

Daily Coping Strategies and Their Relationships with Mood, Activity Level and Health
Care Use in Sickle Cell Disease: Analysis of Daily Diary Data

Gregory L. Stonerock, Jr., B.A.

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Approved by:

Karen M. Gil, Ph.D.

Daniel J. Bauer, Ph.D.

Deborah J. Jones, Ph.D.

ABSTRACT

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Care Use in Sickle Cell Disease: Analysis of Daily Diary Data
(Under the direction of Karen M. Gil, Ph.D.)

Both adults and adolescents with sickle cell disease (SCD) tend to show better adjustment when using cognitive-behavioral coping strategies during SCD pain episodes. However, little is known about how daily coping affects the relationship between SCD pain and adjustment. For the present study, cognitive-behavioral coping strategies were hypothesized to moderate the relationship between daily SCD pain and mood, activity level, and use of health care resources. Additionally, distraction, relaxation and cognitive restructuring were hypothesized to attenuate the pain-adjustment relationship significantly more than other strategies. Multilevel models were developed to analyze an archival data set of daily diaries from 56 adults and 54 adolescents with SCD. The results indicated that the impact of coping strategies varied between outcomes; occasionally, strategies that related to benefits for one outcome showed costs for another. The findings suggest that for optimal adjustment, individuals should select coping strategies based on their appropriateness for their current situation.

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Introduction

Sickle cell disease (SCD) represents a major health problem for 50,000 to 60,000 African Americans, or approximately one out of every 400 (NHLBI, 2002). SCD refers to a number of heritable genetic disorders, all of which cause irregularities in hemoglobin, a component of red blood cells. This abnormality causes the cells to form a sickle shape after releasing oxygen. This irregular shape results not only in anemia, but also in vascular occlusion, a blocking of blood flow that can lead to tissue injury and organ damage (Serjeant & Serjeant, 2001). Until the middle of the 20th century, complications from the disease such as heightened risk for infection during the first five years of life severely limited the number of people with SCD who survived through adulthood, but recent medical advances, including screening in infancy, have improved the survival rate for people with SCD (Serjeant & Serjeant, 2001).

For individuals of all ages with SCD, the most distressing symptom of vaso-occlusive episodes is the experience of acute ischemic musculoskeletal pain secondary to tissue damage (Gil, Williams, Thompson, & Kinney, 1991). These experiences are often called ‘pain crises,’ or more recently “pain episodes.” The definition of “pain episode” is not agreed upon by all experts in the field (Gil, Carson, Porter, Ready, Valrie, Redding-Lallinger, & Daeschner, 2003). Pain from vaso-occlusive episodes occurs most often in the soft tissues, abdomen, and bones, and can last from hours to several days (Gil et al., 1991). Although SCD pain can be experienced in many areas of the body, patients are able to reliably differentiate SCD pain from pain from other sources (Gil et al., 2003).

Patients with SCD report a wide range of frequency of pain episodes, from one or two episodes a year to several per month, with frequency of pain episodes typically increasing during adolescence and peaking in early adulthood (Chen, Cole, & Kato, 2004).

Episodes of SCD pain also vary in intensity, not only because of physiological differences in the severity of vaso-occlusion, but also because of psychological factors that affect one's interpretation and appraisal of the episode and consequently modify pain perception (Gil et al., 2003).

Some pain episodes are mild enough that patients experience little to no disruption in their ability to perform their usual daily activities, but some can be so severe that hospitalization, intravenous administration of fluids and application of potent analgesics all may be necessary to address fully the complications of the episode (Chen et al., 2004). The intensity of a pain episode has predictive value for how active patients with SCD can be, whether they will miss time usually spent on daily activities in order to manage their pain, and whether or not they will need to use health care resources (e.g., contact a physician or go to a hospital). These behavioral measures of the impact of SCD pain, as well as psychological variables such as mood and stress, are part of a broad array of outcomes related to psychological well-being and occupational and social functioning, collectively termed *adjustment*.

In particular, psychosocial adjustment is considered to be one of the most important measures of outcome for people with SCD (Gil, Abrams, Phillips, & Keefe, 1989). Psychosocial adjustment consists of both behavioral and psychological dimensions, often with greater emphasis on improving behavioral outcomes for patients

with SCD, such as engagement in one's usual daily activities (Thomas, Dixon, & Milligan, 1999). To assess activity level, adult SCD patients are often asked whether SCD pain has caused them to miss time at work or rendered them unable to perform household tasks such as cleaning; adolescents and children are asked about school absences and time lost from participating in extracurricular activities (Gil et al., 2003). Psychosocial adjustment to SCD also includes psychological measures of well-being, such as daily positive and negative mood, that are impacted by the disease (Gil et al., 2003).

Another important behavioral measure of adjustment is use of health care resources, which can include phone calls or visits to physicians, attempts to obtain prescriptions for analgesics, emergency room visits, and hospitalizations (Gil, Carson, Porter, Scipio, Bediako, & Orringer, 2004). During a hospital or ER visit, a patient with severe SCD pain may receive intravenous fluids or a transfusion of blood with normal hemoglobin to relieve vaso-occlusion, opiate analgesics such as morphine are also administered as a palliative measure to dull intense pain. Such treatments are expensive, yet some patients use these health care resources during milder pain episodes that may not demand such intense measures. Thus, a primary goal in treating patients with SCD is to enhance their ability to recognize when using such expensive health care resources is truly necessary (Thomas et al., 1999).

Because no cure exists for SCD, the goal of a comprehensive or multidisciplinary treatment plan for patients with SCD focus on improving adjustment to the disease. For behavioral aspects of adjustment, patients with SCD can be educated on how to avoid

potential behavioral triggers for episodes, such as low fluid intake, exposure to extreme temperatures, and overexertion (Chen et al., 2004). However, vaso-occlusive episodes can occur without exposure to any of these stressors (Barbarin, Whitten, Bond, & Conner-Warren, 1999); psychological stress alone has been hypothesized as a sufficient to trigger a pain episode (Gil et al., 2003). Thus, some interventions focus on coping with SCD pain through psychological means (Chen et al., 2004). Individuals with SCD can undergo training in the use of cognitive coping strategies to make pain episodes more bearable with fewer disruptions in daily activity.

Coping Strategies and SCD Pain

Although physiological factors may contribute to the onset, intensity and disruptiveness of an SCD pain episode, psychological variables such as stress also play a considerable role, accounting for a considerable portion of the variance in reported pain intensity across pain episodes, even when physiological variables are controlled; this finding also holds true in the broader literature on pain (e.g., Haythornthwaite, Menefee, Heinberg, & Clark, 1998). The relationship between pain severity and psychosocial adjustment is impacted by one's appraisal of potentially painful stimuli and one's positive or negative cognitions relating to the perception of pain (Haythornthwaite et al., 1998). Thus, the cognitive and behavioral coping strategies that one uses to address and manage SCD pain are important pieces of the relationship between SCD pain and psychosocial adjustment.

A growing body of literature aims to examine how well cognitive-behavioral coping strategies predict psychosocial adjustment to SCD pain. Gil et al. (1989)

conducted a cross-sectional analysis of coping strategies used by 79 adult outpatients with SCD. The investigators conducted structured interviews and administered an adapted version of the Coping Skills Questionnaire (CSQ; Rosenstiel & Keefe, 1983), a prominent 80-item self-report measure on 13 subtypes of cognitive and behavioral coping strategies, including diverting attention, praying and hoping, and reinterpreting pain sensations. The CSQ asks participants to describe how frequently they use particular strategies to cope with their pain, using a Likert scale ranging from 0 (never) to 6 (always), and to describe their perceived ability to control and decrease their pain. No instructions for a timeframe of reference are given, so the ratings given are somewhat general in nature. An exploratory factor analysis of the CSQ yielded two significant factors, Coping Attempts and Negative Thoughts/Passive Adherence, after controlling for age. Strategies in the Coping Attempts factor involved cognitive and behavioral distractions from pain and cognitive reappraisal of pain signals. The Negative Thoughts/Passive Adherence factor encompassed a variety of cognitive and behavioral coping strategies associated with worse outcomes. The factor label Negative Thoughts refers to two constructs: catastrophizing (an exaggeration of the severity of the pain coupled with a feeling of inability to handle the pain) and fearful and angry self-statements. Passive Adherence refers to behaviors that are related to the SCD pain episode but of uncertain merit to relieving SCD pain, such as resting and passively hoping for pain to subside. Participants who were higher in Negative Thoughts/Passive Adherence reported more severe pain, more health care use (HCU) and less daily activity than others, whereas patients higher in Coping Attempts reported more daily activity (Gil

et al., 1989). Individuals who showed increased Negative Thinking and Passive Adherence at 9-month follow-up showed the greatest activity reduction and health care use (Gil, Abrams, Phillips, & Williams, 1992).

When compared to adults, younger individuals with SCD appear to experience similar improvements in adjustment outcomes when they use active cognitive-behavioral coping strategies. A sample of 72 outpatients aged 7 to 17 (Gil et al., 1991) provided some confirmatory evidence for the Coping Attempts factor and established the usefulness of these strategies in younger patients with SCD. Data from this study yielded factors on the CSQ similar to those found in adults (Gil et al., 1989). However, data were collected from outpatients with SCD only. Coping Attempts remained a significant factor for this sample and again comprised several behavioral and cognitive techniques including distraction, relaxation and cognitive restructuring. However, Negative Thinking and Passive Adherence were found to be independent factors in this study. Children and adolescents high in Coping Attempts reported not only more daily activity, but also lower HCU than those low in Coping Attempts. These younger SCD patients reported fewer pain episodes than adults did in prior studies (about 6 per month versus 12 in Gil et al., 1989). Thus, their lower HCU might be attributable to a lower need for those services. The results of this prior study suggest that the same coping strategies can be considered useful for all younger individuals with SCD, regardless of age; however, differences between children and adolescents were not analyzed.

This sample of younger SCD patients (ages 7 to 18) again completed the CSQ and adjustment measures in a 9-month follow-up study (Gil, Thompson, Keith, Tota-Faucette,

Noll, & Kinney, 1993). Children and adolescents who scored higher on the Coping Attempts factor at baseline engaged in more school and social activity during SCD pain episodes, according to reports by parents. At 18-month follow-up, Gil et al. (1997) found that the children and adolescents who used coping strategies from the Coping Attempts factor of the CSQ consistently over long periods of time experienced better psychosocial adjustment, whereas long-term increases in Negative Thinking predicted worse adjustment.

However, these longitudinal tracking studies have a number of limitations. Some coping strategies from the CSQ (e.g., praying and hoping, taking fluids) loaded similarly on both factors; the factorial model chosen forced these strategies into one factor alone based on the absolute highest loading of the two, leaving the function of these coping strategies somewhat unclear and raising questions about the validity of the two factor labels (e.g., Barbarin & Christian, 1999). Indeed, subsequent studies have renamed the Passive Adherence group of strategies Illness-Related Behaviors (Gil, Edens, Wilson, & Raezer, 1997). Additionally, the regression analyses conducted in these studies used summary variables for each factor, namely the sum of the products of the coping strategy rating and its factor loading. This strategy does not allow one to test for any unique impact of individual strategies. Moreover, participants reported on their coping strategy use retrospectively using a vague and broad timeframe. This early research allowed very little to be determined about which coping strategies individuals used on a daily basis and how their choice of coping strategies related to their adjustment more proximally.

Gil et al. (1989) also suggested that using an outpatient sample limits generalizability for people with SCD who do not seek outpatient care. Individuals in outpatient care may experience (or merely report) more intense pain than a non-patient sample; if that is the case, it is unclear whether to attribute that difference to physical factors, psychological factors, or both. Still, this research established a framework for associating particular coping strategies with positive or negative psychosocial adjustment outcomes for adults with SCD, and thus provides an initial characterization of particular strategies as adaptive or maladaptive within the context of adjustment in SCD.

In addition to longitudinal observational research, intervention studies have been conducted to explore the effects of cognitive coping skills training on adjustment. The results of these studies have generally been encouraging. One group (Gil, Wilson, Edens, Webster, Abrams, et al., 1996) trained 64 adult SCD patients over three once-a-week sessions to use several cognitive coping strategies, including diverting attention from pain, cognitive restructuring of pain, and relaxation. This group was compared to a psychoeducational control group. Participants' pain reporting thresholds were also assessed using a pressure stimulator that caused mild to moderate pain on a finger. Participants in the experimental group not only showed increases in use of the adaptive coping strategies they were taught, but also showed decreases in Negative Thinking strategy use. Furthermore, individuals who received training showed increased thresholds for reporting experimental pain compared to pre-intervention thresholds.

In another intervention study, adults with SCD in a European sample participated in a community-based cognitive-behavioral intervention aimed at increasing the use of

adaptive coping strategies (Thomas et al., 1999). These participants showed immediate improvements in pain tolerance, as well as greater engagement in usual daily behaviors, a behavioral measure of psychosocial adjustment. Participants in education-only or no-treatment conditions did not show these improvements. These studies not only help to replicate the results of the observational studies, but demonstrate that adults with SCD can learn and apply cognitive coping strategies and experience improved psychosocial adjustment outcomes.

However, although the adult patients examined by Gil et al. (1996) did show improved pain tolerance, they did not show any significant improvement in HCU. Higher pain thresholds also are not direct measures of psychosocial adjustment, though they may relate to an improved tolerance for milder pain episodes (Chen et al., 2004). Still, because patients with pain conditions often identify reductions in pain as a primary goal for treatment, increased pain tolerance likely represents an important improvement in quality of life (Cepeda, Africano, Polo, Alcala, & Carr, 2003). Thus, higher pain tolerance and better adjustment each are highly desirable outcomes for people with SCD. Individuals with SCD who use strategies within the Coping Attempts factor are more likely to achieve these gains. However, because participants in these studies were trained in the use of multiple strategies, one cannot determine whether any individual coping strategies were more valuable for positive adjustment than others.

Children and adolescents with SCD were trained to use cognitive coping strategies in a separate intervention study (Gil et al., 1997). Participants who received coping skills training that included distraction, relaxation and cognitive restructuring

showed higher pain thresholds on similar standardized experimental pain task. In addition, these participants reported better psychosocial adjustment in follow-up after three weeks of training than those in an education-only control group (Gil et al., 1997). A similar intervention study of adults with SCD indicated that those who had undergone cognitive skills training and continued to practice and use the techniques after training maintained their lower HCU, particularly on days during pain episodes when they reported using their skills, at 3-month follow-up (Gil, Carson, Sedway, Porter, Wilson Schaeffer, & Orringer, 2000).

To summarize, prior research offers some promising findings on cognitive and behavioral coping strategies for improving adjustment to SCD pain. Individuals with SCD who report using strategies from the Coping Attempts factor of the CSQ tend to experience better adjustment outcomes, whereas individuals who use those strategies less, and tend to use more negative coping strategies, experience worse outcomes. These findings appear to apply across age groups, though some of the analyses did not separately address children and adolescents. Though this research is promising, some questions remain. Because the intervention studies have trained individuals in the use of several coping strategies, one cannot discern whether any of the individual strategies offers more benefits to adjustment than others. Also, these studies tended to use a retrospective self-report of coping, rather than the more ecologically valid approach of measuring coping and adjustment during SCD pain. Thus, it remains unclear how coping affects the relationship between pain and adjustment on a daily basis.

Adolescence and SCD

Studies of coping in younger individuals with SCD have typically combined data from young children and adolescents. However, when these groups are combined, one cannot take into account unique challenges that individuals with SCD face during adolescence. During adolescence, individuals with SCD typically begin to manage the disease on their own and begin to transfer care from pediatricians to adult physicians. Adolescents with SCD experience delays in sexual maturation, which may contribute to problems with self-image, teasing and lack of acceptance by peers, and depression (Kinney & Ware, 1996). Adolescents with SCD face physical limitations to the activities they can pursue; continuing to engage in physically taxing activities may worsen SCD symptoms, yet withdrawing from such activities may lead to psychological stress (Kinney & Ware, 1996).

In particular, coping by seeking social or emotional support may have mixed results for this group. Both peer and family relationships can be strained by SCD; for example, adolescents may not receive adequate social and emotional support from family members who may not adequately accept and adapt to the challenges that the disease presents (Kell, Kliwer, Erickson, & Ohene-Frempong, 1998; Pinckney & Stuart, 2004). Thus, coping by seeking social and emotional support may have different, possibly negative consequences for adolescents.

Adolescents with SCD cope differently from children in two key ways. First, Gil and colleagues (1997) reported that adolescents with SCD show greater overall use of coping strategies within the Negative Thinking and Passive Adherence factors, which are associated with worse psychosocial adjustment. The researchers hypothesize that

adolescents who tend to use these strategies may increase their likelihood of using maladaptive coping habits as adults (Gil et al., 1997). Second, adolescents show a less stable pattern of coping strategy use than that of other groups. Adolescents showed significantly lower correlations on coping strategies from the CSQ between baseline and at 9-month follow-up than children (Gil et al., 1993). In another longitudinal study, over 100 adults and 100 children and adolescents completed the CSQ at baseline, 9 months and 18 months; repeated-measures analysis of variance indicated that adolescents have less stable patterns of coping than either children or adults (Gil et al., 1997).

Few studies on coping with SCD pain analyze adolescents separately from other age groups; thus, it is unclear whether adolescents experience improved outcomes from the same coping strategies as other age groups. Although distraction, relaxation and cognitive restructuring of pain appear to be related to better adjustment within other age groups, adolescents may not benefit from them as much or feel that they are as useful. Unfavorable appraisals of the value of these coping strategies could prompt adolescents to engage in less adaptive coping, leading to lower psychosocial adjustment (Edwards, Telfair, Cecil, & Lenoci, 2001).

In a broad analysis of the literature on chronic pain, Turk and Okifuji (2002) assert that passive behaviors like resting and avoiding stress are adaptive for chronic, continuous pain, but not for acute episodes of pain like those found in SCD. As adolescents begin experiencing SCD pain more frequently, they may begin to use coping strategies that would be more adaptive for dealing with chronic pain, such as lowering

daily activity. This change in coping would not only lower adolescents' psychosocial adjustment to SCD, but also would fail to address the acute nature of their disease.

Because adolescents with SCD begin to experience pain episodes more often than they did as children, coping strategies that were adaptive in childhood no longer seem useful to them, provoking them to use more negative thinking strategies such as catastrophizing (Sullivan, Thorn, Haythornthwaite, Keefe, Martin, Bradley, & Lefebvre, 2001). The increase in pain episode frequency for adolescents may also increase somatic awareness (i.e., attention paid to bodily sensations), which would interfere with using distraction from pain as a coping strategy (McCrae & Lumley, 1998).

Collectively, prior research seems to show a relationship between using a group of certain coping strategies and better adjustment in individuals with SCD. However, because previous studies on coping with SCD pain have assessed a collection of coping strategies grouped through factor analysis, no direct comparisons have been made among individual coping strategies. Thus, little information exists on whether certain individual strategies among this group are better at increasing pain tolerance or improving psychosocial adjustment than others. In addition, these studies have relied on retrospective recall of coping strategies using a vague or global timeframe. Little is known about how daily variation in coping strategy use relates to adjustment at the moment pain is present. This problem has been established for all age groups (e.g., Gil et al., 1997).

Thus, further study is needed to clarify whether particular strategies most strongly attenuate the relationship between pain and adjustment during SCD pain. By using a

daily diary approach, one can measure pain, coping and adjustment outcomes simultaneously rather than retrospectively. This strategy can provide new and unique information on which coping strategies relate to the best outcomes at the moment of crisis. Furthermore, because pain can have a negative impact on different outcomes from episode to episode, a daily measurement strategy allows one to determine whether beneficial strategies differ by outcomes or whether certain coping strategies are ‘universally’ helpful during SCD pain. Clarifying which strategies are the most useful and under which circumstances has the potential to improve adjustment to SCD pain across all age groups.

Specific Aims and Hypotheses

The present study was designed to determine which cognitive coping strategies relate to the best adjustment outcomes for patients experiencing pain from SCD, as measured by positive and negative mood, continuance of daily activities, and use of health care resources. Because the data for this study were collected using daily diaries in a naturalistic setting, the present study also aims to provide observational data on the coping strategies that adolescents and adults with SCD use during SCD pain before any specific intervention has taken place and to describe their benefits and costs.

Prior research has established the benefits to adjustment to SCD pain that are associated by both trained and untrained coping skills use (e.g., Gil et al., 1996; Gil et al., 1993). However, these studies typically have employed only a few measurement points, such as baseline and 9-and 18-month follow-up (e.g., Gil et al., 1997; Gil et al., 1993; Gil et al., 1989). No prior research has used daily measurement to establish the relationship between individual coping strategies and adjustment at the moment of SCD pain. Analysis of data gathered in close proximity to the experience of pain could uncover new information about how the relationship between pain and adjustment is modified by coping.

To address this, the present study analyzed data that were collected from patients using daily diaries. Daily diaries offer numerous benefits for statistical inference. First, daily diary methodology increases the reliability of self-report data by reducing the amount of time between one's experience and one's recorded report of the experience. In

addition, daily diary designs dramatically increase the number of data points available for analysis, substantially raising statistical power. Finally, the increase in measurement frequency allows for more fine-grained interpretation of the relationships between pain, adjustment, and coping.

Hypothesis 1: Optimal coping strategies. Typically, when clinical pain is unpredictable and sudden, coping strategies that directly address pain and its immediate consequences relate to the best adjustment outcomes (Gil, 1992). Within the strategies that load on the Coping Attempts factor of the CSQ, distraction from pain, relaxation, and cognitive restructuring of pain sensations appear to be strategies that address the specific symptoms of SCD pain most directly and immediately. In addition, distraction, relaxation, and cognitive restructuring have been used in coping skills training for SCD patients (Gil et al., 2000). Thus, one would expect these particular strategies to have a stronger association with positive adjustment outcomes than strategies that address less immediate consequences of pain sensation, such as seeking social or emotional support.

Previous research on coping and chronic pain conditions has supported viewing coping as a moderator of the relationship between pain and several psychological outcomes (e.g., Gil et al., 2000). Thus, Hypothesis 1 is that as pain increases, individuals will report more positive mood, less reduction of daily activity and more efficient HCU when they report using distraction, relaxation, and cognitive restructuring. Thus, the negative impact of SCD pain on mood, activity and HCU should be significantly attenuated by the use of these three coping strategies (Figure 1).

Hypothesis 2: Individual strategies versus aggregated strategies. Although findings from prior research suggest that the best outcomes should be associated with distraction, relaxation, and cognitive restructuring, many other constructive coping strategies lie within the CSQ's Coping Attempts factor, which in its totality has been associated with better outcomes for SCD patients. Thus, strategies that do not address sensations of SCD pain directly, such as seeking social and emotional support, relying on spiritual beliefs and thinking about solutions, still should relate to better mood, better maintenance of daily activities, and more efficient HCU. The best outcomes may be associated with using as many of these coping strategies as possible, rather than the use of any particular strategy. Thus, an alternative model (Figure 2) would suggest that the relationship between SCD pain intensity and adjustment will be moderated best by the absolute number of coping strategies one uses endorsed, rather than specific individual strategies.

Hypothesis 2 is that distraction, relaxation and cognitive restructuring will account for more of the relationship between SCD pain and outcomes (i.e., have a greater moderating effect) than the number of coping strategies endorsed.

Hypothesis 3: Differences between age groups. Finally, clinically significant differences in coping may exist between adults and adolescents with SCD. Adults and adolescents alike may benefit from distraction, relaxation, and cognitive restructuring strategies. However, because adults and adolescents experience different challenges due to SCD, and experience them differently, individuals of different ages may show different adjustment outcomes even when they use the same coping strategies. The preliminary

analyses aim to determine whether adults and adolescents with SCD tend to select different strategies during pain episodes. Subsequent analyses assess whether the coping strategies that relate to the best adjustment outcomes differ across age groups.

Prior literature on individuals with SCD of all ages has indicated that when patients are trained in distraction, relaxation and cognitive restructuring of pain, the use of these strategies relates to better mood and lower levels of perceived stress (e.g., Gil et al., 2000). Thus, Hypothesis 3 is that these three strategies will relate to better adjustment in the face of intense pain; these strategies should be superior to other coping strategies (e.g., seeking support) and the aggregate number of coping strategies. This hypothesis can be tested using separate models for Hypotheses 1 and 2, in addition to a combined sample using age as a covariate. This strategy allows one to make observations that can lead to global inferences on the utility of individual strategies.

Method

Participants and Setting

The present study makes use of data from two daily diary studies, one for adults and one for adolescents. Findings based on data from these two samples have been published elsewhere (Gil et al., 2004; Gil et al, 2003). In these studies, adolescents were separated from adults by age alone; participants ages 13 through 17 are considered adolescents. Age is the best measure available of developmental status within this dataset and has been used previously within this population (e.g., Gil et al., 2003, Kell et al., 1998). However, determining adolescence using age alone omits information on a participant's level of psychological and physiological development during his or her participation in the study. Results are interpreted in light of this limitation.

Adult participants were recruited from the SCD clinic at UNC Hospitals. The sample consisted of 56 African American adults (31 female; ages 18-71 years, mean age=34.9, SD=12.35). Participants were screened by their primary physicians to detect any medical contraindications for participation (e.g., neurological impairment). Participants had been previously diagnosed with SCD using standard laboratory methods including hemoglobin electrophoresis. Medical records and physician verification were used to determine each participant's SCD phenotype; 45 (80.36%) had homozygous SS (sickle cell anemia), generally considered the most severe phenotype; 8 (14.29%) had hemoglobin SC disease, and 3 (5.36%) had sickle cell thalassemia syndrome.

Adolescents were recruited from SCD clinics at UNC and East Carolina University. A total of 54 adolescents (33 female; ages 13-17 years, mean age=14.72, SD=1.39) participated in the study after passing a screen for medical contraindications to participation. Each participant's SCD phenotype was determined by hemoglobin electrophoresis; 41 had homozygous SS, 4 had hemoglobin SC disease, and 9 had sickle cell thalassemia syndromes. (One participant's status was not reported.)

General Procedures

Institutional Review Boards (IRB) at UNC-Chapel Hill and East Carolina University approved the study protocols. Informed consent was obtained from participants and, for adolescents, their caregivers. As previously reported (e.g., Gil et al., 2004; Gil et al, 2003). Participants completed a number of baseline measures were collected on stress and psychological distress at an initial visit. After the initial evaluation, participants entered the diary phase of the study for up to 6 months. The current study focuses solely on data collected during this diary phase.

Daily Diary Measure

The daily diary was a simple form modeled after the diary used by Porter and colleagues (Porter, Gil, Carson, Anthony, & Ready, 2000). Participants were directed to complete a diary every day while in the study. The diary consisted of self-report items on the day's SCD pain, HCU, activity level, stress and stressors, coping strategies and mood. Some questions on the adolescent version were reworded in simpler language. For example, adults gave yes or no responses to the distraction item, "I diverted attention away from the situation by thinking about other things or engaging in activity," whereas

adolescents responded to the item, “I thought about something else or did something else so I would not think about the situation.” Adolescent and adult forms were otherwise identical in content, except where noted below.

All participants were trained in person by an investigator on how to complete the diary; trainers helped participants to complete sample diaries. Each participant was given a folder with personalized training materials to refer to when completing diaries, including definitions of common SCD complications. Participants were given a wristwatch programmed to give a prompt at the same time at the end of each day as a reminder to complete a diary sheet. Participants were also provided with stamped, addressed envelopes in which to return completed diaries weekly. Study representatives contacted participants by phone weekly to reinforce diary completion and to answer any questions about the study.

SCD pain and other pain. The first section of the diary assessed pain associated with SCD and with other sources. Questions in this section were modified from the Structured Pain Interview and Daily Self-Monitoring Record developed by Gil (1994). Participants were asked whether they had experienced an episode of SCD pain that day, defined as pain located in the body that had no known cause other than SCD. Participants who reported a pain episode then gave a rating of the average intensity of the pain on a 100-mm visual analog scale (VAS) anchored at 0 (no pain) and 100 (worst pain imaginable). Previous research has shown that this method of obtaining ratings of pain intensity is reliable and valid in adolescents as well as adults in samples of patients with SCD (Franck, Treadwell, Jacob, & Vichinsky, 2002; Ballas & Delengowski, 1993) as

well as in other illness groups (Williamson & Hoggart, 2005). In this study, participants supplied two pain ratings – one focused on the physical sensations of the pain and the second focused on the emotional discomfort of the pain using a separate VAS.

Participants also reported the duration of the pain in hours. Participants gave additional VAS ratings when experiencing pain with a cause other than SCD (e.g., headache, menstrual pain). A day was considered a *pain day* if the participant answered “yes” to the question, “Are you having an episode of sickle cell pain today?” or gave a pain rating for SCD higher than 2 on the VAS. This cutoff was selected to account for entries in which no pain was experienced but the VAS was rated slightly above 0 due to error.

HCU. To assess HCU, participants reported whether they called or visited their doctor, took prescription medication (narcotic or analgesic), went to the emergency room or were admitted to the hospital that day. Reliability and validity of these items have been reported in prior studies (e.g., Porter et al., 2000; Gil, Abrams, Phillips, & Williams, 1993). Additionally, participants were asked whether they had taken enough fluids, had become too hot or cold, or overexerted themselves physically that day, all of which are considered likely physiological precipitants of SCD pain episodes.

Activity level and reduction. The next section of the diary assessed whether SCD pain had interfered with daily activities. Individuals vary considerably in their ability to continue working despite SCD pain, so activity reduction is considered an important measure of adjustment to chronic pain conditions (for examples, see Gil et al., 1993). Adults reported whether they had missed work that day because of SCD pain. Many of the adult participants were not employed; these participants were asked to think about

their completion of their regular household tasks instead. Adolescents reported whether they had missed school or work and additionally whether they had decided not to participate in extracurricular activities or to do household chores because of SCD pain that day.

Stress and stressors. Daily stress was assessed through an approach used by Stone and colleagues (Stone, Broderick, Porter, & Kaell, 1997; Stone & Neale, 1982; Stone & Neale, 1984) and similar to that used in Porter et al. (2000). Participants identified a primary stressor, rated their perceived stress for that day on a 100mm VAS, and had the option to provide a narrative explaining the stressor. Data from this section were not used in the present study.

Coping strategies. To assess coping strategy use, participants reported whether they had used any coping strategies from a list to address the day's main stressor. Nine strategies were assessed using a version of the Daily Coping Inventory, a measure specifically designed for daily measurement that captures strategies similar to those from the CSQ (Stone & Neale, 1984). These strategies were as follows: distracting oneself, using cognitive restructuring, thinking about solutions/gathering information, actively attempting to solve the problem, expressing emotions, accepting the situation, obtaining social and emotional support from others, doing something to relax, and relying on spiritual beliefs. Participants endorsed strategies they had used that day with a checkmark. Participants could endorse all, some, or none of these strategies; thus, a total number of coping strategies used for a particular day was tabulated for this study.

Notably, individuals who completed diaries were asked to indicate which coping strategies were used in response to their primary stressor, not to SCD pain sensations specifically. For the purposes of the present study, only coping strategies endorsed on SCD pain days were considered, under the assumption that SCD pain was among the individual's primary stressors during a pain episode.

Mood. The final diary section consisted of the Daily Mood Scale developed by Diener and Emmons (1984; Emmons & Diener, 1985). Participants rated the degree to which they felt various mood states comprising both positive and negative mood. Participants rated each mood state daily from 0 (not at all) to 5 (extremely) on a 6-point Likert scale (positive states: happy, enjoyment/fun, joyful, or pleased; negative states: depressed/blue, unhappy, angry/hostile, frustrated, or worried/anxious). For each day, the sum of the positive items was computed, creating the positive mood variable (ranging from 0 to 25), and the sum of the negative items was computed, creating the negative mood variable (range 0 to 20); these procedures were described by the original authors (Diener and Emmons, 1984). These mood variables have shown adequate reliability and validity in daily diary studies with college students (Diener & Emmons, 1984; Emmons & Diener, 1985) and have proven useful in examining the relationships of stress, pain, and mood in participants with pain (e.g., Stone et al., 1997).

Strategy for Data Analysis

To address the study hypotheses, a multilevel modeling (MLM) approach was employed. MLM addresses many of the challenges that daily diary data present to ordinary linear regression techniques (Stone & Neale, 1982). Specifically, daily diary

observations are non-independent, are nested within participants, and are not equal in number across participants. These characteristics violate the assumptions of ordinary linear regression but are acceptable for MLM (Raudenbush & Bryk, 2002). MLM allows one to avoid unnecessary sacrifices in variation, reliability and available degrees of freedom by taking into account all available observations; such an approach is not possible for data aggregated by participant.

MLM offers some specific advantages for analyzing daily diary data. First, daily diary studies typically suffer from problems with missing data; in the present study, participants may be less likely to complete a diary during significant pain or stress. Additionally, daily diary data often exhibits serial autocorrelation; that is, diaries that a participant completes closer in time are likely to be more similar to one another than entries spaced farther apart in time. MLM offers several methods to control for serial autocorrelation. Finally, each participant has a unique baseline for their experience of pain, use of coping strategies, and other key variables. Using MLM, one can control for these differences by using person-centered variables to yield accurate measures of the overall, within-person effects of interest.

Results

Preliminary Analyses

Before testing for moderation, initial multilevel analyses were conducted to reaffirm the expected relationship between SCD pain intensity and adjustment outcomes. This initial analysis is not strictly necessary to test if the interaction between pain and coping significantly predicts adjustment, but lends support to the subsequent analyses. All of the initial analyses revealed statistically significant relationships for both adolescents and adults between SCD pain and the outcomes of interest (see Table 1). Pain was a significant predictor of lower positive mood, higher negative mood, greater activity reduction, and more frequent HCU. These findings provide justification for the subsequent analyses of moderating effects of coping.

The results of the analyses are grouped into three sections. First, general descriptive statistics are reported. Then, the multilevel models for each outcome and its predictors and moderators are discussed. Finally, a summary of the findings across outcomes is provided. For all of the major study analyses, only data from participants' pain days were used. Conducting analyses on these data alone helped to ensure that the coping strategies reported by the individual were directed towards that day's SCD pain. (See *Limitations* for more comments on this decision.)

For all multilevel models, between-persons predictors (i.e., predictors that do not differ across measurements, but differ across individuals) included the participant's age and mean pain rating from all of his or her pain days. Three types of within-person

predictors (i.e., daily variables) were included in each model: a person-mean-centered pain rating indicated the level of pain experienced on that day relative to that person's usual pain rating on pain days; binary variables represented each of the nine coping strategies employed (i.e., a 1 indicated that a coping strategy was used); and interaction terms were created by multiplying pain rating by coping strategy. A random intercept was included to account for nestedness in the data, and a spatial power term was used to account for serial autocorrelation. These terms were significant ($p < .0001$) for all outcomes tested, indicating that observations were significantly correlated within individuals and when completed closer in time to one another. All other effects (i.e., main effects and interactions) were treated as fixed effects.

Descriptive Statistics

Simple analyses were conducted and visual plots obtained of coping strategy use to describe coping strategy patterns on pain days versus days without pain. These preliminary analyses were conducted by aggregating data for each participant in each group, then computing a percentage of pain days and non-pain days on which each coping strategy was used. Finally, these percentages of coping strategy use were aggregated into an average percentage, plotted and analyzed using within-subjects *t*-tests. Although this method lacks the refinement offered by MLM and does not account for nestedness within the data, it offers some descriptive information on the participants' characteristics.

For adults (Figure 3), several coping strategies were used more on pain days than on days without pain. Distraction, cognitive restructuring and relaxation are among the

most frequently used on pain days, as are expressing emotion, relying on spiritual/religious beliefs, and actively trying to solve the problem. For adolescents (Figure 4), only distraction and relaxation were used significantly more often on pain days than on days without pain. Thus, adults and adolescents appear to use different coping strategies upon being confronted with the specific stressor of SCD pain. In addition, these groups appear to differ in the average number of coping strategies reported on pain days.

Preliminary multilevel models were tested using age, gender and SCD type both as predictors and as moderators of the relationship between SCD pain and adjustment outcomes. Of these, only age showed a significant main effect for any of the adjustment outcomes. Prior research on the differences in challenges faced by adolescents and adults with SCD indicated that such an effect was likely. The effects of age were thoroughly investigated for each adjustment outcome using two methods. First, adolescent and adult samples were analyzed separately (based on the hard age cutoff of 18 years and older for adulthood). Second, data from both the adult and adolescent samples were combined into a single dataset that was then tested using age as a predictor variable. This method was chosen in order to provide data on age from both dichotomous and continuous points of view. Due to the high volume of adolescent data present in this archival dataset, the distribution of ages was highly skewed. Age was transformed to a distribution closer to the normal distribution using a natural log transformation in order to avoid any inappropriately heavy influence of high or low ages on the overall model. Findings on the effect of age on each outcome variable are reported when significant.

Mood

Moderation of the relationship between SCD pain and positive and negative mood by coping strategies was evaluated using a multilevel linear regression model, specifically PROC MIXED in SAS/STAT® software, version 9.1.3 (SAS Institute, 2004). Analyses were completed first for the combined sample, then for adults and adolescents separately. Results concerning the main effects of daily SCD pain, mean SCD pain rating and age on positive and negative mood, when coping is included as a predictor and a moderator, are shown in Table 2. As predicted, higher daily pain ratings and higher mean pain ratings each were related to lower positive mood and higher negative mood. Interestingly, for the adolescent sample, adding coping strategies as moderators of the relationship between pain and positive mood reduced this relationship to nonsignificance. The adult sample showed a main effect of age, indicating higher positive mood scores for individuals at higher ages.

Positive mood. For the combined sample, only seeking emotional support showed a main effect on positive mood and was associated with *lower* positive mood scores ($\beta = -.62$; $t(1344) = -2.03$, $p = .0430$). Looking at coping strategies as moderators of the pain-mood relationship, thinking about solutions ($\beta = .061$; $t(1344) = 4.00$, $p < .0001$) and acceptance ($\beta = .028$; $t(1344) = 2.32$, $p < .0205$) were related to more positive mood as pain ratings increased. In reference to Hypothesis 1, distraction, cognitive restructuring and relaxation showed no significant main or moderating effects for the combined sample.

In the adult sample, a main effect was observed for distraction; individuals using distraction reported higher positive mood ($\beta = 1.14$; $t(1067) = 3.39$, $p = .0007$). No other coping strategies had significant main effects. Significant moderating effects were found for two strategies; thinking about solutions was related to greater positive mood as pain increased ($\beta = .007$; $t(1067) = 4.63$, $p < .0001$), but relying on religious and spiritual beliefs was related to lower positive mood as pain ratings increased ($\beta = -.032$; $t(1067) = -2.67$, $p = .0077$). Distraction, relaxation and cognitive restructuring again showed no significant moderating effects. The relationship between distraction and positive mood is shown in Figure 5.

In the adolescent sample, no coping strategies showed significant main effects on positive mood. Significant moderation was found for two strategies: expressing emotion was related to higher positive mood as pain increased ($\beta = .11$; $t(258) = 3.02$, $p = .0028$), but seeking emotional support was related to lower positive mood as pain increased ($\beta = -.096$; $t(1344) = -2.44$, $p = .0153$). Note that interaction effects should be interpreted very cautiously, given that main effects of pain and coping were not found in the overall model. Distraction, cognitive restructuring and relaxation once again showed no significant main or moderating effects for positive mood.

To test Hypothesis 1 more directly, contrasts were examined to determine whether distraction, relaxation and cognitive restructuring taken as a set were associated with more positive mood in the face of increasing pain than the other coping strategies as a set. These contrasts allow one to infer whether there are significant differences between the strategies hypothesized to deal most directly with pain sensations and the other available

coping strategies. For the combined and adult samples, no significant difference was found, indicating that the two sets of strategies did not moderate the pain-positive mood relationship any differently. A significant contrast effect was found for adolescents ($F(1,158)= 4.70, p=.0311$). Surprisingly, when estimated in PROC MIXED, the values of slopes and intercepts for the two sets of coping strategies indicated that distraction, cognitive restructuring, and relaxation combined predicted *lower* positive mood as pain increased than the other strategies combined ($F(1,258)= 4.70, p=.0311$, when these three used, $\beta = -0.1548$; when other six used, $\beta = 0.07107$)

The count of coping strategies showed an unexpected significant main effect for the combined and adolescent samples. Reporting using more coping strategies was associated with *lower* positive mood in these groups (combined: $\beta = -0.184, t(1360)= -2.37, p=.0178$; adolescent: $\beta = -0.385, t(274)= -2.70, p=.0075$). For adults, no main or moderating effects were observed.

Negative mood. For the combined sample, several coping strategies showed main effects on negative mood; however, in each case, using the strategy was associated with *higher* negative mood. The strategies were thinking about solutions ($\beta = 1.66; t(1351)= 4.04, p< .0001$), expressing emotions ($\beta = .88; t(1351)= 3.11, p=.0019$), seeking emotional support ($\beta = 1.17; t(1351)= 3.54, p=.0004$), and using spiritual or religious beliefs ($\beta = .96; t(1351)= -2.03, p=.0075$). Examining the interaction of coping strategies with pain ratings, three coping strategies showed significant moderation. With increasing pain, thinking about solutions was related to lower negative mood ($\beta = -.088; t(1351)= 4.00, p< .0001$). Cognitive restructuring was related to higher negative mood as

pain ratings increased ($\beta = .034$; $t(1351) = 2.60$, $p = .0094$), as was acceptance ($\beta = .029$; $t(1351) = 2.21$, $p = .0270$). Distraction and relaxation showed no significant main or moderating effects for the combined sample.

Similar to the results for positive mood, a main effect was observed for distraction on negative mood in the adult sample. Individuals using distraction on a pain day reported lower negative mood on average ($\beta = -1.13$; $t(1077) = -2.91$, $p = .0037$). In addition, main effects on negative mood were also found for relaxation ($\beta = -.95$; $t(1077) = -2.83$, $p = .0047$) and acceptance ($\beta = -1.16$; $t(1077) = -2.55$, $p = .0110$), both of which were associated with lower negative mood. Other coping strategies were related to higher negative mood scores, specifically thinking about solutions ($\beta = 1.39$; $t(1077) = 2.94$, $p = .0034$), expressing emotions ($\beta = .84$; $t(1077) = -2.83$, $p = .0047$) and seeking emotional support ($\beta = -.82$; $t(1077) = 2.27$, $p = .0236$). Significant moderating effects were found for two strategies: thinking about solutions was related to lower negative mood as pain increased ($\beta = .09$; $t(1077) = -5.22$, $p < .0001$), but acceptance was related to higher negative mood scores with increased pain ($\beta = .03$; $t(1077) = 2.45$, $p = .0143$). Regarding moderation, the individual strategies of distraction, cognitive restructuring and relaxation again showed no significant moderating effects for the adult sample.

In the adolescent sample, no coping strategies showed significant main effects on negative mood. This finding is again similar to results for positive mood; however, for negative mood, no significant moderation effects were found for any individual coping strategy.

A set of contrasts were again examined to determine whether the combination of distraction, relaxation and cognitive restructuring was associated with lower negative mood in the face of increasing pain than the other coping strategies combined. The only significant contrast was found for the combined sample ($F(1,1351)= 4.61, p=.0320$). These analyses indicated that individuals using the combination of distraction, cognitive restructuring and relaxation showed lower negative mood when experiencing their average level of pain (intercept: $\beta = -2.459$; when using the other strategies, $\beta = 3.340$), but experienced greater increases in negative mood as pain increased (slope: $\beta = 0.757$; when using the other strategies: $\beta = -0.020$).

The count of coping strategies showed a significant main effect for the combined and adolescent samples. Reporting using more coping strategies was associated with higher negative mood in these groups (combined: $\beta = 0.433, t(1367)= 4.94, p<.0001$; adolescent: $\beta = 0.741, t(271)= 5.95, p<.0001$). For adults, a moderating effect was observed, but in the opposite direction. As pain increased, adults who reported using more coping strategies showed lower negative mood ($\beta = -0.007; t(1093)= -2.71, p=.0067$). No main effect of number of coping strategies was observed for adults.

Activity Reduction

The next analyses describe the relationship between SCD pain and activity reduction, as measured by a binary variable representing whether the participant missed work or stayed home from school. This relationship, and the potential moderating effect of coping strategies, was evaluated using a multilevel generalized linear model, specifically by using PROC GLIMMIX in SAS/STAT software. Unlike a direct log-

likelihood estimation technique (e.g., PROC NLMIXED), PROC GLIMMIX implements a quasi-likelihood estimator (specifically penalized quasi-likelihood, or PQL) for multilevel generalized linear models. PROC GLIMMIX was selected for purposes of efficiency. Even though PROC NLMIXED can produce highly precise estimates of the fixed and random effects, using PROC NLMIXED proved too inefficient to pursue because of the high number of effects being estimated in this model.

Analyses were conducted first for the combined sample, then for adults and adolescents separately. Results concerning the main effects of daily SCD pain, mean SCD pain rating and age on activity, when coping is included as a predictor and a moderator, are shown in Table 3. Age was not a significant predictor of activity level when scaled in either years or in log-years. Participants reduced their activity by staying home from work or school on 17.3% of pain days for the combined sample (16.2% of adult pain days, 21.5% of adolescent pain days).

Generally, higher person-centered daily pain ratings were related to a greater likelihood of missing school or work, as predicted; however, individuals' mean pain ratings were not significant predictors of missing school or work. Thus, an individual's average pain rating on pain days was not a significant predictor, whereas person-mean centered pain ratings (i.e., ratings reflecting whether the pain was more or less than what is typically experienced during a pain episode) did significantly predict activity reduction.

For the combined sample, relaxation showed a main effect on activity level, but in the unexpected direction. Individuals who reported using relaxation on a pain day reported significantly *more* same-day activity reduction ($\beta = .456$; $t(1333) = 2.04$, $p =$

.0407; OR=1.56). No other main effects of coping strategies were observed. Cognitive restructuring was the only strategy that significantly moderated the pain-activity relationship. With increasing pain, individuals who reported using cognitive restructuring were less likely to miss work or school ($\beta = -.028$; $t(1333) = -2.58$, $p = .0100$; OR=.97). No other significant relationships between pain, coping and activity reduction were found. The relationship between relaxation and activity level is shown in Figure 6.

In the adult sample, no coping strategies showed any main effects on activity level. However, several coping strategies appeared to act as moderators and were associated with lower activity reduction as pain increased: cognitive restructuring ($\beta = -.030$; $t(1059) = -2.25$, $p = .0246$; OR=.97), thinking about solutions ($\beta = -.033$; $t(1059) = -2.07$, $p = .0385$; OR=.97), accepting the situation ($\beta = -.047$; $t(1059) = -2.76$, $p = .0059$; OR=.95), and relaxation ($\beta = -.029$; $t(1059) = -2.34$, $p = .0197$; OR=.97).

For adolescents, one main effect of coping was observed. Thinking about solutions was significantly related to lower activity reduction ($\beta = -1.611$; $t(255) = -2.23$, $p = .0266$; OR=.20). No moderating effects were observed. However, the contrast between the combination of distraction, cognitive restructuring, and relaxation and the combination of the other six strategies was significant ($F(1,255) = 4.37$, $p = .0376$). When the slopes for these two groups of strategies were estimated using PROC GLIMMIX, distraction, cognitive restructuring and relaxation ($\beta = 1.1760$, SEM = .7619; $t(255) = 1.54$, $p = .1239$; OR=3.24) were related to *greater* activity reduction than the other six strategies combined ($\beta = -2.6060$, SEM = 1.1320; $t(255) = -2.30$, $p = .0221$; OR=0.07). Note that standard error for these estimates is much higher than for individual coping

strategies. The contrast was not statistically significant for the combined or adult samples.

The count of coping strategies used did not have a significant main or moderating effect for the combined sample. However, in the adult sample, a significant interaction was observed. As pain increased, individuals who used more coping strategies reported lower activity reduction ($\beta = -0.006$; $t(1075) = -2.88$, $p = .0041$; OR=.99). The interaction between pain and number of coping strategies was close to, but did not meet, significance ($\beta = 0.006$; $t(271) = 1.89$, $p = .0601$; OR=1.01). Note that this moderation was in the opposite direction to adults; when adolescents reported using more coping strategies in the face of increasing pain, they were more likely to miss school or work.

Health Care Use

The relationships between pain, coping strategies, and HCU were analyzed using PROC GLIMMIX as described for activity reduction. Three particular behaviors were of interest: visiting the doctor, visiting the hospital, or going to the emergency room. For the combined sample, individuals reported seeing their doctor on 10.0% of pain days, compared with visiting the hospital and going to the emergency room on 5.2% and 3.7% of these days, respectively. Because of the relatively low base rates of these outcomes, a binary aggregated variable was created to represent HCU. HCU was rated 1 on days when individuals engaged in at least one of the three behaviors above, and 0 for all other days. For all analyses, age had no significant main effect on HCU when measured in years or log-years.

For the combined sample, two strategies demonstrated main effects on HCU. Individuals who made active attempts at solutions engaged in HCU less often ($\beta = -0.569$; $t(1369) = -2.07$, $p = .0386$; $OR = .57$). Conversely, people who reported seeking emotional support engaged in HCU more often ($\beta = 1.067$; $t(1369) = 3.84$, $p = .0001$; $OR = 2.91$). Distraction significantly moderated the pain-HCU relationship. As pain increased, an individual who used distraction was less likely to engage in HCU ($\beta = -0.027$; $t(1369) = -2.15$, $p = .0319$; $OR = .97$). No significant main or moderating effects were observed for cognitive restructuring or relaxation.

In the adult sample, only one strategy showed a significant main effect. Individuals who reported seeking emotional support again engaged in more same-day HCU ($\beta = 1.410$; $t(1095) = -4.04$, $p < .0001$; $OR = 4.09$). Two significant moderating effects were observed. As pain increased, an individual who used distraction was less likely to engage in same-day HCU ($\beta = -0.042$; $t(1095) = -2.73$, $p = .0064$; $OR = .96$), but individuals who reported religious/spiritual coping were more likely, as pain increased, to engage in same-day HCU ($\beta = 0.036$; $t(1095) = 2.63$, $p = .0088$; $OR = 1.04$). Again, no main effects were observed for cognitive restructuring or relaxation.

For adolescents, no main effects of coping strategies on HCU were observed. However, seeking emotional support showed a moderating effect on the pain-HCU relationship; as pain increased, individuals who reported seeking emotional support again showed high same-day HCU ($\beta = 0.071$; $t(255) = 2.28$, $p = .0234$; $OR = 1.07$).

For all age groups, contrasts of the combination of distraction, cognitive restructuring and relaxation against the other strategies showed no statistically significant

differences. Similarly, when the total number of coping strategies used on a given day was entered as a predictor and moderator, no significant relationships with HCU were revealed.

Discussion

Pain represents a significant obstacle for individuals of all ages with SCD. Prior research has shown that SCD pain leads individuals to have less positive mood and more negative mood, to reduce their participation in their typical daily activities, and to engage in more frequent HCU. The association between SCD pain and adjustment difficulties has been confirmed through a number of methods, including family interviews (e.g., Barbarin & Christian, 1999), global and retrospective self-report (e.g., Gil et al., 1989), and daily diary studies (e.g., Gil et al., 2004). The analyses in the present study reaffirm these relationships; adolescents and adults in this sample typically reported worse mood, reduced activity, and increased HCU as their ratings of SCD pain increased.

Prior research has also indicated that a significant portion of the variance in these adjustment outcomes, beyond age, gender, and disease severity, is accounted for by strategies one uses to cope with the noxious experience of pain. Generally speaking, regardless of age group, strategies that are generally construed as negative thinking and passive coping worsen outcomes, whereas more active cognitive and behavioral forms of coping have an association with greater positive adjustment.

The results of this study suggest that the relationship between coping strategies and outcome measures is more complex than prior research has indicated, especially when viewed at a daily level. Taken together, the findings of this study tend to refute the initial hypotheses, as distraction, relaxation and cognitive restructuring were not optimal coping strategies for all outcomes and age groups. Indeed, in some cases these strategies

were related to significantly worse same-day outcomes. Still, for each outcome, some notable findings were obtained that build upon existing knowledge about how selection and use of coping strategies influence one's experience of pain and quality of life.

Perhaps the most interesting finding of this study is that the use of relaxation was directly related to greater reduction of daily activity. This finding appears to contradict the initial hypothesis that this strategy would predict better adjustment for all outcomes, as well as previous findings from cognitive interventions for SCD pain (e.g., Gil et al., 2000). However, attempts at relaxation such as resting or avoiding physical activity could be considered a more appropriate technique for chronic pain than an episode of acute pain (Turk & Okifuji, 2002).

Given the nature of the study questions, it is possible that participants interpreted the strategy of relaxation more broadly than anticipated. Rather than considering techniques directly aimed at reducing arousal and anxiety (e.g., progressive muscle relaxation), participants may have relaxed by attempting to lower physical exertion or subjective feelings of anxiety or distress; it is possible that missing work or school was itself viewed as a way of promoting relaxation. This hypothesis could explain why a direct relationship between relaxation and activity reduction was observed rather than moderation.

A number of strategies showed relationships with positive and negative mood for adults. Distraction was the only strategy related to both positive and negative mood, and as expected, it showed a consistent relationship with both more positive and less negative mood in adults. This finding is very encouraging; however, the relationship was a main

effect rather than the expected moderation. The apparent benefits of distraction do not appear to differ by pain severity. Thinking about solutions seemed to show the most consistent moderating relationship, as it moderated the relationship between both positive and negative mood for adults. At higher levels of pain, thinking about solutions helps to attenuate the unpleasant effects of pain on positive and negative mood. It is possible that when adults engage in thinking about solutions, they feel a greater sense of self-efficacy for dealing with SCD pain, which then leads to better mood. One prior study showed that greater self-efficacy for coping with SCD pain can lead to reductions in one's perceived intensity of physical symptoms (Edwards et al., 2001).

Regarding HCU, relatively few significant relationships were observed between coping, pain and HCU. This finding is somewhat puzzling, given that prior intervention studies have indicated that adults who receive training in coping skills tend to exhibit less HCU (Gil et al., 2000). HCU was the only outcome for which active attempts at solutions showed a significant effect; however, HCU itself might be considered an active attempt at resolving SCD pain. In prior adult studies, use of Negative Thinking and Passive Adherence strategies were predictors of greater HCU, but Coping Attempts strategies were not (Gil et al., 1992). It is possible that without explicit training in using coping strategies to reduce HCU, HCU may not be strongly affected by the coping attempts assessed in this study;

Coping Strategies in Adults versus Adolescents

Previous studies of coping in individuals with sickle cell disease have often included only adults or only adolescents, or in some cases have combined older

adolescents with adults. In the present study, similarities and differences in coping and its effects between these age groups were examined. The results show numerous differences in the influence of coping between adults and adolescents when they are examined separately. The most common difference was that coping strategies were significantly related to outcomes for one group but not the other. No coping strategy showed a positive relationship for one age group and a negative relationship for the other for the same outcome. Thus, the hypothesis that the most beneficial coping strategies would be similar across age groups was only partially supported. Taken together with the fact that the continuous age variable was not a significant predictor for any outcome, these differences between age groups could indicate that the unique challenges faced by adolescents alter the usefulness of particular coping strategies, but do not change the directionality of their association with adjustment.

As expected, adolescents who sought support from others in their environment showed worse adjustment, particularly when they sought emotional support. This finding is consistent with clinical observations on the challenges adolescents with SCD face, including diminished peer contact due to missed school time, lack of understanding from family members, and increased difficulty in participating in some activities with peers (Pinckney & Stuart, 2004; Kell et al., 1998; Noll, Vannatta, Koontz, Kalinyak, Bukowski, et al., 1996). For some adolescents, even adherence to a physician's treatment recommendations, through behaviors such as frequent clinic visits and avoidance of vigorous activity, can itself interfere with the development of positive social relationships (Barakat, Lutz, Smith-Whitley, & Ohene-Frampong, 2005). Thus, for several reasons

adolescents who seek emotional support appear more likely to get responses from others that are not beneficial, and therefore have a harder time adjusting to SCD. Adolescents who benefit less from coping strategies are more likely to view these strategies in a negative light, even when they might be helpful in the future, leading to more severe difficulties with adjustment later in life (Edwards et al., 2001).

Unexpectedly, seeking emotional support was associated with worse outcomes in the adult sample, as well as the combined sample. These findings on seeking emotional support are still consistent with broader clinical observations on the difficulties individuals with SCD of all ages face with seeking treatment. Because SCD pain does not show any external manifestations, individuals with SCD are more likely to receive worse support and care from caretakers and medical staff who believe that their reports of pain are exaggerated (Booker, Blethyn, Wright & Greenfield, 2006; Connelly, Wagner, Brown, Rittle, Cloues, et al., 2005). One should note that participants were not asked to report on whether their attempts to garner emotional support were *effective*. For example, peer support groups in which empathy and understanding are expressed are generally considered helpful for adolescents with SCD (Telfair & Gardner, 2000). It is possible that successful and unsuccessful attempts to obtain emotional support relate to different outcomes. This question warrants future exploration.

It is somewhat puzzling that for adolescents, higher numbers of coping strategies were directly related to *worse* mood, both positive and negative. Because the study design is observational in nature, one cannot tell whether coping directly influences mood or vice versa; perhaps when adolescents experience worse mood, they use more coping

strategies in response to their unpleasant mood state. Adults may not show this relationship because their coping strategies are more stable (Gil et al., 1997). Very few coping strategies showed significant relationships with mood for adolescents, whereas several were observed for both positive and negative mood for adults. Given this, one might speculate that these adolescents used the coping strategies less effectively or less intensely than adults, and thus did not experience a strong impact of coping strategies on their mood. Unfortunately, because coping was assessed by checklist, no additional information is available to infer how vigorously coping was attempted or how successful the participants felt their coping attempts were.

To summarize, no single strategy was related to better outcomes for all adjustment outcomes, although one strategy was found to relate consistently to worse adjustment outcomes. For some strategies (e.g., relaxation and cognitive restructuring), the same strategy predicted better adjustment for one outcome variable and worse adjustment for another. The number of coping strategies used on a given day was a predictor in some cases, but was generally related to worse mood outcomes in adolescents and better outcomes for adults.

That each adjustment outcome showed significant associations with different coping strategies highlights the importance of matching coping strategies to the adjustment outcome most relevant to the current situation. This matching concept has been explored in other domains of health psychology, particularly in coping with stressful medical procedures. In a review, Schultheis, Peterson and Selby (1987) explored the differences between those who seek information about medical procedures and their

potential risks and those who avoid or distract themselves from that information. These authors found that the interaction between one's coping style and aspects of the medical procedure at hand (e.g., how much pain to expect, level of risk) was often a useful predictor of subjective distress, anxiety, use of pain medications, and other aspects of adjustment. Across studies, individuals who tended to monitor and seek information about their procedure and its risks appeared to report higher overall distress; their distress was exacerbated when they were provided with little information regarding their procedure and generally alleviated when information was obtained. Intervention studies in other illness populations, including temporomandibular disorders and fibromyalgia syndromes, has also shown benefits of matching aspects of illness (e.g., acute or chronic pain), psychological characteristics of patients, and the means of intervention (Turk & Okifuji, 2002).

Thus, the findings of this study may have particular importance for future cognitive interventions for management of SCD pain. Individuals who are trained to use cognitive coping skills to manage pain might benefit from additional psychoeducation, in which they are not only trained on how to use these strategies during pain episodes, but also informed about the ways in which the strategies are most likely to help (i.e., to have a better mood or to go to work despite mild pain). Psychoeducation on coping strategy selection could be particularly useful for individuals who experience chronic pain from SCD as well as acute pain episodes, as different coping strategies may be appropriate for acute and chronic pain (Turk and Okifuji, 2002). Future studies could evaluate this matching hypothesis by providing coping skills training with and without this additional

psychoeducation to individuals with SCD, then monitoring their application of strategies to particular adjustment outcomes on a daily basis.

Owing to the daily diary measurement approach, the results of this study provide rich new information on the daily impact of coping on adjustment which has not been captured in studies with fewer measurement points. By exploring the relationships between daily pain, adjustment, and particular coping strategies, this study expands upon past intervention studies in which several coping strategies were taught to participants without targeting specific outcomes with particular strategies. The findings reaffirm the high complexity of the relationship between coping and adjustment by showing that coping strategies that could have been considered universally useful show disadvantages when viewed at a daily level. Future studies will gain from continued use the daily diary approach to more thoroughly characterize the relationship of coping to adjustment during SCD pain.

Study Limitations

The results of these analyses should be interpreted in light of a number of limitations. First, diaries were missing for a substantial portion of study days (25% of study days for adolescents, 29% for adults) and therefore could not be included in the analyses. Although a 100% response rate is ideal, incomplete data is fairly typical in daily diary research. Multilevel modeling techniques that account for serial autocorrelation between diaries help to minimize the impact of missing data. Multilevel models assume that data are missing completely at random; if participants miss days of participation systematically, this could have a significant impact on the result. However,

pain intensity, the variable by which missing data may have systematically varied, was entered as a predictor in these analyses. For this reason, the assumption that records are missing completely at random has not been violated, and the models can still be interpreted.

Participants fail to complete diaries for many reasons, including fatigue, excessive stress or pain. In the present study, participants might have had more difficulty with completing diaries while experiencing pain, especially severe pain. If data from severe pain days were systematically missing from these data, then the conclusions drawn about the utility of coping could be neglecting a key aspect of how individuals experience and cope with SCD pain. Although one cannot determine with certainty whether high pain was a principal reason for missing data in these samples, a qualitative analysis of pain days with near-maximal pain is revealing. Adults gave pain ratings ranging from 90 to 100 on 14.3% of pain days, whereas adolescents gave pain ratings ranging from 90 to 100 on 6.5% of pain days. These data indicate that participants did complete diaries even when experiencing what they perceived to be their most severe pain; however, adolescents may have had more difficulty than adults in this regard. Whereas adults reported pain on 33% of completed diaries, adolescents reported pain on only 8%, fewer than expected in light of prior estimates of SCD pain frequency in children (12 to 30%; Gil et al., 2000; Gill et al., 1997). Findings in the current study should be interpreted more cautiously for adolescents than adults given the possibility that some information on how these adolescents coped during pain episodes may be absent. Though participants in this study received weekly check-in phone calls, future studies could address concerns

about systematic missing data by cataloging participants' specific difficulties with diary completion, especially for adolescents.

Next, the strategy employed to assess coping strategy use was problematic in some ways. Participants were asked to report which coping strategies they used to deal with their identified primary stressor for the day. (Findings on the relationship between stress and adjustment outcomes have been reported elsewhere, e.g., Gil et al., 2003.) SCD pain was one of five to six possible primary stressors, including interpersonal relationship problems and school or work. To help ensure that the coping strategies analyzed had been applied to the experience of pain, only pain days were included in the analyses. However, adult and adolescents reported a primary stressor other than SCD pain on 95% and 94% of pain days, respectively. Individuals with SCD might have directed few or none of their reported coping strategies at pain specifically.

Future diaries aimed at the impact of pain on adjustment outcomes must take care to assess coping strategies used for pain specifically. For example, one could provide participants with instructions reading, "People do many different things to deal with pain from sickle cell disease – for example, someone might try to pay attention to something other than the pain in order to feel better. Which of the following strategies did you try today to deal with pain from sickle cell disease?" Given the results of this study, one might expect that the overall number of coping strategies reported would decrease, which might alter the relationships found between pain, adjustment, and the total number of strategies used. It is also possible that, by refining the measurement of coping strategies in this way, strategies that had no clear relationship to adjustment in this study might be

shown to be significant predictors or moderators. However, one cannot speculate which, if any, coping-adjustment relationships would be altered by this change in design.

Finally, the daily diary assessed the use of coping strategies, but it did not assess the way in which they were used or whether participants perceived them to be effective. Even though they received training on diary completion, participants interpreted may have coping strategies in an idiosyncratic way (e.g., using “relaxation” to signify taking time off from work). A narrative was collected from participants to describe their primary stressor; perhaps a similar narrative could be collected to assess how coping strategies were implemented to further distinguish effective and ineffective coping and to confirm that participants and investigators agree on the meanings of coping strategies. Such a narrative might also allow participants to disclose additional coping strategies that they may find helpful for SCD pain specifically.

Future Directions

This study demonstrated the feasibility and benefits of using MLM and daily diary methodology to examine the unique effects of individual coping strategies on the relationship between SCD pain and adjustment on a daily basis. Future studies on the relationship between pain, coping, and adjustment should continue to use these methods, as they offer the flexibility and statistical power necessary to draw conclusions about individual coping strategies and their utility on a more immediate scale than pretest/posttest designs.

The mixed results for these analyses indicate that coping strategies may not strongly moderate the pain-adjustment relationship in all cases. However, the results of

this study support the hypothesis that, in some cases, certain coping strategies indeed have an association with positive adjustment outcomes. The optimal coping strategies to use necessarily will depend upon the adjustment outcome of interest (e.g., for maintaining work activity, cognitive restructuring appears important); future studies should take into account an individual's ability to use that strategy effectively. An interesting option for future research would be to replace strategies from the Coping Attempts factor with strategies from the Negative Thoughts/Passive Adherence factors. It is possible that more subtle relationships between particular negative coping strategies and adjustment would be found, as they were in this study. Such a study might also offer new and important information on adolescents who use these negative strategies more often and tend to show more activity reduction and greater HCU (Gil et al., 1993).

As indicated by this and other studies, no single coping strategy is likely to be beneficial for every adjustment outcome for individuals with SCD or other chronic illnesses. Rather, people with chronic health problems are likely to experience the best adjustment outcomes if they possess a full complement of coping strategies that they can choose from and use effectively. For this reason, researchers who wish to explore the benefits of individual coping skills for SCD and other conditions should bear in mind that a coping strategy that appears to be effective in one area of adjustment may prove ineffective or costly in another. Similarly, cognitive interventions for management of SCD pain should give particular consideration to which outcomes are the most important to the individual's quality of life. Finally, the daily diary approach appears to offer substantial additional information on how individuals adjust to pain in SCD compared to

approaches that use fewer measurement points. Future research that incorporates this method of measurement is more likely to supply researchers with deep, nuanced conclusions on the complex ways in which coping strategies affect the relationship between SCD and adjustment.

Table 1
Main Effects of Daily SCD Pain Ratings on Adjustment Outcomes

	Adult		Adolescent		Combined	
	β	<i>t</i>	β	<i>t</i>	β	<i>t</i>
Mood						
Positive	-.043	-8.43****	-.056	-4.02****	-.045	-9.31****
Negative	.054	8.89****	.055	4.36****	.058	10.16****
Activity	.031	6.27****	.017	2.36*	NA ^b	NA ^b
Reduction ^a						
HCU ^a	.037	7.27****	.042	4.78****	.039	8.81****

Estimates of β are taken from initial models and do not include coping strategies or interaction terms. Analyses included between-person SCD pain means and age as control variables.

^aEstimates are from multilevel logistic regression models.

^bSAS PROC GLIMMIX did not converge on a solution for this test.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

**** $p < .0001$.

Table 2

Main Effects of Daily and Average Pain Ratings on Mood

	Adult		Adolescent		Combined	
	β	t (df)	β	t (df)	β	t (df)
Positive Mood						
Intercept (fixed)	.916	.17 (46)	41.802	1.80 (35)	12.017	3.68*** (84)
Age	3.279	2.11* (46)	-10.389	-1.20 (35)	.294	.29 (84)
Mean Pain Rating	-.079	-3.26** (46)	-.058	-1.45 (35)	-.066	-2.98** (84)
Daily Pain Rating	-.052	-4.79**** (1067)	-.050	-1.93 (258)	-.055	-5.55**** (1344)
Negative Mood						
Intercept (fixed)	6.958	.93 (46)	-31.004	-1.60 (35)	-1.489	-.42 (84)
Age	-1.507	-.71* (46)	10.827	1.50 (35)	.573	.51 (84)
Mean Pain Rating	.130	3.89*** (46)	.136	4.06*** (35)	.126	5.14**** (84)
Daily Pain Rating	.052	4.14**** (1077)	.017	.74 (255)	.054	4.88**** (1351)

Analyses included between-person SCD pain means and age as control variables, as well as within-person variables of daily pain rating, coping strategies and interaction terms.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

**** $p < .0001$.

Table 3

Main Effects of Daily and Average Pain Ratings on Activity Reduction

	Adult		Adolescent		Combined	
	β	t (df)	β	t (df)	β	t (df)
Intercept (fixed)	-2.0908	-1.45 (46)	-0.6750	-0.25 (35)	-1.9571	-2.58*
Age	.0005	-0.30 (46)	-.05754	-0.04 (35)	-0.0055	-0.07 (84)
Mean Pain Rating	-0.0055	0.01 (46)	-0.0006	-0.32 (35)	-0.0009	-0.28 (84)
Daily Pain Rating	.0312	6.27**** (1135)	0.0172	2.36* (273)	0.0284	6.49**** (1342)

Analyses included between-person SCD pain means and age as control variables, as well as within-person variables of daily pain rating, coping strategies and interaction terms.

Note: Combined parameters include coping strategies as independent variables due to lack of convergence for preceding models.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

**** $p < .0001$.

Table 4

Main Effects of Daily and Average Pain Ratings on Health Care Use

	Adult		Adolescent		Combined	
	β	t (df)	β	t (df)	β	t (df)
Intercept (fixed)	-3.6061	-3.42**** (47)	-6.7320	-2.35* (35)	-3.5957	-5.60**** (85)
Age	.0016	.07 (47)	.2121	2.18* (35)	.0021	.14 (85)
Mean Pain Rating	.0301	2.31* (47)	.0322	1.21 (35)	.0302	3.09** (85)
Daily Pain Rating	.0374	7.26**** (1172)	.0425	4.78**** (273)	.0390	8.81**** (1446)

Health care use (HCU) is a binary variable marked “true” for any day a participant visits his or her doctor, is admitted to the hospital, or visits the emergency room.

Analyses included between-person SCD pain means and age as control variables, as well as within-person variables of daily pain rating, coping strategies and interaction terms.

* $p < .05$.

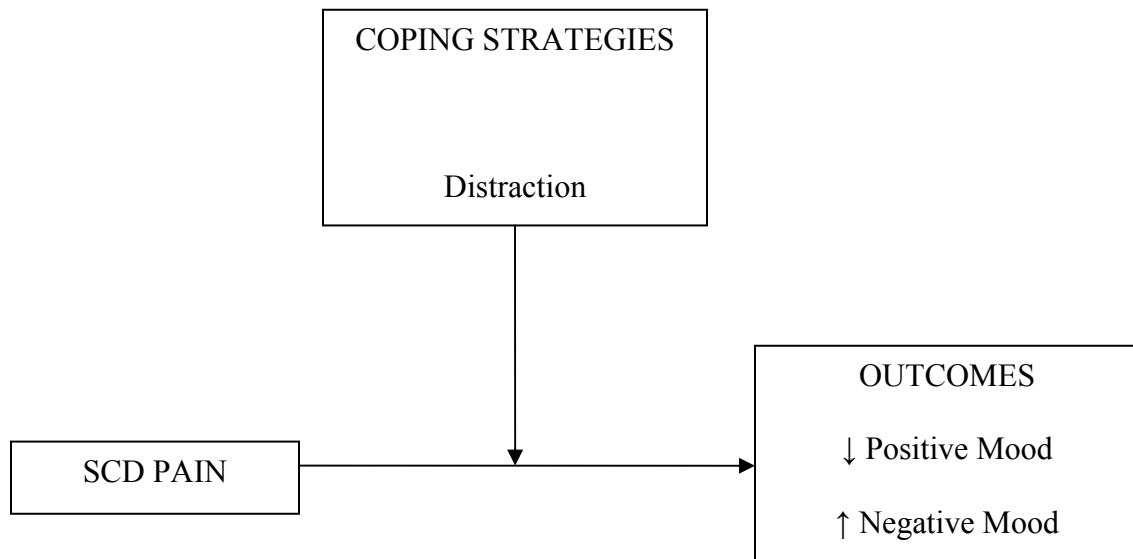
** $p < .01$.

*** $p < .001$.

**** $p < .0001$.

Figure 1

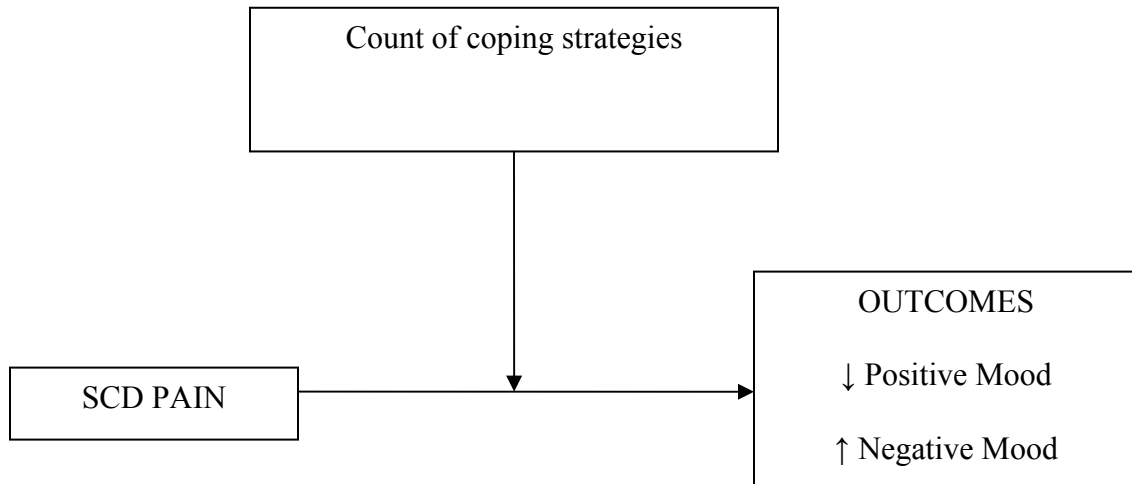
Hypothesis 1, Moderation of SCD Pain-Adjustment Relationship by Coping Strategies



Coping strategy use will moderate the pain-outcomes relationship, with increasing use of coping strategy being associated with more positive mood, less negative mood, higher daily activity and lower health care use.

Figure 2

Hypothesis 2 and Alternate Model of Moderation of SCD Pain-Negative Adjustment Relationship



The number of coping strategies used should moderate the relationship between pain and adjustment outcomes, with increasing number of coping strategies used strategy being associated with more positive mood, less negative mood, higher daily activity and lower health care use. It was hypothesized that this variable will not moderate the relationship as much as distraction, relaxation, and cognitive restructuring.

Figure 3
Adults: Coping Strategy Usage on Pain Days and Non-Pain Days

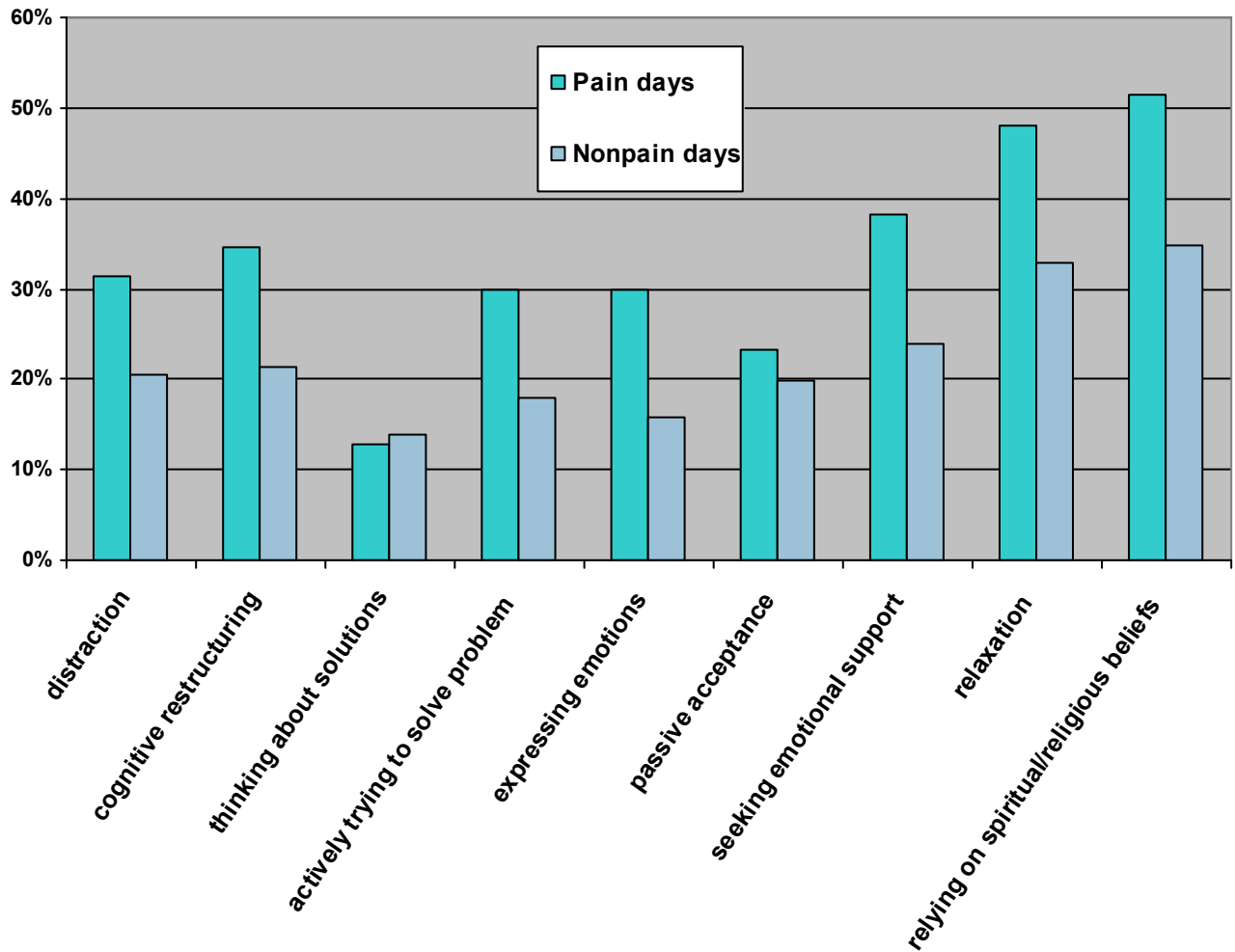


Figure 4

Adolescents: Coping Strategy Usage on Pain Days and Non-Pain Days

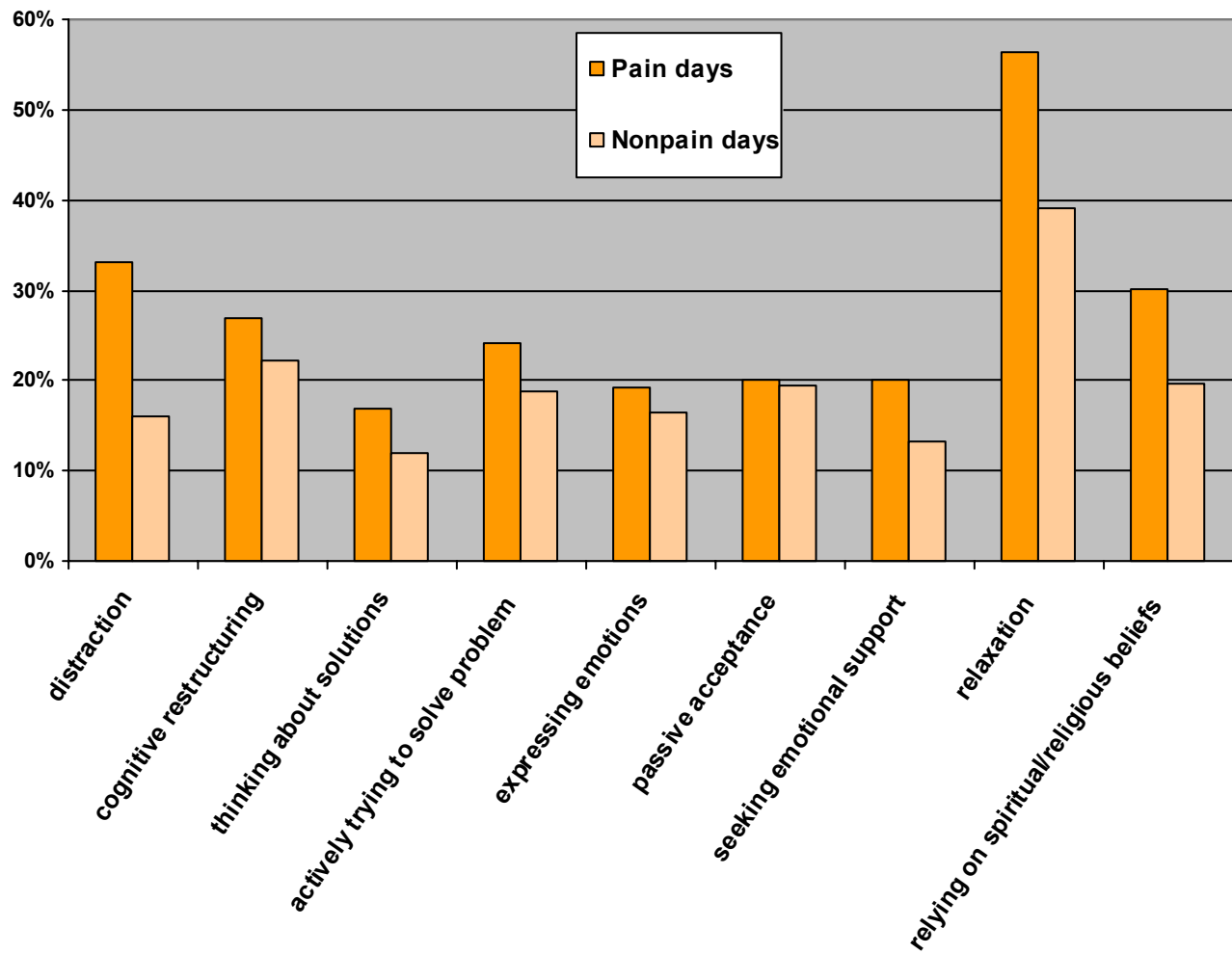


Figure 5
Relationship between Distraction and Positive Mood, Adult Sample

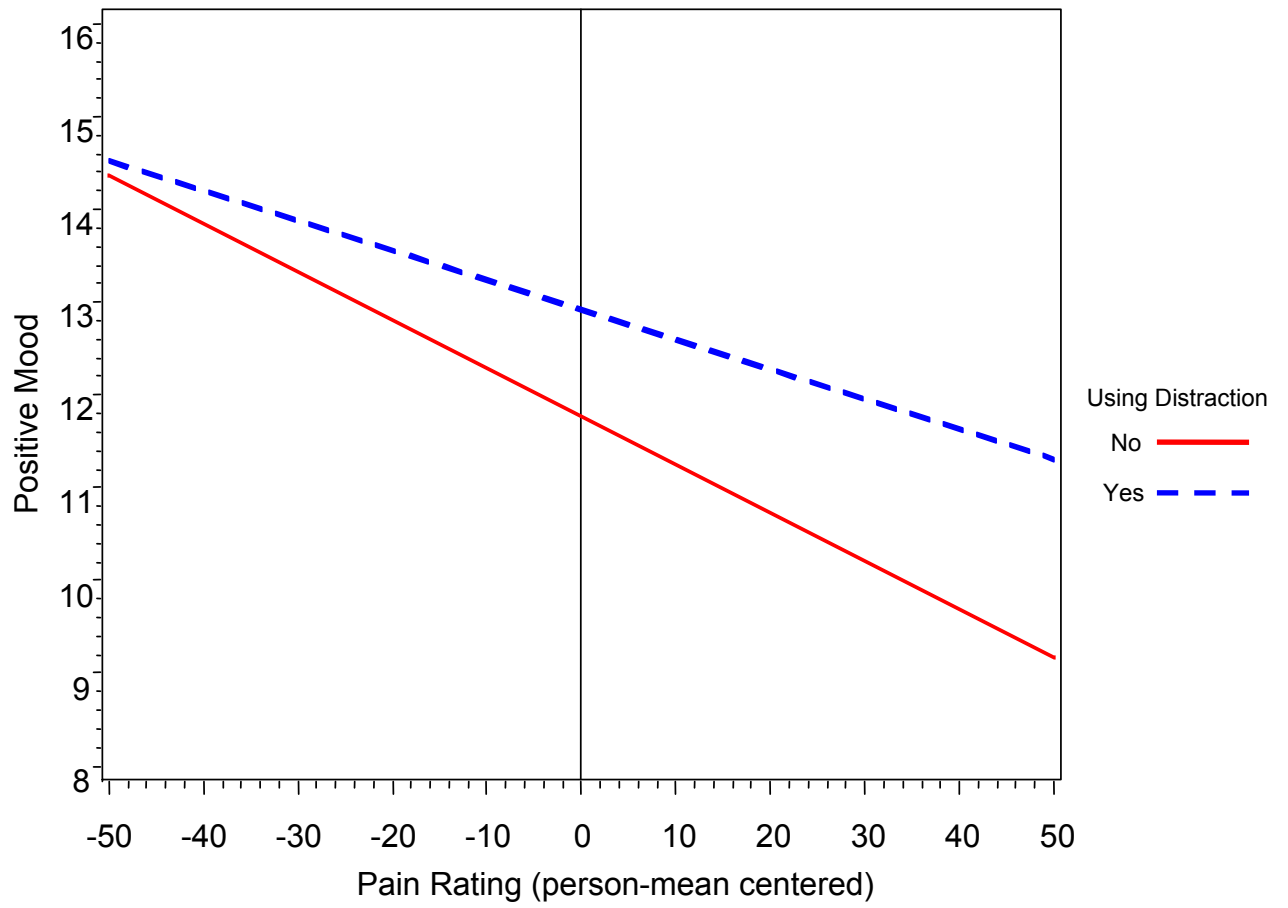
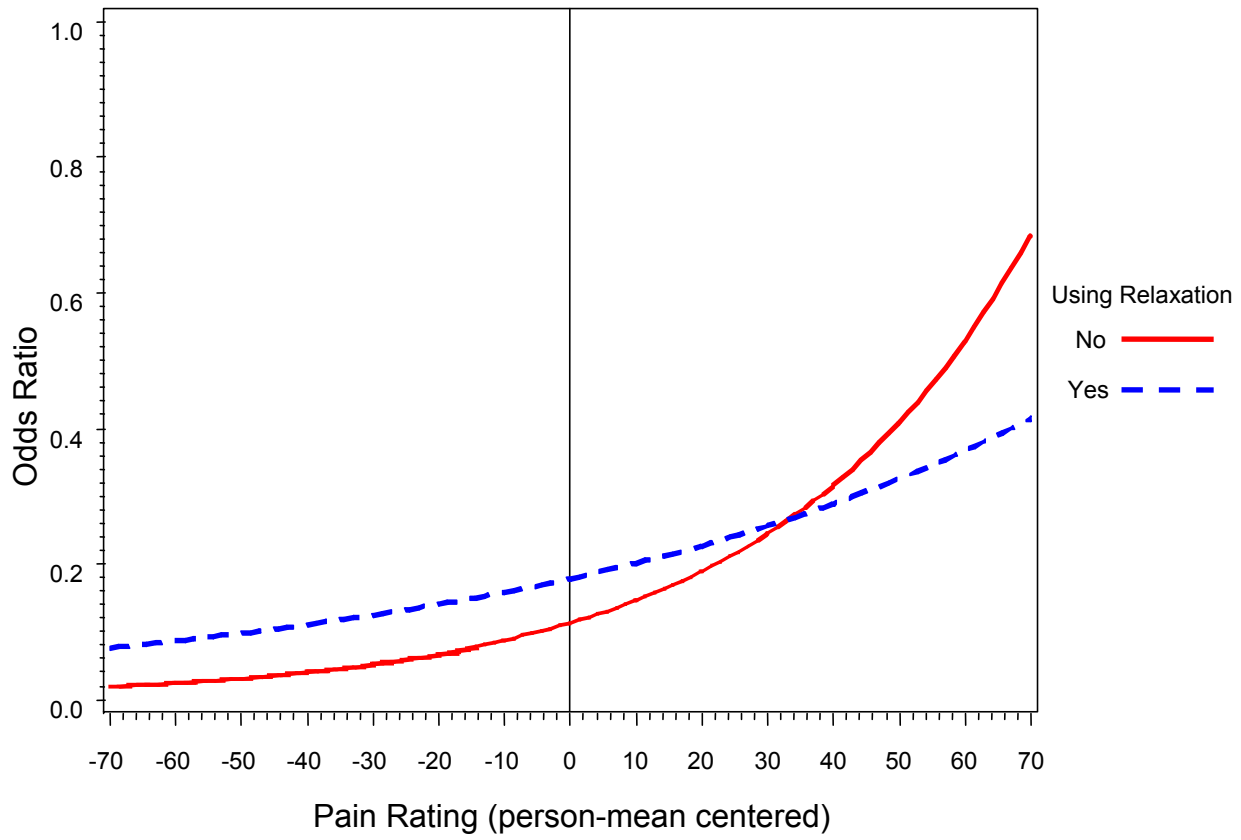


Figure 6
Relationship between Relaxation and Activity Level, Combined Sample



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