Information-Seeking Coping Behaviors During Painful Procedures in African-American Children with Sickle Cell Disease

Alyssa M. Schlenz, BA,* Jeffrey Schatz, PhD,* Catherine B. McClellan, PhD,† Sarah M. Sweitzer, PhD,‡ and Carla W. Roberts, MD§

ABSTRACT:
This study examined the frequency of information-seeking coping behaviors in 37 African-American children (ages 5-17 years) with sickle cell disease during venipuncture. The relationships between coping behaviors and child- and parent-reported pain and observational distress were also assessed. The majority of children attended to the procedure, but did not seek information via questions. This pattern of coping was only partially effective at reducing distress and had no relation to pain. This pattern of coping is discussed within the context of cultural factors that may be important in understanding responses to procedural pain in pediatric sickle cell disease.

Procedural pain is a recurrent part of disease management in pediatric sickle cell disease (SCD) that can arise from routine venipunctures, immunizations to prevent infections, and intravenous starts (American Academy of Pediatrics, 2002). Procedural pain management has remained largely unstudied in children with SCD, although it has been studied in several other clinical and nonclinical pediatric populations with predominantly non-Hispanic European-American children (Powers, 1999). These studies have generally found that information-seeking coping behaviors result in greater pain and distress during painful procedures versus avoidance-oriented strategies. Generalizing these findings to diverse populations of children has not been a primary focus of procedural pain research. Given the prominence of SCD among African Americans in the United States, it is important to understand whether these findings extend to African-American children. The present study examined the information-seeking coping behaviors of African-American children with SCD during venipuncture. This report describes how the use and effectiveness of these behaviors in reducing procedural pain and distress may be distinctive for this population.
Information seeking has been widely studied as a coping construct in procedural pain research and is defined by how much patients seek procedure-related information (e.g., attending to the procedure as it occurs) (Peterson & Toler, 1986). Information seeking has also been categorized as approach coping and can be contrasted to more avoidance-oriented strategies (e.g., looking away during the procedure) (Slifer, Tucker, & Dahlquist, 2002). Current recommendations for minimizing pain during medical procedures support the use of avoidance techniques (e.g., distraction), as opposed to approach techniques, unless avoidant behaviors are incompatible with a child’s preferred coping method (Cohen, 2008).

The small number of studies of acute and procedural pain focused on African-American children suggests that avoidance-oriented strategies may be less effective for African-American children with SCD. For example, a study of acute laboratory pain found that African-American children experienced less pain when they attended to a painful stimulus, in contrast to non-Hispanic European-American children, who experienced less pain when they distracted themselves (Evans, Lu, Tsao, & Zeltzer, 2008). In addition, a procedural pain intervention study with African-American children found that children in an avoidance coping condition did not anticipate or experience less pain or anxiety during immunizations compared with anesthetic and standard of care conditions (Cohen et al., 2001). A different effect has been found in adult populations, with African-American adults exhibiting greater attending behavior, yet also greater pain, than non-Hispanic European Americans (Campbell, Edwards, & Fillingim, 2005).

The present study sought to establish the frequency of information-seeking coping behaviors in children with SCD and to determine their relationships with pain and distress. Two behaviors were examined: attending to the procedure and asking questions. Because of conflicting results found with African-American children versus adults, specific hypotheses for these effects were not made. Relationships between coping behaviors and age were also examined to determine if any differences in the frequency of these behaviors might be due to the developmental stage of the child. A multimodal approach to pain was used that incorporated child- and parent-reported pain and observational distress.

**METHODS**

**Participants**

The sample is a subsample of participants reported in McClellan et al. (2009). The larger study was focused on measurement of procedural pain in SCD and understanding factors that predict procedural pain in this population. Participants were recruited from Palmetto Richland Children’s Hospital in Columbia, South Carolina, over a 9-month period. Infants were not recruited because they rarely receive venipuncture at this center. Participants with a history of overt stroke or who had consumed opioid medication within the preceding 7 days were excluded. Because of the goals of the larger study, children between 10 and 12 years of age (the transition period between pre- and postpubescence) were also excluded. In the larger study, four families refused to participate, citing insufficient available time (two parents), unwillingness to have the procedure captured on videotape (one parent), and no reason (parent). The present sample consisted of 37 African-American children and adolescents with SCD aged 5-17 years (median 13.07 years; 64.9% female) who completed a coping measure in addition to the original study protocol. Frequencies of SCD subtypes were as follows: HbSS (n = 23), HbSC (n = 4), HbSβ+ (n = 4), and HbSβ0 (n = 6). Children under the age of 5 years were not included in the present study, because these children were too young to complete self-report measures of coping and pain. There were no other differences between this subsample and the larger sample of children in the previous study.

**Measures**

**Coping Measure.** A revised version of the Child Approach-Avoidance Rating Scale (CAARS-R) was used to assess children’s coping behaviors (Bernard, Cohen, McClellan, & MacLaren, 2004). This scale uses simple graphical displays to query children about their coping behaviors in a forced-choice format. The first set of pictures shows a child who watches the needle during the procedure and a child who looks away during the procedure. The second set of pictures shows a child who asks questions about the procedure and a child who does not ask questions. Children were asked “Which one will you be?” before the procedure and “Which one were you?” after the procedure for each set of pictures. Children were queried about their coping behaviors before and after the venipuncture to assess the consistency of their reports. Correlations were moderately high for predicted and actual reports of attending to the procedure [r(35) = 0.77; p < .001] and asking questions [r(35) = 0.62; p < .001], indicating that children were fairly reliable in predicting their own coping behaviors.

**Child-Reported Pain Ratings.** Self-reports of baseline (prevenipuncture) and procedural (postvenipuncture) pain were obtained for children ≥5 years old by using a Wong-Baker Faces scale (Wong & Baker, 1988).
The Faces scale uses six cartoon faces as anchors. Each face on the scale is ranked with a number from 0 to 10, with higher numbers indicating more pain. This scale is a valid method of self-report for children within this age range as well as a preferable method of assessing pain in pediatric SCD (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990; Luffy & Grove, 2003).

**Parent-Reported Pain Ratings.** Parent reports of child baseline (prevenipuncture) and procedural (postvenipuncture) pain were obtained using a visual analog scale (VAS). VASs are 100-mm horizontal lines with anchors of no pain and worst pain possible, with scores ranging from 0 to 100. Research has shown VASs to be a valid method of pain assessment preferable to Likert-type scales because VASs result in a more even distribution of scores (McGrath, 1990). In a sample of 25 youths with medical conditions resulting in pain, parent ratings of children’s pain on a VAS correlated significantly with child report of pain, establishing its validity (Varni, Thompson, & Hanson, 1987).

**Observational Measure.** A modified version of the Observational Scale of Behavioral Distress (m-OSBD) was used to measure distress using videotaped recordings of the procedure. Distress behaviors were tallied and recorded during the three phases used in the original OSBD (baseline, procedural, and after procedure). The m-OSBD assesses 11 behaviors (crying, screaming, physical restraint, verbal resistance, seeking emotional support, flail, muscular rigidity, verbal pain, verbal fear, nervous behavior, and information seeking). Information seeking is the primary predictor of interest in the present study, so this item was removed in the derivation of the total score of distress for the data analysis to avoid any artificial association between coping behaviors and distress. The OSBD is a widely used measure of procedural distress in children, and the modified version does not significantly differ from the original regarding validity (Jay & Elliott, 1984).

**Procedures**

Study procedures were approved by the Institutional Review Board of Palmetto Richland Hospital, which provided approval concomitantly with the University of South Carolina, Columbia, before the recruitment of any participants. Eligible participants were identified by reviewing medical charts of patients. The attending hematologist approached eligible families, and those interested met with a research assistant who explained that the purpose of the study was to help the medical community develop a greater understanding of venipuncture pain and SCD pain. Caregivers provided consent before participation, and children >12 years old provided verbal assent. The participants and caregivers completed prevenipuncture forms that consisted of background information, child and parent reports of baseline levels of pain, and child report of anticipated coping behaviors. The research assistant used a remote control to start videorecording before the child entered the laboratory room and to stop the recording after the child had exited. Upon return to the laboratory waiting room, participants completed postvenipuncture measures (child and parent procedural pain ratings and child report of coping). Children and caregivers each received a participation incentive of a $5 gift card.

**Data Analysis**

To determine if there were tendencies toward the use of certain coping behaviors (i.e., attending versus looking away), the frequency of each behavior was evaluated using the binomial distribution to determine if it differed from a 50% chance of occurrence. To evaluate the relationships between coping behaviors and pain and distress, a series of between-groups t tests (two-tailed) were conducted with pain and distress scores as dependent variables. To test the relationship between age and coping behaviors, a series of Pearson correlations was conducted. On account of substantial positive skews in all three outcome variables (child and parent reports of pain and observational distress), these variables were log-transformed to produce a more normal distribution. Additionally, because of the possibility that children with SCD may have been experiencing vaso-occlusive pain before venipuncture, pain and distress were calculated through standardized residual scores by using linear regression to remove variability in venipuncture pain that could be predicted from baseline (prevenipuncture) pain. Results are reported in standardized residual scores. Alpha was set to .05 for all analyses.

Within the sample used in this study, two children had missing data. One child had information on coping and distress but not child or parent reports of pain, as the result of to experimenter error. One child had information on coping and child and parent reports of pain but not distress, as the result of video malfunction.

**RESULTS**

**Attending to the Procedure**

The majority of children (67.6%) chose to watch the procedure, which was significantly higher than chance \( p = .013 \). Between-groups t tests revealed no significant differences between children who attended to the procedure (mean 0.15, SD 1.16) and those who looked away during the procedure mean \((-0.31, SD 0.47)\) on child report of pain: \( t(34) = 1.33; p = 0.193; d = 0.47; 95\% \text{ confidence interval} \)
Age and asking
A significant, negative association was found between age and attending to the procedure \((t(34) = -1.19; p = 0.242; d = 0.42; 95\% \text{ CI } -0.28-1.12\). For observational distress, attending to the procedure \((mean = -0.04, SD = 0.86)\) was associated with greater distress versus looking away \((mean = -0.60, SD = 0.55)\): \(t(34) = 2.05; p = 0.049; d = 0.72; 95\% \text{ CI } 0.01-1.43\).

**Asking Questions**
The majority of children \((73.0\%)\) chose not to ask questions during the procedure, which was significantly higher than chance \((p = .003)\). Between-groups \(t\) tests revealed no significant differences between children who asked questions \((mean = 0.27, SD = 1.08)\) and those who did not ask questions \((mean = -0.10, SD = 0.97)\) on child report of pain: \(t(34) = 1.00; p = 0.325; d = 0.37; 95\% \text{ CI } -0.37-1.10\). Similarly, no significant difference was found for asking questions \((mean = -0.10, SD = 0.78)\) versus not asking questions \((mean = 0.04, SD = 1.08)\) on parent report of pain: \(t(34) = -0.39; p = 0.702; d = 0.15; 95\% \text{ CI } -0.59-0.87\). For observational distress, asking questions \((mean = 0.29, SD = 1.07)\) was associated with greater distress versus not asking questions \((mean = -0.42, SD = 0.59)\): \(t(34) = 2.56, p = 0.015, d = 0.95; 95\% \text{ CI } 0.18-1.71\).

Age and Information Seeking
No association was found between age and attending to the procedure \([r(35) = -0.02; p = .888]\); however, a significant, negative association was found between age and asking questions \([r(35) = -0.43; p = .007]\).

**DISCUSSION**
The results of this study suggest that African-American children with SCD may adopt a distinctive pattern of coping during painful procedures that is partially effective at reducing distress. The minimal literature on information-seeking behavior in African-American children suggests that there may be important cultural factors to consider in understanding this pattern of behavior.

The frequency of attending to the procedure \((68\%)\) in this study was somewhat higher than previously reported in studies of procedural pain. For example, in a study of Australian children aged 3-17 years, Goodenough et al. \(1998\) reported that 59\% of children chose to watch the procedure. Similarly, a study of non-Hispanic European-American children aged 4-6 years \(Bernard et al., 2004\) found that \(51\%\) of children chose behaviors characterized by an approach style \(watching the procedure and asking questions\). These authors did not examine attending behavior and asking questions separately. These differences across studies may suggest a greater preference of African-American children with SCD for attending behavior during medical procedures; however, a non-Hispanic European-American control group would be necessary to confirm this interpretation. This finding would be consistent with research with African-American adults, which suggests a greater preference for attending to acute pain compared with non-Hispanic European-American adults \(Campbell et al., 2005\). Within African-American populations, it has been speculated that sociocultural factors, such as health-related anxiety or stress due to minority status, may explain the use of attending behavior as a coping strategy during painful events \(Evans et al., 2008\). Importantly, although attending behavior occurred with greater frequency, this behavior was related to greater observational distress compared with looking away, which is consistent with current intervention literature \(Cohen, 2008\).

A high percentage of children also chose to not ask questions, and this behavior was related to lower levels of distress and increased age. Asking questions may have drawn upon factors beyond the child’s preference for procedural information, such as the child’s interactive style \(Katz, Kellerman, & Siegel, 1980\). Research on communicative behavior within medical settings also suggests that African-American children may be less likely to be called upon to answer questions by their caregivers and by pediatricians \(Stivers & Majid, 2007\). Thus, asking questions may have been a learned behavior that was less likely to occur during the procedure. Alternatively, the relationship between asking questions and distress may have been influenced by age differences between groups, because older children tended to not ask questions. Older children may refrain from asking questions because of familiarity with the procedure or because they have learned it is a less effective coping strategy for reducing pain.

The present study was limited by a small sample, which can raise concerns about power to detect significant effects and generalizability. The observed effect sizes indicated that information-seeking coping behaviors had a small effect on child and parent report of pain versus observational distress; however, the confidence intervals were fairly wide for these estimates. Replication of these findings with larger samples may be helpful in establishing whether these results represent a trend in this population and whether the effects of information-seeking coping behaviors extend to pain. Finally, the present sample was taken from a population of children with SCD who receive routine hematologic care, and the results may not generalize to children who receive infrequent care or to African-American children without SCD. The preliminary
findings of this study should be replicated in a larger sample, but given the paucity of data, they provide a useful basis for planning future studies.

Although many studies of SCD focus on pain management for vaso-occlusive episodes, children with SCD may endure frequent pain from medical procedures each year (American Academy of Pediatrics, 2002). Furthermore, children with SCD likely exhibit more intense pain and distress during medical procedures when they have co-occurring pain from vaso-occlusion (McClellan et al., 2009). Appropriate procedural pain management in SCD should be a component of routine care (Schechter, 1999); however, additional research is needed to understand whether existing procedural pain interventions generalize to children with SCD. The results from the present study suggest that African-American children with SCD may cope with painful procedures in a distinctive manner characterized by attending to the procedure and not asking questions. Interventions to improve coping with pain in this population may benefit from considering cultural factors that influence the successful adoption of avoidance-oriented strategies. Additional studies of procedural pain with African-American children would also be beneficial in understanding whether the findings of the present study represent a consistent trend in children with SCD and in African-American children generally. Further research is needed to understand the extent to which current procedural pain interventions can be applied to children from different cultural backgrounds.

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REFERENCES


