial maladjustment in parents of children with SCD are similar to the rates of individuals diagnosed with a medical condition (20%-25%; American Psychiatric Association, 2005).

It is not clear why caregivers of children with SCD have such high rates of maladjustment; however, there are models that provide possible reasons. Wallander and Varni (1998) developed the Disability, Stress, and Coping Model to understand the psychosocial factors at play in patients with chronic physical disorders. They found that functional independence (e.g., hygiene, ambulation, communication), disease-related stress, and stress processing (coping) predict child psychosocial functioning. This framework might explain the functioning of caregivers of children with chronic illness, as research suggests that the general outcome for caregivers of a child with a chronic illness is similar to that of the child (Timko, Stovel, & Moos, 1992). In fact, Wallander and Varni found psychosocial stress to be a risk factor for parental functioning. Stressful events can be either directly (e.g., hospitalization) or indirectly (e.g., loss of career opportunity) related to the child's illness. Child illness stress in addition to daily life events stress accounts for a substantial portion of the variation in maternal psychosocial functioning (Wallander & Varni, 1998).

Evans, Burlew, and Oler (1989) found that the mere presence of a child with SCD has an influence on how caregivers interact with one another and with the child. Specifically, caregivers of younger children with SCD reported increased stress and less positive affect in the relationship with each other than caregivers of healthy children. However, the quality of their relationship with their children did not differ. Results also suggested that single-parent families were less positive than two-parent families regarding their child's behavior traits and their relationship with the child. It is likely that a lack of support and the demands associated with caring for a chronically ill child affect single-parents' perceptions of their child. Given the impact of pediatric SCD on caregiver perceptions of their relationships with their partner and their child, it will be important to examine the contributive psychosocial factors which may predict overall psychosocial functioning.

1.2 Caregiver Stress

Raising a chronically ill child can lead to an increase in parenting stress, which has been found to lead to poor parental mental health outcomes (Kovacs, 1985), decreased ability to learn illness-related management skills (Gillis, 1993), increased stress in the ill child (Melamed & Ridley-Johnson, 1988), and a negative influence on child self-management (Auslander, Thompson, Dreitzer, & Santiago, 1997; Hanson, DeGuire, Schnikel, & Kolterman, 1995). For example, Streisand, Swift, Wickmark, Chen, and Holmes (2005) examined parenting stress in 134 caregivers of children age 9-17 years with type I diabetes. They found that approximately one-third of the stress experienced by parents was due to their lack of confidence in their ability to manage their child's medical care. Parenting stress was related to parental psychosocial and behavioral functioning, including lower self-efficacy, and greater responsibility for disease-management. Furthermore, Pianta and Egeland (1990) found that maternal stress experienced

when the child was between eight and nine years old was related to subsequent increases in depression.

Streisand, Kazak, and Tercyak (2003) examined the association between pediatric parenting stress and family functioning in 116 caregivers of children with cancer. Results of this study indicate that caregivers who experience increased parenting stress were more likely to experience less behavior control in their family. It appears that stress is related to increase family dysfunction, specifically when the child was involved in active treatment. This is important to consider in caregivers of children with SCD because the unpredictability and life-long nature of their disease and subsequent treatment may put caregivers at an increased risk for stress.

Barakat, Patterson, Tarazi, and Ely (2007) examined developmental factors involved in parenting a child with SCD in 67 caregivers of children and adolescents. They found that developmental level was a significant predictor of disease-related communication stress in caregivers of adolescents than caregivers of preschoolers. Furthermore, family income and family functioning significantly predicted increased disease-related parenting stress. These results provide support for the need to examine stress associated with caring for a child with chronic illness especially in caregivers of children with SCD given its relation to the child's developmental level, family functioning, and family income.

Bachanas, Kullgren, Schwartz, McDaniel, and Smith (2001) found that stress and coping significantly predicted psychosocial functioning in caregivers of children with HIV. In turn, parental psychosocial maladjustment was a significant predictor of their child's psychosocial maladjustment. Moskowitz et al. (2007) found that in addition to time providing crisis care, parents of children with SCD are spending a greater proportion of time in disease-related technical care such as medication administration and diagnostic procedures than parents of a

child with HIV. Furthermore, possibly due to the unpredictability of pain crises, caregivers of children with SCD are also reporting greater care burden. Fifty percent of the caregivers of children with SCD in this study were at risk for clinical depression compared to 34% of the parents of children with HIV.

Although these results might apply to families with a child with SCD, it is important to note some differences. For example, as compared to SCD, diabetes can sometimes be reasonably well managed with diet and insulin. Cancer is variable, but often there are treatment phases followed by phases with no treatment. Children with SCD receive fairly continuous treatment interrupted by unpredictable pain episodes, which can be exacerbated by extremes in weather and poor nutrition.

1.3 Caregiver Coping

Parenting of children with SCD requires coping with a number of stressors, such as administering medication, helping the child manage their pain, frequent hospital visits, and helping the child cope with negative feelings about having SCD (Moskowitz et al., 2007). The ability of a caregiver to employ effective coping strategies is essential to healthy parental psychosocial functioning. For example, Wallander and Varni (1998) identify coping as a key factor predicting parental functioning. Lazarus and Folkman (1984) defined coping or stress processing as the appraisal of the experience and implementation of coping strategies to manage it. Lazarus and Folkman (1984) further defined coping as cognitive and behavioral efforts that constantly change in order to manage daily demands that are straining to respective resources. Parental coping is important in its own right, but also because coping patterns are often passed on to the child, creating a lineage of either adaptive or maladaptive coping behaviors.

Gil, Williams, Thompson, and Kinney (1991) examined specific coping strategies used by children with SCD to cope with pain, the relation between parents' pain coping to the child's psychosocial functioning, and the relation between child and parent pain coping strategies. Gil et al. (1991) found that parental increases in coping attempts were significantly related to the child's functioning (i.e., physical activity) with SCD. Although the impact of parental coping on psychosocial functioning in the SCD population has not been conducted, research has been done in this area with other pediatric populations. For example, McCubbin et al. (1983) studied parents coping with stressors associated with their child's cystic fibrosis. They found that parental coping patterns such as maintaining social support, self esteem, and psychosocial stability is associated with improvements in child health.

An additional study by Williamson, Walters, and Shafer (2002) examined caregiver attachment-related models, coping, and distress as predictors of child functioning. Fifty-nine children in outpatient therapy for chronic pain and their mothers were assessed. Twenty-two percent of the subjects were seeking therapy for SCD related pain. Caregiver reported coping strategies and depression and child reported pain and depression were examined. Results suggest that African American caregivers reported more avoidant coping (e.g., denial, avoidance) strategies, which are associated with increased caregiver and child reports of depression. Moreover, approach coping (e.g., seek social support, positive reappraisal) strategies in parents are associated with fewer reports of depression in children.

In another study, Bachanas et al. (2001) examined coping styles in caregivers of children with HIV. They found that the increased use of emotion-focused coping strategies as opposed to problem-focused coping strategies was significantly correlated with relatively poor psychosocial functioning. Although some of these findings might apply to caregivers of children with SCD,

research is necessary to further evaluate the influence of stress and coping on psychosocial functioning. It is especially important because this line of inquiry might demonstrate that coping may serve as a buffer to the stressors which may influence caregiver psychosocial functioning and child health.

1.4 African-American Racial Identity

The concept of racial identity has received much support in the literature for its influence on psychological well-being in African Americans, especially across the lifespan (for a review, see Phinney & Kohatsu, 1997). African-American racial identity refers to the mechanism by which African Americans define themselves in the context of other groups (Sellers et al., 1997). Racial identity can be further conceptualized in terms of private regard (individuals positive or negative feelings toward African Americans and their membership in that group), public regard (the extent to which individuals feel that others view their race as positive or negative), and centrality (the extent to which a person normatively defines himself in terms of race).

Sellers, Caldwell, Schmeelk-Cone, and Zimmerman (2003) examined racial identity, perceived stress, and psychological distress in 555 African-American young adults. The results of this study suggest an indirect relation between racial centrality and public regard on psychosocial maladjustment. Reporting race as central to one's identity was significantly correlated with lower levels of psychological distress. These findings provide further support for racial identity as a critical factor in the examination of psychosocial functioning in an African American population

Furthermore, Azibo (1998) reported that racial identity in healthy African American adults serves as an extension of one's collective identity, which serves as a risk or protective factor that interacts with various psychological factors. For African Americans, racial identity

attitudes, characterized by the pre-encounter stage of racial identity development (where the individual devalues his or her race or racial group and attempts to deny membership in that group), were linked to increased psychosocial maladjustment (Carter, 1991). Positive feelings about one's racial group (private regard) were correlated with less perceived stress (Caldwell, Zimmerman, Bernat, Sellers, & Notaro, 2002) and increased self-esteem (Rowley, Sellers, Chavous, & Smith, 1998).Though racial identity has been thoroughly researched as a critical aspect in the lives of healthy adult African Americans, it has received only minimal attention in the health psychology literature. With SCD affecting primarily people of African descent it is important to explore the concept of racial identity in this population.

Brook and Pahl (2005) explored the protective and moderating effects of ethnic/racial identity with regards to drug use in 333 low SES African Americans young adults. Their findings provide support for ethnic and racial identity as having moderating effects through enhancing characteristics of psychological well-being. Additionally, those who reported valuing their racial group also reported lower levels of depression. Sellers et al. (1998) termed valuation of one's racial group as "racial self-esteem", which has been linked to personal self-esteem (Crocker, Luhtanen, Blaine, & Broadnax, 1994; Hughes & Demo, 1989). Thus, racial identity serves not only as a buffer for negative behaviors but can serve as a protective factor for psychosocial functioning.

With respect to caregiving, Caldwell et al. (2002) examined the roles of racial identity and maternal support on psychosocial maladjustment in African American adolescents. Results of this study indicate that maternal support was related to racial identity attitudes in adolescents. In addition, private regard (the extent of positive or negative feelings about one's own racial group) was related to significantly less perceived stress, whereas increased levels of perceived

stress were significantly related to symptoms of both depression and anxiety. These results suggest that developing positive feelings about one's race may assist in the reduction of stress and indirect reduction of psychosocial maladjustment symptoms in African Americans.

African American parents are also faced with the task of preparing their children for racial challenges that they may encounter. These parents must not only adequately inform their children of these issues but foster positive social identities in terms of race (Hughes et al., 2006; Lesane-Brown, 2006; Peters, 2002). This process has been referred to as "racial socialization" and involves the teaching of cultural pride and preparation for racial discrimination in children of all ages (Stevenson, Reed, & Bodison, 1996). Importantly, Branch and Newcombe (1986) examined the relation between racial identity and racial socialization, which suggests that parents who reported higher levels of Black ethnocentrism were likely to foster a positive racial attitude (private regard) in their children. Neblett et al. (2008) examined the relations among racial socialization, discrimination, and adjustment in 361 African American adolescents. Their findings provided further support for racial socialization serving as either risk, compensatory, or protective factors in the psychosocial adjustment of African American youth. Therefore, it appears that parents' racial identity has important implications for not only their own functioning but for the development of healthy racial identity and psychosocial functioning in their children, strengthening the need to asses this variable in caregivers of children with SCD.

To date, only one study has examined the concept of racial identity within an SCD population. Barbarin (1999) compared the roles of parental coping, involvement, religiosity, and racial identity as mediating factors in the psychological adjustment of children with SCD to healthy controls. Specifically, Barbarin's model posits that sociocultural variables influence family functioning which mediates the effects of illness-related stress on outcomes in children

with a chronic illness. Results of this study indicate that parents of children with SCD asserted Black identity more strongly than parents of control children. Barbarin (1999) found that parent racial identity (the extent to which parents racial attributions are used to explain the conditions and outcomes of African Americans) significantly predicted child behavior problems.

Clay, Mordhorst, and Lehn (2002), reported on the paucity of cultural variables in pediatric psychology literature. They examined the role of diversity in several empirically supported treatments and found that the amount of attention paid to cultural variables was minimal. Specifically, only 27% reported the race/ethnicity and 18% reported the SES of their participants. Furthermore, only 6% discussed culture as a possible moderating variable suggesting that the applicability of these treatments to minority populations may be unfounded. Thus, incorporating cultural variables such as the relation between parents' racial identity and their own psychosocial functioning is critical to the development of future interventions.

1.5 Study Purpose and Hypotheses

The purpose of this current study was to investigate how stress and coping relate to psychosocial functioning in caregivers of children with SCD. Specifically, this study examined the potential moderating effects of coping with a chronically ill child on the relation between caregiver pediatric parenting-stress and psychosocial functioning. In addition, relations among racial identity, stress, coping, and functioning were explored in caregivers of children with sickle cell disease. Because of the paucity of research with caregivers of children with SCD, few interventions targeting this population exist. An underlying aim of this study was to provide valuable information about stress, coping, racial identity, and functioning in caregivers of children with SCD, which might lead to theoretically derived and culturally sensitive interventions for children and their caregivers. It was hypothesized that caregivers with high

levels of pediatric parenting stress who utilize more effective coping strategies will report healthier psychosocial functioning than caregivers with high levels of pediatric parenting stress who utilize ineffective coping strategies. Furthermore, it was hypothesized that caregivers whom report positive racial identity will also report decreased stress, effective coping, and healthy psychosocial functioning.

CHAPTER 2

METHOD

2.1 Participants

Participants included 103 caregivers, ranging in age from 28 to 68 years of age (*M* = 41.1, *SD* = 8.04) presenting with their child at a regularly scheduled pediatric SCD appointment in the southeastern United States between May 2008 and August 2008. The majority of children were accompanied by their mother (*n* = 86, 83.5%). The remaining children were accompanied by either their father (*n* = 9, 8.5%), a grandparent (*n* = 6, 5.8%), or a legal guardian identified as "other" (*n* = 2, 1.9%). One-hundred (97.1%) of the caregivers identified as "Black or African American", 1 (1.0%) identified as "Native Hawaiian or Pacific Islander", and 2 (1.9%) caregivers failed to report their race. With regards to ethnicity, 1 (1.0%) caregiver identified as "Hispanic or Latino" and 9 (8.7%) failed to report. The average years of education were 13.86 (*SD* = 2.06). Fifteen (14.5%) of caregivers reported an annual income of below $20,000, 37 (36%) ranged between $20,001 and 50,000, 23 (22.4%) ranged between $50,001 and $80,000, and 19 (18.4%) reported annual income greater than $80,000. Two (1.9%) caregivers failed to report their education level and 9 (8.7%) did not report income. The majority (*n* = 58) of caregivers were married (56.3%), 24 were single (23.3%), 16 were divorced (15.5%), 3 were separated (2.9%), and 2 (1.9%) did not report. Twenty-six (26.2%) caregivers reported having a chronic illness, most common of which included asthma (*n* = 9, 8.8%), sickle cell disease (*n* = 9, 8.8%), and diabetes (*n* = 3, 2.9%). Seven caregivers (6.8%) reported having a psychosocial disorder, which included anxiety (*n* = 4, 3.9%), depression (*n* = 3, 2.9%), and bipolar disorder (*n* = 1, 1.0%; See Table 1).

The sample of children whom the caregivers accompanied to the medical visit ranged in age from 8 to 18 years (*M* = 12.88, *SD* = 3.09). Fifty-six (54.4%) of the children were female and forty-seven (45.6%) were male. One-hundred (97.1%) of the children were "Black or African American", 1 (1.0%) was "Asian", and 2 (2.9%) caregivers failed to report their child's race. Eighty-eight (85.4%) of the children were not "Hispanic or Latino" and 15 (14.6%) failed to report. The most common SCD type was Sickle Cell Anemia (HbSS; N = 69, 67%), 13 (12.6%) had SCD (HbSC), 6 (5.8%) had Sickle Beta Thalassemia (HbS), and 15 (14.5%) did not specify a subtype. Thirty-four of the children had a co-existing chronic illness, most common of which was asthma (*n* = 31, 30.3%), 3 had heart murmurs (3.0%), and 2 had acute chest syndrome (2.0%). Five (4.9%) children were diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), 1 (1.0%) with anxiety, 1 (1.0%) with depression, and 1 (1.0%) with bipolar disorder. Most commonly, 1 (*n* = 33; 32.0%) additional sibling lived in the home, followed by 0 (*n* = 29; 28.2%) siblings, 2 (*n* = 24; 23.3%) siblings, 3 siblings (*n* = 9; 8.7%) or 4 or more (*n* = 4; 3.9%) siblings; 4 (3.9%) caregivers failed to report how many additional children lived in the home. Nine (8.7%) caregivers reported having at least 2 children in the home with SCD and 16 (15.5%) failed to report (See Table 2).

2.2 Measures

Background information. Caregivers completed the Background Information Form (Appendix A). Questions assessed background information about the parent (e.g., relation to child, gender, age, ethnicity, race, education, occupation, family income, health status) and child (e.g., gender, age, ethnicity, race, and health status).

Stress. The Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001; Appendix C) was completed by the caregivers to assess stress related to parenting a

chronically-ill child. The PIP is a 42-item self-report measure that asks caregivers to rate the frequency and intensity of particular stressors. The PIP assesses Communication, Emotional Functioning, Medical Care, and Role Functioning and utilizes a 5-point Likert scale (1 = *not at all* to 5 = *extremely)* for difficulty and a 5-point Likert scale (1 = *never* to 5 = *very often*) for frequency. The items on the PIP are summed separately to yield Difficulty and Frequency scores and are added together to form an overall score. Higher scores on the PIP represent higher levels of parenting stress. The PIP overall score was found to be reliable in this sample with Cronbach's alpha = 0.97 indicating good reliability; subscale Cronbach alphas ranged from 0.82 – 0.96. For the current study, the overall score was analyzed and the Difficulty and Frequency scores were used descriptively and for exploratory analyses.

Coping. The Coping Health Inventory for Parents (CHIP; McCubbin et al., 1983; Appendix D) was completed by caregivers to assess patterns of coping with caring for a chronically ill child. The CHIP is a 45-item self-report measure that asks caregivers to rate the helpfulness of certain coping behaviors. The CHIP assesses 3 coping domains including Coping Pattern I- Family integrations, Cooperation, and an Optimistic Definition of the Situation (19 items), Coping Pattern II- Maintaining Social Support, Self Esteem and Psychosocial Stability (18 items), and Coping Pattern III- Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff (8 items). The CHIP has been minimally revised by adding an endorsement column. It asks caregivers to endorse whether they have used a particular coping behavior in the past and utilizes a 4-point Likert scale (0 = *not helpful* to 3 = *extremely helpful*) to assess how helpful each coping behavior has been. Items within each pattern were summed to yield three coping pattern scores. The items on the CHIP were summed separately to yield a Helpfulness and Utilization score. Total Helpfulness score

were divided by Utilization score to yield a weighted Overall coping score which was analyzed for the current proposal**.** In order to compute Cronbach's alphas the Helpfulness score was utilized yielding a Cronbach's alpha = 0.82, suggesting adequate reliability; subscale Cronbach's alphas ranged from 0.79 – 0.86.

Psychosocial functioning. The Brief Symptom Inventory-18 (BSI-18; Derogatis, 2000; Appendix B) was completed by caregivers to assess psychosocial functioning. The BSI-18 is an 18-item psychosocial functioning measure written at a sixth grade reading level designed for adults eighteen years and older. The BSI-18 measures three scales (depression, anxiety, somatization) and one index (global severity). It utilizes a 5-point Likert scale (0 = *not at all* to 4 = *extremely*) to measure the amount by which certain problems have caused distress in the past seven days. The global severity index was used for primary analyses in the current proposal, and the subscales were analyzed for descriptive and exploratory purposes. The BSI-18 was designed for both primary care and community populations. Within this sample, Cronbach's alpha was 0.92, suggesting internal consistency.

Racial identity. The Multidimensional Inventory of Black Identity (MIBI; Sellers, Rowley, Chavous, Shelton, & Smith, 1997; Appendix E) was completed by caregivers to assess racial identity. More specifically, the regard scale which consists of Private Regard and Public Regard and the Centrality subscale were utilized in the present study. Private regard refers to whether individuals feel positively or negatively toward African Americans and their membership in that group. Public regard refers to the extent to which individuals feel that others view African Americans positively or negatively. The Centrality scale refers to the extent to which individuals define themselves in terms of race. There are a total of 20 items with each of the regard subscales consisting of 6 items and the Centrality subscale consisting of 8 items.

Caregivers rated how strongly they agree or disagree to each item on a likert scale with scores ranging from 1 to 7 (1 = *strongly disagree* to 7 = *strongly agree*). Higher scores on the regard scales indicate the belief that the caregivers and other groups hold more positive attitudes towards African-Americans. Higher scores on the Centrality subscales reflect caregiver beliefs that race is a central component of their definition of self. Within this sample, the following Cronbach's alphas were found for each subscale: Centrality Cronbach's alpha = 0.67, Private Regard Cronbach's alpha = 0.67, Public Regard Cronbach's alpha = 0.72, and the Regard composite Cronbach's alpha = 0.72 suggesting moderate reliability. The MIBI scores were used to describe racial identity in this sample and for exploratory analyses to determine whether racial identity is related to stress, coping, or psychosocial functioning.

2.3 Procedures

Caregivers of children presenting at an SCD clinic at two urban children's hospitals in the metro Atlanta area were informed about the study by clinic personnel and directed to receive additional information from a nearby researcher. The research assistant further explained the study and obtained consent if the caregiver was interested in participating. Families presented for one of four services at the clinics: a standard SCD appointment (47.6%), a standard SCD appointment with a pulmonary clinic (35.0%), a pain clinic (2.9%), or for infusion treatment (14.6%). Of the 115 caregivers approached to participate in the study, 11 declined participation. Five caregivers reported not being interested in research, two caregivers identified time as their reason for decline, one did not feel comfortable due to current legal involvement, one father did not feel comfortable without the permission of the child's mother, one child was not officially diagnosed with SCD, and one male child was not interested but did not state his reason. In addition, one caregiver agreed to participate but reported that English was their second language

and required considerable assistance completing the forms, thus she was eliminated from the final sample resulting in a final sample size of 103.

Before meeting with the physician, the caregiver was individually administered the measures (Background Information Form, BSI-18, PIP, CHIP, and MIBI) in the waiting room. If caregivers were unable to complete the measures prior to their child's clinic visit, they were encouraged to complete them during additional wait time while in the physician's office (e.g., while waiting between the nurse and physician visits).

CHAPTER 3

RESULTS

3.1 Data Analyses Overview

Data analyses were conducted in a series of steps. Preliminary analyses were conducted to characterize the sample, inspect statistical assumptions, examine associations between demographic characteristics and the dependent variable (i.e., BSI-18 Global Severity Index) to determine if covariates should be taken into consideration in primary analyses, and examine associations among the study variables. Primary analyses were conducted utilizing a hierarchical regression equation to examine the main effects of stress and coping and their interaction effects on psychosocial functioning. Secondary analyses with racial identity were conducted by examining Pearson's correlation coefficients between the racial identity variables and primary variables.

3.2 Preliminary Analyses

Pearson's correlation revealed significant negative correlations between psychosocial functioning and parent age, $r = -0.22$ $p = 0.03$ positive correlations between functioning and the amount of days the child has missed school, $r = 0.23$, $p = 0.03$ and the parent has missed work, $r = 0.27$, $p = 0.01$ over the past year. As such these variables were controlled for in the primary analyses. Whereas Analyses of Variance (ANOVAs) revealed that parent functioning did not differ by parent relation or site of data collection, there were differences among parents who themselves have a chronic illness, F (1, 97) = 77.9, $p = 0.006$. Follow-up t tests suggested that on average, parents with a chronic illness reported significantly greater psychosocial maladjustment ($M = 11.33$, $SE = 2.55$) than parents without a coexisting illness ($M = 5.4$, $SE = 0.89$). This difference was significant t (28.89) = -2.79, $p = 0.04$ with a medium sized effect, $r = 0.38$.

Pearson's correlation analyses were conducted to investigate the association among PIP (stress) scores, CHIP (coping) scores, and the BSI-18 (psychosocial functioning) score (See Table 4). Pearson correlation coefficients revealed statistically significant positive correlations between the global severity index (GSI) and all PIP stress (i.e., Frequency, Difficulty, Communication, Medical Care, Emotional Distress, and Role Function). Similarly, BSI-18 Depression, Somatization, and Anxiety subscales were correlated with all PIP subscales.

In the examination of relations among CHIP scales (Helpfulness and Utilization) and the three coping domains with caregiver psychosocial functioning, Pearson correlations revealed no significant associations with either the global severity index or the individual subscales. Thus, within this sample no patterns of coping were associated with psychosocial functioning.

3.3 Primary Analyses

Primary analyses consisted of a three-step hierarchical regression equation to test for moderation. The first step controlled for the effects of the covariates (i.e., parent age, parent chronic illness, child days missed school, and parent days missed work), the second step examined the main effects of stress (PIP overall score) and coping (CHIP overall score) and the third step examined the stress x coping interaction on psychosocial functioning (BSI-18 Global Severity Index). The independent variables were mean-centered prior to computing the interaction term to reduce multicollinearity. The first step which included the aforementioned covariates, was not significant, F (4, 22) = 1.46, p = 0.25. On the second step, the model including stress (PIP Overall Score; M = 198.04, SD = 53.97) and coping (CHIP overall score; M = 1.76, SD = 0.62) was a significant predictor of psychosocial functioning (BSI-18 GSI; M = 6.85, SD = 9.34), F (2, 20) = 7.78, p = 0.003. There was a statistically significant main effect of stress on psychosocial functioning, β = 0.64, SE = 0.02, p = .001, indicating that relatively high

reports of stress associated with parenting a chronically ill child are accompanied by relatively low reports of psychosocial functioning. However, there was not a significant main effect for coping, $\beta = -0.15$, $SE = 1.82$, $p = 0.39$, suggesting that caregiver patterns of coping with a chronically ill child was not associated with psychosocial functioning. At the third step, the interaction term did not account for a significant amount of unique variance over the prior steps, $F(1, 19) = 0.3$, $p = 0.6$, and was not statistically significant, $\beta = -0.1$, $SE = 0.04$, $p = 0.6$. These analyses indicate that caregiver coping did not significantly moderate the relation between caregiver stress and psychosocial functioning within this sample. Using the definition of "caseness" as defined by Derogatis (2000), results revealed that 18 of 103 (17.31%) caregivers were in the clinical range for high distress (See Tables 3 and 5).

3.4 Secondary Analyses

Secondary correlation analyses were conducted to examine the relations between racial identity and stress, coping, and psychosocial functioning in caregivers (See Table 6). Results revealed significant associations between racial identity and certain aspects of caregiver stress. Specifically, the analyses revealed significant negative correlations between Regard and the following PIP subscales: Communication Difficulty ($r = -0.24$, $p = 0.03$), Emotional Distress Difficulty ($r = -0.27$, $p = 0.02$) and Frequency ($r = -0.25$, $p = 0.03$), and Medical Care Difficulty ($r = -0.22$, $p = 0.04$). Additionally, there was a significant negative correlation between Private Regard and Medical Care Difficulty ($r = -0.22$, $p = 0.04$). These results suggest that relatively greater levels of positive feelings towards African Americans are associated with relatively fewer reports of communication difficulty with their child and the health care team, stress related to the demands of their child's medical care, and the impact of stressors associated with emotional functioning. In contrast, both the extent to which one normatively defines him or herself in terms

of race (Centrality) and the extent to which individuals believe that others view their race negatively or positively (Public Regard) was not significantly correlated with other aspects of stress, coping, or psychosocial functioning in caregivers of children with SCD.

CHAPTER 4

DISCUSSION

The aim of this study was to examine stress, coping, functioning, and racial identity in caregivers of children with SCD. The population consisted primarily of mothers who were on average in their early 40s and of middle-class income. This is similar to other populations of SCD parents in the literature (Barakat et al., 2007; Barakat et al., 2005), but these caregivers were more likely to report being married and having a higher annual income (Brown et al., 2000; Barbarin et al., 1999, Kaslow et al., 1997) than other comparison samples. Caregivers of children with SCD reported relatively healthy psychosocial functioning, with the average score falling approximately 1 standard devation below established clinical cut-offs (Derogatis, 2000; See Table 3). Although encouraging, the healthy functioning of these parents is inconsistent with previous research, which suggests that caregivers of children with SCD are experiencing significant maladjustment (Thompson et al., 2002; Brown et al., 2000; Thompson et al., 1993). These differences might reflect variability in the methods and/or demographics. Specifically, the Thompson, et al. (2002) sample consisted of caregivers of newborns and psychosocial functioning was measured with the longer Brief Symptom Inventory-53 GSI. Additionally, the Brown et al. (2000) sample consisted of slightly younger parents (M = 33.3, SD = 7.6) and functioning was assessed with the Symptom Checklist-90-R GSI.

Whereas the average parenting stress frequency (PIP-F; M = 99.8, SD = 29.0) score was generally similar to samples of parents of children with cancer (PIP-F, M = 94.0, SD = 33.3; PIP-D, M = 112.4, SD = 35.1; Streisand et al., 2001), diabetes (PIP-F, M = 106.2, SD = 26.9; PIP-D, M = 103.3, SD = 28.9; Lewin, et al., 2005), and obesity (M = 98.0, SD = 34.4; Ohleyer et al., 2007), their difficulty scores were slightly lower (PIP-D; M = 95.1, SD = 29.5). Further, these

stress levels in the current sample parallel those found in another sample of parents of children with sickle cell disease (Barakat et al., 2007; Logan, Radcliffe, & Smith-Whitley, 2002). Taken together, these data suggest that the stress of raising a child with SCD is high and deserves attention.

The coping of these parents was slightly lower (*M* = 83.9, *SD* = 22.2) than that found in parents of children with diabetes (*M* = 95.4, *SD* = 16.5; Stallwood, 2005), relatively higher than that found in epilepsy (*M* = 74.2, *SD* = 22.6; Mu, 2005), and significantly higher than that found in cystic fibrosis (*M* = 17.3, *SD* = 8.3; Cappelli et al., 1988). Further research with parents of children with SCD, suggests that high levels of coping helpfulness are associated with positive sibling adjustment. Though some of these differences may be attributable to unique disease variables, the Stallwood (2005) sample only consisted of parents of children younger than 9 years of age. In addition, the Mu (2005) sample consisted of Taiwanese mothers and may reflect confounding cultural differences in the expression and utility of various coping variables. Though Cappelli's (1988) cystic fibrosis (CF) sample represents a genetic disorder which is similar in that capacity to sickle cell disease, at the time of the research the median age of survival for a CF patient was 23 years. However, as of 2008, the median survival age of a CF patient has risen to 37.4 years (CF Foundation, 2009). Overall, in conjunction with research on other pediatric diseases, it appears that coping is an important issue for caregivers of children with SCD.

Racial identity in this sample suggests that the caregivers were similar to the African American college students in the MIBI development study. Specifically, both the current and the college sample were above the midpoint with regards to private regard and centrality (Sellers et al., 1998). This is consistent with other samples of African American college students

(Schmermund, Sellers, Mueller, & Crosby, 2001) and high school students (Caldwell et al., 2002). However, Yip et al.'s (2006) research examining age differences among adolescents, college students, and adults in racial identity status suggests that all groups reported higher scores on the centrality subscale in comparison to the current sample. Additionally, whereas the adolescents were similar to the current sample in terms of public regard, the college students and adults were slightly lower. Moreover, all groups were slightly lower than the current sample with regards to private regard. Taken together these results suggest that racial identity is an important and influential factor in the lives of African Americans.

Younger caregivers and caregivers diagnosed with a chronic illness themselves reported poorer psychosocial functioning. In tandem, increases in both the number of days their child had missed school and they missed work over the past year was also associated with caregiver psychosocial maladjustment. The co-existence of chronic illness in the caregiver, children missing school, and having to miss work may tax the caregiver's ability to provide care to their child while fulfilling their professional and financial responsibilities, which might contribute to heightened psychosocial maladjustment. These findings suggest that stress has an additive effect, by which the frequency of simultaneously attending to a variety of stressors negatively impacts functioning (Streisand et al., 2003).

The lack of a relation between coping and psychosocial functioning is inconsistent with that of caregivers of children with chronic pain (Williamson et al., 2002), HIV (Bachanas et al., 2001), and SCD (Thompson, et al., 1993). The variation in findings with regard to the present sample is possibly due to differences in the operational definition of coping, unique disease-related variables, and/or demographic differences. For example, the unpredictability of SCD may impact the effectiveness of coping in relation to caregiver functioning. Thus, caregivers may be

less able to develop a stable repertoire of coping mechanisms to moderate the stress-adjustment relation.

In the primary analyses, consistent with hypotheses and prior research examining parents of children with HIV (Moskowitz et al., 2007; Bachanas et al., 2001), diabetes (Lewin et al., 2005; Streisand et al., 2005), and cancer (Streisand et al., 2005), pediatric parenting stress significantly predicted caregiver psychosocial functioning in the current sample. Overall, increased parenting stress across all domains (communication difficulties, medical care demands, emotional distress, and fulfilling various roles), controlling for coping and demographic factors, predicted approximately 43% of variance in caregiver psychosocial functioning. It might be that attending to a variety of difficult pediatric stressors on a frequent basis limits the amount of psychosocial resources that the caregiver can devote to maintaining their own psychosocial well-being. In fact, there is a rich body of literature linking stress and functioning (Arnetz, 1996). Given that these are cross-sectional data, another interpretation is that caregivers with heightened maladjustment experience greater frequency of and difficulty with stress related to parenting an ill child. Data with other populations support the notion that psychosocial factors such as maladjustment may serve as intervening factors that eliminate or modify the source of the stressor, alter the meaning of the stressful stimulus, or regulate the emotional reactivity associated with the stressor (Lazarus & Folkman, 1984; Pearlin & Schooler, 1978).

There is also the possibility that other variables explain the significant stress-functioning relation. As an example, Logan, et al. (2002) found the stress associated with parenting children with SCD – when controlling for disease severity – was associated with both routine and urgent care service utilization. Frequent medical care use or other variables might drive the association among stress and functioning. Regardless of the explanation, parents of children with high stress

will likely have high maladjustment, which suggests that assessment and treatment of these domains might be in order. Specific to the current study, it is also possible that unique aspects of the data collection site which represents a large community of SCD families, dedicated and consistent care providers, and frequent outreach opportunities (i.e., summer camps, foundations, family events, and transition clinics) may provide these caregivers with a more supportive environment resulting in healthier functioning.

In contrast to previous research findings (Wallander & Varni, 1998), coping did not predict functioning in this sample. This is also inconsistent with research that has supported the coping-functioning relation in several pediatric populations including SCD (Gil et al., 1991), CF (McCubbin, 1983), and HIV (Bachanas et al., 2001). Several explanations might be provided. For example, the overall low level and minimal variability in scores of maladjustment in the sample might have minimized the ability to find significant coping-functioning relations. Another explanation is simply that coping is not related to functioning in this sample of parents of patients with SCD. In the Lutz et al. (2004) study, whereas parent active coping did not moderate the disability stress and child adjustment relationship, it did predict parent-rated child quality of life. Thus, it appears that previous research is mixed with regards to the role of coping or this sample could simply reflect higher functioning parents.

Previous research has been inconclusive with regards to the specific psychosocial resources that moderate the stress-functioning relation. One explanation is simply that coping does not moderate the relation. Additional research is in order to evaluate this position and to identify other variables that might influence the stress-functioning relation. It also could be that the CHIP is not sufficiently sensitive to identify relevant coping that buffers the stress-functioning relation. Along these lines, Pearlin and Ansehensel (1986) suggested that coping

must be understood through examination of not only psychosocial resources but biological/physiological and social measures as well. It is possible that defining coping through the lens of pediatric chronic illness may be too narrow a definition of coping within this population. For example, religious coping may have been important to examine given that it could serve not only as a basis for optimism (Barbarin, 1993) but an adaptive resource within itself (Dezutter, Soenens, & Hutsebaut, 2006; Hackney, 2003; Levin, Chatters, & Taylor, 1995), particularly in African Americans (Chatters, Taylor, Jackson, & Lincoln, 2008; Yeates et al., 2002). In fact, research has documented that spirituality and religiosity are high in African-American adults and these aspects are related to how they cope with various stressors including SCD (Cooper-Effa, Blount, Kaslow, Rothenberg, & Eckman, 2001), chronic pain (Edwards, Moric, Husfeldt, Buvanendran, & Ivenkovich, 2005; Tan, Jensen, Thornby, & Anderson, 2005), and disability (Cano, Mayo, & Ventimiglia, 2006).

Consistent with previous research demonstrating that racial identity is as important factor in the assessment of mental health outcomes in African Americans (Pierre & Mahalik, 2005; Pillay, 2005), significant negative associations were revealed among racial identity and stress in the current study. Specifically, caregivers who had positive evaluative beliefs towards African-Americans (Regard) tended to report lower parenting stress in communication difficulties, medical care demands, and emotional distress. Additionally, having positive feelings towards one's self as an African American (Private Regard) was also associated with lower medical care distress. Positive Private Regard has been found to serve as a protective factor in African American youth (Willis et al., 2007), and it appears that it might has this same function in parents of youth with SCD. Ensel and Lin (1991) provide an explanation for this association. Their distress-deterring model suggests that psychosocial resources, such as positive private

regard, can reduce the likelihood of encountering stressful events. Furthering the explanation of these findings is previous research with adolescents, which has found that private regard serves a compensatory function with regards to perceived stress (Sellers et al., 2006). Thus, it is likely that high private regard in caregivers is a source of resilience that compensates for the negative outcomes associated with medical care stress (Zimmerman, Bingenheimer, & Notaro, 2002). On the other hand, it might be that lower parenting stress leads to more positive views of self. Given that the findings are correlational, causal explanations cannot be provided. Regardless, racial identity should be further explored in the coping and stress of parents of children with SCD.

4.1 Limitations and Future Directions

Limitations of this study should be noted. First, the data collected relied exclusively on caregiver self-report. In the absence of corroborating direct observation or ratings from other individuals, it is possible that method variance might have influenced significant relations. Additionally, caregivers may have felt the need to respond in a manner that portrayed themselves in a more positive manner, thus limiting the ability to detect significant distress. Specifically, high reports of private regard within the current sample may be related to social desirability. It will be an important future direction to incorporate multiple reporters (e.g., spouse, child, and medical staff) and/or incorporate other forms of measurement such as observational scales or other data collection modalities (i.e., laptop versus paper and pencil measures). In addition, data gathered from other sources could be used to support the validity and reliability of the self-report measurement data.

Second, the results suggested that coping had limited effects on the stress-functioning relation in caregivers of children with SCD. Operationalizing the coping variable in terms of its relation to their child's medical care may have been too narrow of a definition. Future research

should seek to understand whether there are unique aspects of coping, such as spirituality and religiosity, that impact functioning in parents of children with SCD. Further exploration of global aspects of coping will also be important to determine the function of coping behaviors on caregiver well-being. Given that coping has been supported as an instrumental factor in stress-management, it is unclear why these relations were not apparent in the current sample.

Third, the implementation of the study in an outpatient medical setting (e.g., children's hospital) limits the ability to generalize the results to families presenting for emergent care, which may reflect a population with more severe distress. Additionally, time constraints associated with the site of data collection restrained the quantity and length of measures that could be completed during the typical wait time. Future studies may want to use more comprehensive measures, that might be completed via the mail, longer appointments, or home visits. In tandem, the correlational design of the study limits the ability to make inferences regarding the causal relations between the independent and dependent variables. Longitudinal or treatment studies would provide richer information about the directionality of stress, coping, and functioning in parents of children with SCD.

4.2 Conclusions

Overall, these parents generally have healthy psychosocial functioning. However, several demographic variables as well as parenting stress were found to be associated with caregiver psychosocial functioning in expected directions. On the other hand, coping was neither a significant predictor of psychosocial functioning nor a moderator of the stress-functioning relation. Exploratory analyses revealed that positive views of self in terms of being African-American were inversely associated with parenting stress. In conclusion, this study suggests that parenting stress is an integral factor in the psychosocial functioning of caregivers of children

with SCD, and data highlight the importance of considering racial identity in this population of African-American parents of children with SCD. Findings from this study contain important avenues for further research in caregiver functioning, stress, coping, and racial identity with the goal of better understanding this population and ultimately developing culturally-sensitive and evidence-based interventions for caregivers of children with SCD.

REFERENCES

American Psychiatric Association. (2005). *Diagnostic and statistical manual of mental disorders (4th ed.) text revision.* New Delhi, India: Jaypee Brothers Medical Publishers (P) Ltd.

Arnetz, B. B. (1996). Causes of changes in the health of populations: A biopsychosocial viewpoint. *Social Science Medicine, 43*(5), 605–608.

Auslander, W.F., Thompson, S.J., Dreitzer, D., & Santiago, J.V. (1997). Mothers' satisfaction with medical care: Perceptions of racism, family stress, and medical outcomes in children with diabetes. *Health and Social Work, 22*, 190-199.

Azibo, D.A. (1998). *The distinction between African personality personologists and other African personality scholars: Implications and entreatment for reconceptualization of racial identity issues.* In R.L. Jones (Ed.), African American identity development (pp. 207-215). Hampton, VA: Cobb & Henry.

Bachanas, P.J., Kullgren, K.A., Schwartz, K.S., McDaniel, J.S., Smith, J., & Nesheim, S. (2001). Psychosocial adjustment in caregivers of school-aged children infected with HIV: Stress, coping, and family factors. *Journal of Pediatric Psychology, 26*, 331-342.

Balkaran, B., Char, G., Morris, J.S., Thomas, P.W., Sergeant, B.E., & Sergeant, G.R. (1992). Stroke in a cohort of patients with homozygous sickle cell disease: A review of the literature. *Child Neuropsychology, 13,* 120-131.

Barakat, L., Lutz, M., Nicolaou, D., & Lash, L. (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., Patterson, C., Tarazi, R., & Ely, E. (2007). Disease-related parenting stress in two sickle cell disease caregiver samples: Preschool and adolescent. *Families, Systems, & Health*, *25*, 147-161.

Barbarin, O.A. (1993). Coping and resilience: Exploring the inner lives of African American children. *Journal of Black Psychology, 19,* 478-492.

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

Branch, C.W., & Newcombe, N. (1986). Racial attitude development among young Black children as a function of parental attitudes: A longitudinal and cross-sectional study. *Child Development, 57*, 712-721.

Brown, R.T., Buchanan, I., Doepke, K., Eckman, J.R., Baldwin, K., Goonan, B., & Schoenherr, S. (1993). Cognitive and academic functioning in children with Sickle-Cell disease. *Journal of Clinical and Child Psychology, 22*, 207-218.

Brown, R.T., Lambert, R., Devine, D., Baldwin, K., Casey, R., Doepke, K., Ievers, C.E., Hsu, L., Buchanan, I., & Eckman, J. (2000). Risk-resistance adaptation model for caregivers and their children with sickle cell syndrome. *Annals of Behavioral Medicine, 22*, 158-169.

Brook, J.S., & Pahl, K. (2005). *The protective role of ethnic and racial identity and aspects of an afrocentric orientation against drug use among African American adults.* The Journal of Genetic Psychology, 166, 329-345.

Caldwell, C.H., Zimmerman, M.A., Bernat, D.H., Sellers, R.M., & Notaro, P.C. (2002). Racial identity, maternal support, and psychosocial distress, among African American adolescents. *Child Development, 73*, 1322-1336.

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.

Cappelli, M., McGrath, P., MacDonald, N., Boland, M., Fried, P., & Katsanis, J. (1988). Parent, family, and disease factors as predictors of psychosocial functioning in children with cystic fibrosis. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, *20*, 413-423.

Carter, R.T. (1991). Racial identity attitudes and psychosocial functioning. *Journal of Multicultural Counseling and Development, 19*, 102-114.

Chapar, G.N. (1988). Chronic disease of children and neuropsychological dysfunction. *Developmental and Behavioral Pediatrics, 9*, 221-222.

Chatters, L.M., Taylor, R.J., Jackson, J.S., & Lincoln, K.D. (2008). Religious coping among African Americans, Caribbean Blacks and Non-Hispanic Whites. *Journal of Community Psychology, 36*, 371-386.

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

Cooper-Effa, M., Blount, W., Kaslow, N., Rothenberg, R., & Eckman, J. (2001). Role of spirituality in patients with sickle cell disease. *Journal of the American Board of Family Medicine, 14,* 116-122.

Crocker, J., Luhtanen, R., Blaine, B., & Broadnax, S. (1994). Collective self-esteem and psychosocial well-being among White, Black, and Asian college students. *Personality and Social Psychology Bulletin, 20,* 503-513.

Cystic Fibrosis Foundation. About Cystic Fibrosis (2009). Retrieved July 27, 2009, from http://www.cff.org/AboutCF/Faqs/#Is_there_a_cure_for_cystic_fibrosis?

Dahlquist, L.M., Czyzewski, D.I., & Jones, C.L. (1996). Parents of children with cancer: A longitudinal study of emotional distress, coping, style, and marital adjustment two and twenty months after diagnosis. *Journal of Pediatric Psychology, 21*, 541-554.

Daly, B.P., Kral, M.C., & Brown, R.T. (2008). Cognitive and academic problems associated with childhood cancers and sickle cell disease. *School Psychology Quarterly, 23*, 230-242.

Davis H., Schoendorf, K.C., Gergen, P.J., & Moore, R.M. (1997). National trends in the mortality of children with sickle cell -disease, 1968 through 1992. *American Journal of Public Health, 87,* 1317-1322.

Derogatis, L.R. (2000). The SCL-90-R and Brief Symptom Inventory (BSI) in Primary Care. In *Handbook of psychosocial assessment in primary care settings.* Mahwah: Lawrence Erlbaum Associates Publishers.

Dezutter, J., Soenens, B., & Hutsebaut, D. (2006). Religiosity and mental health: A further explanation of the relative importance of religious behaviors vs. religious attitudes. *Personality and Individual Differences, 40*, 807-818.

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.

Ensel, W.M., & Lin, N. (2000). Age, the stress process, and physical distess. *Journal of Aging and Health, 12,* 139-168.

Evans, R.C., Burlew, A.K., & Oler, C.H. (1988). Children with sickle-cell anemia: Parental relations, parent-child relations, and child behavior. *Social Work, 33,* 127-130.

Fowler, M.G., Johnson, M.P., & Atkinson, M.S. (1985). School achievement and absence in children with chronic health conditions. *Journal of Pediatrics, 106,* 683-687.

Fowler, M.G., Whitt, J.K., Lallinger, R.R., Nash, K.B., Atkinson, S., Wells, R.J., & McMillan, C. (1988). Neuropsychologic and academic functioning of children with sickle cell anemia. *Developmental and Behavioral Pediatrics, 9*, 213-230.

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.

Gillis, J.S (1993). Effects of life stress and dysphoria on complex judgments. *Psychosocial Reports, 72,* 1355-1363.

Hackney, S.P. (2000). Religiosity and mental health: A meta-analysis of current studies. *Journal for the Scientific Study of Religion, 42*, 43-55.

Hanson, C.L., DeGuire, M.J., Schnikel, A.M., & Kolterman, M.G. (1995). Empirical validation for a family-centered model of care. *Diabetes Care, 18,* 1347-1356.

Hughes, M., & Demo, D.H. (1989). Self-perceptions of Black Americans: Self-esteem and personal efficacy. *American Journal of Sociology, 95,* 132-159.

Hughes, D., Rodriguez, J., Smith, E.P., Johnson, D.J., Stevenson, H.C., & Spicer, P. (2006). Parents' ethnic-racial socialization practices: A review of research and directions for future study. *Developmental Psychology, 42*, 747-770.

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.

Kinney, T.R., Sleeper, L.A., Wang, W.C., Zimmerman, R.A., Pegelow, C.H., Ohene-Frempong, K., et al. (1999). Silent cerebral infarcts in sickle cell anemia: A risk factor analysis. *Pediatrics, 103*, 640-645.

Kovacs, M. (1985). The children's depression inventory. *Psychopharmacology Bulletin, 21*, 995-998

Kral, M.C., Brown, R.T., & Hynd, G.W. (2001). Neuropsychological aspects of pediatric sickle cell disease. *Neuropsychological Review, 11*, 179-196.

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

Lemanek, K.L., Buckloh, L.M., Woods, G., & Butler, R. (1995). Diseases of the Circulatory System: Sickle Cell Disease and Hemophilia. In M.C. Roberts (Ed.) *Handbook of Pediatric Psychology*, 2nd Edition, (pp. 286-309). New York: Guilford Press.

Lesane-Brown, C.L. (2006). A review of race socialization within Black families. *Developmental Review, 26,* 400-426.

Levin, J.S., Chatters, L.M., & Taylor, R.J. (1995). Religious effects on health status and life satisfaction among black Americans. *Journal of Gerontology Series B: Psychosocial Sciences and Social Sciences, 50*, S154-S163.

Lewin, A., Storch, E., Silverstein, J., Baumeister, A., Strawser, M., & Geffken, G. (2005). Validation of the pediatric inventory for parents in mothers of children with type 1 diabetes: An examination of parenting stress, anxiety, and childhood psychopathology. *Families, Systems, & Health*, *23*, 56-65.

Logan, D. E., Radcliffe, J., & Smith-Whitley, K. (2002). Parent factors and adolescent sickle cell disease: Associations with patterns of health service use. *Journal of Pediatric Psychology, 27,* 475–484.

Lutz, M., Barakat, L., Smith-Whitley, K., & Ohene-Frempong, K. (2004). Psychological adjustment of children with sickle cell disease: Family functioning and coping. *Rehabilitation Psychology*, *49*, 224-232

McCubbin, H.I., McCubbin, M.A., Patterson, J.M., Cauble, A.E., Wilson, L.R., & Warwick, W. (1983). CHIP-Coping health inventory for parents: An assessment of parental coping patterns in the care of a chronically ill child. *Journal of Marriage and Family*, *45*, 359-370.

Melamed, B.G., & Ridley-Johnson, R. (1988). Psychosocial preparation of families for hospitalization. *Developmental and Behavioral Pediatrics, 9*, 96-102.

Moskowitz, J.T., Butensky, E., Harmatz, P., Vichinsky, E., Heyman, M.B., Acree, M., Wrubel, J., Wilson, L., & Folkman, S. (2007). Caregiving time in Sickle Cell Disease: Psychosocial effects in maternal caregivers. *Pediatric Blood Cancer, 48*, 64-71.

Mu, P. (2005). Paternal reactions to a child with epilepsy: Uncertainty, coping strategies, and depression. *Journal of Advanced Nursing*, *49*, 367-376

National Heart, Lung, and Blood Institute. Disease and Conditions Index. Sickle Cell Anemia. (2006). Retrieved December 18, 2006, from http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhatIs.html

Neblett, E.W., White, R.L., Ford, K.R., Nguyen, H.X., & Sellers, R.M. (2008). Patterns of racial socialization and psychosocial adjustment: Can parental communications about race reduce the impact of discrimination. *Journal of Research on Adolescence, 18*, 477-515.

Ohene-Frempong, K., Weiner, S., Embury, S., Moohr, J.W. et al. (1998). Cerebrovascular accidents in sickle cell disease. Rates and risk factors. *Blood, 91*, 288-294.

Ohleyer, V., Freddo, M., Bagner, D., Simons, L., Geffken, G., Silverstein, J., et al. (2007). Disease-related stress in parents of children who are overweight: Relations with parental anxiety and childhood psychosocial functioning. *Journal of Child Health Care*, *11*, 132-142.

Pearlin, L.I., & Ansehensel, C. (1986). Coping and social supports: Their functions and applications. In L. H. Aiken & D. Mechanic (Eds.), *Applications of social science to clinical medicine and health* (pp. 53-74). New Brunswick, NJ: Rutgers University Press.

Pearlin, L.I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19,* 2-21.

Peters, M.F. (2002). Racial socialization of young Black children. In H.P. McAdoo (Ed.), *Black children: Social, educational, and parental environments* (2nd ed., pp. 57-72). Thousand Oaks: Sage.

Pianta, R.C. & Egeland, B. (1990). Life stress and parenting outcomes in a disadvantaged sample: Results of the mother-child interaction project. *Journal of Clinical Child Psychology, 19*, 329-336.

Pierre, M., & Mahalik, J. (2005). Examining African self-consciousness and black racial identity as predictors of black men's psychological well-being. *Cultural Diversity and Ethnic Minority Psychology*, *11*, 28-40.

Pillay, Y. (2005). Racial identity as a predictor of the psychological health of African American students at a predominantly white university. *Journal of Black Psychology*, *31*, 46-66.

Phinney, J.S., & Kohatsu E.L. (1997). *Ethnic and racial identity development and mental health.* In J. Schulenberg, J.L. Maggs, & K. Hurrelmann (pp. 420-443). New York: Cambridge University Press.

Rowley, S.J., Sellers, R.M., & Chavous, T.M. (1998). The relationship between racial identity and self-esteem in African American college and high school students. *Journal of Personality and Social Psychology, 74*, 715-724.

Schmermund, A., Sellers, R. M., Mueller, B., & Crosby, F. J. (2001). Attitudes toward affirmative action as a function of racial identity among Black college students. *Political Psychology, 22,* 759-774.

Sellers, R.M., Caldwell, C.H., Schmeelk-Cone, K.H., & Zimmerman, M.A. (2003). Racial identity, racial discrimination, perceived stress, and psychosocial distress among African American young adults. *Journal of Health and Social Behavior, 43*, 302-317.

Sellers, R., Copeland-Linder, N., Martin, P., & Lewis, R. (2006). Racial identity matters: The relationship between racial discrimination and psychological functioning in African American adolescents. *Journal of Research on Adolescence*, *16*, 187-216.

Sellers, R. M., Shelton, J. N., Cooke, D. Y., Chavous, T. M., Rowley, S. A. J., & Smith, M. A. (1998). A multidimensional model of racial identity: Assumptions, findings, and future directions. In R. L. Jones (Ed.), *African American Identity Development: Theory, Research, and Intervention (pp. 275-302)*, Hampton, VA : Cobb & Henry.

Sellers, R.M., Rowley, S.A.J., Chavous, T.M., Schelton, 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.

Stallwood, L. (2005). Influence of Caregiver Stress and Coping on Glycemic Control of Young Children with Diabetes. *Journal of Pediatric Health Care*, *19*, 293-300

Stevenson, H.C., Reed, J., & Bodison, P. (1996). Kinship social support and adolescent racial socialization beliefs: Extending the self to family. *Journal of Black Psychology, 22*, 498-508.

Streisand, R., Braniecki, S., & Tercyak, K.P. (2001). Childhood illness-related parenting stress: The pediatric inventory for parents. *Journal of Pediatric Psychology, 26*, 155-162.

Streisand, R., Kazak, A.E., & Tercyak, K.P. (2003). Pediatric-specific parenting stress and family functioning in parents of children treated for cancer. *Children's Healthcare, 32*, 245-256.

Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C.S. (2005). Pediatric parenting stress among parents of children with type I diabetes: The role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology, 30*, 513- 521.

Swift, A.V., Cohen, M.J., Hynd, G.W., Wisenbaker, J.M., McKie, K.M., Makari, G., & McKie, V. (1989). Neuropsychological impairment in children with sickle cell anemia. *Pediatrics, 84,* 1077-1085.

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.

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

Thompson, R.J., Gustafson, K.E., Bonner, M.J., & Ware, R.E. (2002). Neurocognitive development of young children with sickle cell disease through three years of age. *Journal of Pediatric Psychology, 27,* 235-244.

Timko, C., Stovel, K.W., & Moos, R.H. (1992). Functioning among mothers and fathers of children with juvenile rheumatoid disease: A longitudinal study. *Journal of Pediatric Psychology, 17,* 705-724.

Wallander, J.L., & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry, 39*, 29-46.

Williamson, G.M., Walters, A.S.,& Shaffer, D.R. (2002). Caregiver models of self and others, coping, and depression: Predictors of depression in children with chronic pain. *Health Psychology, 21*, 405-410.

Wills, T., Murry, V., Brody, G., Gibbons, F., Gerrard, M., Walker, C., et al. (2007). Ethnic pride and self-control related to protective and risk factors: Test of the theoretical model for the strong African American families program. *Health Psychology*, *26*, 50-59.

Yeates, K.O., Taylor, H.G., Woodrome, S.E., Wade, S.L., Stancin, T., & Drotar, D. (2002). Race as a moderator of parent and family outcomes following pediatric traumatic brain injury. *Journal of Pediatric Psychology, 27*, 393-403.

Yip, T., Seaton, E., & Sellers, R. (2006). African American racial identity across the lifespan: identity status, identity content, and depressive symptoms. *Child Development*, *77*, 1504-1517.

Zabora, J. et al. (2001). A new psychosocial screening instrument for use with cancer patients. *Psychosomatics: Journal of Consultation Liaison Psychiatry, 42,* 241-246.

Zimmerman, M.A., Bingenheimer, J.B., Notaro, P.C. (2002). Natural mentors and adolescent resiliency: A study with urban youth. American Journal of Community Psychology, 30, 221-243.

APPENDICES

Appendix A

Table 1. Parent Demographic Information

Variable	*M (SD)*
Age	41.1 (8.1)
Education Level	13.9 (2.1)
	n (%)
Gender	
Female	88 (85.4)
Male	15 (14.6)
Relationship to Child	
Mother	86 (83.5)
Father	9 (8.7)
Grandparent	6 (5.8)
Other	2 (1.9)
Ethnicity	
Not Hispanic/Latino	93 (90.3)
Hispanic/Latino	1 (1.0)
Missing	2 (1.9)
Race	
Black/African American	100 (97.1)
Native Hawaiian/Pacific Islander	1 (1.0)
Missing	2 (1.9)
Marital Status	
Married/Partnered	58 (56.3)

Single	24 (23.3)
Divorced	16 (15.5)
Separated	3 (2.9)
Missing	2 (1.9)
Family Income	
Up to $10,000	6 (5.8)
$10,001 - $20,000	9 (8.7)
$20,001 - $30,000	12 (11.7)
$30, 001 - $40,000	14 (13.6)
$40,001 - $50,000	11 (10.7)
$50,001 - $60,000	11 (10.7)
$60,001 - $70,000	5 (4.9)
$70,001 - $80,000	7 (6.8)
$80,001 - $90,000	3 (2.9)
$90,001 and above	16 (15.5)
Missing	9 (8.7)

Table 1

Parent Demographic Information (n = 103)

Appendix B

Table 2. Child Demographic Information

Variable	*M (SD)*
Age	12.88 (3.1)
	n (%)
Gender	
Female	56 (54.4)
Male	47 (45.6)
Ethnicity	
Not Hispanic/Latino	88 (85.4)
Missing	15 (14.6)
Race	
Black/African American	100 (97.1)
Asian	1 (1.0)
Missing	2 (1.9)
SCD Type	
HbSS	69 (67.0)
HbSC	13 (12.6)
Beta Thalessimia	6 (5.8)
Missing	13 (12.6)

Table 2

Child Demographic Information (n = 103)

Appendix C

Table 3. Means and Standard Deviations of Study Variables

Measures	*M (SD)*
Pediatric Inventory for Parents (PIP) [a]	
Communication Difficulty	16.98 (5.81)
Communication Frequency	21.64 (6.04)
Communication Total	38.82 (10.70)
Emotional Distress Difficulty	39.87 (14.39)
Emotional Distress Frequency	38.14 (12.89)
Emotional Distress Total	78.63 (26.40)
Medical Care Difficulty	16.12 (5.58)
Medical Care Frequency	21.89 (7.08)
Medical Care Total	38.06 (10.86)
Role Function Difficulty	21.69 (7.58)
Role Function Frequency	22.17 (6.69)
Role Function Total	43.78 (13.53)
Difficulty Total	95.09 (29.54)
Frequency Total	99.80 (29.04)
Overall Score	198.04 (53.97)
Coping Health Inventory for Parents (CHIP) [b]	
Family Subscale	45.08 (8.42)
Medical Subscale	16.25 (5.45)
Support Subscale	29.16 (12.06)
Helpfulness Total	83.89 (22.21)
Utilization Total	49.43 (6.64)

Weighted Overall Score	1.76 (0.62)
Brief Symptom Inventory-18 (BSI-18) [c]	
Anxiety Subscale	2.34 (3.77)
Depression Subscale	3.06 (4.26)
Somatization Subscale	1.97 (3.42)
Global Severity Index (GSI)	6.85 (9.34)
Multidimensional Inventory of Black Identity (MIBI) [d]	
Centrality	4.65 (1.07)
Regard	5.45 (0.66)
Private Regard	6.66 (0.56)
Public Regard	4.32 (1.08)

Note. [a] Scores on the PIP range from 1 to 5, with higher scores reflecting greater stress. [b] Scores on the CHIP range from 0 to 3, with higher scores representing more helpful coping strategies. [c] Scores on the BSI-18 range from 0 to 4, with higher score reflecting poorer psychosocial functioning. [d] Scores on the MIBI range from 0 to 7, with higher scores indicating a more positive perception of African Americans.

Table 3

Means and Standard Deviations of Study Variables

Appendix D

Table 4. Associations among Main Study Variables

	BSI	PIP	CHIP
BSI-18 GSI	---	---	---
PIP Overall Score	0.66 **	---	---
CHIP Overall Score	-0.68	0.22	---

Note. **p<.01

Table 4

Associations among Main Study Variables

Appendix E

Table 5. Regression Analysis: Stress, Coping, and Stress x Coping

As Predictors of Psychosocial Functioning

Predictor	Beta	Δ R^2	Cumulative R^2	*F* Change
		BSI-18 Global Severity Index		
Step 1		0.209	0.209	1.46
Parent Age	-0.26			
Parent Chronic Illness	0.178			
Child Missed School	0.373			
Parent Missed Work	-0.166			
Step 2 **		0.346	0.556	7.797
Stress	0.636			
Coping	-0.154			
Step 3		.007	.563	0.303
Stress x Coping	-.103			

Note. ***p* = .001

Table 5

Regression Analyses: Stress, Coping, and Stress x Coping as Predictors of Psychosocial Functioning

Appendix F

Table 6. Associations among Racial Identity and Study Variables

	MIBI			
	Centrality	Regard	Public Regard	Private Regard
PIP				
Communication Difficulty	0.04	-0.24 *	-0.15	-0.21
Communication Frequency	-0.13	-0.19	-0.12	-0.20
Emotional Distress Difficulty	-0.07	-0.27 *	-0.21	-0.19
Emotional Distress Frequency	-0.08	-0.25 *	-0.19	-0.19
Medical Care Difficulty	0.15	-0.22 *	-0.13	-0.22 *
Medical Care Frequency	-0.19	-0.09	0.01	-0.19
Role Function Difficulty	0.15	-0.07	-0.02	-0.09
Role Function Frequency	0.04	-0.04	-0.01	-0.06
Difficulty Total	0.11	-0.14	-0.08	-0.19
Frequency Total	-0.06	-0.12	-0.08	0.09
Overall Score	0.08	-0.18	-0.1	-0.26
CHIP				
Family Subscale	-0.06	0.17	0.19	-0.01
Medical Care Subscale	0.02	0.16	0.17	0.00
Support Subscale	-0.03	0.28	0.22	0.2
Helpfulness Score	0.02	0.13	0.11	0.07
Utilization Score	0.03	-0.19	-0.19	-0.04
Overall Score	0.05	0.14	0.11	0.1
BSI-18				
Anxiety	-0.09	-0.11	-0.12	-0.03
Depression	0.14	-0.15	-0.15	-0.09
Somatization	-0.18	-0.07	0.01	-0.15
Global Severity Index	-0.03	-0.09	-0.04	-0.13

Note. * $p < .05$

Table 6

Associations among Racial Identity and Study Variables

Appendix G

SCD Background Information Form

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 psychosocial disorder (i.e., anxiety, depression, etc.)?
    YES NO
    If so, what _____

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

Questions about the Child

16. Child's Gender: ___Male ___Female

17. Child's Date of Birth: ____/____/____

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 psychosocial 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: _____

    Address: _____

    _____

    Phone: _____

Appendix H

The Brief Symptom Inventory-18

BSI© 18

DIRECTIONS: Below is a list of problems people sometimes have. Read each one carefully and circle the number that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Do not skip any items. If you change your mind, erase your first mark carefully and then fill in your new choice.

HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Faintness or dizziness	**0**	**1**	**2**	**3**	**4**
2. Feeling no interest in things	**0**	**1**	**2**	**3**	**4**
3. Nervousness or shakiness inside	**0**	**1**	**2**	**3**	**4**
4. Pains in heart or chest	**0**	**1**	**2**	**3**	**4**
5. Feeling lonely	**0**	**1**	**2**	**3**	**4**
6. Feeling tense or keyed up	**0**	**1**	**2**	**3**	**4**
7. Nausea or upset stomach	**0**	**1**	**2**	**3**	**4**
8. Feeling blue	**0**	**1**	**2**	**3**	**4**
9. Suddenly scared for no reason	**0**	**1**	**2**	**3**	**4**
10. Trouble getting your breath	**0**	**1**	**2**	**3**	**4**
11. Feelings of worthlessness	**0**	**1**	**2**	**3**	**4**
12. Spells of terror or panic	**0**	**1**	**2**	**3**	**4**
13. Numbness or tingling in parts of your body	**0**	**1**	**2**	**3**	**4**
14. Feeling hopelessness about the future	**0**	**1**	**2**	**3**	**4**
15. Feeling so restless you couldn't sit still	**0**	**1**	**2**	**3**	**4**
16. Feeling weak in parts of your body	**0**	**1**	**2**	**3**	**4**
17. Thoughts of ending your life	**0**	**1**	**2**	**3**	**4**
18. Feeling fearful	**0**	**1**	**2**	**3**	**4**

Appendix I

The Pediatric Inventory for Parents

PEDIATRIC INVENTORY FOR PARENTS

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you <u>in the past 7 days</u>, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. <u>Please complete both columns for each item.</u>

	HOW OFTEN?					&	HOW DIFFICULT?				
EVENT	**1= Never**	**2= Rarely**	**3= Sometimes**	**4= Often**	**5= Very Often**		**1= Not at all**	**2= A little**	**3= Somewhat**	**4= Very much**	**5=Extremely**
1. Difficulty sleeping	1	2	3	4	5		1	2	3	4	5
2. Arguing with family member(s)	1	2	3	4	5		1	2	3	4	5
3. Bringing my child to the clinic or hospital	1	2	3	4	5		1	2	3	4	5
4. Learning upsetting news	1	2	3	4	5		1	2	3	4	5
5. Being unable to go to work/job	1	2	3	4	5		1	2	3	4	5
6. Seeing my child's mood change quickly	1	2	3	4	5		1	2	3	4	5
7. Speaking with doctor	1	2	3	4	5		1	2	3	4	5
8. Watching my child have trouble eating	1	2	3	4	5		1	2	3	4	5
9. Waiting for my child's test results	1	2	3	4	5		1	2	3	4	5
10. Having money/financial troubles	1	2	3	4	5		1	2	3	4	5
11. Trying not to think about my family's difficulties	1	2	3	4	5		1	2	3	4	5
12. Feeling confused about medical information	1	2	3	4	5		1	2	3	4	5
13. Being with my child during medical procedures	1	2	3	4	5		1	2	3	4	5
14. Knowing my child is hurting or in pain	1	2	3	4	5		1	2	3	4	5
15. Trying to attend to the needs of other family members	1	2	3	4	5		1	2	3	4	5
16. Seeing my child sad or scared	1	2	3	4	5		1	2	3	4	5
17. Talking with the nurse	1	2	3	4	5		1	2	3	4	5
18. Making decisions about medical care or medicines	1	2	3	4	5		1	2	3	4	5
19. Thinking about my child being isolated from others	1	2	3	4	5		1	2	3	4	5
20. Being far away from family and/or friends	1	2	3	4	5		1	2	3	4	5
21. Feeling numb inside	1	2	3	4	5		1	2	3	4	5

EVENT	HOW OFTEN? 1= Never	2= Rarely	3= Sometimes	4= Often	5= Very Often	& HOW DIFFICULT? 1= Not at all	2= A little	3= Somewhat	4= Very much	5=Extremely
22. Disagreeing with a member of the health care team	1	2	3	4	5	1	2	3	4	5
23. Helping my child with his/her hygiene needs	1	2	3	4	5	1	2	3	4	5
24. Worrying about the long term impact of the illness.....	1	2	3	4	5	1	2	3	4	5
25. Having little time to take care of my own needs.....	1	2	3	4	5	1	2	3	4	5
26. Feeling helpless over my child's condition.....	1	2	3	4	5	1	2	3	4	5
27. Feeling misunderstood by family/friends as to the severity of my child's illness	1	2	3	4	5	1	2	3	4	5
28. Handling changes in my child's daily medical routines	1	2	3	4	5	1	2	3	4	5
29. Feeling uncertain about the future.....	1	2	3	4	5	1	2	3	4	5
30. Being in the hospital over weekends/holidays	1	2	3	4	5	1	2	3	4	5
31. Thinking about other children who have been seriously ill	1	2	3	4	5	1	2	3	4	5
32. Speaking with my child about his/her illness.....	1	2	3	4	5	1	2	3	4	5
33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing)……	1	2	3	4	5	1	2	3	4	5
34. Having my heart beat fast, sweating, or feeling tingly.....	1	2	3	4	5	1	2	3	4	5
35. Feeling uncertain about disciplining my child	1	2	3	4	5	1	2	3	4	5
36. Feeling scared that my child could get very sick or die	1	2	3	4	5	1	2	3	4	5
37. Speaking with family members about my child's illness	1	2	3	4	5	1	2	3	4	5
38. Watching my child during medical visits/procedures	1	2	3	4	5	1	2	3	4	5
39. Missing important events in the lives of other family members	1	2	3	4	5	1	2	3	4	5
40. Worrying about how friends and relatives interact my child.....	1	2	3	4	5	1	2	3	4	5
41. Noticing a change in my relationship with my partner	1	2	3	4	5	1	2	3	4	5
42. Spending a great deal of time in unfamiliar settings.....	1	2	3	4	5	1	2	3	4	5

Appendix J

The Coping Health Inventory for Parents

Revised CHIP©

DIRECTIONS: Below are behaviors that parents have used when a child has a special health need. Circle the Y for YES or N for NO to indicate whether you have done the behavior before. ***If Y*, circle the number that shows how helpful** each behavior has been to you**. If you did not use a behavior, do *not* circle a number**.

	Behaviors	*Used this behavior* If YES, circle 0-3		*Not Helpful*	*Minimally Helpful*	*Moderately Helpful*	*Extremely Helpful*
1.	Trying to maintain family stability	Y	N	0	1	2	3
2.	Engaging in relationships and friendships which help me to feel important and appreciated	Y	N	0	1	2	3
3.	Trusting my spouse (or former spouse) to help support me and my child(ren)	Y	N	0	1	2	3
4.	Sleeping	Y	N	0	1	2	3
5.	Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	Y	N	0	1	2	3
6.	Believing that my child will get better	Y	N	0	1	2	3
7.	Working; outside employment	Y	N	0	1	2	3
8.	Showing that I am strong	Y	N	0	1	2	3
9.	Purchasing gifts for myself and/or other family members	Y	N	0	1	2	3
10.	Talking with other individuals/parents in my same situation	Y	N	0	1	2	3
11.	Taking good care of all the medical equipment at home	Y	N	0	1	2	3
12.	Eating	Y	N	0	1	2	3
13.	Getting other members of the family to help with chores and tasks at home	Y	N	0	1	2	3
14.	Getting away by myself	Y	N	0	1	2	3
15.	Talking with the Doctor about my concerns about my child with the medical condition	Y	N	0	1	2	3
16.	Believing that the medical center/hospital has my family's best interest in mind	Y	N	0	1	2	3
17.	Building close relationships with people	Y	N	0	1	2	3
18.	Believing in God	Y	N	0	1	2	3
19.	Developing myself as a person	Y	N	0	1	2	3
20.	Talking with other parents in the same type of situation and learning about their experiences	Y	N	0	1	2	3
21.	Doing things together as a family (involving all members of the family	Y	N	0	1	2	3

	Behaviors	Used this Behavior *If YES, circle 0-3*		Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful
22.	Investing time and energy in my job	Y	N	0	1	2	3
23.	Believing that my child is getting the best medical care possible	Y	N	0	1	2	3
24.	Entertaining friends in our home	Y	N	0	1	2	3
25.	Reading about how other persons in my situation handle things	Y	N	0	1	2	3
26.	Doing things with family relatives	Y	N	0	1	2	3
27.	Becoming more self reliant and independent	Y	N	0	1	2	3
28.	Telling myself that I have many things I should be thankful for	Y	N	0	1	2	3
29.	Concentrating on hobbies (art, music, jogging, etc.)	Y	N	0	1	2	3
30.	Explaining our family situation to friends and neighbors so they will understand us	Y	N	0	1	2	3
31.	Encouraging child with medical condition to be more independent	Y	N	0	1	2	3
32.	Keeping myself in shape and well groomed	Y	N	0	1	2	3
33.	Involving myself in social activities (parties, etc.) with friends	Y	N	0	1	2	3
34.	Going out with my spouse on a regular basis	Y	N	0	1	2	3
35.	Being sure prescribed medical treatments for child are carried out at home	Y	N	0	1	2	3
36.	Building a closer relationship with my spouse	Y	N	0	1	2	3
37.	Allowing myself to get angry	Y	N	0	1	2	3
38.	Investing myself in my child(ren)	Y	N	0	1	2	3
39.	Talking to someone (not professional counselor/doctor) about how I feel	Y	N	0	1	2	3
40.	Reading more about the medical problem which concerns me	Y	N	0	1	2	3
41.	Talking over personal feelings and concerns with spouse	Y	N	0	1	2	3
42.	Being able to get away from the home care tasks and responsibilities for some relief	Y	N	0	1	2	3
43.	Having my child with the medical condition seen at the clinic/hospital on a regular basis	Y	N	0	1	2	3
44.	Believing that things will always work out	Y	N	0	1	2	3
45.	Doing things with my child(ren)	Y	N	0	1	2	3

Appendix K

The Multidimensional Inventory of Black Identity

Parent 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.	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.	1	2	3	4	5	6	7
7. My destiny 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 than other racial groups.	1	2	3	4	5	6	7
11. I have a strong sense of belonging to Black people.	1	2	3	4	5	6	7
12. I often regret 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.	1	2	3	4	5	6	7