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The Development of a Culturally Sensitive Pediatric Pain Management Intervention for African American Adolescents With Sickle Cell Disease

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Abstract

This article describes a cognitive-behavioral pain management intervention for adolescents with sickle cell disease with particular emphasis on description of components that enhance its cultural sensitivity. To date, 25 participants have been randomized to the pain management intervention. Treatment expectation ratings at baseline and midpoint (after Session 2) and participant feedback regarding interest in, enjoyment of, and helpfulness of the intervention are presented. Preliminary data indicate that most of the participants have been engaged in and have responded well to the intervention. Challenges of the intervention are discussed.

Pain is a significant complication of many pediatric chronic health conditions that relates to quality of life and functional status including school attendance, sleep, family functioning, and children's mood (Hunfeld et al., 2001; Palermo, Schwartz, Drotar, & McGowan, 2002). Promising pain management interventions, which primarily include cognitive-behavioral components, have been studied among various pediatric chronic conditions (for a review, see Walco, Sterling, Conte, & Engel, 1999). Despite the potential of these pain management interventions, there has been little examination of ethnic/cultural factors in implementing effective interventions. Cognitive-behavioral pain management interventions may be more effective if tailored to be more culturally sensitive for specific populations of children, adolescents, and families rather than designed with a "one-size-fits-all" perspective (Goldberg & Remy-St. Louis, 1998). However, most empirically validated psychological treatment outcome studies have been conducted primarily with participants who are Caucasian and of middle to upper class socioeconomic status (SES), exacerbating the gaps in knowledge about generalizability and effectiveness of such treatments for individuals of diverse backgrounds.

To create more effective interventions, it is necessary to identify unique aspects of working with ethnically, racially, and socioeconomically diverse pediatric populations and to include key components that constitute a culturally sensitive intervention (American Psychological Association [APA], 2003; Clay, Mordhorst, & Lehn, 2002; Kaslow & Brown, 1995). This has also been identified as a priority of the Surgeon General and the APA given the lack of

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information on key components of cultural appropriateness and what impact they have on clinical outcomes for minorities (APA, 2003; U.S. Department of Health and Human Services, 2001). It has been argued that culturally specific adaptations of empirically based interventions may increase recruitment and retention and improve subsequent outcomes (Kumpfer, Alvarado, Smith, & Bellamy, 2002; Martinez & Eddy, 2005).

Understanding key components of culturally sensitive interventions with African American children and adolescents with chronic illness and their families is important for many reasons: Most individuals with sickle cell disease (SCD) in the United States are African American, African American children and adolescents are overrepresented in some childhood chronic illnesses (e.g., asthma, diabetes; Tucker, 2002); and African American children may have more limited access to health and mental health resources (Tucker, 2002). To develop effective psychological interventions with African American children, adolescents, and families, an understanding of effective generalizable components that contribute to successful implementation and efficacy is needed. Thus, the aim of this article is to describe a pediatric cognitive-behavioral pain management intervention with particular emphasis on the components that contribute to the cultural sensitivity of the intervention. The intervention is intended for adolescents with SCD, a chronic health condition that afflicts mostly individuals of African descent and, thus, a condition for which the development of a culturally sensitive pain management intervention is particularly important and relevant. The intervention borrows from other successful cognitive-behavioral pain management interventions while adding culturally sensitive components expected to enhance retention and the effectiveness of the intervention with African American adolescents with SCD.

SCD is a genetic disorder that afflicts 1 in every 500 individuals of African ancestry in the United States (National Heart, Lung, and Blood Institute [NHLBI], 1996). Among the complications of SCD is pain (both recurrent and chronic) that typically increases in intensity and frequency in adolescence and adulthood, in addition to other complications that affect all organ systems (Platt et al., 1991). Pain and other complications can have a significant impact on quality of life for African American youths living with SCD when compared with African American children without SCD (Palermo et al., 2002). Because pain is a central and common complication of SCD, learning to manage pain effectively is essential to maintaining an active lifestyle and optimal quality of life. Developing effective pain management strategies by adolescence will allow patients with SCD to manage the transition to adult services more effectively and to become more competent adult patients (Benjamin et al., 1999). In fact, researchers and clinicians working with children and adolescents with SCD have called for more targeted psychosocial interventions to manage pain (Chen, Cole, & Kato, 2004). Cognitive-behavioral pain management interventions have been established with some success, but none have been developed to specifically target pain management with adolescents with SCD (see Chen et al., 2004, for a review of related interventions).

One study with children (*M* age = 11.9, *SD* = 3.0) with SCD tested a cognitive-behavioral one-session (plus review session) intervention that taught deep breathing, imagery, and self-statements (Gil et al., 1997). After the intervention, children did not differ from the control group on reported pain. However, within group analyses revealed that use of active coping strategies on high pain days was associated with fewer health care contacts and less reduction in daily activities (Gil et al., 2001). Thus, it was concluded that the intervention worked when it was practiced and utilized during times of intense pain. Another study with individuals ages 15 to 35 tested an intervention involving 2 months of weekly group cognitive-behavioral therapy compared with standard care and an attention placebo (Thomas, Dixon, & Milligan, 1999). Those receiving group cognitive behavioral therapy (CBT) endorsed more positive coping strategies, greater self-efficacy to deal with pain, and greater pain control compared with the other groups. In addition, SCD pain intervention studies utilizing biofeedback with individuals ages 10 to 20 (Cozzi, Tryon, & Sedlacek, 1987), and group hypnosis training with patients ages 5 to 51 found reductions in pain (Dinges et al., 1997).

Intervention studies for adolescents with SCD, not directly targeting pain, have found some related improvements in symptoms. One 8-week group psychoeducation intervention with adolescents with SCD found that the adolescents showed some improvement in their ability to manage their pain (Baskin, 2000). Also, in a study investigating the efficacy of a support group intervention for adolescents with SCD, patient well-being was found to be positively related to satisfaction with the support group and to absence of SCD complications, including pain (Telfair & Gardner, 1999). Although both these studies demonstrated that adolescents respond favorably to psychosocial interventions designed specifically for this age group, neither study focused on pain management as a direct target of intervention for adolescents with SCD.

Overall, cognitive-behavioral techniques can help to reduce pain or increase positive coping in SCD. However, as previously articulated (Chen et al., 2004), only Gil et al.'s study (1997) met criteria for a "superior to placebo" intervention (Chambless & Hollon, 1998), meeting these criteria because it was manualized and included well-described sample characteristics. However, maintenance of treatment effects has not been documented (Gil et al., 1997), and most SCD interventions did not have follow up longer than 6 months posttreatment. Also, sample sizes are generally small in these studies, although this is not surprising given difficulty engaging African Americans in intervention research (Green et al., 2000). Therefore, although these interventions yielded some positive outcomes, it is possible they may be more efficacious when modified to be more consistent with the unique presentations, needs, and resources of those living with SCD.

Kaslow and colleagues (Kaslow et al., 2000; Kaslow & Brown, 1995) were among the first to argue that to be most effective, interventions with children and adolescents with SCD must be culturally sensitive. They developed and tested a six-session intervention for children and adolescents with SCD ages 7 to 16 and their families that included culturally sensitive components; these included involvement of the family and focus on family strengths, collaborative nature of the intervention, training of the research team on cultural sensitivity with African Americans, and diversity of the research team. This intervention resulted in improved disease knowledge of parents and children, but no differences in distress or family functioning were found. Unfortunately, the study did not assess changes in pain. Despite the cultural sensitivity of the intervention, 6 of the 53 eligible participants refused to participate, and 8 participants dropped out. Older age was a significant predictor of drop-out, indicating that retention of adolescents is particularly challenging. It was recommended that future research include home-based interventions, follow-up assessments past 6 months, and assess a wider range of outcomes including pain, school attendance, and parent and child report of symptoms and distress.

Taken together, the studies reviewed earlier describe potentially effective pain management strategies, whereas the Kaslow studies (Kaslow et al., 2000; Kaslow & Brown, 1995) provided examples of culturally sensitive components of an intervention with children and adolescents with SCD and valuable recommendations for future research. Thus, the intervention described in this article extends previous related research by combining cognitive-behavioral techniques and culturally sensitive components to implement a potentially efficacious and more accepted intervention aimed to reduce pain and improve psychological and functional outcomes among African American adolescents with SCD. This article describes culturally sensitive features of the pain intervention for adolescents and presents initial data on acceptability and feasibility.

METHOD

Participants

Participants were recruited in the sickle cell clinic at an East Coast children's hospital or through phone calls following clinic visits, according to procedures approved by the hospital's institutional review board. Eligibility criteria were (a) between ages 12 and 18, (b) not receiving transfusion or hydroxyurea therapy (to assess the efficacy of CBT with adolescents in the absence of intensive and consistent medical treatment of pain), (c) having either SS- or S-beta-thalassemia type SCD (having these SCD types increases the likelihood of experiencing pain; NHLBI, 1996), and (d) able to recruit a responsible support person to participate in and reinforce information and skills learned in the program. Of 234 potential participants who were approached, 132 were found to be ineligible based on exclusion criteria of being on transfusion or hydroxyurea treatment. Of 102 remaining eligible patients, 58 (57%) agreed to participate, and 49 have completed baseline assessment and have been randomized.[1] Nonparticipants refused mostly due to being too busy (27%) and not being interested in this research (39%). Of the 49 randomized participants, 25 are in the pain management intervention, and 24 are in the disease education attention control condition. Descriptive information and data focus on those in the pain management treatment condition.

The pain management condition consists of 14 females and 11 males with a mean age of 14.32 years old (range = 12–18; *SD* = 1.88). Twenty-two have SCD-SS, whereas 3 have S-beta-thalassemia type SCD. About 46% ($n = 11$) of the sample reported an annual income below $35,000; 5 reported an income between $35,000 and $49,000, 3 reported an income between $50,000 and $74,999, and 5 reported a salary above $75,000 (1 refused to report). Eighteen were from urban areas, and 7 were form suburban areas.

Of 25 participants randomized to the pain intervention who completed baseline measures, 8 discontinued due to no longer being interested, 1 reported being too busy due to starting a new job, and 1 became ineligible prior to starting Session 1 due to the start of hydroxyurea treatment. Many who were not interested or too busy were involved with after-school and evening activities such as tutoring, jobs, and sports; and many parents reported being protective of their adolescents' time. Fourteen have completed the four-session intervention.

Measures

Results focus on treatment expectations and feedback within the pain management experimental treatment group. Measures of treatment expectations and feedback are described below.

Treatment expectations—One question assessed the extent to which the intervention was expected to help adolescents cope with SCD on a 5-point scale ranging from 1 (*won't work*) to 5 (*definitely will work*). Similar one-question treatment expectation questions have been used in other pediatric pain interventions (e.g., Hicks, von Baeyer, & McGrath, 2006)..

Intervention feedback—Three questions using a 5-point scale ranging from 1 (*not at all*) to 5 (*extremely*) asked the extent to which the intervention was perceived by the adolescents and caregivers as helpful, interesting, and enjoyable. This measure is administered during an assessment session that takes place after the intervention is completed, usually around 4 months after the baseline assessment. Assessment of "helpful" was intended as a global measure of the perceived benefit of the intervention. "Interest" was intended to assess the extent to which the participants believed the new information was of interest to them. "Enjoy" was intended

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[1] Recruitment is ongoing. The targeted enrollment for the intervention is 114 (57 in each group).

to assess the extent to which the participants felt they were engaged in and enjoyed participation. In addition, participants were asked if they would recommend the intervention to a friend and to provide any additional comments.

Procedure

Initial sessions are scheduled with interested potential participants whereby consent (and assent for those < 18 years) is attained and baseline measures of disease status, disease knowledge, psychological functioning, and treatment expectations are completed. Unless the families prefer another arrangement, all sessions are held in their homes. Next, participants are randomized to the pain management intervention or the attention control disease education condition. Two trained research assistants conduct each intervention; the pair consists of an interventionist who is in a clinical psychology doctoral program or a postdoctoral fellow and another study team member. Interventionists are trained to conduct both treatment and control interventions. Assignments of interventionists to cases are made based on availability of the interventionists and are independent of the treatment condition to which the case is assigned. Interventionists make weekly telephone calls to the adolescents to answer questions, provide support, and to assess progress on homework.

Pain management intervention—Each intervention involves four 90-min manualized sessions that are audiotaped to facilitate supervision and monitoring of treatment fidelity. Both the adolescent and the support person are required to attend all sessions and are asked to practice treatment components together in between sessions. The sessions include cognitive-behavioral components of pain management such as deep breathing, relaxation, guided imagery, and positive coping self-statements with the goal of increasing independence in using these skills together for the participant and the support person. Two follow-up assessments occur—one takes place after completion of Session 4 at approximately 4 months after baseline assessment. The other posttreatment assessment takes place at 1 year from baseline.

The main objectives of Session 1 are to build rapport, provide an overview of the intervention, understand the adolescent's experience of pain, and introduce deep breathing and relaxation and guided imagery. For the duration of the intervention, participants are expected to practice relaxation and deep breathing and guided imagery with the support person twice daily and to complete the pain diary daily. Session 2 occurs 2 weeks later and entails practicing deep breathing and relaxation and guided imagery with the support person beginning the process of learning to guide the adolescent through the guided imagery. The session also introduces positive coping self-statements, which are to be practiced twice daily from this point forward for the duration of the intervention. Session 3 occurs 2 weeks later and reviews and practices the skills taught in the previous sessions. A tape is made with the support person leading the adolescent through relaxation and deep breathing and guided imagery. Session 4, known as the booster session, occurs 1 month from Session 3 and reviews the cognitive-behavioral pain management components, troubleshoots any barriers to long-term implementation of the skills, and targets any other issues relevant to the adolescent and family's well-being.

Culturally sensitive components—To identify components of the intervention necessary to improve its cultural sensitivity and effectiveness with an African American sample, a review of literature describing issues of cultural competence in interventions with African Americans was conducted. In addition to referring to Kaslow and colleagues' research (N. J. Kaslow et al., 2000; N. K. Kaslow & Brown, 1995), guidelines of the APA (2003) and the recommendations of the report of the Surgeon General (U.S. Department of Health and Human Services, 2001) were also referenced in addition to multiple other sources related to research with African Americans and patients with SCD. This review yielded 10 culturally sensitive components to consider when providing interventions to African American children, adolescents, and families. These include need for family-based intervention, emphasis on empowerment, recognition of stress related to ethnic minority status, identification of stress related to SES (e.g., potential limited resources African Americans of low SES or potential barriers faced by African Americans who have achieved economic success), inclusion of culturally sensitive content, awareness of stigma attached to mental health problems, possible mistrust of research, provision of community- or home-based intervention, flexibility in scheduling, and ongoing training in cultural sensitivity with the research team. These components are described in Table 1, and explanations of how each component are applied and implemented in the current CBT intervention are provided.

One notable feature of the intervention is that it is conducted in a location of the family’s choosing, almost always their home. Conducting the intervention in the home is intended to increase feasibility and acceptability, given that many families of children with SCD have limited resources or time to come to the hospital, and promotes participation of multiple family members in the intervention. In other words, its application represents the need to mitigate the implications of low SES or the demanding schedules of many African Americans and to conduct a family-based intervention. A second important and unique feature of the intervention is that a support person is required to attend all sessions. To date, 16 of the support persons have been mothers, 5 have been siblings, 2 cousins, and 1 each for father and uncle. The aim of this feature is to acknowledge the importance of the extended family in African American culture and to empower the family to work together effectively to manage SCD pain during adolescence. Thus, involvement of a support person is intended to emphasize that pain management need not happen in isolation as adolescents become more autonomous and may be mastered and supported by the family. A last example is that the content of guided imageries is chosen by the adolescents themselves to promote cultural consonance; thus, this content may include action-oriented images rather than typical relaxation scripts such as solitude in nature. Adolescents have chosen images such as playing in a basketball game, going to a church carnival, and playing hopscotch with friends.

To illustrate the integration of some of the components described earlier and in Table 1, consider the case of a 15-year-old girl whose father was identified as the primary support person; however, the mother participated in sessions as her work scheduled allowed. During recruitment phone calls and subsequent participation in the home, the caregivers asked many questions regarding the purpose of the research study and specifics of what was offered through both arms of the intervention, the training and preparation of interventionists, and the time commitment involved. Each question was answered thoroughly to create an atmosphere that accepted the appropriateness of their questions and reinforced them for their time, care, and commitment to meeting all their daughter’s SCD needs. This message was maintained throughout the intervention as, after agreeing to participate and completing the baseline assessment, the caregivers and adolescent continued to ask many challenging questions of the interventionist regarding SCD, aspects of guided imagery that make it potentially effective, and the nature of self-statements. In addition, because of the mother’s nontraditional work schedule and inability to attend all sessions, the interventionist phoned the mother on occasion to inform her of the skills being taught, report progress made, and to answer questions.

Material for the guided imagery came from television shows and activities relevant to the adolescent such as, “The Bernie Mac Show” and bowling. Positive coping statements used relevant language such as “I can work through this,” “I have the power to manage this,” and “God and others can help me.” As the interventionist engaged the adolescent and her caregivers in discussions around each question and included them as collaborative team members, the family began to dedicate time and effort in practicing pain coping strategies daily.

RESULTS

Treatment expectations and participant feedback are presented to support the contention that culturally sensitive components may improve the effective implementation of empirically supported pain management interventions with African American adolescents. In addition, the feasibility of the intervention is discussed.

Treatment Expectations

The average treatment expectation rating for the adolescents at the time of randomization was 4.32 (*SD* = .90; range = 2–5). The average rating of the care-givers was 4.4 (*SD* = 1.13; range = 1–5). After Session 2, the midpoint of the intervention, the average rating for the adolescents (17 have completed Session 2) was 4.07 (*SD* = .92; range = 3–5); the average rating for the caregivers was 3.93 (*SD* = 1.0; range = 3–5). Thus, despite a slight decrease in average treatment expectations at the second time point, adolescents and caregivers had positive expectations for the intervention at the start and at the midpoint. In addition, as opposed to baseline, no one at Time 2 was reporting low treatment expectations as indicated by all answers ranging from 3 to 5.

Intervention Feedback

The adolescents reported an average rating of 3.64 (*SD* = 1.22; range = 1–5) on the helpfulness item, an average interest rating of 3.43 (*SD* = 1.34; range = 1–5), and an average enjoyment rating of 3.64 (*SD* = 1.22; range = 2–5). Caregivers' reported an average rating of 3.93 (*SD* = .83; range = 3–5) on the helpfulness scale, an average interest rating of 3.86 (*SD* = 1.29; range = 1–5), and an average enjoyment rating of 3.57 (*SD* = 1.01; range = 1–5). Thus, all the average ratings were in the range of moderately to extremely in terms of endorsement of helpfulness, interest, and enjoyment.

All adolescents and all but 1 caregiver endorsed that they would recommend the intervention to a friend. Adolescents commented, "Make this intervention available to all sickle cell patients," "The intervention was fun," and "The girls (interventionists) did great." Open-ended comments from caregivers included, "The experience was good for my daughter and myself," "It was a must to have the intervention in the home because I think we wouldn't have been able to participate otherwise. I see the value in the program and hope to use the techniques in other areas and will encourage my teen to do the same," and "It was nice to be able to help my son 'go to the beach' when he was in the hospital." Negative feedback related to too much paperwork.

Feasibility

Despite the challenges of implementing a home-based pain management intervention, the experiences of the study team indicate that it is feasible based on considerations of staff size, time commitment, and safety. On average, four part-time interventionists have been involved in provision of treatment at any given time and three additional staff are assigned to recruitment and assessment. Overall, the staff includes a postdoctoral psychology fellow, graduate students in various mental health programs, and post-bachelor's level research assistants. As indicated in Table 1, all staff receive training on working with African American families, implementing the manualized treatment, and maintaining safety during home visits. Interventions are typically conducted in the late afternoons and evenings primarily during the week, although weekend times are possible. The team has worked flexibly with the adolescents and families' scheduling requirements including varying intervention days and times and between session telephone contacts. Given the extensive safety procedures in place (e.g., traveling in pairs, training in home visit safety, access to a study cell phone and emergency numbers), no study team member has reported feeling unsafe or unwilling to meet the families in their homes. As a result, the interventionists have been successful in maintaining contact with families and traveling safely to home visits.

DISCUSSION

This article describes a cognitive-behavioral pain management intervention for adolescents with SCD that incorporates culturally sensitive components in its design, implementation, and ongoing supervision. The specific components thought to enhance cultural sensitivity of pediatric psychological interventions with African American children and adolescents and their families were presented. Such components include a family-based intervention that not only integrates African American content but also addresses potential barriers to participation such as difficulty coming to the hospital for interventions and mistrust of medical research. Thus, this article documents the importance of addressing cultural variables in the design and implementation of pediatric psychological interventions to improve their acceptability and efficacy. The description of culturally sensitive components also contributes to the broader psychotherapy research literature by highlighting important principles to consider when designing interventions for African Americans.

Treatment expectancy ratings at baseline and after Session 2 indicated that the majority of adolescents and caregivers who agreed to participate in the study were enthusiastic and hopeful about the study, indicating willingness to participate and engagement in the intervention. The treatment satisfaction ratings indicated adolescents and their caregivers generally viewed the intervention as helpful, interesting, and enjoyable. That all the caregivers found the intervention “somewhat” to “definitely” helpful is consistent with other research assessing satisfaction with culturally adapted interventions (e.g., Martinez & Eddy, 2005). However, some adolescents found it was not helpful, and there were some care-givers who found the intervention was less interesting and enjoyable. Many of the adolescents and their caregivers commented that there was too much paperwork and homework. The adolescents’ level of pain may also impact overall satisfaction with the intervention. Those with either chronic severe pain or relatively little pain and their caregivers may have difficulty engaging in CBT pain management. Future analyses will examine the impact of baseline pain on subsequent treatment efficacy and engagement.

The fact that over 50% of those approached agreed to participate in the study is consistent with predicted recruitment rates based on previous time-intensive studies in the sickle cell clinic and the fact that many participants are approached for multiple studies over the same period in the clinic. Unfortunately, 8 of the 25 randomized participants withdrew from the study. Although these findings are preliminary and recruitment and retention rates may change in the final analysis, the rate of drop-out after beginning the intervention is similar to that of the Kaslow and colleagues (Kaslow et al., 2000; Kaslow & Brown, 1995) studies testing a culturally sensitive family-based intervention with youths with SCD and their families. The Kaslow studies found that teenagers were more likely to drop out than younger children, and many studies have found recruitment and retention of adolescents, especially those of ethnic minority status, to be a major challenge (Jenkins & Parron, 1995; Turner, Weilding, & Allen, 2004). Adolescents often have multiple demands on their time including schoolwork, external employment, and extracurricular activities. In addition, requiring involvement of support persons who have similarly demanding schedules, and the need for the availability of the primary caregiver to complete pre- and post-intervention assessments, may also limit availability to participate in the study, despite the provision of flexible hours and home visits. These preliminary findings speak to the need to address perceived barriers early in the recruitment process and to develop strategies to engage adolescents in intervention research. It is possible that recruitment and retention may be more effective with younger adolescents who may have fewer demands on their time. For older adolescents, 1-day workshops with a booster session might address the scheduling problems (e.g., Gil et al., 1997).

Conducting a home-based pain management intervention, with a relatively small research and interventionist team, has proven to be feasible. However, time requirements for maintaining patient contact and receiving ongoing supervision throughout the duration of the intervention are substantial. Modifications based on final examination of efficacious components of the intervention and feedback from the sample following completion of the study may be needed to reduce the time requirements of participants and study team members. Future research should explore the efficacy of a briefer cognitive-behavioral pain management intervention for African American adolescents and their families.

Implications for Practice

As discussed by Kaslow and colleagues (Kaslow et al., 2000; Kaslow & Brown, 1995) and described here, engaging African American children, adolescents, and families in pediatric psychological interventions is challenging, yet important. This is particularly true for specific populations such as children and adolescents with SCD. Interventions should consider the diversity and cultural background of recipients to be most effective. It is hoped that the 10 components of culturally sensitive interventions presented here serve as a guideline for successfully engaging and working with African American pediatric patients and their families. Because the four-session, home-based, cognitive-behavioral pain management intervention described here is unrealistic for standard of care, efforts to develop shorter interventions to teach pain management both in clinic and in the homes should be made. Such interventions could be provided by nurses, social workers, psychologists, or other mental health staff. Implementing such interventions, especially in the home, requires flexibility in scheduling on the part of the interventionists in addition to training in working with African Americans to be best received by patients. Given that most families prefer to schedule sessions at night in their homes, the study would not likely be successful if intervention times were limited to standard working hours in the clinic. Flexibility in the content of guided imagery and coping statements is also recommended when teaching pain management skills to African American children and adolescents. Images that are culturally congruent and distracting rather than traditional relaxing scenarios may be likely to be more accepted and effective with African American adolescents. Similarly, positive coping statements that incorporate the adolescent’s language and include reference to spirituality and ethnic/racial pride may be most effective for African American adolescents.

Although this intervention study identified challenges, preliminary data indicated that most participants engaged in and received the intervention well. Future articles are planned to describe pain and other outcomes of the intervention once data collection is completed. It is hoped that reports of similar intervention research and clinical practice with African Americans describe experiences of successes and failures related to participant recruitment and retention as well as treatment satisfaction and efficacy. Such practice should facilitate a continued dialogue on how to best engage African American children, adolescents, and families into pediatric psychology research and how to provide them with the most effective interventions.

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TABLE 1

Components of Culturally Sensitive Clinical Intervention Research With African Americans

General Components	Broader Explanation and Application	Examples in Pain Management Intervention
1. Family-based (Celano & Kaslow, 2000; Kaslow et al., 2000; Stevenson & Renard, 1993: Sue & Sue, 2003)	• Emphasize role of family. • Open to multiple members of extended family (related or not related) taking part. • Include family in assessment to elicit other viewpoint.	• Adolescent designated support person (family member or friend) attends sessions and works with the adolescent to implement pain management strategies. • Allow for multiple family members to be present and to learn the skills being taught. • Reinforce role of family in adolescent's disease management. • Collaborate with adolescent and support person to develop realistic and feasible pain coping strategies.
2. Emphasize empowerment (Kaslow & Brown, 1995; Stevenson & Renard, 1993; Yoos, Kitzman, Olds, & Overacker, 1995)	• Acknowledge family's social, emotional, and cultural strengths. • Encourage and teach advocacy for self. • Support ethnic/racial pride and spirituality.	• Train adolescent and support person to be in control of managing pain. Assess for and reinforce adaptive coping skills and resources for dealing with SCD and related pain. • Self-statements may be of African American perspective and may include ethnic/racial pride or relate to their faith.
3. Recognize stress related to being of minority status (Clark, Anderson, Clark, & Williams, 1999; Sue & Sue, 2003)	• Understand that African American minority status: (a) results in chronic stress given discrimination and lower status in society, (b) relates to health disparities, (c) may impact how individuals and institutions (e.g., government, healthcare system, school) treat individuals.	• Acknowledge/validate stressors related to minority status, including those that may contribute to pain or to perceived lack of awareness or neglect by medical system or school system. • Allow time and maintain flexibility to problem solve related stressors.
4. Recognize stress associated with SES (potential limited resources or potential barriers faced by African Americans who have achieved economic success (Evans, 2004; N. K. Kaslow & Brown, 1995; McLoyd, 1998)	• Understand that (a) majority of African Americans in the United States are of lower SES, (b) low SES is a chronic stressor given the limited resources and financial struggle, (c) limited resources contributes to health disparities and reduced access to education, (d) African Americans who have achieved economic success often have faced unique barriers and struggles that are not encountered by Caucasians, (e) managing chronic illness may not be family's main priority given need for basic survival, but that does not indicate lack of concern about illness.	• Acknowledge/validate stressors related to limited resources or strive for economic independence that may contribute to pain and limit access to medical care and medication, or that may create additional cumulative stressors. • Address and problem solve related stressors as they arise. • Be flexible and accommodating with regards to scheduling to respect work schedules (often jobs with non traditional hours), limited child care, and transportation issues. • Provide guidance in identifying manageable steps to achieving goals related to managing disease when such goals may conflict with goals related to basic survival.
5. Content should be culturally sensitive (Kaslow et al., 2000; Sue & Sue, 2003)	• Use culturally sensitive assessment materials, supportive materials (handouts, books, pamphlets), and language (i.e., language that is understandable, not offensive, and at appropriate reading level).	• Language of possible self-statements is flexible, broad, and chosen by adolescent. Suggestion list is based on feedback from African American adolescents and young adults. • Participants choose imagery to promote cultural consonance, including active and exciting event like sports or familiar settings. • Music may be incorporated into guided imagery.

General Components	Broader Explanation and Application	Examples in Pain Management Intervention
		• Manual, measures, and handouts are reviewed by members of the medical and research teams who know the adolescents with SCD. Many members of the teams are African Americans.
6. Awareness of stigma of mental health problems (Thompson, Bazile, & Akbar, 2004; U.S. Department of Health and Human Services, 2001; Whaley, 2001)	• Understand the stigma associated with mental health problems and accessing mental health services for African Americans. • Normalize, not pathologize, problems. • Support and reinforce openness, disclosure, and help-seeking behavior. • Join with respected medical providers in advertising and delivering the intervention to avoid association with mental health.	• Intervention is framed as a supplement to adolescents' care to provide additional ways to manage disease. • Structure of intervention is flexible to limit open-ended discussion if it is uncomfortable for participant. • Medical team (including the widely admired program director) help to recruit for and support the intervention. • Reinforce disclosure and openness. • Identified mental health problems are referred to clinic social worker, a respected, and nonthreatening resource.
7. Awareness that many African Americans have a mistrust of medical research (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Green, Maisiak, Wang, Britt, & Ebeling, 1997; Green et al., 2000)	• Understand historical mistrust of medical research on the part of African Americans given past history of exploitation (e.g., Tuskegee airman study). • Recognize increased importance of building rapport and trust.	• Objectives of the study are clearly reviewed during informed consent/assent procedures and at each session; no deception is involved. • Make effort to immediately familiarize participants with the research team via a handout with teams' pictures and names. • Allow time in sessions and weekly phone contact to explore and problem solve other issues, concerns, and questions to build rapport and trust. • Send birthday cards and personalized notes from interventionists after each visit to build rapport and reinforce appreciation of continued participation.
8. Provide community- or home-based intervention (Celano & Kaslow, 2000)	• Appreciate the barriers (e.g., lack of money, time, access to transportation or child care, need to prioritize other family needs) to getting to the hospital or clinic setting for interventions. • Offer interventions that are based in the home or community to increase access to them.	• Participants choose location of the intervention. Almost all prefer their homes. • Develop and maintain procedures for safety of interventionists with regard to questionable neighborhood settings and/or houses.
9. Allow flexibility in scheduling (Kaslow & Brown, 1995)	• It is difficult to maintain a rigid intervention schedule due to the fact that (a) many African American caregivers juggle the needs of extended family members and friends, are working many (and unusual) hours outside the home, and experience many cumulative stressors; and (b) African American adolescents commonly work outside the home or care for younger children.	• Interventions may be conducted at any time in the day ending by 9:00 p.m. to accommodate various preferences and work schedules. • Weekend times are offered. • Participants are reminded of appointment times via phone calls (1 day in advance and within 1 hr of appointment), appointment cards, and letter sent after each session.
10. Research team must be trained in cultural sensitivity with African Americans (American Psychological	• A research team, whether directly involved with patients or not, should have training with regards to culturally sensitive approaches to working with African Americans.	• Research team trained to understand high prevalence of and related complications of SCD, and impact on family, especially within the context of other stressors such as minority status, limited resources, and health disparities.

General Components	Broader Explanation and Application	Examples in Pain Management Intervention
Association, 2003; Kaslow & Brown, 1995	• Team should recognize and address their own misconceptions and prejudices related to working with African Americans. Research team is trained to understand how to effectively interact with and be received positively by African Americans.	• Interventionists are supervised on how their own beliefs impact the delivery of intervention. • Research team is ethnically diverse. • Journal club focuses on articles related to cultural sensitivity and working with diverse populations.

Note. SCD = sickle cell disease; SES = socioeconomic status.