Parent Perspectives on Pain Management in Preschool-Age Children With Sickle Cell Disease

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Kelsey Smith, MA, MEd¹, Laura Reinman, MA¹, Jeffrey Schatz, PhD¹,
and Carla W. Roberts, MD²

Abstract

Pain episodes occur for many preschoolers with sickle cell disease (SCD), but little is known about parent perceptions of managing pain episodes in young children. We surveyed parents of young children with SCD who had managed pain episodes in the past year to assess their management and satisfaction with their strategies, challenges of pain management, and interest in additional education. Parents were recruited from health maintenance visits at a SCD specialty clinic. Forty-two of 51 parents (82%) of 2- to 6-year-olds reported managing pain over the past year. Parents who had managed pain primarily reported using medications. These parents reported at least moderate satisfaction with current management strategies and resources. At least one-third of parents found each facet of pain management queried as at least somewhat challenging. Identifying when their child was in pain, encouraging functional activities, and managing irritable behavior were reported as most challenging. Parents of young children with SCD reported interest in additional pain management education, which could promote better parent and child coping skills.

Keywords

sickle cell disease, preschool-age children, parent management of child pain

Sickle cell disease (SCD) is a genetic blood disorder with multiple disease complications that increase in incidence over the first decade of life. Painful vaso-occlusive episodes are the most frequent form of disease morbidity and the most frequent reason for hospitalization in SCD (Yaster, Kost-Byerky, & Maxwell, 2000). Caregivers of young children with SCD report worrying about their child experiencing disease-related pain even before their child's first pain episode or crisis (Rao & Kramer, 1993); and pain crises can emerge as early as 6 to 12 months of age (Dampier et al., 2014). Typically, approximately 1 to 2 severe pain crises per year require emergency medical care or hospitalization during childhood, with another 10 pain episodes per year, on average, managed at home (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Dampier, Ely, Brodecki, & O'Neal, 2002a; Nottage et al., 2013). The frequency of pain increases as children get older and continues into adulthood (Gill et al., 1995). Thus, pain episodes are recurrent stressors for both parents and youth with SCD.

Because of the frequency and stressful nature of painful episodes early in life in SCD, more work is needed to understand parent perspectives in this caregiving role with young children. Management of pain episodes early in life by parents may be an important developmental

context for later child and family coping with pain, as well as coping with other aspects of this chronic health condition. Very young children have limited coping skills and ability to communicate pain, leaving it up to the primary caregiver to correctly interpret and treat the pain that a child may be experiencing (Hadjistavropoulos et al., 2011; Palermo, Valrie, & Karlson, 2014; Pillai Riddell et al., 2009). In a 3-year longitudinal study of infants and young children with SCD, half of the children were reported to have minimal or no pain, one quarter showed low rates of recurrent pain (~3 episodes per year), and one quarter showed extended periods of recurrent pain with high recurrence (8–12 episodes per year) (Dampier et al., 2014). Thus, the parenting burden of pain management in young children appears to vary significantly in frequency and timing during early childhood. Caregivers of young children with SCD most often use

¹University of South Carolina, Barnwell College, Columbia, SC, USA

²University of South Carolina Medical School, Columbia, SC, USA

Corresponding Author:

Laura Reinman, Department of Psychology, University of South Carolina, 1512 Pendleton Street, Barnwell College, Suite 220, Columbia, SC 29208, USA.
Email: lreinman@email.sc.edu

medication (94% of the time) to treat their child's pain. Strategies such as massage or holding the child (64% of the time) are also reported at a high rate, with parents feeling confident in their ability to identify, observe, and record SCD pain episodes (Ely, Dampier, Gilday, O'Neal, & Brodecki, 2002). However, the use of formal behavioral strategies typically associated with cognitive behavioral therapy (CBT) is reported more infrequently (Dampier, Ely, Brodecki, & O'Neal, 2002b).

What remains unclear from the existing data on preschool-age children with SCD are parents' perceptions of the caregiving burden related to helping their young child manage pain. These perceptions are critical for understanding appropriate engagement with parents to promote increased use of behavioral strategies that are developmentally appropriate for managing pain. To address this, we surveyed parents of young children with SCD about the management and characteristics of their children's pain, the nature of their current pain management strategies, and their future interest in engaging in a psychosocial pain management program. The aims of this study were to gather descriptive data on the current pain management practices of parents of young children with SCD and to gain information on attitudes toward participating in a pain management program. We also explored whether age, sickle cell genotype, or frequency of pain episodes were associated with parent perceptions of managing pain episodes in order to understand if there are potential moderating effects to consider in the parent perceptions.

Materials and Methods

Participants and Procedures

Parents of children diagnosed with SCD aged 2 to 6 years were recruited from a Southeastern children's hospital between October 2013 and September 2014. Parents were approached before their clinic appointment to fill out a pain management survey, which took approximately 10 minutes. Families were compensated for participating in the study by choosing a developmentally appropriate book for their child. The total sample for our analyses consisted of 42 parents of children with SCD (22 males, 12 females, 8 missing gender data). Fifty-one out of 104 eligible caregivers in that age range who came to the clinic during the recruitment period agreed to participate in the survey. Nine parents reported no pain history for their child, so their responses were not based on parenting experience with a sickle cell pain episode. Because of this lack of experience managing sickle cell pain, these data were excluded from the study analyses. Data were collected without unique identifiers. The refusal rate was low (<8%) based on the number of participants relative to eligible parents seen over the time frame of the study. The most common reason for

refusal was lack of time to complete the survey. The remaining parents were not approached because of limited staffing to approach every eligible family.

Measures

Survey. The survey was developed by the authors modeling relevant questions from the "My Say Survey" developed for the Stepping Stones Triple P parenting program that assessed attitudes toward engaging in a parenting program (Emser, Mazzucchelli, Christiansen, & Sanders, 2016). We adapted question content to increase relevance to pain management and preferences for delivery of pain management information. In addition, questions were added to assess pain frequency and current pain management strategies. The questions were selected based on current practices in pain management and relevance to this specific population, and were reviewed by clinic staff including a pediatric psychologist and hematologist/oncologist. After all survey responses were collected, data were entered into SPSS and used for statistical analysis. A total pain frequency score was computed by combining the number of pain episodes managed at home with the number of episodes treated at a hospital in the past year per parent report. SCD genotype was dichotomized into more severe types (eg, HbSS and HbBeta-Thal⁰) and less severe types (eg, HbSC, HbBeta Thal⁺) (Rees, Williams, & Gladwin, 2010).

Statistical Methods

We used descriptive data to summarize demographic information, frequency of use of particular pain management strategies, percentages of parents who report specific parenting challenges associated with pain episodes, and beliefs about their current pain management strategies and available resources. Descriptive data were also used to assess attitudes toward participating in a pain management program. The 95% confidence interval was calculated around the proportion of parents selecting a given response to provide a basis of comparison across questions with similar response formats. As exploratory analyses we also examined the intercorrelation of use of pain strategies to examine which strategies are commonly used together. Pearson correlations were used to explore co-occurring pain management strategies with an alpha level of .01 to balance the risk of type I and type II errors due to the number of correlations examined. To test our hypotheses about variables that might help identify parents with higher levels of pain management challenges, we conducted preliminary correlations between pain episodes in the past year (hospitalizations and at home), sickle cell genotype (dichotomized into lower versus higher

Table 1. Sample Demographic Characteristics (N = 42).

Variable	n (%)				
Child age	2 Years	3 Years	4 Years	5 Years	6 Years
	15 (36)	9 (21)	9 (21)	5 (12)	4 (10)
Child gender	Male	Female	Unknown		
	22 (51)	12 (29)	8 (20)		
Sickle cell genotype	HbSS	HbSC	HbS Beta Thal Plus	HbS Beta Thal Zero	Other
	33 (79)	4 (9)	3 (7)	0 (0)	2 (5)
How do you get to the hospital?	Drive Myself	Driven by Someone	Medicaid Van	Taxi	
	31 (74)	8 (19)	2 (5)	1 (2)	
Distance from clinic	0-24 Miles	25-49 Miles	50-74 Miles	75-100 Miles	>100 Miles
	16 (38)	13 (31)	5 (12)	3 (7)	5 (12)
Frequency of hospitalizations for pain (past 12 months)	Never	1-2 Times	3-4 Times	5-6 Times	>6 Times
	6 (14)	23 (55)	9 (22)	1 (2)	3 (7)
Frequency of pain treated at home (past 12 months)	Never	1-2 Times a year	Once a month	Several times a month	No response
	3 (7)	20 (48)	8 (19)	9 (21)	2 (5)

risk genotypes), and age of child in relation to responses to pain management questions to identify potentially important related variables using an alpha level of .05.

Results

Basic Demographic and Pain Characteristics

Sample Characteristics. The modal age group of children was 2 years and parents ranged in age from 19 to 50 years. Most of the parents who responded to the questionnaire were mothers, although some caregivers were fathers and custodial grandparents who completed the measure. Developmental screenings are conducted with 2-year-olds at this clinic, which may have increased the number of respondents in this age group. Most children were diagnosed with sickle cell anemia (ie, HbSS) ($n = 33$), which reflects the distribution found in the general population and within the clinic. See Table 1 for additional information about the sample.

Frequency of Managing Child Pain. Forty-two of the 51 parents (82%) who agreed to participate in the study reported experience in managing pain in their child over the past 12 months by taking them to the hospital for pain, treating the pain at home, or both. Among the

42 parents who reported a pain management experience, 95% reported managing their child's pain at home at least one time in the past year, and 86% reported at least one hospitalization for pain in the past 12 months. Parents most frequently reported that their child was hospitalized 1 to 2 times in the past year because of pain (55% of respondents). Parents also reported managing 1 to 2 pain episodes in the past year at home most frequently (48% of respondents). See Table 1.

Pain Management Strategies and Challenges

Strategies for Pain Management at Home. The data indicated high usage of medication to treat pain (88% of respondents) with subsets of parents who reported relying on traditional homeopathic methods or common behavioral strategies to supplement pain medication. Medication was the most commonly reported pain management strategy, followed by warm baths, massage, distraction, and using a hot or cold compress (see Table 2). An examination of the intercorrelations among strategies indicated parents who reported using massage also frequently reported using warm baths, $r(42) = .44, P < .001$. In addition, deep breathing and progressive muscle relaxation, though infrequently used, tended to be used together as

Table 2. Current Pain Management Strategies.^a

Variable	n (%) [95% CI]				
Medical and Homeopathic Methods Used	Medication	Warm Baths	Massage	Hot/Cold Compress	Other
	37 (88) [0.75, 0.95]	29 (69) [0.56, 0.82]	28 (67) [0.52, 0.79]	12 (29) [0.17, 0.44]	3 (7) [0.03, 0.19]
Psychological Related Methods Used	Distraction	Deep Breathing	Progressive Muscle Relaxation	Guided Imagery	Biofeedback
	17 (40) [0.27, 0.56]	8 (19) [0.10, 0.33]	7 (17) [0.08, 0.31]	0 (0) [0.00, 0.08]	1 (2) [0.00, 0.12]
Helpfulness of Current Pain Management Strategies	Not Helpful	Somewhat Helpful	Very Helpful		
	0 (0) [0.00, 0.09]	17 (40) [0.29, 0.58]	23 (55) [0.42, 0.71]		

^aParents were instructed to check all pain management strategies that applied for all medical, psychological, and homeopathic methods.

Table 3. Parent-Reported Pain Management Challenges and Confidence in Managing Child's Pain.

Variable	n (%) [95% CI]				
Parent Pain Management Challenges	Not Challenging	Somewhat Challenging		Very Challenging	
How challenging to know child is in pain?	18 (43) [0.29, 0.58]	14 (33) [0.21, 0.48]		10 (24) [0.13, 0.39]	
How challenging to decide when to give medication?	27 (64) [0.47, 0.76]	12 (29) [0.18, 0.45]		3 (7) [0.03, 0.20]	
How challenging to decide which pain management strategies to use other than medication?	19 (45) [0.31, 0.60]	16 (38) [0.25, 0.53]		7 (17) [0.08, 0.31]	
How difficult to get your child to do things when in pain (eg dress himself or herself, brush teeth, etc)?	6 (14) [0.07, 0.28]	17 (41) [0.27, 0.56]		19 (45) [0.31, 0.60]	
Confidence managing pain	Not Confident	Somewhat Confident	Confident	Very Confident	No Response
Confidence in helping child feel better if pain is making him or her sad, blue, or down	0 (0) [0.00, 0.08]	6 (14) [0.07, 0.28]	22 (53) [0.38, 0.67]	14 (33) [0.21, 0.48]	0 (0) [0.00, 0.08]
Confidence managing child's fussy, irritable, or angry behavior when she or he is in pain	1 (2) [0.00, 0.13]	13 (31) [0.20, 0.48]	19 (45) [0.33, 0.63]	7 (17) [0.09, 0.32]	2 (5) [0.01, 0.06]

strategies, $r(42) = .43$, $P < .001$. All parents reported that collectively their current strategies were at least somewhat helpful in managing their child's pain (see Table 2).

Parenting Challenges for Child Pain Management. At least one-third of all parents indicated some level of challenge across each of the dimensions assessed (see Table 3).

Deciding when to give medication appeared to be the least challenging facet, followed by deciding which non-medication pain management strategies to use, and knowing when their child is in pain. Getting their child to do functional activities when in pain was the most challenging. Encouraging functional activities when in pain was the one facet that showed a greater degree of perceived

Table 4. Participation in Pain Management Services.^a

Variable	n (%) [95% CI]				
Current Services	Very Dissatisfied	Somewhat Dissatisfied	Neither Dissatisfied nor Satisfied	Somewhat Satisfied	Very Satisfied
How satisfied with current things you do to provide care to your child when he or she is in pain?	0 (0) [0.00, 0.09]	1 (2) [0.00, 0.13]	2 (5) [0.01, 0.16]	17 (40) [0.28, 0.57]	21 (50) [0.36, 0.66]
How satisfied with information and services available to you to support you in role as caregiver of a child with SCD?	1 (2) [0.00, 0.12]	2 (5) [0.01, 0.16]	2 (5) [0.01, 0.06]	10 (24) [0.12, 0.39]	27 (64) [0.49, 0.77]
	Doctor or Nurse	Internet	Family Member	Friend	Other
Where do you receive information about providing care when child is in pain (check all that apply)?	41 (98) [0.88, 0.10]	18 (43) [0.29, 0.58]	16 (38) [0.25, 0.53]	6 (14) [0.07, 0.28]	1 (2) [0.00, 0.12]
Which source of information about providing care to child in pain is most helpful?	40 (95) [0.84, 0.99]	1 (2) [0.00, 0.12]	0 (0) [0.00, 0.08]	1 (2) [0.00, 0.12]	0 (0) [0.00, 0.08]
Future Services	Very Unlikely	Somewhat Unlikely	Neither	Somewhat Likely	Very Likely
How likely that you would participate in a pain management program in the future?	3 (7) [0.02, 0.19]	2 (5) [0.01, 0.16]	0 (0) [0.00, 0.08]	12 (29) [0.17, 0.44]	25 (59) [0.44, 0.73]
	Not Important	Somewhat Important	Very Important		
How important to speak directly to clinic staff about new pain management information?	0 (0) [0.00, 0.09]	5 (12) [0.05, 0.26]	36 (86) [0.74, 0.95]		
	None	15 Minutes	30 Minutes	30-60 Minutes	
How long after clinic appointment would you spend learning about pain management?	2 (5) [0.01, 0.17]	10 (24) [0.14, 0.40]	10 (24) [0.14, 0.40]	18 (43) [0.31, 0.60]	
	No	Yes			
Willing to attend additional appointment to receive information on home pain management	8 (19) [0.11, 0.35]	32 (76) [0.65, 0.90]			

Abbreviation: SCD, sickle cell disease.

^aSome survey items were not completed by all 42 participants.

challenge based on nonoverlapping confidence intervals with the other facets, whereas the remaining facets had overlapping confidence intervals suggesting that the trends may not be reliable. More than half of parents reported confidence in managing negative mood states in their children, though more than one third of parents were less than fully confident they could manage fussy, irritable, or angry behavior when their child was in pain.

Participation in Pain Management Services

Satisfaction With Current Knowledge and Resources. Overall, most of the parents reported being somewhat or very satisfied with current information and resources for pain management (see Table 4). The vast majority of parents also indicated that the primary source of useful information was from health care providers.

Table 5. Correlations Between Child Characteristics and Pain Management Responses.

Pain management responses	Child Characteristics		
	Child's Age	Pain Score	Sickle Cell Genotype ^a
How frequently does your child have pain that is treated at home?	.16	.88**	.45**
How challenging is it: Knowing when my child is in pain?	-.14	-.01	-.04
How challenging is it: Deciding when to give my child pain medication?	-.14	.03	-.09
How challenging is it: Deciding which pain management strategies to use other than medication?	-.11	.07	-.05
Considering all the things that you do to manage pain, how much do you feel these things help your child?	.26	.01	.14
How confident do you feel that you can identify when your child is in pain?	.22	.33*	-.09
How difficult is it to get your child to do things when he or she is in pain (eg dress themselves, brush their teeth, etc)?	.26	.21	-.10
How confident do you feel in managing your child's pain medication?	.32*	.15	-.01
How confident do you feel that you can help your child feel better if pain is making him sad, blue, or down?	-.16	-.31*	.06
How confident do you feel that you can manage your child's fussy, irritable, or angry behavior when she or he is in pain?	-.28	-.10	-.22
How satisfied are you with the current things you do to provide care to your child when he or she is in pain?	.10	.18	-.02

^aFor sickle cell genotype, 1 = higher risk (HbSS and beta thalassemia zero), 0 = lower risk (HbSC and beta thalassemia plus).

* $P < .05$. ** $P < .01$.

Interest in Pain Management Education. Despite reporting satisfaction with current resources, the vast majority of parents were somewhat or very interested in additional pain management education (see Table 4). The most cited reason for not participating in such a program currently was lack of awareness of any pain management programs (49%), with only one report (2%) of not participating due to lack of interest in such a program. Parents also indicated high interest in involving health care providers in future pain management training.

Relationship Between Child Characteristics and Parenting Challenges

We ran correlations to explore if age, pain frequency, and genotype risk were associated with parent perceptions of managing pain episodes. Child genotype was significantly correlated with frequency of pain treated at home, $r(42) = .45$, $P < .01$, with higher risk genotype associated with higher pain frequency. In terms of associations with parent perceptions, parent confidence in their ability to identify when their child was in pain was significantly positively associated with pain frequency, $r(42) = .33$, $P < .05$, indicating if the child had more frequent pain, parents were more confident they could identify pain. There was also a significant negative association found between parent confidence in helping their child feel better when they are sad or down and child pain frequency, $r(42) = -.31$, $P < .05$. This

suggests that parents with children with more frequent pain are less confident they can manage their child's sad mood. See Table 5 for a full list of correlations.

Discussion

The present study evaluated parent perspectives on pain management of preschool age children with SCD. The primary aim of the study was to gather descriptive information regarding pain and pain management strategies in preschool-age children with SCD to better understand caregiver perceptions of their child's pain as a parenting challenge. We also gathered data to assess parent interest and preferences for additional pain management training. Finally, we explored the relationships between parent-reported difficulties with pain management with child age, sickle cell genotype, and frequency of pain episodes. The data indicate that approximately four out of five parents of young children seen at our clinic reported managing their child's pain over the past year, and that most parents emphasized pain medication and alternative medicine strategies. Although parents reported a high degree of satisfaction with their current pain management resources, more than one-half of parents find it at least somewhat challenging to identify when their child is in pain, and to decide on what non-medication-based approaches to use. In addition, more than 4 out of 5 parents reported it was at least somewhat challenging to get their child to do functional activities when the child was

experiencing pain. In terms of current and future pain management education, parents receive information from a variety of sources, but overwhelmingly find health care providers to be the most helpful resource. Most parents reported an interest in additional pain management education, but incorporating health care providers into the training is very important to them. A parent's extent of experience in managing pain episodes may be important to consider in tailoring pain management education, as parents of children with more frequent pain reported more confidence in their ability to identify pain, but less confidence in managing their child's negative mood.

Descriptive information revealed that for this sample the majority of children aged 6 years and younger with SCD have experienced pain in the past year, but the frequency of pain varies. This is generally commensurate with recent longitudinal data showing approximately half of the very young children in the study were reported to have experienced a pain episode (Dampier et al., 2014), though the base rate of both pain treated at home and requiring hospitalization may have been somewhat higher in our sample than in the previous report. It is possible that the present sample had an overrepresentation of children with pain due to differences in attendance at health maintenance visits. The low refusal rate suggests that it is less likely that this rate was because of a sampling bias in who chose to participate in the study. Despite these differences in pain frequency across studies, both the current and previous data on the prevalence of pain in preschool-age children with SCD indicate that pain is a relevant issue for many parents of these children, and perhaps more so for parents who are highly adherent to medical appointments.

Parents in this study reported using a variety of strategies to help their young children manage their sickle cell-related pain. Overall, parents reported relying heavily on pain medication, warm baths, and massage as interventions. This finding is consistent with previous work (Ely et al., 2002). Parents in the present study not only reported using medication as a common pain management strategy for treating their child's pain but most parents also reported feeling confident in their ability to decide when pain medication was appropriate. Despite this finding, parents may still experience difficulty with medication adherence in this population because confidence ratings do not necessarily correlate with following prescriptions accurately (Jensen et al., 2005; Witherspoon & Drotar, 2006). Parents appeared to be less confident about other elements of pain management with the most difficulties in encouraging functional activities when the child is in pain. In older children with chronic pain, engagement in functional activities precedes decreases in pain during recovery and is believed to directly or indirectly reduce pain (Lynch-Jordan et al., 2014). Future work should

assess if there are similar benefits to encouraging functional activities for younger children that could inform parents' decisions about managing these activities during pain episodes.

Many parents also cited using strategies such as massage and warm baths to help manage their child's pain. There is evidence that these strategies are effective in managing pain in some populations (Adams, White, & Beckett, 2010), but less is known about their effectiveness for long-term or specifically for SCD-related pain. Because these strategies do not fit clearly into a category of pain treatment, they can be considered complementary and alternative medicine strategies or home remedies. Such strategies are not unusual in individuals with a range of different chronic pain conditions, but are more commonly used among ethnic minority groups (Adams et al., 2013; Grzywacz et al., 2006; Peters et al., 2005; Rosenberg et al., 2008). Interestingly, there is some evidence that individuals who use these home remedy strategies tend to have better medication adherence (Tilburt, Dy, Weeks, Klag, & Young, 2008).

Although satisfaction with current pain education and resources was reported to be high, our findings suggest that there is an opportunity to bolster skills in other areas. Pain management strategies such as distraction, which is a potent tool for the behavioral management of pain, were reportedly used by only about 40% of parents. The low rate of intentional use of distraction, relaxation, and other common CBT-based techniques suggests an opportunity for additional implementation of behavioral strategies. These CBT strategies have the most efficacy data for behavioral pain management in school-age children with SCD (Gil et al., 1997; Gil et al., 2000; Schatz et al., 2015), yet likely need some adaptation to be used with preschool age children. In addition, the use of CBT strategies also may provide parents with approaches that are helpful beyond pain management, such as helping to manage distress from other causes.

Most parents reported that they were interested in participating in a future pain management program and were willing to spend time after a clinic appointment to participate. This finding is especially significant considering that almost 60% of the study population lives greater than 25 miles away from the clinic and has a significant commuting burden. Many parents reported that it is desirable for them to obtain information from clinic staff as part of the pain management program and indicated that they are open to a variety of delivery methods. E-health and other Internet-based approaches to delivering health information have become very popular, but the present data suggest direct involvement of clinic staff and face-to-face contact were considered important to parents as at least a component of additional education.

There are several limitations that should be kept in mind when considering the results of this study. One factor that potentially limits the generalizability of the results is the small sample size. The data were collected at one clinic and the sample is most representative of families who are adherent to medical appointments. In addition, the questionnaire that was created for the purposes of this study emphasizes parent perceptions and beliefs. It is not a validated measure designed to address the epidemiology of pain episodes and its correspondence with actual behavior is not known.

Among families with a young child that has SCD, pain management is a common challenge and families may benefit from increased pain management education. Most parents of children who have managed a pain episode report satisfaction with their current pain management education, yet express at least some concerns about managing specific facets of a pain episode, and were interested in learning additional strategies for pain management. Behavioral strategies, similar to the CBT strategies that have been used with older children, may be underused in young children. Adaptations of how to teach these skills in younger children are needed given existing interventions target older children and adolescents. Increasing parent knowledge about how to manage pain episodes could improve mood and other outcomes for young children in pain, help parents to learn behavioral strategies that can be used both for pain episodes and other parenting challenges, and could help reduce the development of dysfunctional coping patterns that make pain management more difficult for both teens and parents (Barakat, Patterson, Tarazi, & Ely, 2007).

Authors' Note

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent/permission was obtained from all parent participants included in the study.

Declaration of Conflicting Interests

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Author Biographies

Kelsey Smith, MA, MEd, is a doctoral candidate in Clinical-Community Psychology at the University of South Carolina and a predoctoral intern at Nemours Alfred I. duPont Hospital for Children in Wilmington, Delaware.

Laura Reinman, MA, is a doctoral candidate in Clinical-Community Psychology at the University of South Carolina and psychology extern at Palmetto Health Children's Hospital Center for Cancer and Blood Disorders in Columbia, South Carolina.

Jeffrey Schatz, PhD, is an associate professor in the Department of Psychology at the University of South Carolina and licensed psychologist at Palmetto Health Children's Hospital Center for Cancer and Blood Disorders in Columbia, South Carolina.

Carla W. Roberts, MD, is an assistant professor of Clinical Pediatrics at the University of South Carolina School of Medicine and a board-certified pediatric hematologist at Palmetto Health Children's Hospital Center for Cancer and Blood Disorders in Columbia, South Carolina.