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The Cellie Coping Kit for Sickle Cell Disease: Initial acceptability and feasibility

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Abstract

Sickle Cell Disease (SCD) and its treatment can place physical and psychosocial strain on children and their families, underlining the need for behavioral and emotional support. Much of SCD is often managed at home, which may prevent children from obtaining supportive services from medical and psychosocial teams. Children with SCD report a restricted number of coping strategies specific to managing SCD and may benefit from education on adaptive coping. To address this unmet need, a coping tool for children with cancer (Cellie Cancer Coping Kit) was adapted for children with SCD. The Cellie Coping Kit for SCD (Cellie Coping Kit) includes a stuffed "Cellie" toy, coping cards for children, and a book for caregivers. This study sought to assess the acceptability and feasibility of an intervention utilizing the Cellie Coping Kit. Fifteen children with SCD (ages 6-14) and their caregivers participated in a baseline assessment including

Disclosure: Dr. Marsac is a co-inventor of the Cellie Coping Kit for Sickle Cell Disease. The Children's Hospital of Philadelphia and co-inventors have filed a provisional patent for the kit and may benefit financially from the kit. Revenue will be steered back into research in accordance with CHOP's non-profit status. The research presented in the paper has been approved by the Hospital's Conflict of Interest committee.

semi-structured interviews to examine SCD-related stressors and coping strategies. Next, families received a brief introduction to the Cellie Coping Kit and were provided with a kit to use independently over the next four weeks before completing a follow-up assessment. Results indicated strong intervention acceptability overall. While families reported using and learning information and skills from the Cellie Coping Kit, several challenges were identified (e.g., child's living situation, busy schedules). The Cellie Coping Kit is a promising tool to support children with SCD and their families. Future research should examine whether use of the Cellie Coping Kit impacts behavioral change and improved health outcomes.

Keywords

sickle cell disease; coping; family intervention; coping tool

In the United States alone, 72,000 to 98,000 individuals are currently diagnosed with sickle cell disease (SCD; Hassell, 2010). SCD occurs in approximately 1 in every 500 African Americans and 1 in every 36,000 Hispanic Americans (National Heart Lung and Blood Institute, 2009). Children with SCD experience many stressors related to unpredictable and chronic pain episodes, invasive medical procedures, and long hospitalizations. These children also are at-risk for significant medical complications including strokes, infections, anemic episodes, liver disease and deterioration in vision (Ambruso, 2007). Children and their families are particularly challenged by pain symptoms and often (i.e., 90% of the time) manage these symptoms at home (Barakat, Patterson, Daniel, & Dampier, 2008; Shapiro et al., 1995). In addition to medical treatment and complications, children with SCD also report significant psychosocial stressors such as disruptions in daily routines (e.g., frequent school absences), inability to participate in age-appropriate activities (e.g., playing outside in extreme temperatures), social challenges (e.g., feeling different from peers), and communication issues (e.g., disclosing information about SCD; Hildenbrand, 2013). Education about SCD disease and the management of complications is recommended as part of a comprehensive management plan (Ballas, 2002).

Children with SCD are also at risk for psychological symptoms such as flashbacks to previous pain crises, treatment-related anxiety, depression and impaired quality of life (Barakat, et al., 2008; Hofmann, de Montalembert, Beauquier-Maccotta, de Villartay, & Golse, 2007). These symptoms are particularly problematic given that distress resulting from psychological sequelae can result in further physical symptoms. For example, the memory of a previous pain crisis can result in increased anxiety, which is related to the onset of pain crises (Hofmann, et al., 2007). SCD also can affect family functioning. Given that caregivers are often required to devote substantial time towards managing SCD, they may have less time for other responsibilities and are at risk for reduced quality of life (Brown & Lambert, 1999; van den Tweel et al., 2008).

Children with SCD employ a variety of strategies to cope with SCD and its treatment including approach (e.g., social support, maintaining normalcy, practical strategies, emotional expression, relaxation) and avoidant (e.g., distraction, cognitive/behavioral avoidance) coping strategies (Fuggle, Shand, Gill, & Davies, 1996; Hildenbrand, 2013).

Approach-oriented strategies are adaptive when dealing with controllable stressors and invasive procedures while avoidant strategies may be effective in managing uncontrollable situations and time-limited stressors (Compas, Malcarne, & Fondacaro, 1988; Manne, Bakeman, Jacobsen, & Redd, 1993; Sorgen & Manne, 2002; Suls & Fletcher, 1985). While children with SCD report numerous coping strategies, individual families report limited range of strategies (Hildenbrand, 2013; Lutz, Barakat, Smith-Whitley, & Ohene-Frempong, 2004). Coping with SCD complications has been associated with health outcomes including general functioning and less health care utilization (Gil et al., 1993; Gil, Williams, Thompson, & Kinney, 1991).

Psychosocial interventions for children with SCD and their families are in early development. Reviews of empirically supported psychosocial interventions for pediatric SCD indicate that cognitive-behavioral therapy (CBT) techniques may be efficacious in reducing SCD-related pain; results are inconclusive regarding CBT's effect on coping and health care utilization (Anie & Green, 2012; Chen, Cole, & Kato, 2004). Although several CBT interventions have demonstrated promise in increasing disease knowledge, perceived pain control, self-efficacy, and coping related to pain management, most interventions have yet to impact primary psychological (e.g., anxiety, depression) or health-related outcomes (e.g., severity or frequency of pain, health care utilization) among children with SCD (Chen, et al., 2004). Current interventions have also been limited by a number of barriers including poor treatment engagement and retention (Barakat, Schwartz, Salamon, & Radcliffe, 2010; Kaslow et al., 2000). Additionally, most interventions to date have focused primarily on acute pain crises, with little integration of other guidelines for optimal management of SCD (e.g., daily prevention and adherence behaviors; Chen, et al., 2004). Considering the impact of SCD on children and their families as well as the frequent management of pain symptoms at home, low-cost, easy to implement interventions are needed to help promote positive adjustment. Universal, preventive interventions may be helpful for all families who are facing SCD. In particular, culturally competent family-based approaches that are comprehensive and can be tailored to children and families may be beneficial (Barakat, et al., 2010; Chen, et al., 2004).

To address this gap in psychosocial interventions for children with SCD, we created the Cellie Coping Kit for Sickle Cell Disease. The Cellie Coping Kit was originally developed for children with cancer (Marsac et al., 2012) and later adapted (as described here) for children with SCD. The Cellie Coping Kit includes a stuffed toy (Cellie), coping cards for children, and a caregiver book. The Cellie Coping Kit provides instructions for caregivers to work with their child to identify stressors that are relevant to their family and to choose strategies that work best for them. For a detailed description of the Kit and its development see "Description of the Cellie Coping Kit Intervention" in the Methods section of this paper.

The purpose of this study was to assess the acceptability (i.e., engagement, comprehensiveness, understandability) and feasibility (i.e., usage, learning, barriers) of an intervention using the Cellie Coping Kit for SCD. Specifically, we investigated if and how children with SCD and their caregivers engaged with and used the Cellie Coping Kit. We also examined child and caregivers' understanding of the kit content and whether the kit provided comprehensive coverage of stressors and coping techniques for dealing with SCD

and its treatment. Finally, we assessed if families learned coping strategies from using the kit.

Method

Participants

Participants were recruited through the sickle cell center of a pediatric hospital in the northeastern region of the United States. Children were eligible to participate if they were between 6- 14 years of age, diagnosed with any variant of SCD, cognitively able to complete study tasks, one legal guardian/caregiver provided consent, and the child and caregivers understood English well enough to complete study tasks and understand intervention content. Fifteen children and one caregiver per child participated (see Table 1 for demographics). Twenty families were approached to participate in the study (75% participation rate). Reasons families provided for electing not to participate include having no stressors related to SCD and disinterest in research. Follow-up assessments were completed by 80% of children and 87% of parents.

Procedure

Potential participants were identified using hospital records. Research Assistants (RAs) approached caregivers of eligible child participants while children were at an outpatient or day hospital appointment or hospitalized for treatment. Once parental consent was obtained, children provided assent. Caregivers and children individually completed semi-structured interviews to assess SCD-related challenges and coping strategies. Families then participated in the intervention using the Cellie Coping Kit for SCD. RAs introduced the Cellie Coping Kit to families. Introductions to the Kit were tailored to each family by using stressors identified during the baseline interview. RAs spent approximately 5-10 minutes with each child and his or her caregiver reviewing the coping cards and pages in the caregiver book specific to the family's needs. For example, if during the baseline interview a caregiver reported that their child becomes distressed during injections, the RA reviewed the relevant coping cards on needle sticks and identified the corresponding pages on helping children cope with injections in the caregiver book. RAs also informed families about the other categories and types of stressors and coping strategies encompassed in the kit materials and encouraged them to use the Kit as stressors were identified within their family. This completed the introduction to the intervention. No follow-up contact was made specific to the intervention (i.e., the only follow-up was for assessment).

At four weeks post-baseline, children and caregivers were contacted to complete follow-up assessments during a medical appointment in the hospital or via phone. The assessment included a semi-structured interview to examine use of the Cellie Coping Kit during the past four weeks, barriers to using the kit, and satisfaction with the kit materials.

Description of the Cellie Coping Kit Intervention

The Cellie Coping Kit is designed to be implemented predominantly by children and caregivers together. It suggests a variety of coping strategies that can be tailored to each child's experience, allowing children (with support from caregivers) to determine the most

important issues and types of strategies that work best for them. The Kit includes a stuffed toy (Cellie), coping cards and a book. Cellie is a plush toy that children are encouraged to use while implementing coping strategies (e.g., squeeze it during a painful procedure). Forty SCD coping cards contain developmentally appropriate, evidence-based techniques for children to reduce SCD-related distress (e.g., strategies for dealing with pain crises; peer teasing). The caregiver book provides parents with concise, specific tips (parallel to those in the coping cards) to help their child use Cellie and the coping cards. The book also includes stressors related to parenting a child with SCD (e.g., sharing information about diagnosis and treatment, supporting siblings/partners). The Cellie intervention is unique in that children and their caregivers can use the kit across settings (i.e., home/clinic/hospital) and providers (e.g., doctors, nurses, therapists, phlebotomists) ensuring that the intervention is available at the time a SCD-related stressor arises. See Figure 1 for a sample coping card and Figure 2 for an example of a child using the kit.

Using a translational research approach, the content included in the Cellie Coping Kit is based on empirical evidence in combination with stakeholder input. In developing the Cellie Coping Kit, we first reviewed literature to identify common stressors for families with SCD (e.g., pain) and coping strategies that have been effective in dealing with these stressors (e.g., distraction). Next, ten hematology clinicians (including psychologists, social workers, nurse, education specialist, hematologist) reviewed and 25 parents of children with SCD responded to materials and suggested modifications (e.g., add education on SCD, peer teasing, nutrition; confirmed the kit was needed and the content was applicable). This feedback helped to ensure completeness and promote cultural sensitivity of the intervention materials. Following these revisions, the Flesch-Kincaid reading level was grade 3.8 for the coping cards and 7.4 for the caregiver book.

Measures

Sickle Cell Disease Pre Semi-Structured Interview (parallel child and caregiver versions): Adapted from a previous study, this interview guide assesses children and caregivers SCD-related challenges and coping strategies by parent and child report (Marsac, et al., 2012). Interviews were utilized to assess the comprehensibility of the coping cards and caregiver book (i.e., whether the intervention materials included all relevant content). Children were asked about the most stressful/hardest parts SCD and its treatment in the past/current/future, what types of strategies they use to deal with SCD and its treatment, and what types of strategies caregivers/family members engage in to help them deal with SCD and its treatment. Caregivers were asked parallel questions about their child and themselves.

Sickle Cell Disease Post Semi-Structured Interview (parallel child and caregiver versions): This interview guide was a modified version of the Pre Semi-Structured Interview (described above). Administered during the follow-up assessment, the interview was used to re-assess SCD challenges and coping strategies by child and parent report. The interview also assessed feasibility and acceptability of the Cellie Coping Kit by examining the ways in which children and caregivers utilized the kit and any barriers or challenges to using the kit.

Satisfaction Questionnaire (parallel child and caregiver versions): This measure was adapted from a previous study (Marsac, et al., 2012). The Satisfaction Questionnaire was administered as part of the follow-up assessment and gathered families' overall impressions of the Cellie Coping Kit materials. This measure consisted of several open-ended questions eliciting strengths and areas for improvement. The measure also included forced-choice items which required the child/caregiver to respond either “yes” or “no” or on a 3-pointon a Likert scale (“A lot”, “Some”, “Not at all”). The measure assessed the Cellie Coping Kit's feasibility, usability, and visual appeal as well as the trustworthiness of the materials.

Data Analysis—To analyze open-ended data, all interviews were audio-recorded and transcribed. To determine the comprehensiveness of the intervention materials, two RAs compared every stressor and coping strategy reported by children and caregivers during interviews to the intervention materials (results confirmed by principal investigator). After determining whether each stressor and strategy was represented in the materials, the number of new stressors/strategies suggested by families during interviews was calculated and the content of the new strategies was recorded. The number of strategies provided in the Cellie Coping Kit that were not generated by families during baseline interviews was also calculated. Next, a RA (supported by the PI) reviewed and categorized transcription content for intervention feasibility and acceptability. The RA extracted comments regarding 1) how families used the Cellie Coping Kit, 2) barriers that prevented use, and 3) challenges incurred during use. Each comment was placed into a category summarized in Results and used to explicate the forced-choice data. Forced-choice responses on the satisfaction questionnaire were quantified using frequencies.

Results

Cellie Coping Kit acceptability: engagement, understandability, and comprehensiveness

Acceptability-engagement: Do children with SCD and their caregivers engage with the Cellie Coping Kit?—As evidenced by results presented on Table 2, children and caregivers indicated that the Cellie Coping Kit was engaging. For example, one caregiver stated “I like [the Cellie Coping Kit] because it gives a basic definition of the disease and then it gives you details, things to do to help prevent pain crisis, like drinking plenty of fluids, and then it also tells you when pain crises do arise, how to deal with them.” Another child explained, “The pain tips help me ... and the pain thermometer, the faces, and the belly breathing card, that helped me a lot.” Another child commented, “I like Cellie, he's great.” See Table 2 for frequency data regarding engagement.

Acceptability-understandability: Do children and caregivers understand the content of the Cellie Coping Kit?—All caregivers who completed the follow-up assessment (n= 14; 87%) reported that the Cellie Coping Kit was easy to use. Most children (n=9, 75%) and caregivers (n=9, 81.8%) reported that the coping cards were easy for children to use. A caregiver commented that “the way [the Cellie Coping Kit is] set up is that it's actually really self-explanatory... We could comprehend it.” All children (n=12, 100%) reported knowing how to use the kit. However, some children and caregivers

expressed difficulty with using the materials (e.g., too many words [coping cards $n=7$; 58%; book $n=2$; 17%], directions were confusing [$n=5$; 42%]).

Acceptability-comprehensiveness: Does the Cellie Coping Kit provide comprehensive coverage of stressors and coping techniques for dealing with SCD and its treatment?—

The Cellie Coping Kit materials provide information on 39 SCD-related stressors. Children and caregivers articulated 6 additional stressors that were not included in Cellie Coping Kit materials: feelings of anger and uncertainty about SCD, feeling or looking different, SCD-related medical complications (e.g., significant fatigue), missing work, and transitioning to adulthood. Additionally, there are over 250 unique tips/coping strategies in the Cellie Coping Kit materials which families did not identify independently. Six coping strategies reported by children and caregivers were not already included in the Cellie Coping Kit materials: granting children autonomy for nutrition choices or medical care, avoiding thinking or talking about SCD, managing symptoms at home rather than coming to the hospital, staying overnight at the hospital with children, using visual imagery, and praying.

Cellie Kit feasibility: usage, learning, barriers

Feasibility-usage: Will children with SCD and their caregivers use the Cellie Coping Kit, and if so, how do they use the Kit?—

All children and caregivers who completed the follow-up assessment reported using the Cellie Coping Kit and that they would use it again. Families used the Cellie Coping Kit across different settings and in a variety of ways (See Table 3). Children and caregivers reported that they utilized the Cellie Coping Kit for fun, comfort, education, and coping. For example, one child commented, “I hug him tight. I sleep with him.” Another reported, “I play with [Cellie] every day. I get all my favorite dolls and [Cellie] and we play school.” In using the Cellie Coping Kit for education, one caregiver noted, “I use the cards maybe like twice a week with [my son]. We read [them] to each other. I’ve tried to explain to him the stuff that he can go through.” Children reported using Cellie Coping Kit strategies such as hugging Cellie during a needle stick, using a pain scale, and telling caregivers when they are in pain. For example, one child stated, “I used the cards, just like to see the things I have, what I can do to calm down,” and another “I hugged him really tight so I didn’t get hurt with this (needle stick).”

Feasibility-learning: Do children and their caregivers learn from using the Cellie Coping Kit?—

Most children ($n=10$; 83%) and caregivers ($n=7$; 64%) who completed the follow-up assessment reported learning from the Cellie Coping Kit. Children and caregivers reported gaining a greater appreciation of SCD signs, symptoms, and progression. For example, one child said, “I learned signs for when my sickle cell was starting.” A caregiver commented on her child’s learning: “She’s just become more aware about it by reading the cards and by asking a lot of questions. Some of the things on the cards she didn’t understand [before] so she has more of an education now.” Caregivers commented on their own learning: “[I learned] about pain crises, how cells are shaped differently than normal red blood cells, the areas of the body that are affected, how to deal with pain, and methods for dealing with pain.” Another commented, “I didn’t know that sickle cell travels through her whole body. I didn’t know that before [having the Cellie

Coping Kit].” Caregivers also reported learning how to facilitate conversation with children about SCD: “I learned how to just talk to (my daughter) more about sickle cell.”

Feasibility-barriers: What are the barriers of using the Cellie Coping Kit?—

Most barriers reported by families centered on busy work and school schedules. One caregiver said, “Honestly, I just showed it to [my wife] and told her about it, and then pretty much everything got hectic, so I didn't really use it.” A child remarked, “Sometimes my homework will get into the way of me and Cellie spending time together.” Living and family situations were another barrier, with one caregiver commenting, “[My daughter] lives between me and her father, so she uses it when she's here because the kit is here.” One child also noted, “Sometimes I used the cards with Cellie, but I hide them from my brother because he always tries to play with them.”

Discussion

It is well documented that children with SCD experience many stressors related to SCD and its treatment (Hildenbrand, 2013; Lutz, et al., 2004). Ways to best support children with SCD has yet to be determined. These research findings suggest that the kit shows promise in helping to achieve this unmet need. As described here, the development of the Cellie Coping Kit for SCD applied a translational research approach by taking adaptive coping strategies based on research and delivering strategies in an intervention that helps children and parents learn how to manage SCD and its associated procedures and complications. Overall, results indicate that families with children ages 6-14 years old find using the Cellie Coping Kit engaging and easy to use. Families learned information about SCD, how to communicate about SCD, and new techniques for coping with SCD and its treatment.

The Cellie Coping Kit expands the type of support offered in current interventions for children with SCD. While cognitive-behavioral therapy (CBT) techniques have been shown to decrease pain and improve disease knowledge (Chen, et al., 2004), much of SCD disease management occurs in the home setting without the presence of the medical team (Shapiro, et al., 1995). Thus, interventions that are amenable to deliver at-home may be helpful. Additionally, given the learning outcomes specific to understanding SCD, it may be helpful to provide this type of intervention as a preventive intervention universally. Results presented here suggest that the Cellie Coping Kit may be an avenue for delivery of this support but more research is needed to determine the effectiveness of this tool and whether or not families can commit to using this tool over a longer period of time.

Of note, most families who were approached (75%) elected to participate in this intervention study. Many intervention studies have had difficulty recruiting and retaining children with SCD and their families (Barakat, et al., 2010). For example, Broome and colleagues' (2001) intervention enrolled 59% of eligible children, and only 55% of those enrolled into the study completed the intervention and follow-up assessments (Broome, Maikler, Kelber, Bailey, & Lea). Though this study was not a randomized controlled trial (compared to the others above), this type of intervention that allows families to work independently without additional appointments, may be a promising way to deliver evidence-informed coping strategies to families. Additionally, it is also important to note that the Cellie Coping Kit is

not intended to serve as “treatment” for symptoms and should not be used as a replacement for psycho-social supportive services. Rather, the kit can be used in conjunction with other supports or as a tool for medical teams to facilitate communication with families. The Kit could also be used as a universal preventive tool to promote education for understanding and managing SCD.

Several barriers to implementation of the Cellie Coping Kit were identified. First, some children and caregivers noted difficulty understanding the materials. Given the educational level of the sample (i.e., 2/3rds had at least “some college”), it is possible that this difficulty is not related to reading level alone; it may speak to the challenge of translating evidence-based psychological techniques into easily digestible information for direct application by families. Thus, prior to distribution of the Cellie Coping Kit, revisions are recommended. Revisions to the intervention material should include reducing the amount of text and the way in which the text is presented to improve readability. Additionally, materials should be revised to ensure techniques are effectively translated and further research should be conducted to ensure comprehensibility. As expected, some families noted that busy schedules and chaotic life-situations interfered with using the Cellie Coping Kit; given that this is likely to be a challenge for many families, medical teams could help overcome this barrier by encouraging use of the Cellie Coping Kit during medical care. Families also reported that use of the Kit was limited when children traveled between more than one household; thus, it may be helpful to provide each caregiver with a kit. Additionally, while most parents used the coping cards, almost half (43%) did not use the caregiver book. More research is needed to better understand how to make the book more useful and appealing to parents. Future research should also evaluate the extent to which family resources (e.g., socio-economic status) and education may influence the use of the Kit.

In addition to addressing the barriers noted above, findings indicate that several content areas should be expanded in future iterations of the Cellie Coping Kit. Specifically, including additional information on feelings of anger and uncertainty about SCD, feeling and looking different from others, SCD-related medical complications, missing work, and transitioning to adulthood may be helpful for families and will result in a more comprehensive tool. While families suggested several coping tips that are not currently included in the Cellie Coping Kit (grant the child autonomy, avoidance, manage symptoms at home rather than coming to the hospital, stay overnight at the hospital with the child, use visual imagery, pray), not all of these tips should be added. Tips families suggested such as visualization techniques and caregivers stay overnight during hospital visits may be helpful for families and should be considered in revised intervention materials. However, caution is needed suggesting that caregivers provide autonomy in medical care and to manage symptoms primarily at home. While encouraging autonomy in adolescence is important for their future transition to adult care, this may not be appropriate for the target age group of this kit (i.e., 8-14 years old; DeBaun & Telfair, 2012). Home management exclusive of regular medical care could lead to poor overall disease management (Edwards & Edwards, 2010; Jacob et al., 2003). Full avoidance of discussion of SCD could also affect disease management. Though a structured assessment of cultural acceptability was not conducted in this study, the ways in which families from diverse backgrounds used the Kit suggests that this population found the kit culturally acceptable. However, to ensure cultural diversity is

respected (particularly with regard to religion) and cultural acceptability is maximized, more research is needed to determine how to include coping tips that reference religious beliefs or practices.

While results are promising, several study limitations should be noted. First, this pilot evaluation of the Cellie Coping Kit for SCD was conducted with a small sample of children across a large age range. Thus, the generalizability of results should be interpreted with caution. Additionally, the current study solely examined acceptability and feasibility rather than behavioral (e.g., changes in coping strategies, improved quality of life) and/or health outcomes (e.g., fewer or less severe pain episodes, fewer hospitalizations). Future research should examine these intended outcomes of the Cellie Coping Kit for SCD.

In conclusion, by implementing a translational research approach, we created a low-cost mechanism (i.e., Cellie Coping Kit for SCD) that may be helpful in teaching or reinforcing adaptive coping strategies to children with SCD and their families. Clinically, the Kit may be most helpful if it is distributed by the medical team and integrated into care; however, research presented here suggests that families are able to use the Kit independently following a quick introduction in clinic. While more research is necessary to determine intervention efficacy, results are promising in that they suggest that families engage with the kit and learn new strategies when using the Cellie Coping Kit for SCD.

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My classmates keep asking me what is wrong with me when I am in pain

My classmates keep asking me what is wrong with me when I am in pain

- Tell people about sickle cell and why it makes you have pain.
- Give them a handout that will teach them about sickle cell.
- Ask your teacher to explain sickle cell to your classmates.
- Invite them to sickle cell events (like the sickle cell walk-a-thon).
- My ideas: _____

(FRONT OF CARD)

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Figure 1. Sample Cellie Coping Card

Figure 2. Child using the Cellie Coping Kit for Sickle Cell Disease

Table 1

Participant Demographics

	Study Part 1
CHILDREN	N (%)
Sex	
Male	7 (46.6%)
Female	8 (53.3%)
Racial Background	
Black/African American	15 (100%)
Ethnicity	
Hispanic	2 (13.3%)
Non-Hispanic	13 (86.6%)
Sickle Cell Disease Type	
Sickle cell anemia	9 (60%)
Sickle cell with hemoglobin C disease	3 (20%)
Hemoglobin S-beta-plus thalassemia	2 (13.3%)
Sickle cell hemoglobin 0 Arab	1 (6.6%)
Enrollment setting	
Inpatient hospitalization	6 (40%)
Outpatient clinic	9 (60%)
	<i>M (SD)</i>
Age (years)	9.13 (3.04)
CAREGIVERS	N (%)
Relationship to child	
Mother	10 (66.6%)
Father	4 (26.6%)
Legal Guardian	1 (6.6%)
Racial Background	
Black/African American	14 (93.3%)
Ethnicity	
Hispanic	2 (13.3%)
Non-Hispanic	13 (86.6%)
Education level	
Completed high school or less	5 (33.3%)
Full/partial completion of college	5 (33.3%)
Graduate/professional degree	5 (33.3%)

	<i>M (SD)</i>
Age (years)	41.07 (8.73)

Table 2
Acceptability-Engagement of the Cellie Coping Kit for Sickle Cell Disease

	Child N (%)	Parent N (%)
Likes appearance of Cellie	11 (91.7)	12 (92.3)
Kit is fun to use	12 (100)	11 (91.7)
Kit gives good advice/tips	11 (91.7)	12 (100)
Information in Kit is trustworthy/true	11 (91.7)	12 (100)
Would recommend the Kit to other kids/families	8 (72.7)	13 (100)
Likes appearance of Cellie *	11 (91.7)	12 (92.3)
Likes the tips in Coping Cards/caregiver book *	10 (83.3)	12 (100)

* Item asked on a 3-point Likert scale. "some" and "a lot" were collapsed to "yes" for analyses; "never" was re-coded as "no". All other items presented in this table were asked on a dichotomous scale of "yes" and "no."

Table 3
Feasibility-Usage of the Cellie Coping Kit for Sickle Cell Disease

	Child N (%)	Parent N (%)
Used Cellie Kit	12 (100)	14 (100)
Components of Cellie Coping Kit used		
Cellie Toy	12 (100)	14 (100)
Coping Cards	11 (91.7)	13 (92.9)
Caregiver Book	1 (8.3)	8 (57.1)
Frequency of use:		
1-5 times	3 (25)	8 (57)
5-9 times	3 (25)	3 (21.4)
10 or more times	6 (50)	1 (7.1)
Do not recall	0 (0)	2 (14.3)
Locations of Cellie Coping Kit usage		
Home	12 (100)	13 (92.9)
Hospital	4 (33.3)	5 (35.7)
Other	2 (16.7)	3 (21.4)
Would use Cellie Kit again	12 (100)	13 (100)