Clinical Pediatrics
Volume 46 Number 4
May 2007 311-319
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10.1177/0009922806293985
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Parent Perspectives on Pain Management, Coping, and Family Functioning in Pediatric Sickle Cell Disease

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Pediatric sickle cell disease is a chronic illness for which recurrent pain is a ubiquitous experience. This study used quantitative and qualitative methods to examine relationships between patient and family coping and health care utilization in children with sickle cell disease and to assess parents' recommendations for ensuring patient and family-centered care. Participants were 53 parents of children aged 7 to 13 with sickle cell disease across three large urban children's hospitals. Data showed that positive patient coping was related to positive family functioning and lower health utilization. In addition, parents report the need for comprehensive health care approaches that meet the physical and psychologic needs of patients and families.

Keywords: pediatric sickle cell disease; chronic illness; health care utilization

Sickle cell disease (SCD) is an inherited hemoglobinopathy that occurs in about 1 in every 500 African American births and 1 in every 1000 to 1400 Hispanic American births.[1] Clinical manifestations of SCD include episodes of severe pain (also called vasoocclusive crises), infections (especially pneumococcal), cerebrovascular accidents, anemic episodes (aplastic crises or sequestration crises), compromised nutritional status, retarded growth, and delayed sexual maturation. Although pain presentation varies considerably across pediatric patients (even within genotype), children with SCD experience pain episodes an average of 5 to 7 times per year and require hospitalization 1 to 2 times each year for pain.[2,3]

Treatment has typically focused on symptom control in the form of supportive care, consisting of hydration, warmth, and analgesia, and medications to prevent or reduce complications, such as prophylactic penicillin for infections and hydroxyurea for vasoocclusive crises. Although no definitive cure for SCD exists, new treatment approaches, including bone marrow transplantation and gene therapy, show significant promise as preventative strategies.[4]

As noted, unpredictable and recurrent pain is a common manifestation of SCD. Painful episodes have both physical and emotional implications, particularly for children with SCD. Some children with SCD manage their disease and pain with minimal physical or psychosocial disruptions,[5,6] but many children with SCD experience significant difficulties that may contribute to depression, anxiety, and decreased social activity and school attendance.[6,7] Positive coping has been associated with decreases in negative thinking, increases in active health management, fewer health care contacts and school absences, and more involvement in daily activities on pain days.[8] Previous studies also highlighted the potential for understanding relationships between physical and behavioral health and for integrating pharmacologic and nonpharmacologic approaches to pain management, particularly at home, where most pain episodes occur.[9]

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According to Graumlich et al,[10] an important next step is to better understand how health care providers and intervention approaches can address the physical and psychosocial needs of patients and families. In addition, published guidelines on the principles of care for children and adolescents with SCD state that "services for children with sickle cell disease and their families be organized in ways that families can use them easily" and that "families of children with sickle cell disease will participate in health care decision-making at all levels and will be satisfied with the services they receive."[1]

In light of these proposed directions for research and care, the current study was conducted to qualitatively assess parent perspectives of how care might be optimized for SCD patients and their families. As a complement to the qualitative assessment, quantitative (questionnaire) methods were also implemented to assess the relationship between patient coping, family functioning, and health care utilization. This integrative assessment approach is innovative in the SCD literature and is ideal for highlighting important developmental and contextual factors to be considered in the provision of culturally sensitive and comprehensive health care.[11,12]

Several studies have implemented qualitative methods to understand psychosocial factors in patients with SCD,[13-16] but no studies have integrated quantitative methods to understand how parent perspectives of coping, family functioning, and health care utilization may be interrelated. Furthermore, previous studies have stopped just short of evaluating parent perspectives of how health care service delivery could be optimized to promote positive child and family coping.

The current study contributes to the literature and extends previous studies in several important ways. These contributions include:

1. implementing a qualitative assessment method in the form of focus groups that yields rich experiential data on the management and impact of SCD;
2. using a research design that integrates qualitative and quantitative methods to more fully understand variables understudied in the SCD literature, most especially family functioning and health care utilization;
3. involving multiple sites with a large number of participants, which allows for an understanding of generalizable versus site-specific challenges; and
4. ensuring a standardized approach to conducting focus groups, coding focus group data, and reducing confounds across sites.[17]

This study also offers a novel approach designed to elicit parent perceptions and recommendations for how health care professionals can improve intervention for SCD patients and families.

The primary goal of this study was to assess how health care service delivery and other intervention strategies can be improved and optimized, particularly to improve patient and family coping and health care utilization (eg, number of hospitalizations, emergency department visits). For quantitative data, specifically, we hypothesized that positive coping strategies would be related to positive family functioning and lower health care utilization.

Method

Procedures

This study took place across three large urban children's hospitals in Ohio and included conducting two sets of focus groups at each site with parents of children with SCD aged 7 to 13. Eight focus groups (consisting of 4 to 8 participants) were held with 53 parents of 48 children with SCD. Eligibility requirements for parents included living with the child with SCD and being the primary caregiver for at least the previous 12 months. Parents of children with well-documented developmental delays (eg, IQ < 70) or documented severe neurologic damage (eg, brain damage resulting from stroke) were not contacted for participation. Participants who arrived after the first 15 minutes of the group were also not eligible to participate to preserve the integrity of the group dynamics across sites.

Participants were recruited via letters, telephone calls, and clinic visits. All eligible participants were mailed a letter from a member of the sickle cell care team of their respective hospital. Approximately 1 week after the letter was mailed, families were called, and the study was described in further detail. All groups began with a meal/social to facilitate group cohesion and discussion among participants. The meal lasted approximately 30 minutes, during which time participants completed questionnaires, followed by the focus group discussion that lasted 60 to 75 minutes for parents and 45 to 60 minutes for children. The moderators and co-moderators, as well as the scheduling, conduct, and incentives, were

the same for each phase of the study across all three sites. Participants in each phase of the study were paid $25 for their time, and families were paid $10 for transportation and parking. Each group was audiotaped and videotaped. The audiotapes were transcribed verbatim, and the videotapes were used to assign identification numbers to maintain confidentiality and to accurately distinguish moderator from participant comments and participant comments from one another.

Participants

Fifty-three parents/guardians of 48 children with SCD (representing 46 families) participated in 1 of 8 focus groups. All but 1 participant were African American (1 adoptive parent was white). Forty-six (88%) of the participants were women (43 mothers/foster mothers and 3 grandmothers/aunts) and 6 (7%) were men (3 fathers, 3 uncles/male caregivers). The mean age of the 48 children (of the parent participants) with SCD was 10.66 years, and 50% (24) were female. Self-reported annual family income data of 46 participants is summarized as follows: $10 000 or below, 26%; $10 000 to $19 999, 26%; $20 000 to $29 999, 19%; $30 000 to $49 999, 18%; and $60 000 to $100 000, 11%.

Measures

Coping Strategies Questionnaire. The Coping Strategies Questionnaire (CSQ) is an 80-item questionnaire that measures how often participants use cognitive, behavioral, and physiologic coping strategies. Respondents rate the frequency of use of strategies on a 6-point Likert scale ranging from 1, "never use this strategy" to 6, "always use this strategy." The questionnaire was designed specifically to be used with sickle cell populations.[18] The CSQ produces 3 factor scores: Coping Attempts, which measures "active" coping strategies such as talking with someone, going on despite pain, play outside; Negative Thinking, which includes behaviors such as pessimistic thinking and worry; and Passive Adherence, which includes behaviors such as praying, resting, and taking medications. The CSQ Factor scores have been reported in a number of studies with parents of children with SCD, and reliability coefficients for the 13 CSQ subscales range from .55 to .89.[18-20]

Family Assessment Device. The Family Assessment Device (FAD) is a 60-item questionnaire that measures family functioning based on the McMaster Model of Family Functioning.[21] The McMaster Model proposes that how a family functions affects its ability to accomplish essential tasks. The FAD assesses 7 dimensions of family functioning: Problem Solving, family members' ability to solve conflicts and disagreements; Communication, use of effective, clear and direct communication among members; Roles, allocation and accountability of roles across the family members such that physical and emotional needs are met; Affective Responses, affective patterns and exchanges that promote positive and quality family interactions; Affective Involvement, perceived adequacy of physical and emotional availability of family members/quality time spent with one another; Behavioral Control, style of managing conflicts and behavioral challenges, which may be classified as chaotic, rigid, laissez-faire, flexible; and General Functioning, an independent subscale that assesses respondents' general perceptions of how their family functions across situations and dimensions. Parents rate items on a 4-point Likert scale, with lower scores indicating higher/better functioning. The FAD has been cited as having clinical validity because it has been shown to differentiate clinical from nonclinical families.[22,23] Psychometric properties for the FAD have been described in detail in previous research, and reliability coefficients range from .72 to .92.[24,25] Several studies have shown the FAD to yield important and clinically useful information with African American and other ethnic minority samples,[26] although the construct validity of this measure with culturally diverse families has not been fully evaluated.

Demographics and medical history form. Family, child, and parent demographics were assessed, as well as the child's medical history, including the number of hospitalizations, pain days, clinic visits, emergency department visits, and school days missed during the previous 12 months. These medical variables are referred to generically as disease severity/health care utilization variables throughout this report. This form and other questionnaires were completed by all parent participants before the focus groups.

Focus Group Questions, Conduct, and Coding

Focus group questions were developed through several meetings with site collaborators and organized around the primary goals of the study. The open-ended questions used in this study were

Table 1. Example of Within-Site Consensus (WSC) Coding and Identification of WSC Themes

Site 1	Coder 1	Coder 2	Coder 3	Within-Site Consensus[a]
Q1	Theme A1	Theme A1	Theme A1	WSC Theme A1
	Theme B1	Theme B1	Theme C1	WSC Theme C1
	Theme C1	Theme C1		
Q2	Theme A2	Theme A2	Theme B2	WSC Theme B2
	Theme B2	Theme B2	Theme C2	WSC Theme D2
	Theme C2	Theme D2	Theme D2	
	Theme D2			
Q3, Q4, etc.				

a. Within-site consensus was defined as having been identified by all 3 coders.

drafted and refined during a series of meetings with experts across sites in SCD management and intervention, SCD and chronic illness research, and qualitative analysis/focus groups, and were included based on their fit with the goals of the study, which was to assess family and patient coping and perspectives on pain management and care.

All focus groups were conducted with a trained moderator who asked the focus group questions in the format recommended by Krueger,[17] including providing an introduction to the groups that generally described the purpose of focus groups, the goals of the study, the purpose of audiotaping and videotaping, and guiding principles for the group (eg, it is alright to agree or disagree, to speak loudly and clearly, to give everyone a chance to talk, discussion may be redirected or tabled if it gets off topic).[17]

Consistent with protocol, the discussion was initiated with an opening question, followed by an introductory question, transition question, key questions, ending questions, and a final question.[17] Acceptable prompts were identified a priori and used for each question to further standardize focus group conduct across sites (unpublished data). After the formal discussion, points were summarized by the moderator, and participants were invited to clarify or augment responses as needed to accurately reflect their experiences (unpublished data).

Focus group data from each phase (parent and child) were analyzed and summarized separately using consensus ratings among three trained coders.[15,17] Transcripts were also assigned such that each transcript had at least one coder from the transcript site, one off-site coder, and one independent coder who were not involved in the focus groups. Each coder independently read the transcript before coding to facilitate understanding of the depth and breadth of information discussed in the focus group. Coders then reviewed the transcripts and coded all transcribed discussions using one of 4 categories:

1. *Question/Prompt*: includes mostly facilitator discussion questions presented to the group and prompts used to gain clarification or elicit further discussion.
2. *Major themes*: topics that represent "shared experiences" as discussed in-depth by members of the group with little or no dissension or topics that have breadth as they recur through interactive discussion among group members.
3. *Minor themes*: topics brought up by a member of the group that are relevant to the goal of the study but do not appear to reflect the "shared experience" of the group owing to the lack of breath or depth of the discussion.
4. *Other topics/Other discussion:* topics that are off-topic from the questions posed, the direction of the group discussion, or are otherwise not related to the goals of the study.

Transcripts were coded independently and then analyzed to assess within-group and across-site consensus using a 2-step process implemented and culminating in face-to-face meetings. First, major themes for which there was agreement among all coders comprised the within-group list of themes. Second, themes were collapsed for each site (*within-site consensus themes*) and themes for which there was agreement across-sites (*cross-site consensus themes*).

The focus of this report will be the *cross-site consensus themes* that capture the depth and breadth of participants' collective experiences. For a visual description of how within-site and cross-site consensus themes emerged see Tables 1 and 2.

Table 2. Example of Cross-Site Consensus (CSC) Coding and Identification of CSC Themes

	Site 1	Site 2	Site 3	Cross-Site Consensus[a]
Q1	WSC Theme A1	WSC Theme A1	WSC Theme A1	Theme A1
	WSC Theme C1	WSC Theme D1	WSC Theme C1	Theme C1
		WSC Theme F1	WSC Theme G1	
Q2	WSC Theme A2	WSC Theme C2	WSC Theme B2	Theme B2
	WSC Theme B2	WSC Theme D2	WSC Theme C2	Theme C2
	WSC Theme C2	WSC Theme F2	WSC Theme D2	Theme D2
		WSC Theme G2	WSC Theme H2	
Q3, Q4, etc.				

a. Cross-site consensus was defined as having emerged at 2 or 3 of the sites.

Results

Patient and Family Coping and Health Care Utilization

Parents reported that children most often used Passive Adherence strategies, with an average use of 4.1 (out of 6.0), followed by the use of Coping Attempts (3.7/6.0) and Negative Thinking (2.4/6.0). In addition, higher scores on Negative Thinking were significantly correlated with a higher number of emergency department visits in the previous 12 months ($r = 0.37$; $P < .02$), and higher scores on Passive Adherence were significantly related to fewer hospital admissions ($r = -0.31$; $P < .05$) in the previous 12 months. The CSQ and disease severity/health care utilization correlation data are summarized in Table 3.

Patient coping (CSQ), as rated by parents, was also related to several aspects of family functioning (FAD). Specifically higher rates of (active) Coping Attempts were related to better family Problem Solving, Communication, and General Functioning ($r = -0.31$ to -0.37). Lower use of Negative Thinking was related to better family Communication, more healthy family Roles, better Affective Involvement, and better Behavioral Control ($r = 0.32$ to 0.52). Finally, higher rates of Passive Adherence were related to better family Problem Solving, Communication, Roles, Affective Responsiveness, and General Functioning ($r = -0.30$ to -0.45). Contrary to our hypothesis, FAD Dimension Scores were not related to any disease severity/health care utilization factors (eg, number of hospitalizations, emergency department visits, or pain days). Table 3 summarizes CSQ and FAD correlations.

Cross-Site Consensus Focus Group Themes

Questionnaire data are complemented by qualitative analyses that highlighted the following themes (see Table 4 for a summary):

Parent and Family Coping Highlights

Data indicated that parents rely on children to monitor symptoms, tell them when they are experiencing pain, provide them with direction and cues in making decisions, and comply with parental requests regarding treatment recommendations. As one parent reported, "She [her daughter] will write me a little note. 'Mommy, I think it's time to go to the hospital. I go pack my bag, because I know I'm going to stay'." Another caregiver noted, "She told me step by step how to pick her up and carry her to the ambulance." Parents also acknowledged the limitation in their own ability to make decisions independent of their child. One parent commented that, "When he [her grandson] was about 5, I started relying more on what he was telling me versus what I was seeing."

Across groups and sites, parents reported that SCD impacts personal and family life, including friendships, employment, school, participation in activities, and family activities and relationships, including interactions and quality time with siblings. Many parents revealed sentiments similar to this single parent who stated, "When she [my daughter] is in the hospital, I don't have anybody to stay with my other daughter so . . . I ship her over to her grandmother's . . . so it makes my family routine very hectic." Another parent cited the physical drain

Table 3. Correlations between Coping Strategies Questionnaire Factor Scores, Family Assessment Device Dimensions, Hospitalizations, and Emergency Department Visits

	N=46	FAD PS	FAD COM	FAD ROLES	FAD AR	FAD AI	FAD BC	FAD GF	Hospital Visits	ED Visits
CSQ CA	*r*	−.367*	−.307*	−.215	−.131	−.115	−.068	−.308*	−.022	.073
CSQ NT	*r*	.059	.350*	.517***	.216	.350*	.317*	.273	.253	.369*
CSQ PA	*r*	−.398**	−.365*	−.300*	−.336*	−.272	−.245	−.452**	−.309*	.165

Note: CSQ, Coping Strategies Questionnaire; FAD, Family Assessment Device; CA, Coping Attempts Factor; PS, Problem Solving Dimension; NT, Negative Thinking Factor; COM, Communication Dimension; PA, Passive Adherence Factor; ROLES, Roles Dimension; AR, Affective Responsiveness; AI, Affective Involvement; BC, Behavioral Control; GF, General Functioning

*$P < .05$.

**$P < .01$.

***$P < .001$.

of illness and mentioned, "You just get tired because it drains you when they are sick."

Recommendations for Improving Care

Across sites, parents offered a number of suggestions for improving care that positively impacts pain management and family functioning. Parents expressed the need for increased support, education, and sensitivity to parents and patients, and for improved staff training and medication dispensing/options, and they highlighted the need to offer more activities for patients, including programs that allow for children with SCD to interact. Parents and children also mentioned the importance of enhancing community education and awareness of SCD. One parent described her frustration with staff poorly trained on SCD when she stated, "I knew we were in trouble when the nurse looked at me and said, 'so . . . how long has your daughter had sickle cell disease.' She did not even know that it was an inherited disease." Parents also report frustration with the perceived limited attention that SCD receives relative to other chronic pediatric illnesses.

Discussion

Although previous qualitative research studies have documented experiential aspects of SCD management, these data have seldom been complemented with quantitative data methods. This multisite study used focus group discussions and questionnaire methods to assess patient coping, family functioning, and health care utilization variables and to examine relationships among these factors as a means of designing optimal pain management interventions.

Quantitative data analyses revealed that there was a relationship between patient and family coping, in that patients with less adaptive coping strategies tend to have families that function less adaptively. This relationship was further placed in context through qualitative data that reveal that parents and children have complementary roles in managing SCD and related pain. For example, parents noted their reliance on their child's verbal and nonverbal cues when deciding how to proceed with pain management (eg, medications, going to the emergency department).

This finding suggests that in addition to using traditional approaches to engaging a designated caregiver in disease education and management, educational approaches need to include the children, who are critical agents in their own health care and disease management. In this study, parents reported that children as young as five years of age were administering medications and making decisions for themselves. Inherent in the need to create child-parent partnership paradigms of care is the reality that a large number of children with SCD in this study and other reported pediatric SCD studies live in nontraditional and single-parent families. In ensuring that intervention models are effective, inclusive, and accessible as proposed in SCD care guidelines, then individual and family barriers would need to be considered. The importance, and perhaps the challenge, of developing family-friendly and family-centered care is further highlighted by the high prevalence rates of nonbiologic maternal primary caregivers reported in SCD studies, including 20% of nonmaternal caregivers who participated in this study.

Data analyses also revealed that children with less adaptive coping strategies used the emergency department and were admitted to the hospital at

Table 4. Summary of Parent Focus Group Questions and Themes

Patient Coping and Care	
Questions	Cross-Site Consensus Themes
When your child is in pain at home, how do you manage their pain?	– Encourage distraction – Use heat – Massage child – Administer/encourage use of medicines – Encourage relaxation
What makes it difficult to manage your child's pain?	– No consensus themes
What kind of things does your child do to manage his/her pain?	– Monitors own symptoms – Uses distraction – Uses prevention strategies – Takes hot bath – Meditates/relaxes
What kind of things could health providers do that would help you better manage your child's pain?	– Provide support – Parent education – Improved staff training – Be sensitive to child/family
Family Coping and Support	
Parent Questions	Cross-Site Consensus Themes
Think about when your child is in pain–how is your family affected?	– Siblings impacted – Use support systems – Have to make difficult decisions
How is your family routine affected when your child is in pain?	– Siblings' lives disrupted – Employment disrupted – Personal schedule/routine affected – Have to alter/limit family activities – Have to stop/cancel activities – Have to be prepared for activities
How has your child's sickle cell disease pain affected his/her overall life?	– Friendships compromised – Activities limited – Appearance, development affected – Nutrition/appetite compromised – Children have greater sense of mortality – Misses school
How do you make decisions about your child's participation in activities?	– Child makes decision – Child's behaviors
How has your child's sickle cell disease affected your personal life?	– Limited social/personal life – Have support system – Employment challenges
What kind of things could health providers do that would help children and families cope better?	– Better staff training – Be more sensitive

higher rates. The relationship between positive coping strategies and health care utilization factors in this study would further argue that although interventions may need to be family focused, they must also engage children as active participants in their own disease management. The findings from the CSQ and the diversity of qualitative themes that emerged with respect to patient coping suggest that rather than encouraging a particular strategy (eg, active coping exclusively, which has been touted in the literature), children may benefit from having an array of active coping and passive adherence strategies and by limiting negative thinking. Each of these strategies appeared to have differential relationships to family and health care utilization variables. In addition, national recommendations for managing SCD include the use of both passive coping (eg, resting, sleeping) and active coping (being functional

when possible), depending on pain severity and other developmental patient risk factors. Hence, the child's developmental level, coping style and ability, and disease factors would need to be considered in promoting optimal coping.

Finally, the hypothesis of the relationship between family functioning and health care utilization factors was not supported. Additional studies will need to bring consensus to the SCD literature, which is only beginning to define and understand the correlates and predictors of health care utilization. The data from this study also support that a next step may be to use a larger sample to test a model that proposes child coping as a moderator of the relationship between family functioning, health care utilization, and disease severity.

Although understanding SCD beyond traditionally assessed variables using an integrated qualitative and quantitative research, this study is limited in that the supported relationships do not offer insight into causality. For example, it is feasible that better family functioning encourages better patient coping. Conversely, better patient coping may facilitate better family functioning. Similarly, lower rates of hospitalization and emergency department visits may either facilitate or be a consequence of the use of more effective coping strategies. It is also possible that coping and health care utilization are influenced by a third factor, such as disease severity. These hypotheses will need to be explored in subsequent prospective and multidimensional studies.

Another limitation, not only of this study (Dickstein et al, [22] Hayden et al[23]) but of this literature as a whole, is that the interpretation of health care utilization data is unclear. Although parents are encouraged to bring their child to the emergency department and advocate for hospitalization when children experience fever, lethargy, or extreme pain, criteria for defining appropriate health care utilization among children with SCD has not been defined. This study, contrary to many published studies, defined health care utilization in terms of "less" or "more" rather than "better" or "worse" given that disease severity and health care utilization are likely interrelated. This decision was based, in large part, on the fact that the risks of under-utilization and over-utilization are not well defined in the general literature and are not easily measured in the current study. Finally, as with many pediatric and clinical studies, both the quantitative and qualitative assessments of parents and patients should be interpreted in light of the fact that they relied heavily on self-report, which may be biased and inherently correlated.

Conclusion

Parent perspectives on care and the relationships between coping, family functioning, and health care utilization have been rarely highlighted in the SCD literature and have not been a focus of pediatric sickle cell intervention efforts. Qualitative and quantitative data from this study, including focus group data that offered humanity and insight into the existing literature, suggest that if pediatric SCD interventions are to be optimized, physicians will need to promote positive patient and parent coping, which may empower patients to use health services appropriately and effectively.

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