Psychosocial Treatments in Pain Management of Sickle Cell Disease

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The principal symptom of sickle cell disease (SCD) is pain. Many studies have been conducted on pain management strategies for this illness. There is recognition that psychosocial factors influence clinical disease outcomes; therefore, more attention is being provided to behavioral interventions that address psychosocial problems. This review examines the psychosocial interventions that have been researched for children and adults with SCD, the limitations of these studies, and barriers to implementing the treatments. The intervention receiving the most empirical support was cognitive-behavioral therapy. Additional research is needed to define the efficacy and effectiveness of the other psychosocial treatments. Suggestions for future investigations include conducting research that has better methodology, and providing more education for health care providers about psychosocial treatments and the importance of considering cultural factors in health care delivery. In addition, individuals with SCD need to have more information about their illness and better access to psychosocial interventions.

Keywords: psychosocial ■ pain management ■ sickle cell anemia ■ pain ■ chronic illness

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INTRODUCTION

Sickle cell disease (SCD) refers to a category of inherited conditions in which the hemoglobin is irregular.[1] This gene mutation causes the hemoglobin to assume a sickled shape that promotes vaso-occlusion[1] and painful episodes with disability.[2] These painful episodes are unpredictable and vary in frequency among people with SCD.[2] Vaso-occlusion also restricts circulation of blood with oxygen and nutrients to tissues throughout the body (ischemia) and can lead to subsequent necrosis.[3] SCD is inherited by recessive genes from both the mother and father.[3] Nearly 50 000 Americans in the United States have SCD, and the majority are of African descent.[1] It has been estimated that 1 out of 300 to 400 African Americans has some form of SCD.[4] SCD is an illness characterized by repeated hospitalizations, decreased psychological functioning, and poor quality of life.[5,6] SCD pain is unique from other chronic illnesses because of its erratic, reoccurring, and persistent pain.[7] There is growing recognition that psychosocial factors influence clinical disease outcomes,[8-12] and as such, much attention is being provided to behavioral interventions that address psychosocial contributors.

Psychosocial treatments are increasingly considered as part of the standard of care for patients with SCD but are often neglected in formal literature reviews and meta-analytic pursuits.[13] The current review focuses exclusively on this often-neglected sector of the literature. A search was conducted using the PsycINFO database and the words *sickle cell* and *pain*. Studies were included in this review if they investigated the use of a psychosocial pain management intervention for individuals with SCD. No biomedical interventions were included in this review. This review will articulate the 5 psychosocial interventions most frequently utilized in the management of pain in the sickle cell population (Table). These methods include cognitive-behavioral treatments, self-regulation strategies, interventions aimed to produce behavioral change, psychosocial support treatments, and educational programs. In addition, the review addresses the impediments to using psychosocial interventions and the methodological issues that should be considered when researching psychosocial treatments for the management of SCD pain. Finally, the implications of the research and future directions are discussed.

PSYCHOSOCIAL INTERVENTIONS FOR SICKLE CELL DISEASE PAIN

Cognitive-Behavioral Strategies

Cognitive-behavioral strategies are the most thoroughly researched behavioral interventions for managing SCD pain.[14] One of the central components

of cognitive-behavioral therapy is to investigate and modify patients' thoughts, beliefs, feelings, and behaviors.[15] In addition, cognitive-behavioral therapy incorporates behavior therapy strategies to promote change. Such techniques may include training in relaxation techniques, graded practice, and homework assignments toward the reduction of pain.[11] Cognitive-behavioral therapy aims to reduce the occurrence and intensity of pain. However, alleviating pain is not the main objective; the goal is to help individuals have a good quality of life in spite of the pain.[16]

Gil and colleagues examined whether cognitive coping skills can help children and adolescents cope with pain and alter their perception of pain.[17] Forty-nine African American children and adolescents with SCD participated in this study. The participants were split into 2 groups: a cognitive coping skills group and a standard care control group. Pre-post measurement included a laboratory pain

Table. Summary of Psychosocial Treatments for Individuals With Sickle Cell Disease

Cognitive-Behavioral Treatments	Subjects	Type of Study/ Intervention	Outcome
Gil et al, 1997	49 African American children and adolescents	Cognitive coping skills group vs standard care group	Participants in the coping skills group had lower negative thinking scores and less pain when administered laboratory pain task (Forgione-Barber focal pressure stimulator).
Gil et al, 1996	64 African American adults	Cognitive coping skills training group vs disease-education control group	Adults in the brief cognitive training group had more attempts at coping, less negative affectivity, and fewer reports of pain during experimental pain stimulation (Forgione-Barber stimulator).
Gil et al, 2000	68 African American adults	Coping skills condition vs education control group	Those in the intervention group had lower levels of laboratory pain and more coping attempts.
Gil et al, 2001	46 African American children	Coping skills condition vs standard care control condition	Children in the coping skills condition reported using more active coping strategies than those in the control condition. On days when in pain, children who used their coping strategies had less contact with health care providers, fewer absences from school, and fewer problems with doing activities in the household than when they did not practice their skills.
Thomas, Dixon, & Milligan, 1999	59 Adolescents and adults	Cognitive-behavioral therapy administered in a group setting vs attention placebo group vs treatment as usual	Participants in the intervention had more positive coping skills, were more active, and had more self-efficacy in managing pain.
Anie et al, 2002	35 Black adults in the United Kingdom	Self-help manualized treatment	Individuals who received treatment coped more effectively with pain; cognitive-behavioral therapy did not decrease actual pain experiences.
Cummins & Anie, 2003	36 Black adults in the United Kingdom	Cognitive-behavioral therapy vs hydroxyurea	Individuals in the cognitive-behavioral therapy group had shorter hospitalizations, better general health perceptions, used more psychological coping strategies for pain, and had more pain episodes than those using hydroxyurea.
Schwartz, Radcliffe, and Barakat, 2007	49 Adolescents aged 12-18 years	Culturally sensitive cognitive-behavioral therapy for pain vs disease education	The cognitive-behavioral therapy intervention was feasible and participants reported that they enjoyed the intervention and that it was interesting and helpful.
McClellan et al, 2009	19 individuals between 9 and 20 years of age	Cognitive-behavioral therapy with handheld wireless device within subjects design	Found that such an intervention was feasible.

task and questionnaires. The Forgione-Barber focal pressure stimulator[18] was used in which a plastic edge applies pressure to a finger continuously. Eventually, the pressure builds to a dull aching pain. Applying different weights to the pressure stimulator results in varying pressure intensities. The study used 4 levels of intensity: light, medium, heavy, and very heavy. At posttest, children who received the intervention had lower negative thinking and reported less pain when the stimulus was at a low level than those in the control group. There was a positive correlation between improving coping skills and improving pain sensitivity (or reports of pain).

The Gil and colleagues study[17] is notable because it incorporated laboratory procedures for measuring pain perception into a clinical approach in order to understand treatment-related factors in children with SCD pain. The study also highlighted individual differences in expression of pain. They found that some children's report of pain is immediate and their pain response is intense, whereas others are stoic and endure pain for longer periods before reporting discomfort. This can make assessing pain difficult. Using pain stimuli that are calibrated can allow painful stimuli to be standardized and reliable, and it can allow for the examination of individual differences in reporting and responding to pain.[19]

The research's weakness is that no follow-up data were reported to see if the results would be sustained over a long period of time. Also, children in the skills training condition had the opportunity to use the laboratory pain stimulation device before the experiment so as

Table. Summary of Psychosocial Treatments for Individuals With Sickle Cell Disease (cont)

Self-Regulation Strategies	Subjects	Type of Study/ Intervention	Outcome
Hall, Chiarucci, and Berman, 1992	1 Participant	Case study using relaxation, imagery, and biofeedback	The participant's pain decreased; recommend that self-regulation techniques be used with mild sickle cell pain
Cozzi, Tryon, and Sedlacek, 1987	8 Participants between the ages of 10 and 20	Biofeedback-assisted relaxation training	No significant change in number of hospitalizations. There were significant decreases in headaches as a symptom of SCD, medication use, reported pain intensity, and painful episodes that were self-managed.
Thomas, et al, 1984	15 Patients	Training in relaxation, cognitive strategies, thermal biofeedback, and self-hypnosis	Outcomes were not significant, but did show trends in decreased contact with hospital staff, less use of medication, and less time spent hospitalized.
Manusov, 1990	1 Participant who was a 28-year-old woman in labor and also having SCD pain episode	Case study, anecdotal	Through hypnosis, the therapist induced glove anesthesia in which the woman transferred the suggestion of analgesia in a hand to painful areas of her body.
Zeltzer, Dash, and Hollabd, 1979	Two 20-year-old participants with frequent hospitalizations and complications	Case study, anecdotal	The 2 individuals were able to have pain relief from SCD through the use of hypnosis.
Dinges et al, 1997	Cohort of 37 individuals with SCD who were children, adolescents, and adults	Cognitive-behavioral therapy with self-hypnosis vs treatment as usual	Significantly reduced frequency of SCD pain episodes, less reliance on pain medication; reduced pain unrelated to SCD. The intervention was shown to be more effective against milder vaso-occlusive pain, but not as effective for severe SCD pain.
Behavioral Interventions	**Subjects**	**Type of Study/ Intervention**	**Outcome**
Burghart-Fitgerald, 1989	1 participant who was an adolescent	Case study, anecdotal	This was a case study that described some of the reasons for using pain contracts with adolescents who had a sickle cell pain episode and how nurses could create and implement behavioral contracts in a clinical setting.

to practice their skills. Having access to that pain stimulation may mean that they acclimated to the pain because of feeling it before and knowing what to expect. The results obtained may have less to do with the skills training and more to do with having previous contact with the device.

The authors note that future studies need to incorporate controls for contact with the pain stimulation device. Additionally, some have questioned whether laboratory pain methods are similar to clinical pain.[19] The authors defend their technique by stating that in another study, the correlation between ratings from 2 different McGill Pain Questionnaires (one for lab pain, another for SCD pain) were significant, although not high. It is important to note that the findings of this study showed that children in the coping skills training group reported less pain only when the stimulation intensity was low. However, SCD pain can be of a very high intensity, and more research is needed to find out what skills can be taught that can deal with this high amount of pain.

Gil and colleagues completed a follow-up study,[20] which found that among children who received a 1-session cognitive-behavioral treatment and who actively coped with their pain when it was high, there were fewer health care contacts and less impairment in daily activities. The study also indicated that brief training in coping skills led to less negative thinking and reports of pain in the short-term, but such outcomes were not maintained after 1 month even with minimal therapist contact. The outcomes not being maintained after 1 month could be the result of the intervention not being potent enough to lead to longer-term change in negative thinking and reports of pain. Future research should be done in which participants receive a stronger and more intense intervention, such as treatment that includes more therapist contact with the patients. In addition, long-term follow-up for a minimum of 1 year should be done to ascertain whether the results would be maintained over a longer period of time.

Another study by Gil and colleagues investigated

Table. Summary of Psychosocial Treatments for Individuals With Sickle Cell Disease (cont)

Psychosocial Support Techniques	Subjects	Type of Study/ Intervention	Outcome
Butler and Beltran, 1993	24 Participants	Qualitative study of a patient education program which later developed into a support group	The authors found that participants who were in a social support group tended to report improvement in their confidence to manage their pain, and the members had a shorter recovery time from painful episodes. No statistical information was provided.
Belgrave and Lewis, 1994	49 African American adults with SCD and 78 individuals with diabetes	Survey data	Study found that social support was significantly related to keeping appointments with physicians and adhering to health recommendations for individuals with SCD and diabetes.
Fox and Ingram, 1999	Children with SCD and adults with SCD (sample size not given)	Qualitative Study; Interviews; Anecdotal	Contact with positive role models and social support groups were helpful for pain management. Children seeing their peers coping well with blood draws helped them to cope well with the pain of having their blood drawn.
Educational Programs	**Subjects**	**Type of Study/ Intervention**	**Outcome**
Butler and Beltran, 1993	24 Participants	Education program about SCD	Adults with SCD who participated in the group educational program had better relationships with health care providers, communicated their health concerns better, and were more willing to seek outside help. Some of the psychological interventions taught to manage pain led to hastening recovery from painful episodes. The participants were still very dependent on analgesics for pain management.

Abbreviation: SCD, sickle cell disease.

whether cognitive coping skills training could improve pain coping strategies and change pain perception in adults with SCD.[21] Sixty-four African American adults with SCD were randomly assigned to 1 of either 2 groups: cognitive coping skills training group or a disease-education control group. The study was based on sensory decision theory and pain sensitivity was measured with the Forgione-Barber focal pressure stimulator. Results indicated that the participants in the brief cognitive training group had more attempts at coping, less negative affectivity, and fewer reports of pain during the experimental pain stimulation than the control group.

The pain administered in the Gil and colleagues study was similar to low-intensity SCD pain.[21] It would be interesting to see if the same results would occur with higher-intensity pain. Such an experiment could not occur, according to Gil and colleagues,[21] because they were uncertain if higher, ischemic pain resembling SCD would in fact trigger a pain episode. Furthermore, the study did not find significant effects of coping skills training on disease severity (pain frequency, severity, and duration). The reason for these results could be that the study only evaluated effects after 1 month; painful episodes usually occur only once every 4 to 6 weeks.[22]

To address weaknesses in the Gil and colleagues research,[21] another study was conducted that followed the same participants along with 4 more individuals over a 3-month postintervention period.[23] Participants were randomly assigned to either a coping skills condition with daily diaries or education control group. The results indicate that those in the intervention group reported significantly lower levels of laboratory pain and significantly more coping attempts. It was found that the benefits of coping skills training obtained in the original study[21] were only maintained after a 3-month period if those skills were continuing to be practiced. This study is the first to support the belief that using coping skills on a daily basis will lead to more successful self-management of pain and fewer contacts with health care professionals. However, no significant effects were found regarding coping skills training and disease severity. Relying solely on group membership and disease severity may lead to patient improvements in severity of symptoms being overlooked. However, because of the study's use of daily diaries tracking participants' experience of pain and coping mechanisms, more information was able to be obtained about coping mechanisms and improvements in severity of symptoms.

Analyzing the diaries allowed for 2 more observations: although participants in the coping skills condition were told to practice the skills daily, sometimes they did not; and pain, coping practice, and contacts with health care professionals could be examined on a daily basis. While there are benefits to using daily diaries, there are some limitations to this method of data collection.[23] There may be missing data, and there may be variables that bias the information in the diary. Nonetheless, the qualitative information that a diary provides can lead to more insights into ineffective and successful pain management.

Schwartz, Radcliffe, and Barakat[24] conducted a study in which a culturally sensitive cognitive-behavioral pain management treatment was administered to adolescents with SCD. The authors focused on a description of the cultural sensitivity factors within the intervention and the feasibility and participant feedback regarding the treatment. The participants reported that the intervention was interesting, helpful, and enjoyable.

The participants were between the ages of 12 and 18 years and were eligible for the study if they did not receive transfusion or hydroxyurea.[24] The authors stated they did not include patients who were receiving transfusions or hydroxyurea because they wanted to exclude patients who were receiving regular and intensive medical treatment of pain. However, transfusions and hydroxyurea are not used solely in the medical treatment of pain. For example, blood transfusions also are used to prevent stroke and treat acute chest syndrome,[25-27] and hydroxyurea also has indications for preventing acute chest syndrome, stroke, and spleen dysfunction.[28,29]

In attempting to exclude individuals who are receiving regular and intensive medical treatment of pain, the authors failed to exclude or consider an important variable: narcotics for chronic pain management. Of the 234 participants who were approached for the study, 132 did not meet inclusion criteria and of the 102 remaining eligible patients, 49 participated and were randomized to the treatment and control groups. If the inclusion criteria were less stringent, more participants would have been eligible for the study, thereby impacting power. In addition, the authors provided no information about the participants who were randomized to the pain education condition. It would have been helpful to have information about attrition in order to ascertain whether both groups were similar to one another and to assess for bias. Instead, the authors explained that the study focused mainly on the treatment expectations and feedback and that, therefore, data would be provided only on the pain intervention condition. The study was notable in that it incorporated cultural sensitivity in implementing the pain management intervention, the treatment was mobile and was able to be delivered at home or wherever the participants felt most comfortable, and the authors demonstrated feasibility of the intervention. In addition, the authors indicated that the participants had positive feedback regarding the intervention. It would have been useful to have information regarding whether the participants in the education control condition had similar comments as the intervention group and to assess for whether such endorsements related to the actual intervention or having increased attention from mental health care providers.

Studies have investigated several ways of delivering

cognitive-behavioral therapy. Three methods include cognitive-behavioral therapy delivered in a group setting, manualized self-help cognitive behavioral therapy, and cognitive-behavioral therapy administered via handheld wireless devices. Thomas, Dixon, and Milligan[30] researched the effectiveness of cognitive-behavioral group therapy for pain management. The researchers found that adolescents and young adults who received 2 months of cognitive-behavioral therapy sessions administered weekly had more positive coping skills, were more active, had more self-efficacy in managing their pain, had better pain control, and reported less pain ratings that were affective (which may indicate perceiving the pain as being less distressing) than controls.

Anie and colleagues investigated self-help manualized treatment in conjunction with a cognitive-behavioral therapy intervention to examine if pain, coping ability, and health care use could be improved.[31] The results indicated that participants who received cognitive-behavioral therapy coped more effectively with their pain. That is, the participants' affective coping (emotionally responding to pain through fear, anger, or catastrophizing) decreased, active coping (increasing activity and redirecting attention away from pain) increased, and passive adherence coping (adhering to physician's recommendations such as fluid intake and rest) increased. However, objective measures of pain revealed that cognitive-behavioral therapy did not reduce the patients' actual pain experience. This shows that although pain may not be directly affected by a psychosocial intervention such as cognitive-behavioral therapy, the perception and psychological coping ability of individuals who use cognitive-behavioral therapy may be changed. This highlights the importance of using not only objective measurements of pain but also investigating the subjective experiences and psychological management of pain.

McClellan and colleagues[32] investigated whether using a handheld electronic wireless device to implement a cognitive behavioral coping skills protocol would be feasible in a pediatric SCD population. The study entailed having participants between the ages of 9 and 20 years complete a single session training on the use of cognitive-behavioral coping skills followed by directions for how to use the device to practice the skills and monitor daily pain. The results indicated that the rates of participation, daily diary completion, and consumer satisfaction were high. While the focus of the study was on the feasibility of using an electronic handheld wireless device for cognitive-behavioral therapy, finding out whether such an intervention would lead to other outcomes (ie, decreased reports of pain, improved coping, decreased psychological symptoms) would have been helpful. Future research is needed to find out if such an innovative intervention would lead to improved psychosocial and physiological outcomes.

Self-regulation Strategies

Self-regulation strategies refer to hypnosis and biofeedback techniques aimed at managing and controlling pain.[33] Hall and colleagues speculated that SCD pain is caused by ischemic tissue damage as a result of sickled cells blocking blood flow.[33] Vasodilating drugs have been shown to be effective in reversing ischemic injury in the retina.[34] Hypnosis has been related to increased temperature in different parts of the body, such as the hand and foot.[35] Such increases in temperature may provide an estimate of vasodilation, which indicates that the blood vessels are expanded.[33] Hall and colleagues suggest that self-regulation approaches may affect SCD in a positive way psychologically and physically because of vasodilation.[33] The authors also gave information about a specific case in which the self-regulation training in relaxation and imagery was used in addition to biofeedback and resulted in decreased pain. The authors recommend that self-regulation techniques be used with mild sickle cell pain, and that more intense pain should be managed with medical treatment.

Cozzi, Tryon, and Sedlacek[36] investigated whether biofeedback-assisted relaxation training sessions could produce vasodilation and reduce emotional factors that lead to vaso-occlusion. The results indicate that although there was no significant change in hospital visits, there were significant decreases in headaches as a symptom of SCD, medication use, reported pain intensity, and painful episodes that were self-managed. The authors suggest that the biofeedback-assisted relaxation strategies may either be useful for milder forms of painful episodes, or the participants may need more training in the techniques in order for it to be effective for more intense pain. The researchers also state that participants should use their relaxation skills to control pain only after the techniques are well developed so as to prevent the reported frustration that the subjects had in this study. Because Cozzi and colleagues[36] only had patients who had been admitted to the hospital at least 3 times in the past year, they may have missed other patients who have milder cases of SCD. In addition, the small sample size limits the generalizability of the results. There was no control group, so it is unknown if this is a placebo effect or not.

Thomas conducted a noteworthy study in which 15 patients with SCD were trained in progressive relaxation, cognitive strategies, thermal biofeedback, and self-hypnosis to help them manage their pain.[37] This research is remarkable in that it is one of the earliest studies investigating the role of biofeedback therapy in pain management for SCD. The participants were allowed to participate in 15 sessions along with their families, but they were permitted to go at their own pace.[37] While the results did show decreased contact with hospital staff, less use of medication, and less time spent hospitalized, the outcomes were not significant. Nonetheless, the author made some strong points with

the research. As a preliminary study, it suggests the potential of biofeedback therapy and psychological management of pain. However, there was much variability in the interventions administered because the individuals in the study were allowed to participate at their own pace. Therefore, it cannot be made certain that the specific strategies taught would be related to any of the results they found, although nonsignificant. Furthermore, the small sample size may account for the lack of significance of the results. In addition, the authors stated that the participants had apprehension about doing well with self-management of their pain for fear that they would receive less or no analgesia for pain. Perhaps this fear affected their responses on the outcome data.

Although some have argued the limited use of hypnosis in managing medical outcomes,[38] the notion that hypnosis may be used to manage pain discomfort in SCD has received attention. Research that has delved into hypnosis as a way to manage sickle cell pain has been scarce; the few studies that have been done lack methodological and statistical rigor, however they have provided preliminary data that suggest this technique does have some merits.

Manusov,[39] for example, discussed the case of a 28-year-old woman who was in labor and who was also having an SCD pain episode. Her pain was unresponsive to usual medical treatment. Through hypnosis, the therapist induced glove anesthesia in which the woman transferred the suggestion of analgesia in a hand to painful areas. While Manusov's article provided general information about hypnotherapy and its possible use in SCD pain management, the limitation is that there is a lack of detail on the case he presented and the information provided is mostly anecdotal and based on the author's experience.

Zeltzer, Dash, and Holland[40] were actually the first to investigate whether hypnosis was effective in the treatment of SCD pain. They described 2 cases in which the participants were 20 years of age and had a history of frequent hospitalizations and complications resulting from SCD. The authors found that the 2 individuals were able to have pain relief from SCD through the use of hypnosis. The case studies that the authors presented provided an impetus for future research into hypnosis as a treatment for sickle cell pain; however, they provided few details concerning the hypnosis sessions and techniques offered to the participants. Also, no statistical information was given regarding whether the results obtained were significant.

Dinges and colleagues[4] investigated self-hypnosis training and its effectiveness in SCD pain. This study is important in that it has better methodology and provides more rigorous evidence to the effectiveness of hypnosis in pain management. A cohort of 37 individuals with SCD (children, adolescents, and adults) who had 3 or more pain episodes in the last year participated in a cognitive-behavioral pain management program consisting of self-hypnosis training in a group setting and the use of daily pain diaries for 18 months. The study compared treatment-as-usual for SCD pain to conventional plus self-hypnosis interventions. The authors found that the frequency of SCD pain episodes and reliance on pain medication were significantly reduced after the self-hypnosis pain intervention was administered. However, participants who did not improve as much were less likely to decrease their pain medication use. Twenty-four percent of the participants failed to show any decrease in SCD pain frequency after the intervention; however, these participants also relied more on medication to manage pain episodes at baseline. Self-hypnosis training also was related to a reduction in pain unrelated to SCD. The self-hypnosis was more effective against milder vaso-occlusive pain but not as effective for severe SCD pain. The authors also noted that after adequate training early in the process, benefits can be maintained with periodic "booster" sessions.

Some of the participants in Dinges and colleagues' study[4] declined to participate in the study due to religious reasons. Future research should see if some of the factors inherent in self-hypnosis could be used for these types of participants so that they can receive the benefits while at the same time, not feel that their religious beliefs were being compromised.

The study had limitations in that family and friends were invited to participate in the sessions, which may confound results. Perhaps participants that had family and friends with them had additional support and therefore, were better able to do the self-hypnosis. Additionally, although the group sessions were divided according to age groups, more information regarding developmental considerations was not provided. The developmental considerations are important because they can affect how a child can deal with self-hypnosis in an effective way. There is also a lack of specificity as to which factors may have contributed to the results obtained in the study. The participants were highly motivated to control their pain, there was family and peer support, there was a positive therapeutic relationship with the health care providers, and the participants had less anxiety because they were educated about SCD and pain. If any of the aforementioned factors were missing, it is possible that the same results would not occur.

Behavioral Strategies

Behavioral strategies can include behavior modification and behavioral contracts. An example of a behavioral strategy for managing pain is operant conditioning.[41] The aim of behavior modification is to focus on behaviors, not sensations of pain. Therefore, pain behaviors such as inappropriate groans and complaints are ignored, while attempts toward more physical activity and other positive behaviors are rewarded.[41] Pain behavior contracts refer to an agreement between health care

staff and patients about the behaviors both parties are expected to exhibit during hospitalization.[42] Pain behavior contracts may have the goal of increasing self-care among patients. Self-care occurs when patients are actively involved in maintaining their health and well-being; it involves the skills, abilities, and attitudes that allow individuals to master their environment.[43] Self-care has been shown to be related to better quality of life, less contact with hospital staff, and decreased pain among individuals with SCD.[43]

There is a scarcity of research about behavioral techniques that are being used in pain management in SCD. A few studies have investigated the role of behavioral techniques on a combination of health outcomes, such as adherence and pain behaviors. Burghart-Fitgerald[42] used behavioral strategies specifically to target pain behaviors. This research was a case study that described some of the reasons for using pain contracts with adolescents who have a sickle cell pain episode. Burghardt-Fitzgerald[42] also discussed how nurses could create and implement behavioral contracts in a clinical setting.

Social Support Interventions

The rationale for using social support interventions is the belief that social support may be a protective factor against poor health or early death.[44,45] Berkman and Syme[44] found that social ties and positive health behaviors were strongly correlated with mortality such that individuals residing in a California community who had fewer social contacts were less likely to use preventive health care services. Social support may be an important variable to consider when providing pain management interventions to individuals with SCD especially because ethnic minorities tend to rely more on respected laypersons for health information than health care providers.[46] Obtaining social support may be especially important for individuals with SCD because the illness can cause disruptions in social networks and rejection from peers.[47] Interventions that take into consideration the importance of culture and social support may prove to result in positive outcomes regarding pain management.

Butler and Beltran[47] developed a patient education program comprised of 5 biweekly sessions, which later developed into a support group for adults with SCD. The authors found that participants who were in a social support group tended to report improvement in their confidence to manage their pain, and the members had a shorter recovery time from painful episodes. The study was qualitative and provided information about the participants in the support group that may not have been available through quantitative research. For example, the authors found out about the participants' feelings regarding their distrust of health care providers, which may not have been a topic of concern at the outset of the support group. The authors also learned of the impact of the disease on vocational and social relationships. No statistical information was provided about the support group, such as the degree to which their confidence in pain management improved or the amount of change in recovery time from painful episodes. Furthermore, there was no control group and no data were reported regarding variables (such as self-efficacy and recovery time) pre and post intervention.

Social support may be important to facilitate compliance with medical recommendations that prevent or treat painful episodes. Belgrave and Lewis found that social support was significantly related to keeping appointments with physicians and adhering to health recommendations.[48] This study had limitations in that the participants were individuals who attended an urban clinic, thereby excluding individuals who were noncompliant with recommendations to attend clinic regularly. Also, self-report measures were used to rate adherence to medical regimens, which lends to participants not reporting accurately whether they were following recommendations of health care providers. Interestingly, this study was the earliest of its kind to report a link between social support and health care compliance among the sickle cell population.

Fox and Ingram's qualitative study based on interviews with individuals who had SCD found that contact with positive role models and social support groups were helpful for pain management.[49] The authors reported that children seeing their peers coping well with blood draws helped them to cope well with the pain of having their blood drawn. While this finding is not related directly to a vaso-occlusive event, it demonstrates the possibility that identifying with and being exposed to individuals who cope well with pain may help patients with their own discomfort.

Education and Medical Self-management

Education about SCD and management of the disease is important in preventing pain and serious complications from the illness. Adhering to medical regimens such as taking medications, seeing health care providers regularly, and drinking plenty of fluids can be essential to improving the quality of life of individuals with SCD.[48] In order for such medical adherence to take place, individuals with SCD must be knowledgeable about their illness.

Butler and Beltran completed a qualitative study on an educational program they conducted over 5 sessions on a biweekly basis in which the participants were taught, in a group format, information about SCD.[47] Butler and Beltran's study found that the adults in the educational program had improved relationships with health care providers, communicated their health concerns better, were more willing to seek outside help, and recovered more quickly from painful episodes.[47]

Although this study found positive results concerning

education and better relationships with the health care professionals, the participants were still very dependent on analgesics for pain management. While at first this may seem like a negative outcome, there may be some positive aspects to the individuals relying on pain medication such that the participants may have been following the direction of their health care providers to use medication upon first noticing pain so as to avoid having severe pain. It would have been useful if the authors provided information about the participants' medication use before attending the education program and after so as to ascertain whether their medication use increased or decreased, and to find out whether the individuals had better knowledge about how to correctly take their analgesics.

IMPEDIMENTS TO USING PSYCHOSOCIAL INTERVENTIONS

In order for psychosocial interventions to be administered for pain management, several barriers must be removed. A good relationship between the patients and the health care providers must occur. For example, some health care providers may believe that individuals with SCD are not in pain; that in fact, their experience is purely psychological.[50] In addition, individuals with SCD may try to manipulate the hospital staff and overexaggerate symptoms in order to obtain analgesia.[50] The maladaptive coping patterns of the patients can be reinforced when the hospital staff looks at pain as solely being the result of vaso-occlusion and not consider psychosocial factors that can impact and lead to real pain. Harris, Parker, and Barker reported that individuals with SCD may distrust health care staff.[2] One study found that people with SCD felt that health care providers did not believe that they were in pain and tended to underprescribe medication, while, at the same time, individuals who were rarely admitted to the hospital for pain reported that medical personnel overprescribed drugs.[51] In addition, people with sickle cell disease have reported feeling stigmatized and that health care professionals view them as being drug addicts.[51] Education is needed for the individuals receiving the intervention and the medical personnel as to the benefits of psychosocial treatments.

Additionally, an awareness of the cultural and financial factors that play a role in access to care is needed in order for psychosocial interventions to be truly effective. There may be cultural differences in how individuals exhibit pain behavior; that is, being emotional, stoic, demanding, or vague in describing pain may be reflective of culture.[52] Previous studies have shown that ethnicity affects treatment for acute pain, whereby Caucasians were more likely than African Americans to be prescribed pain medication for fractures.[53] While there have been several studies that have found differences in analgesia prescriptions based on race, there is also research that did not find such a result.[54]

Families from a lower socioeconomic status have been shown to have more barriers to health care for children with SCD.[55] Such barriers may include lack of transportation and lack of resources for health care costs. African Americans are less likely than Caucasians to have a primary physician, and therefore tend to rely on emergency departments for health care.[56] This means there is less likelihood that preventive care will occur and that medical aid is provided as a response to a symptom.

Most importantly, qualified mental health care providers are needed so that psychosocial treatments can be offered to individuals with SCD and their families. There is a paucity of research on the availability of psychosocial providers in sickle cell clinics. However, it has been reported that there is a shortage of mental health care providers in rural settings.[57]

METHODOLOGICAL ISSUES

The aforementioned psychosocial interventions have demonstrated potential in the management of pain associated with SCD. However, there are several methodological issues that should be noted when considering the efficacy of these interventions and when developing future research. Such problems include using small sample size, not using control groups, and not considering treatments that have cultural and developmental sensitivity. In addition, studies that have investigated pain management in SCD tend to not be grounded in theory. Theorizing about the underlying constructs concerning pain management in SCD may allow for there to be better interventions and more structure to the research that is being conducted. For example, it has been shown that cognitive-behavioral interventions have been efficacious in pain management for SCD, but specific intervening variables that affect how individuals cope with discomfort have not been identified in a consistent, organized manner.

It is important to consider the type of pain individuals with SCD have. Walco and Dampier pointed out that the way in which SCD pain is defined directly influences the interventions employed.[58] Vaso-occlusive episodes that occur 1 or fewer times per year with a hospital stay of 7 days was reported as being ideal for acute pain management.[58] Such treatment would include rest, analgesia for pain, and immobilization. After the painful episode, patients usually return to normal functioning. However, for the small amount of individuals who have frequent sickle cell pain, treatment that focuses on acute pain is not appropriate. These individuals were in the hospital longer and admissions ranged from 3 to 12 annually; treatment based on reoccurring acute or chronic pain management would be appropriate.[58] Also, taking a strengths-focused approach may lead to new directions in research and interventions that are more successful. This focus on the strengths of individuals with SCD can possibly lead to new directions and techniques for pain management that may not have been addressed before in the literature (such as the use of prayer and religion). It should be noted that,

although there are some methodological weaknesses, the studies have shown there is promise in managing sickle cell pain via psychosocial techniques.

CONCLUSION

The current review explored psychosocial interventions for the management of symptoms in pediatric and adult patients with SCD. The psychosocial approaches for pain management include cognitive-behavioral therapy, self-regulation strategies, interventions aimed to produce behavioral change, psychosocial support treatments, and educational programs. Each strategy has its strengths and limitations; however, the intervention receiving the most empirical support is cognitive-behavioral therapy. Additional research is needed to define the efficacy and effectiveness of the other behavioral strategies and to build upon their strengths when they exist.

Being that cognitive-behavioral therapy is the treatment that has the most empirical support, mental health care providers as well as those providing health care should encourage patients with sickle cell disease to use cognitive-behavioral strategies as they cope with their pain. Such strategies would include relaxation, imagery, modifying cognitive distortions, and changing negative thoughts into positive ones.[11,15] In addition, health service providers should refer patients to psychologists and mental health care providers who have extensive experience in cognitive behavioral therapy for pain management.

We reviewed barriers to implementing psychosocial interventions and the methodological factors that should be addressed when researching strategies aimed to manage SCD pain. The studies that have been conducted tend to not have a cohesive direction. There is a need for research that is more focused and that can build upon what has already been learned in this area. For example, much of the research has replicated the findings of what already has been done. It would be better if research could focus on having better methodologies that could therefore lead to more specific and stronger conclusions. Research that has theory as a foundation could allow the researcher to have more direction in the hypotheses investigated. Having a model from which research can be conducted could lead to a more unified way of addressing pain management in SCD.

Methods of delivering the interventions and dissemination issues are also important. Individuals with SCD may have financial difficulties preventing them from having access to mental and medical care personnel so that they can obtain the psychosocial intervention. Health care providers and psychosocial interventionists could ensure that treatment is available by reaching out to individuals with SCD in their own community instead of through traditional means such as doctors' offices. This is imperative because many with SCD rely on emergency departments for their health care. Furthermore, educating emergency department personnel about SCD and the need for psychosocial interventions may help in getting individuals with SCD referred to psychosocial treatments. This may also help to diffuse the tension that can sometimes arise between medical staff in the emergency room and individuals with SCD regarding pain management.

Individuals with SCD may be hospitalized on a regular basis, thus missing psychosocial intervention sessions. It would be useful if the number of sessions needed for a successful outcome was known, and having sessions of short duration proven to be effective would especially be helpful. There is ample evidence that pursuing psychosocial interventions in the treatment of pain has merit and can enhance the coping ability of individuals with SCD pain. With additional research that includes better methodology and consideration of possible impediments to intervention delivery, more successful outcomes in pain management are possible.

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