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Coping and coping assistance among children with sickle cell disease and their parents

Aimee K. Hildenbrand, B.S.,

Center for Injury Research and Prevention, The Children's Hospital of Philadelphia, Department of Psychology, Drexel University, 3535 Market St., 11th Floor, Suite 1150, Philadelphia, PA 19104, Fax: 215-590-5425, Telephone: 267-426-5294 (work) or 267-567-2807 (cell)

Lamia P. Barakat, Ph.D.,

Division of Oncology, The Children's Hospital of Philadelphia, Perelman School of Medicine, University of Pennsylvania

Melissa A. Alderfer, Ph.D., and

Division of Oncology, The Children's Hospital of Philadelphia, Perelman School of Medicine, University of Pennsylvania

Meghan L. Marsac, Ph.D.

Center for Injury Research and Prevention, The Children's Hospital of Philadelphia, Perelman School of Medicine, University of Pennsylvania

Aimee K. Hildenbrand: hildenbranda@email.chop.edu

Abstract

The ways in which a family copes with the physical and psychosocial burdens of sickle cell disease (SCD) can influence child and family functioning. However, few studies have examined SCD-related stressors beyond pain or how children and parents cope with these stressors. This study aimed to describe child coping and parent attempts to help their children cope (i.e., coping assistance) with a range of SCD stressors by using a triangulated mixed methods design. We also explored convergence between findings from qualitative interviews and quantitative coping inventories. Fifteen children (aged 6 – 14) with SCD and their parents ($N = 15$) completed semi-structured interviews and self-report measures to assess SCD-related stressors, coping, and coping assistance strategies. Findings indicate that children experience numerous stressors related to SCD and its treatment, including but not limited to pain. To manage these stressors, families employ a range of approach- and avoidance-oriented coping strategies. Quantitative and qualitative assessments provided complementary and unique contributions to understanding coping processes among children with SCD and their parents. Examining a broad range of stressors and integrating multiple assessment methods helps improve our understanding of coping with pediatric SCD, which may inform clinical practice and family-focused intervention development.

Correspondence to: Aimee K. Hildenbrand, hildenbranda@email.chop.edu.

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Keywords

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Introduction

Sickle cell disease (SCD) is an inherited, multisystem blood disorder characterized by rigid, crescent-shaped red blood cells that are prone to aggregating and obstructing blood flow to organs and bones.^{1,2} In the United States alone, between 72,000 and 100,000 children and adults have SCD.³ SCD primarily affects those of African American or Hispanic descent, occurring in approximately 1 in every 500 African American and 1 in every 36,000 Hispanic American births.⁴ Children with SCD and their families face significant medical sequelae that contribute to high rates of morbidity and mortality, including chronic anemia, recurrent pain episodes, acute chest syndrome, jaundice, organ failure, and stroke.⁵ In addition to severe medical complications, many children with SCD also face notable psychosocial challenges related to frequent hospitalizations, delayed puberty, short stature, school absenteeism, and limitations in social, academic, and recreational activities.^{6–8} Given that there is no widely available cure for SCD, management of this condition is primarily comprised of monitoring of growth, nutrition, and hemoglobin, preventative measures such as antibiotics, vaccinations against pneumococcus and influenza, adequate hydration, and early detection and treatment of acute and chronic complications.⁹

Considering the physical and psychosocial burdens that children with SCD and their families experience, it is not surprising that many exhibit distress^{10–11} and impaired family functioning.^{12,13} In fact, it is estimated that between one to two thirds of children with SCD experience significant psychological symptoms and impaired health-related quality of life (HRQOL).^{6,14–16} Several biomedical (e.g., pain, disease complications)^{17–21} and psychosocial factors (e.g., low SES, poor family functioning, parents' adjustment)^{16,22} may challenge a child's ability to adapt to SCD. However, despite the myriad of potential stressors that children with SCD may face, most research has focused exclusively on pain as the primary stressor impacting adjustment and HRQOL.

Child coping and how parents assist in this process (i.e., parent coping assistance) represent important and potentially malleable determinants of adjustment.^{16,23} Coping is a dynamic, context-specific process that varies across individuals, situations, and demands.²⁴ Several coping classifications specific to children with SCD have been suggested. Based on factor analysis of an adaptation of the Pain Coping Strategies Questionnaire,²⁵ Gil and colleagues categorized children's coping into three domains: "coping attempts" (e.g., calming self-statements, diverting attention), "negative thinking" (e.g., catastrophizing, negative self-statements), and "passive adherence" (e.g., resting, fluid intake).²⁶ Children who endorse higher levels of negative thinking tend to require more health care services and exhibit greater distress and pain severity. Children who used more strategies from the coping attempts domain demonstrated better general functioning and less health care utilization.^{27,28} While this classification has been useful in assessing coping with pain

episodes, it may not be sufficient for understanding complex coping processes for the myriad of stressors related to SCD.

To capture key aspects of coping strategies implemented for a range of SCD-related stressors (including but not limited to pain), Roth and Cohen's approach- versus avoidance-oriented coping framework is a useful conceptual model. Approach-oriented coping encompasses efforts directed towards dealing with a stressor, whereas avoidance-oriented coping involves strategies to distance an individual from a stressor.²⁹ Both types of coping may be effective and adaptive depending on the individual, situation, and specific stressor. Research suggests that approach-oriented strategies are particularly adaptive when dealing with controllable stressors^{30,31} and invasive procedures.³² Avoidant strategies may be effective in managing uncontrollable situations³¹ and time-limited stressors.³³ Roth and Cohen's model is among the most widely used and well-validated of coping classifications.^{29,34} This categorization has been found useful for understanding coping with other chronic conditions (e.g., cancer)^{34,35} but has yet to be examined in coping with pediatric SCD.

Beyond children's own coping efforts, parents may also impact child adjustment to SCD by influencing children's coping (i.e., coping assistance).³⁶ Parents can influence the ways in which children manage stressors by providing direct suggestions (i.e., coaching) as well as modeling their own coping responses.^{37,38} Furthermore, caregivers can shape the general family context in which children's coping occurs (e.g., family communication and relations).^{37,38} Research conducted by Kliever and colleagues³⁹ suggests a promising avenue for understanding how parent coping assistance is associated with child coping attempts in the context of pediatric SCD. These findings suggest that parent coaching, modeling, and the family environment each influence the ways in which children with SCD cope with disease-related stressors. However, research regarding the use of specific coping assistance strategies among parents of children with SCD is limited.

To help address gaps in existing literature, this study aimed to describe SCD-related stressors, child coping, and parent coping assistance utilizing a triangulated mixed methods design, applying Roth and Cohen's approach versus avoidance classification as the framework for analyzing data. Mixed methods research has demonstrated utility in enabling a thorough understanding of complex research questions and is thereby well-suited to areas of inquiry as dynamic as coping.⁴⁰ An in depth understanding of the ways in which parents assist their children in coping with SCD could augment the literature around parent socialization of coping³⁷ and provide targets for family-focused interventions. Specific research questions addressed in this study include:

1. What stressors related to SCD and its treatment do children experience?
2. What strategies do children use for coping with SCD stressors?
3. What strategies do parents use to facilitate their child's coping (i.e., coping assistance) with SCD stressors?
4. What unique and consistent contributions do quantitative and qualitative data provide to understanding child coping and parent coping assistance with SCD?

We hypothesize that children and parents will report a range of psychosocial and biomedical SCD stressors (including but not limited to pain) and will use a combination of approach and avoidance coping and coping assistance strategies to manage these stressors. We also expect that qualitative data will provide a more nuanced and contextual depiction of coping with SCD, while quantitative data will offer a broader overview of strategies used by children and their parents. Used together, qualitative and quantitative methods of assessment will enable a thorough, detailed assessment of coping within the context of pediatric SCD.

Materials and Methods

Procedure

Participants were recruited from a large pediatric hospital in the northeastern region of the United States. Children were eligible to participate if they were 6 – 14 years of age, diagnosed with SCD, cognitively capable of assenting and completing the interview and questionnaires, and if at least one parent or legal guardian provided consent and agreed to participate. Potential participants were screened for eligibility and approached by a research team member during an inpatient hospitalization or outpatient clinic visit. Families were asked to take part in a study designed to better understand the challenges children with SCD face, as well as how families deal with SCD and use coping tools. Of the 20 eligible families approached, 75% ($n = 15$) chose to participate. Reasons for non-participation included lack of interest and perceived absence of disease-related challenges. Enrolled children and parents independently participated in semi-structured interviews to assess SCD-related stressors, coping, and coping assistance. Interviews were conducted by trained research assistants and took place either in the inpatient (i.e., child's hospital room) or outpatient (i.e., hematology clinic) setting. Subsequently, children completed the How I Coped Under Pressure Scale (HICUPS)⁴¹ and parents completed the Parent Socialization of Coping Questionnaire (PSCQ)⁴² to assess child coping and parent coping assistance, respectively. Interviews and questionnaires were administered such that results could be examined in the context of the approach-avoidance coping model²⁹ (see “Measures” and “Qualitative coding”). This study was approved by the hospital's Institutional Review Board.

Participants

Participants included 15 children with SCD (8 females) and their parents. Children were between 6 and 14 years of age ($M = 9.13$, $SD = 3.04$). All children in this sample ($n = 15$) were Black/African American, with two parents also identifying their children as Hispanic/Latino (13.3%). SCD diagnoses included HbSS (60%, $n = 9$), HbSC (20%, $n = 3$), Hb S/ β Th (13%, $n = 2$), and Hb SO Arab (7%, $n = 1$). Forty percent of children were enrolled during an inpatient hospital stay; 60% participated during an outpatient clinic visit. Reasons for inpatient admission included pain crises and fever. With regards to family composition, most children lived with two married parents (60%) or a single parent (33.3%). Of the 15 parents who participated in this study, 73% ($n = 11$) were mothers and 27% ($n = 4$) were fathers. Parents were aged between 27 and 56 years ($M = 41.07$, $SD = 8.73$). Most parents identified themselves as Black/African American (93%, $n = 14$), and 13% ($n = 2$) indicated that they were Hispanic/Latino. Parental education level ranged from partial or full completion of high school (33.3%, $n = 5$) to partial or full completion of a college degree

(33.3%, $n = 5$) or graduate/professional degree (33.3%, $n = 5$). With regards to socioeconomic status, 20% ($n = 3$) reported a total household annual income of less than \$5000; 27% ($n = 4$) \$5,000 – \$29,999; 27% ($n = 4$) \$30,000 – \$74,999; 13.3% ($n = 2$) \$75,000 – \$99,999; and 13.3% ($n = 2$) \$100,000 or more.

Measures

Semi-structured Interview (child and parent versions)—A semi-structured qualitative interview was adapted to assess SCD-related stressors as well as child coping and parent coping assistance strategies used to manage these challenges.³⁵ To assess children's SCD-related stressors, children and parents were asked: "What is stressful or hard for (you/your child) about having SCD or treatment for SCD?", "What is the hardest part of SCD or its treatment for (you/your child) right now?", "Is there anything about SCD or its treatment that used to be hard for (you/your child)?", and "Is there anything about SCD or its treatment that might be hard for (you/your child) in the future?" To assess child coping efforts, children were asked, "What do you do to help yourself deal with SCD or its treatment?" and parents were asked, "What does your child do to help him/herself deal with SCD or its treatment?" To assess parent coping assistance, children were asked "What do your parents do to help you deal with SCD or its treatment?" and parents were asked, "What do you do to help your child deal with SCD or its treatment?" All questions were followed by various prompts (e.g., "Can you tell me more?", "What other types of things have you done?") to clarify or expand upon participant responses. On average, child interviews lasted 8 minutes ($SD = 3$, Range = 4 – 14) and parent interviews lasted 14 minutes ($SD = 5$, Range = 8 – 26). Responses to interviews were coded consistent with Roth and Cohen's approach-avoidance coping model²⁹ (see "Data Analysis" for details).

The How I Coped Under Pressure Scale (HICUPS)⁴¹—The HICUPS is a 60-item measure that assesses children's coping strategies with regard to a specific stressor, in this case SCD and its treatment. The HICUPS has well-established reliability and validity⁴³ and has been used across diverse groups of children facing a variety of stressors.^{37,39,41,44–49} The HICUPS yields four primary higher order constructs: Active Coping, Distraction, Support Seeking, and Avoidance Coping.^{41,47} Active coping involves directly focusing on the stressful event to deal with it either cognitively or behaviorally (e.g., cognitive decision-making, direct problem solving, seeking understanding, emotional expression, positive cognitive restructuring). Distraction coping includes strategies used to distract oneself from dealing with or thinking about the problem. Support seeking coping refers to the use of other people as resources to assist in seeking solutions to the problem or in helping manage emotions (e.g., problem and emotion focused support). Avoidance coping is characterized by attempts to avoid or discontinue thinking about the problem (e.g., avoidant actions, cognitive avoidance). Prior research suggests that each of these four factors have good internal consistency.⁴³ Applying these coping dimensions to the approach-avoidance framework utilized in this study, avoidance coping included the scale constructs of Distraction and Avoidance, while Active Coping and Support Seeking were considered approach-oriented coping.⁵⁰ In the current sample, internal consistency reliability was excellent for approach-oriented coping (Cronbach's $\alpha = .94$) but poor for avoidance-oriented coping ($\alpha = .55$).

The Parent Socialization of Coping Questionnaire (PSCQ)⁴²—The PSCQ is a 60-item measure that assesses parents' suggestions regarding children's coping strategies with regard to a specific stressor, in this case SCD, its treatment, and their child's reactions to it. The measure parallels the HICUPS and provides similar subscale scores. Parents are asked to rate the extent to which they have encouraged or discouraged each specific child coping strategy by responding on a 7-point Likert scale (1 = strongly discouraged, 4 = neither encouraged nor discouraged, 7 = strongly encouraged). Reliability and validity of the measure have been established.⁴² The PSCQ yields a six-factor model of parental socialization of coping: Problem-focused Coping, Positive Cognitive Restructuring, Distraction, Support Seeking, Avoidance, and Negative Actions. Problem-focused strategies include cognitive and behavioral efforts to manage or alter the stressor. Positive Cognitive Restructuring refers to thinking about the situation in a more positive way. Negative actions involves blaming or holding others responsible for the stressor.⁴² In this study, Problem-focused Coping, Positive Cognitive Restructuring, and Support Seeking were considered components of approach-oriented coping, while Distraction, Avoidance, and Negative Actions were categorized as avoidance coping.⁵⁰ In this sample, internal consistency reliability was good (approach-oriented coping: $\alpha = .88$; avoidance-oriented coping: $\alpha = .79$).

Data Analysis

Qualitative coding—Interviews were audio-recorded, transcribed, and coded. Qualitative data were entered into NVivo (Version 8)⁵¹ for analysis of themes regarding child SCD-related stressors, child coping, and parent coping assistance (each by child and parent report). Coding criteria were developed through an iterative process that combined both theory^{29,52} and databased hierarchical coding schemes.^{53,54} These coding criteria were not mutually exclusive; a portion of a transcript could be assigned more than one code. Two trained research assistants independently coded each interview transcript for the presence of child SCD-related stressors, child coping, and parent coping assistance strategies. After initial coding of data, raters convened to discuss and resolve inconsistencies in the application of codes and to clarify or revise coding criteria. All transcripts were then re-coded based upon the modified coding criteria. Two rounds of this iterative coding process were employed in order to produce a final collective coding of the data. Final coding inter-rater reliability was high (94.3% agreement). Remaining discrepancies were resolved via collaborative team discussions. Thematic saturation^{65,66} (i.e., when no new themes were identified) for child coping and parent coping assistance data occurred after interviewing the 12th child-parent dyad.^{55,5655,5655–56}

Quantitative data transformation—Data from the HICUPS were used to classify children as to whether or not they endorsed each coping subscale. If children reported that they used one or more coping strategies within a given subscale at least “sometimes”, they were classified as endorsing that coping subscale. On the PSCQ, each subscale was considered to be endorsed if parents reported that they “mildly”, “moderately”, or “strongly” encouraged their child to use one or more coping strategies within that subscale.

Merging qualitative and quantitative data—Following initial thematic and descriptive analyses of qualitative and quantitative data, datasets were merged by mapping quantitative data onto qualitative codes using a procedure frequently utilized in mixed methods studies with triangulated or embedded designs.⁴⁰ The subscales of the HICUPS and PSCQ were viewed as aggregated units similar to qualitative themes. Individual items on the HICUPS and PSCQ were considered individual strategies, similar to those that emerged from qualitative interviews. Quantitative subscales and items were directly compared to the themes and individual strategies derived qualitatively by using a data matrix. The study authors reviewed each qualitatively coded interview segment and assigned, when possible, parallel coping and coping assistance subscales and items from the HICUPS/PSCQ. After independently mapping quantitative subscales and items onto qualitative codes, the authors met to review, discuss, and resolve any discrepancies. A case-by-case analysis was then employed to examine the complementarities between the two forms of data for both coping and coping assistance.

Results

Families reported a range of stressors that children with SCD face, which were categorized into seven domains: SCD-related medical complications, treatment and side effects, disruption in daily routines and activities, emotional reactions, communication issues, social challenges, and concerns about the future (see Table 1). Although pain was reported as a major stressor by many families in this sample, a number of other challenges were also identified. For instance, children and parents reported stressors such as bedwetting, medical complications such as hives, fatigue, painful procedures, treatment side effects, difficulty with medications and hydration, and frequent and/or extended hospital visits. Additionally, families also reported that children face various psychosocial stressors including missing school, problems with participating in age-appropriate activities, dealing with feelings of uncertainty and anger, communicating with others about SCD, feeling different from peers, and being isolated from family members. Finally, children and parents also endorsed concerns about potential future challenges (e.g., transitioning to adulthood, missing work).

To manage these stressors, children utilized a combination of approach- and avoidance-oriented coping strategies (see Table 2). Parents employed similar coping assistance strategies, including promoting social support, encouraging distraction, facilitating emotional expression, and promoting acceptance (see Table 3). Qualitative data suggested that the number of strategies reported per family during interviews was limited (child: $M = 1.73$, $SD = 1.03$; parent: $M = 3.40$, $SD = 1.80$). On the other hand, quantitative results indicated a considerably greater number of endorsed strategies (child coping: $M = 11.57$, $SD = 1.50$; parent coping assistance: $M = 11.50$, $SD = 0.65$), including direct problem solving, acceptance, emotion focused support, and distraction (See Table 4).

A case-by-case analysis suggested that qualitative and quantitative data regarding child coping and parent coping assistance were generally consistent at the subscale/theme level but less comparable at the level of individual items/codes. For example, one mother reported during the qualitative interview that she encouraged her child to “create mental images, mind pictures in [his] head” to help distract him during procedures. This specific strategy

was coded qualitatively as distraction, which converged with the general construct of distraction as measured by the HICUPS/PSCQ. However, no specific item on the questionnaires adequately represented this specific type of distraction (i.e., imagery). Results from combined quantitative and qualitative data analysis (at the subscale-theme level) are provided below.

Child Coping

How do children cope with SCD-related stressors?

Approach coping strategies: Approach-oriented child coping strategies that emerged in both the qualitative and quantitative data included relaxation, emotional expression, practical disease management strategies, making plans and setting routines, seeking help from the medical team, taking control, seeking understanding, direct problem solving, acceptance, emotion-focused support, problem-focused support, and cognitive decision making. Examples of approach-oriented coping attempts from qualitative data are included in Table 2.

Avoidance coping strategies: Avoidance strategies endorsed in both qualitative and quantitative data included distraction, cognitive avoidance, and behavioral avoidance. Examples from qualitative data are provided in Table 2.

What unique contributions do quantitative and qualitative assessments provide to understanding child coping?

Unique approach coping strategies: Unique approach-oriented child coping strategies that emerged from qualitative data but were not reported quantitatively included maintaining normalcy, using comfort items, and social support (see Table 2 for example responses). Strategies endorsed quantitatively that were not reported in qualitative interviews included religious coping (e.g., praying for comfort, asking God for help) and cognitive restructuring (e.g., telling self that things will get better, thinking about only good things in life).

Unique avoidance coping strategies: There were no avoidance-oriented child coping strategies reported in the interviews that were not endorsed on the HICUPS. The sole avoidance-oriented child coping strategy endorsed quantitatively but not reported within the interviews was negative actions (e.g., blame others, cause trouble).

Parent Coping Assistance

How do parents facilitate children's coping with SCD-related stressors?

Approach coping assistance strategies: A range of approach coping assistance strategies were endorsed by parents both qualitatively and quantitatively, such as encouraging cognitive restructuring, emotional expression, direct problem solving, cognitive decision making, acceptance, practical disease management strategies, and religious or spiritual coping, as well as educating others about SCD, providing emotion and problem focused support, modeling self-advocacy, and coordinating with the school and medical team. See Table 3 for examples of these coping assistance strategies from qualitative data.

Avoidance coping assistance strategies: Among the avoidance-oriented coping assistance strategies, encouraging cognitive avoidance and distraction were endorsed in both qualitative and quantitative data (see Table 3 for examples from qualitative data).

What unique contributions do quantitative and qualitative assessments provide to understanding parent coping assistance?

Unique approach coping assistance strategies: Approach strategies that emerged from qualitative interviews with parents but were not reported on the quantitative measures included promoting efforts to maintain normalcy, fostering children's autonomy, engaging in self-care activities, and encouraging social support. Examples of these coping assistance strategies from qualitative data are included in Table 3. The only approach-oriented parent coping assistance strategy endorsed on the PSCQ but not reported during the interviews was encouraging seeking understanding (e.g., encouraging children to try to figure out why things like this happen).

Unique avoidance coping assistance strategies: There were no avoidance-oriented parent coping assistance strategies reported qualitatively that were not endorsed on the PSCQ. The only avoidance-oriented coping assistance strategy that emerged from quantitative data that was not reported during the interviews was encouraging behavioral avoidance (e.g., encouraging child to stay away from problem or avoid people/things that make the child feel upset).

Discussion

Findings indicate that children with SCD face a wide range of biomedical and psychosocial challenges that encompass but extend beyond pain. To manage these varied stressors, children and parents utilize both approach- and avoidance-oriented coping and coping assistance strategies. Coping with pediatric SCD and its treatment is a fluid, complex process that requires multiple methods of assessment to understand children and parents' experiences. Quantitative and qualitative assessments provided complementary and unique contributions to understanding coping processes among children with SCD and their parents. Examining a broad range of stressors and combining two methodological approaches, this investigation advances the existing literature by providing a detailed assessment of coping within the context of the varied stressors children with SCD face. Furthermore, this study demonstrates the utility of Roth and Cohen's approach- vs. avoidance-oriented coping framework²⁹ for understanding and categorizing child coping and parent coping assistance strategies.

Consistent with similar mixed methods investigations of coping with SCD pain¹⁸ and pediatric cancer,⁵⁷ children and parents in this study reported a diversity of coping and coping assistance strategies. Given that strategies vary in their efficacy according to individual (e.g., developmental level) and situational (e.g., acute vs. chronic stressor) factors, children and families may benefit from developing a diverse array of approach- and avoidance-oriented strategies to successfully navigate the variety of psychosocial and physical demands associated with pediatric SCD.¹⁸ The importance of developing a varied coping repertoire is underscored by research suggesting that children who use "active coping

attempts” (a construct encompassing both approach and avoidance strategies) tend to use fewer healthcare services, are more active in social, academic, and household activities, and report less pain.^{26–28} However, future research is needed to better understand how specific approach and avoidance coping and coping assistance strategies may influence child or family adaptation to SCD.

Despite the broad range in strategies reported across the sample, relatively few strategies were reported by each child-parent dyad during interviews. Education and support may be beneficial to help families learn additional skills for coping with SCD. On the other hand, quantitative results indicate that children and their parents use a considerably greater number of strategies to manage SCD-related stressors. It is possible that families may spontaneously recall or discuss only the most salient of strategies in their coping repertoire during interviews.⁵⁸ Additionally, developmental limitations may have restricted the number of coping attempts that children recognize and discuss during qualitative interviews. Thus, clinicians and researchers should consider supplementing interviews with questionnaires or checklists to understand the full breadth of families’ existing coping inventories and to better target interventions.

Children and parents endorsed a variety of coping and coping assistance strategies, yet avoidance strategies were reported with notable frequency on the HICUPS and PSCQ. For instance, every child in the sample reported using behavioral and cognitive avoidance strategies to navigate SCD-related stressors, and all parents reported encouraging distraction as well as cognitive and behavioral avoidance on the PSCQ. While avoidance strategies are considered potentially adaptive for uncontrollable and short-term stressors (e.g., acute pain episodes), they may be associated with negative outcomes (e.g., anxiety) among children with SCD.⁵⁹ Thus, interventions to teach children and parents appropriate circumstances for using avoidance strategies and alternative techniques for controllable or chronic stressors may be helpful. However, most strategies reported during the interviews were categorized as approach-oriented, and several approach strategies on the HICUPS/PSCQ were endorsed by all participants (i.e., cognitive decision making, direct problem solving, and positive cognitive restructuring). Thus, in addition to helping families broaden their coping repertoires and apply techniques strategically, interventions should be tailored to each family’s experience to strengthen children and parents’ self-efficacy in using preferred methods of coping.

Findings suggest a relatively high degree of congruence between child coping and parent coping assistance strategies, providing further support for the socialization of coping model^{37,42} and reinforcing its relevance among families of children with SCD.³⁹ Few differences emerged between reported coping and coping assistance strategies. Specifically, relaxation, establishing plans and routines, and negative actions (e.g., acting out, blaming others) were the only coping strategies children endorsed that parents did not report encouraging. Considering that negative actions may increase caregiver burden and distress, parents likely do not encourage their children to use this strategy. Coping assistance strategies endorsed by parents that children did not report using included parents educating others, coordinating with the school and medical team, fostering child autonomy, modeling self-advocacy, and engaging in self-care. Given the nature of these strategies, children may

not directly observe them (e.g., educating others, coordinating with the school/medical team) or recognize them as ways in which their parents help them cope (e.g., modeling, self-care). Thus, children would not be expected to endorse these specific strategies. Overall, these findings are consistent with prior research suggesting that caregivers play an important role in helping children manage SCD,^{23,39} underlining the utility and importance of involving and partnering with caregivers to support children's physical and psychosocial health.

Finally, results suggest that qualitative and quantitative assessments provide both complementary and novel contributions to understanding coping in the context of pediatric SCD. Interview and questionnaire data were generally comparable when considering broader themes of coping, yet many of the specific strategies that emerged from interviews are not assessed by the HICUPS or PSCQ. For example, during interviews several children reported attempts to maintain normalcy in their lives as a way of coping with SCD. However, this strategy is not included on the HICUPS, as it was not developed specifically for use with medical populations. Similarly, fostering children's autonomy emerged as a form of coping assistance from interviews but is not assessed by the PSCQ. These findings suggest that existing quantitative measures could be expanded to include additional coping and coping assistance strategies relevant to specific pediatric populations. Disease-specific versions of coping measures may also be useful in that some strategies considered distraction for general populations (e.g., taking walks) represent approach-oriented disease management strategies for children with SCD. Thus, qualitative data can provide promising avenues for future measure development and refinement as well as for identifying specific strategies that can be incorporated into interventions. On the other hand, several strategies endorsed on questionnaires were not reported in interviews (e.g., religious coping, seeking understanding). This suggests that qualitative methods alone may not sufficiently assess the breadth of coping strategies children with SCD and their families use and highlight the utility of mixed methods assessments.

Limitations

The small sample size precluded more sophisticated analyses and limited the scope of the quantitative component of this study. In particular, we were unable to examine differences in coping based on factors that may be important in understanding current or future distress. For example, the current sample represents a wide range in developmental levels (ages 6–14 years). Research suggests that as children develop greater metacognitive capacities, they demonstrate greater diversity and flexibility in coping responses.⁶⁰ Thus, future research can expand on our findings by utilizing larger sample sizes and examining the ways in which coping may vary as a function of development as well as other biomedical (e.g., age, disease severity, health status, treatment types) and psychosocial factors (e.g., family functioning, illness perceptions). Furthermore, because of the cross-sectional design of this study, we were not able to assess changes in coping and coping assistance over time. Adjustments in coping are likely to occur due to changes in stressors, resources (e.g., financial, psychological, social), children's developmental maturation, and family mastery. Moreover, research suggests that for individuals with SCD, coping is variable during childhood and adolescence before stabilizing in adulthood.⁶¹ Given that coping with SCD is a lifelong process, longitudinal investigations are needed to understand differences in coping over time

and to inform interventions delivered at various stages of development. Additionally, although the approach vs. avoidance coping framework used in this study fit the data well, internal consistency reliability for the HICUPS avoidance-oriented coping dimension was poor. As noted earlier, it is possible that internal consistency was lower for this dimension because some approach-oriented disease management strategies for children with SCD are considered distraction for non-medical populations. Future research with more robust samples is needed to explore the validity of this construct as measured by the HICUPS among children with SCD. Lastly, this study did not examine potential relationships between types of coping and psychosocial outcomes. Future research should incorporate assessments of coping as well as psychosocial and health-related outcomes to identify strategies that may be most adaptive for children and families.

Conclusion

Children with SCD and their families use a wide array of coping methods to manage disease-related challenges. Findings from this study extend previous research and demonstrate the complementary contributions of quantitative and qualitative assessments to the understanding of coping in the context of pediatric SCD at large. Considering the dynamic and multifaceted nature of coping, future research should consider applying mixed methods designs to obtain more systematic and comprehensive assessments and examining relationships between coping and adjustment. A thorough understanding of coping has important implications for clinical practice, assessment development and refinement, and interventions to promote positive psychosocial outcomes for children with SCD.

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Table 1

Child Stressors Related to SCD and its Treatment from Qualitative Interviews

Reporter			Sample Responses
Child	Parent		
Pain	Pain		"It's frustrating and hard for him when he's in pain for a couple days and he can't get relief." Mother, child age 9
Bedwetting			"It is hard not to pee in my bed because when it goes... I don't notice." Child, male, age 9
Medical complications	Other complications	Other complications	"Sometimes I get hives a lot and all that other stuff." Child, male, age 6
		Lack of energy/fatigue	"[It's hard for my child] when she's playing, she is sluggish." Mother, child age 7
		Co-morbid medical conditions	"On top of the sickle cell, she also has Crohn's Disease, so that's been a big challenge." Mother, child age 9
	Treatment pain and other side effects	Treatment pain and other side effects	"When he goes to the bathroom, sometimes he's had so many pain meds that he can't go." Mother, child age 9
Treatment and side effects	Needle sticks	Needle sticks	"It's stressing for her to get stuck with needles. She doesn't like needles." Mother, child age 9
	Taking medication	Taking medication	"[It's difficult] to take the pills that I have to take. When I was younger they used to just make the medicine into a liquid, now I've got to swallow it." Child, male, age 13
	Hospital visits/stays	Hospital visits/stays	"Staying in the hospital too long is hard for him." Mother, child age 9
		Blood transfusions	"But as far as transfusions, that's something that's really stressful for him. The process, the procedure, bad reactions." Mother, child age 9
		Forgetting to drink water/hydration	"It's very important that he drinks a lot of fluid, and at times he might not be consistent with this." Father, child age 14
	Missing school	Missing school	"It's hard for me because I really want to learn and go to school, but I can't because my feet hurt." Child, female, age 9
Disruption in daily routines and activities	Inability to participate in age-appropriate activities	Inability to participate in age-appropriate activities	"What's hard is that sometimes my sisters get to go outside and play while I just have to stay in." Child, female, age 9
Emotional reactions	Feelings of uncertainty	Feelings of uncertainty	"The hardest [part of SCD] for her right now is not finding the cure." Father, child age 8
	Anger	Anger	"He gets really angry... and I think that's what really stresses him out. I think it's because he feels like he has to be brave all the time because he's been through so much. He thinks

	Reporter		Sample Responses
	Child	Parent	
Communication issues	Talking to doctors or the medical team	Talking to doctors or the medical team	he's supposed to have this wall up to protect himself about him being sick." Mother, child age 14 he's supposed to have this wall up to protect himself about him being sick." Mother, child age 14
	Sharing information about SCD		"It's scary for her when the doctors come and talk to her about treatment because a lot of them don't use kid-friendly words." Mother, child age 9
			"I just don't like talking about it. Probably only one of my friends knows about it. I don't like telling people I have sickle cell." Child, male, age 14
Social challenges	Feeling or looking different from others	Feeling or looking different from others	"What's stressful for her now is that she's really coming into realizing that she's different and that she has a disease that has to be managed." Mother, child age 9
		Family separation	"I think that's the most stressful part, when he has to be away from his brother. Both of them have it, so when there's a separation, when there's a separation of family." Mother, child age 9
	Transitioning to adulthood	Transitioning to adulthood	"It's going to be hard for me because when I get older I have to take care of myself when I get sick." Child, female, age 8
Concerns about the future	Missing work	Missing work	"I will probably have to miss stuff when I'm older, like work, events, [and] parties." Child, female, age 8
		Dealing with uncertainty	"It's kind of like the unknown because she hasn't had a lot of crises. You know and certain things that she hasn't gone through yet, like puberty, will be hard for her. But I would say that's the part in the future, that unknown part, that will be hard for her and hard for us." Father, child age 6
		Future medical procedures	"[He had surgery] in the summer. It just wasn't a very good experience. So I know he'll remember that; he will never forget it. If we ever cross that bridge again, I don't know what we'll do." Mother, child age 9

Table 2

Child Coping Strategies from Qualitative Interviews

	Reporter		Sample Responses
	Child	Parent	
Approach Coping	Social support	Social support	"I have a friend who has sickle cell, so we talk about the same things. He understands my pains and I understand his."
	Maintaining normalcy	Maintaining normalcy	"I try to stay in school."
			Child, female, age 8
	Practical strategies	Practical strategies	"I always take pills at the end of the night, and I drink some water afterwards. It helps me go to sleep so I don't have to stay up." C02
			"I get in a warm bath and put every part of my body that's hurting in there."
			Child, female, age 8
	Emotional expression	Emotional expression	"She's always kept a journal, so that's how she deals with it. She draws pictures and she loves arts and crafts and she likes writing. So that's what keeps her busy or helps her cope with it."
			Mother, child age 9
	Relaxation	Relaxation	"I lay down [and] take rests."
			Child, female, age 7
	Establishing plans & routines		"Do special events to make me feel better... going to amusement parks, having a cookout."
			Child, male, age 12
	Taking control		"During pain crises, she tries to deal with stuff on her own without hearing it from me or another adult."
			Mother, child age 7
	Seeking help from the medical team		"[He tells me] 'Mom, I went to the nurse today because I was having more pain.'"
			Mother, child age 9
	Using comfort item		"He just has some little comfort thing, always something of comfort. Normally there's a stuffed something somewhere with him."
			Mother, child age 9
Avoidance Coping	Distraction	Distraction	"He'll play his video games... and he has an iPod which he likes or he'll get on his computer. Those little things help because it's a distraction."
			Mother, child age 9
	Cognitive avoidance	Cognitive avoidance	"[I try to] not think about the problem."
			Child, female, age 12
	Behavioral avoidance	Behavioral avoidance	"We try to talk to him, but he'll just try to lead to another conversation or just not say much."
			Mother, child age 7

Table 3

Parent Coping Assistance Strategies from Qualitative Interviews

Approach Coping	Reporter		Sample Quotes
	Child	Parent	
Approach Coping	Social support	Social support	"My parents stay with me all the night, and some people visit me." Child, male, age 9
	Practical strategies	Practical strategies	"My mom rubs my feet with a towel. We soak them in hot or warm water." Child, female, age 9
	Emotional expression	Emotional expression	"We talk about [her SCD]. We talk about how she feels, and how it makes her feel. We talk about if she's sad or hurt." Mother, child age 9
		Maintaining normalcy	"We try to encourage her to take care of herself and we have her around regular kids, playing and doing normal stuff as much as possible... We also do fun things. She's a normal kid, so when she does bad things she gets punishments, and rewards, all that good stuff." Mother, child age 9
		Cognitive restructuring	"I try to keep him positive about it, like letting him know, 'I know you're going through stuff but you can still do things. You can get through this. It's just a little bump in the road but you can still do everything you want to do in life.'" Mother, child age 14
		Educating Others	"We educate everybody, all our family, so they all know what's going on with it. They all know what kinds of medicines to give her. They all know what kinds of signs to look out for when she's going through crisis." Father, child age 6
		Coordinating with school	"My son missed a lot of school this year and [had] to make up the work. So we make sure we're in constant communication with the teachers and the school." Father, child age 6
		Fostering child autonomy	"We baby her a little bit but not too much because we want to render that independence so that she can learn how to deal with it on her own." Father, child age 6
		Modeling self-advocacy	"I know that the nurses have a schedule of when medication is due, but things get busy, so I know when to call and say, 'She's getting very uncomfortable, is it due or not?' She doesn't know to call and say, 'I need medication,' so it helps to have one of us here always." Mother, child age 6
		Spirituality	"We pray with him and we just stick by him. We let him know that we're always going to be here." Mother, child age 14
		Coordinating with medical team	"When she's having pain, that's the only thing you can focus on, how to get it better, try to find out from the team as much as possible, that everyone is doing their best to make her comfortable. Just advocating for her." Mother, child age 6
		Engaging in self-care	"Last night she didn't want me to go home, but I had to explain that I had been here since midnight Sunday. My husband was going to be here, but she wanted me here, so I had to explain that I needed to go home and get some sleep and be here for her today wide-eyed." Mother, child age 6
		Promoting acceptance	As [she] gets older, we are very much, "This is something you have to deal with. This is the reality of your situation right now. So you got to learn how to deal with it."

Reporter		Sample Quotes
Child	Parent	
Avoidance Coping	Distraction	Father, child age 6
	Distraction	"My dad takes me to the pool to have fun and forget about it." Child, male, age 12

Table 4

Frequency of Coping Strategies Endorsed on the HICUPS/PSCQ

Coping Subscale	Child Coping		Parent Coping Assistance	
	N	%	N	%
Approach Coping				
Cognitive Decision Making	14	100	14	100
Direct Problem Solving	14	100	14	100
Seeking Understanding	12	85.7	14	100
Positive Cognitive Restructuring	14	100	14	100
Emotional Expression	10	71.4	12	92.3
Problem-focused Support	13	92.9	14	100
Emotion-focused Support	13	92.9	14	100
Acceptance	13	92.9	9	81.8
Spirituality/Religion	12	85.7	14	100
Avoidance Coping				
Distraction	13	92.9	14	100
Behavioral Avoidance	14	100	14	100
Cognitive Avoidance	14	100	14	100
Negative Actions	6	42.9	0	0

* For both the HICUPS and PSCQ, N = 14 (one missing case for each)