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Abigail Radomsky
Wayne State University, abigail.radomsky@med.wayne.edu

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Utility of cognitive behavioral therapy to reduce pain in children with sickle cell disease

ABIGAIL RADOMSKY, Wayne State University School of Medicine, abigail.radomsky@med.wayne.edu

ABSTRACT A clinical decision report appraising:

Schatz J, Schlenz AM, McClellan CB, et al. Changes in coping, pain, and activity after cognitive-behavioral training. *The Clinical Journal of Pain* 2015;31(6):536-47 https://doi.org/10.1097/ajp.0000000000000183.

for a child with sickle cell disease.

Keywords: *cognitive behavioral therapy, sickle cell, pain management, children*

Clinical-Social Context

Jeffrey Evans [pseudonym] is a nine-year-old black male with a history of Sickle Cell Disease (SCD). He presented to the Emergency Department with his mother Jessica [pseudonym] who reports that he has had a two-day history of uncontrolled pain in both his feet that was not relieved by heat or over-the-counter medications. He has a history of vaso-occlusive crisis (VOC) approximately once per month that they can manage at home. His only previous hospitalizations were due to dactylitis at age two. Jeffrey was admitted to the Hematology service for further medical management of his current VOC. He was treated with intravenous fluids, ketorolac, and morphine patient-controlled analgesia.

While in the hospital, Jessica discussed with the healthcare team that she was concerned that as Jeffrey aged, he would have more severe VOCs that would require increased pain medication for treatment. With her knowledge of the current opioid epidemic, she asked if there were any options for non-medication treatments that could help them learn how to better handle his pain at home. She wondered specifically about developing coping mechanisms or speaking to someone through therapy and if there was a way to use them to reduce her son's pain. Of note, Jeffrey lives with his mother and stepfather and is an only child. He is in the fourth grade, has friends and does well in school, but is now beginning to see the effects that SCD could have on his daily life and is very concerned that it will keep him from activities in the future. One of his favorite activities in the summer is swimming in the lakes around Michigan on trips with his family, but the cold water unfortunately often leads to pain episodes. He was on a trip with his family to a cabin and swimming in the lake when this crisis began, which has made his hospitalization difficult for him to cope with effectively.

Jeffrey follows regularly with his hematologist and is up to date on all screening evaluations, lab work as well as prophylaxis treatments. His mother is very involved with his care and is eager and willing to participate in any care that could help her son. They have access to adequate transportation, cell phones and are well supported by their

ABIGAIL RADOMSKY *is medical student at the Wayne State University School of Medicine.*

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extended family. However, they must travel over an hour to the hospital where the offices of Jeffrey's doctors are located, which is stressful for Jessica as she works full-time.

Clinical Question

Can cognitive behavioral therapy help children with sickle cell disease cope more effectively with the pain of a vaso-occlusive crisis?

Research Article

Schatz J, Schlenz AM, McClellan CB, et al. Changes in coping, pain, and activity after cognitive-behavioral training: a randomized clinical trial for pediatric sickle cell disease using smartphones. *Clin J Pain.* 2015;31(6):536-547. https://doi.org/10.1097/AJP.0000000000000183

Description of Related Literature

An initial literature search using PubMed was conducted using the search terms ((cognitive behavioral therapy) AND (sickle cell)) AND (children) resulting in 31 results for review. An additional search was conducted using the same terms substituted with "behavioral therapy" and "psychological therapy" to ensure that all forms of psychotherapy were captured. These searches returned 140 results and 144 results, respectively. So, the search was narrowed to only include studies that were randomized control trials using psychotherapy for children with SCD, resulting in a total of five articles. Finally, Google Scholar was used to look at the "related articles" to the article of interest to ensure that no relevant studies were overlooked, which provided no additional studies.

Two of the clinical trials were related to the iCanCope intervention, an internet-based intervention where children with SCD receive cognitive behavioral therapy (CBT) through smartphones and have access to at-home practice as well as weekly contact with a clinician.[1,2] While this intervention was extremely relevant, these reports only demonstrated the future study design, acceptability and feasibility of the intervention without any results. In addition, it targeted adolescents aged 12-16 who are not a representative population of our patient.

Barakat et al. conducted a randomized control trial of a pain management intervention with adolescents ages twelve to eighteen along with a support person in their life.[3] The intervention included four in-person sessions, daily diaries, homework and bi-weekly phone calls focused on practice of coping skills, use of positive coping statements, guided imagery and relaxation techniques. The aim of this study was to assess health factors (pain coping) and psychosocial outcomes (disease knowledge and family communication) after a year of intervention to determine whether CBT can help with pain management in SCD. However, this intervention was found to not have a statistically significant impact on their primary outcomes related to health or psychosocial impact. Due to the age group studied, this was not the best intervention for our patient as he was under the age of included participants. In addition, this study has a small sample size of 53 which was insufficient to analyze efficacy of the intervention.

Sil et. al. compared the effects of CBT for chronic pain in sickle cell patients ages six to eighteen who either continuously completed CBT, terminated the therapy early, or did not initiate CBT. They showed that those who terminated CBT early had increased rates of hospital admissions and that those with continuous CBT had faster reduction in hospital admissions. In addition, patients with established care in CBT showed decreased reliance on the Emergency Department (ED) for medical care over time. To be included in this study, participants were required to have chronic pain (defined as pain during most days of one month) from SCD. While Jeffrey has had some episodes of pain crisis, he does not have chronic pain and would have been excluded from this study.[4]

Gil et al. examined the effects of a pain coping skills intervention with children with SCD ages eight to seventeen.[5] Forty-seven children were assigned to either the coping skills intervention or the standard of care. The intervention comprised of a baseline pain assessment, an in-person coping skills teaching, audiotaped instructions, a tape player, daily exercises, and diary. The study concluded that children who practiced the coping strategies while experiencing a pain crisis had fewer absences from school, less interference with household activities and fewer contacts with the healthcare system. However, due to this study being published in 2001, the technology used was outdated and not the most effective intervention at this time.

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Finally, Schatz et al. conducted a randomized control trial using an intervention which included an in-person CBT skills training session, CBT coping skills and a daily pain diary completed using a provided smartphone, and weekly telephone calls to discuss any concerns, barriers or challenges the participants were having.[6] This study was an adapted approach from the Gil et al. paper discussed above. As it is the only trial which includes the correct age group as well as utilizes the most updated technology, it is the most appropriate paper to examine further for our clinical-social context. This and multiple other studies were reviewed by Badawy et al. who showed that eHealth interventions are a feasible and effective intervention for self-management of SCD.[7] Inclusion in this larger review shows that Schatz et al. had a well-designed study with conclusions that mirrored those of other trials, further validating the usefulness of this study for clinical appraisal. Given the small number of randomized control trials all with small sample sizes as well as differing results, the discussed body of literature can be considered as Grade-B Strength of Recommendation based upon the SORT criteria.[8]

Critical Appraisal

Schatz et al. conducted a randomized-control trial in which they enrolled 48 children and adolescents ages eight to 21 with SCD, recruited from two SCD clinics. All participants were required to have shown previous adherence to care and had to have one major pain crisis requiring an ED visit or a hospitalization or three major pain episodes that affected their daily functioning. Finally, they could not be receiving chronic transfusion therapies or have cognitive impairments that would affect their self-reporting. The trial was registered with ClinicalTrials.gov, received funding from the NIH and is level 2 evidence according to the SORT criteria.[8]

These procedures for recruiting and inclusion did introduce a selection bias, as only children actively going to the doctor were considered, while there are many children in pain with SCD who are unable to go to appointments due to a variety of psychosocial factors. Additionally, the sample size was small and reduces the power and generalizability of the study.

Participants were randomized to two intervention groups, CBT Coping Skills Training (n = 23) and Waitlist Standard of Care (WLSC) (n = 25). The randomization was successful as both groups were of similar demographics. The children in the CBT group immediately received the intervention and then had post-intervention measures taken in 8 weeks. Those in the WLSC group received the CBT skills training session eight weeks after enrollment and then had post-intervention measures taken at the sixteen-week visit. This form of control group could lend itself to high rates of attrition as children wait to receive the intervention, however, this study only had two children in the WLSC group drop out and their data was not included in analysis. Additionally, with this form of intervention it is impossible to blind the participants as the timeline and experiences are so different, leading to potential participant bias in their responses and daily diaries.

The study intervention included the CBT coping skills session, use of the smartphone application, written materials, and telephone calls. The measures that were evaluated post-intervention included the Coping Strategies Questionnaire for Sickle Cell Disease (CSQ) which is a self-reported measure to assess a child's use of coping strategies. They also assessed the intervention using the Coping Attempts and Negative Thinking scales. Daily diary entries asked about the child's pain level, daily activities, and coping skills used. Finally, the application on the smartphones reported how often the children accessed the coping skills audio files that were sent with the daily diary. This was done to add in a measure that was not self-reported. If this program were utilized broadly, it would require access to a smart device, but this does allow for flexibility with fewer in-person appointments.

Analysis was done per-protocol using MANOVA. Using the CSQ, there was found to be a statistically significant increase in the number of coping attempts in the CBT group ($p = .032$), but there was no significant difference in negative thinking ($p = .394$). Additionally, there was a statistically significant increase in pain controllability in the CBT group ($p = .000$). With regards to patient-reported pain levels, the authors hypothesized that after using coping skills one day, the child's next day pain level would decrease. They found that there was a significant reduction in pain the next day after use of skills as recorded by the smartphones ($p = .048$), but not the day after self-reported use of skills ($p = .546$). This could either indicate that the recorded coping skills were much more effective in pain reduction or that there was a significant amount of participant bias when it came to self-reporting skill use especially since children self-reported over three times more practice of skills over the skills use that was recorded by the smartphone. Although the authors reported statistical significance in their assessment of the intervention, its clinical application and benefit is still fully unknown.

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Clinical Application

Utilization of CBT for reduction of pain in children is an area that continues to be evaluated both in SCD and in other chronic pain conditions. The effects of opioid overuse are now well known, and often leave patients and their families wanting to find alternative and safer methods of pain control, as in the case of Jeffrey. The Schatz et al. trial as well as the previous Gil et al. trial both showed promising results with CBT-based coping skill interventions. However, if such programs do not exist, there is little direction regarding CBT with mental health professional to help reduce pain.

We discussed these findings with Jessica, specifically discussing with her the varied results that CBT can have on pain levels, and that there were limited clinical trials conducted. Additionally, we could not offer Jeffrey a program such as the ones discussed in these studies, however we discussed that there are many mental health professionals who could begin CBT with Jeffrey and focus on strengthening his coping skills. Even though additional visits would be burdensome for Jessica as she works full-time and does not have a lot of flexibility in her schedule, she decided that for Jeffrey's health it would be best to begin therapy with a health professional located close to their home. She had said that even if CBT outside of a program such as those studied could not directly reduce his pain, it may help him cope with his chronic illness as he got older. In the future, an intervention with a design similar the one discussed here could be feasible and useful for many families in our clinics, however, we would always have to consider access to smartphones or other devices as well as to internet at home, as this could greatly hinder the effectiveness of such an intervention.

New Knowledge Related to Clinical Decision Science

SCD is a very debilitating and life-altering condition. While there are newer treatments available to decrease the number of VOCs, these therapies are not feasible for many families. VOCs are incredibly painful and warrant use of opioids, but with more knowledge surrounding the opioid crisis, additional families are bound to feel similarly to Jessica, wanting to find alternative therapies and options for treatment. However, with children with chronic illnesses it is difficult for families to come to additional appointments as the child cannot go by themselves and many parents are working full time with limited flexibility. In light of the current COVID-19 pandemic, telemedicine and internet-based interventions such as the CBT program discussed here will become increasingly more common due to their convenience. However, as providers we need to know the efficacy of these interventions prior to making recommendations to ensure that we always remain dedicated to the best interest of the patient. In addition, it is important to assess the duration of CBT that would best help with pain management as the Sit et al. article indicated that early termination of CBT increases hospital admissions.

Conflict Of Interest Statement

The author declares no conflicts of interest.

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