Published in final edited form as:

Pain Manag Nurs. 2013 September ; 14(3): e54–e58. doi:10.1016/j.pmn.2011.04.001.

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

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Abstract

This study examined the frequency of information seeking coping behaviors in thirty-seven African-American children (ages 5 to 17) 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 SCD.

Keywords

sickle cell disease; procedure pain; cultural issues; pediatrics

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 IV starts (American Academy of Pediatrics, 2002). Procedural pain management has remained largely unstudied in children with SCD, but has been studied in several other clinical and non-clinical pediatric populations with predominantly Non-Hispanic White American children (Powers, 1999). These studies have generally found that information seeking coping behaviors result in greater pain and distress during painful procedures versus avoidant-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. This study examined the information seeking

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Note. “*Information Seeking during Painful Procedures in Pediatric Sickle Cell Patients*” was presented during a poster session at the 31st Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine, Seattle, Washington in April, 2010.

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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 with more avoidant-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 avoidant-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 as opposed to Non-Hispanic White 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 when compared to 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 White Americans (Campbell, Edwards, & Fillingim, 2005).

This study sought to establish the frequency of information seeking coping behaviors in children with SCD and to determine their relationships to pain and distress. Two behaviors were examined: attending to the procedure and asking questions. Due to 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 multi-modal 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 due to the rarity with which they receive venipuncture at this center. Participants with a history of overt stroke or who had consumed opioid medication within the previous seven days were excluded. Due to the goals of the larger study, children between 10 and 12 years of age (the transition period between pre- and post-pubescence) were also excluded. In the larger study, four families refused to participate citing insufficient available time (2 parents), unwillingness to have the procedure captured on videotape (1 parent), and no reason (parent). The present sample consists of 37 African-American children and adolescents with SCD ages five to 17 years (*median age* = 13.07, 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 ($n = 4$), HbS β^+ ($n = 4$), and HbS β^0 ($n = 6$). Children under the age of five are not included in the present study, as

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. One 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, $r(35) = .77$, $p < .001$, and asking questions, $r(35) = .62$, $p < .001$, indicating that children were fairly reliable in predicting their own coping behaviors.

Child-reported pain ratings—Self reports of baseline (pre-venipuncture) and procedural (post-venipuncture) pain were obtained for children 5 years of age and older 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 (pre-venipuncture) and procedural (post-venipuncture) 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 demonstrated VASs to be a valid method of pain assessment preferable to Likert type scales due to a more even distribution of scores (McGrath, 1990). In a sample of 25 youth 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 post-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 this 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 with regard to validity (Jay & Elliott, 1984).

Procedures

Study procedures were approved by the institutional review board of Palmetto Richland Hospital, which provides approval concomitantly with the University of South Carolina in Columbia, SC, prior to 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 prior to participation and children over the age of 12 provided verbal assent. The participants and caregivers completed pre-venipuncture 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 video-recording before the child entered the laboratory room and stopped the recording after the child exited. Upon return to the laboratory waiting room, participants completed post-venipuncture 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 towards 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. Due to substantial positive skewness in all three outcome variables (child and parent report of pain and observational distress), these variables were log-transformed to produce a more normal distribution. Additionally, due to the possibility that children with SCD may have been experiencing vaso-occlusive pain prior to 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 (pre-venipuncture) 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 did not have child or parent reports of pain due to experimenter error. One child had information on coping and child and parent reports of pain, but not distress due to 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 ($M = .15$, $SD = 1.16$) and those who looked away during the procedure ($M = -.31$, $SD = 0.47$) on child report of pain, $t(34) = 1.33$, $p = .193$, $d = 0.47$ 95% CI $[-0.24, 1.17]$. Similarly, no significant differences were observed for attending ($M = -.14$, $SD = 0.92$) versus looking away ($M = .28$, $SD = 1.13$) on parent report of pain, $t(34) = -1.19$, $p = .242$, $d = 0.42$ 95% CI $[-0.28, 1.12]$. For observational distress, attending to the procedure ($M = -.04$, $SD = 0.86$) was associated with greater distress versus looking away ($M = -.60$, $SD = 0.55$), $t(34) = 2.05$, $p = .049$, $d = 0.72$ 95% 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 ($M = .27$, $SD = 1.08$) and those who did not ask questions ($M = -.10$, $SD = 0.97$) on child report of pain, $t(34) = 1.00$,

$p = .325$, $d = 0.37$ 95% CI $[-0.37, 1.10]$. Similarly, no significant difference was found for asking questions ($M = -.10$, $SD = 0.78$) versus not asking questions ($M = .04$, $SD = 1.08$) on parent report of pain, $t(34) = -0.39$, $p = .702$, $d = 0.15$ 95% CI $[-0.59, 0.87]$. For observational distress, asking questions ($M = .29$, $SD = 1.07$) was associated with greater distress versus not asking questions ($M = -.42$, $SD = 0.59$), $t(34) = 2.56$, $p = .015$, $d = 0.95$ 95% CI $[0.18, 1.71]$.

Age and Information Seeking

No association was found between age and attending to the procedure, $r(35) = -.02$, $p = .888$; however, a significant, negative association was found between age and asking questions, $r(35) = -.43$, $p = .007$.

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 ages three to 17 years, Goodenough et al. (1998) reported that 59% of children chose to watch the procedure. Similarly, a study of Non-Hispanic White American children ages four to six years found that about 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 (Bernard, et al., 2004). 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 White 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 to Non-Hispanic White 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 to 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, since 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.

This 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, this sample was taken from a population of children with SCD who receive routine hematological 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, 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 this 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 avoidant-oriented strategies. Additional studies of procedural pain with African-American children would also be beneficial in understanding whether the findings of this 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.

Acknowledgments

This work was supported by: the University of South Carolina School of Medicine Translational Research Grant (to S.M.S., C.W.R.); the University of South Carolina School of Medicine Department of Pharmacology, Physiology, and Neuroscience Seed Grant for Translational Research (to S.M.S. and J.C.S.); the Pfizer Fellowship in Health Disparities (to C.B.M.); and the National Institutes of Health, National Institute of General Medical Sciences (T32 GM081740 to A.M.S.). The authors wish to thank the children and families who participated in this research as well as the following individuals for their assistance in data collection, coding and management: Teresa Mark, Alvin McKelvy, Eve Puffer, Nathan Jones, Jeet Guram, Rabiah Ali, and Brad Pepper.

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