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Coping with Sickle Cell Disease Using Cognitive Behavior Therapy

Helen Alexander
Walden University

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Walden University

College of Health Sciences

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Helen Alexander

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Walden University
2018

Abstract

Coping with Sickle Cell Disease Using Cognitive Behavior Therapy

by

Helen Alexander

MS, Walden University, 2012

BS, University of the Virgin Islands, 1993

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Nursing Practice

Walden University

May 2018

Abstract

This project focused on identifying the best evidence available on the use of cognitive behavior therapy (CBT) for pediatric patients and families with sickle cell disease (SCD) to improve their coping skills with pain management. This resulted from an identified gap in nursing practice regarding psychosocial support for this subset of hospitalized pediatric patients. The practice-focused question was whether there was evidence in the literature on the use of CBT techniques to improve parental coping skills with children who have chronic and life-threatening illness that could be utilized with sickle cell disease. The theory of stress and coping guided the underpinnings of the study process. The Johns Hopkins Nursing evidence-based practice model (JHNEBP) was the framework for this project. A systematic review was conducted utilizing research-based articles from the major healthcare databases. The original search resulted in over 12,000 articles. This pool was further refined based upon a link between the pediatric population with chronic or life-threatening conditions and family coping skills. This was further narrowed down based on the use of social-cognitive therapy and coping skills. This process resulted in 6 research articles on the use of CBT with the target population. An evaluation of these studies found evidence that CBT can improve parental coping skills. Nursing support for parental coping with SCD has the positive social impact of decreased parental stress and improved quality of life for both the child and the family unit.

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Dedication

To my siblings, thanks for nudges of encouragement, and show of interest in my life long goal. Every moment of pride you showed was a secret challenge to do better to earn your support, hence accomplishing my goals. Your pride is reciprocated.

To my parents, I deeply appreciate your commitment and investment in my siblings and myself. The long days and short nights you labored tirelessly has engrained in us the seeds of hard work and perseverance. Thank you for believing in and molding me into whom I am today. Although one of you is physically absent you are present in my heart, forever my love.

To Ken, Al, Stonneal, and Armsby, my wonderfully adorable children, without whom my success in life including this milestone would not be an enjoyable occasion. Your assertiveness and persistence prevented me from giving up in moments of stress even when I bombarded you with excuses why I should quit. You were even more persuasive when I attempted to use the mommy role to convince you that I should end the torture. Your strength, character, and my admiration of you has been an enormous driving force in my life and life accomplishments. With every fiber of my being, I love you dearly.

To my grandchildren, hugs and kisses many times over.

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Section 1: Nature of the Project

Introduction

Sickle cell disease (SCD) is a global public health issue affecting millions of people throughout the world. People with ancestors from Sub-Saharan Africa, the Western Hemisphere, Saudi Arabia, India, and the Mediterranean are more commonly affected with SCD (Centers for Disease Control and prevention (CDC, 2016). Smith and Praetorius (2015) defined SCD as a hereditary blood disorder of the red blood cells which blocks blood vessels causing organ damage and frequent painful episodes. Treatments for SCD and a possible cure are being addressed by both public and governmental healthcare organizations. Currently, drug therapies like hydroxyurea, blood transfusion, and stem cell transplant are the focus of treatment for SCD (Smith & Praetorius, 2015). In the meantime, SCD continues to cause great suffering to patients and families. Though the exact number of people with SCD is not known, it is estimated that approximately 100,000 Americans suffer with the disease (CDC, 2016). In 2008, 197 babies were born in New York with SCD which is 1:1259 births (CDC, 2016). Presently, life expectancy for people with SCD in the United States is 40-60 years (CDC, 2016).

Parents or guardians are the primary caregivers for children with SCD. Children with SCD have the tendency to suffer from psychosocial and behavioral problems (Armstrong, Lemanek, Pegelow, Gonzalez, & Martinez, 2010). As a result, parents become stressed, burdened, and sometimes feel guilty about their child's diagnosis (Armstrong et al., 2010). Researchers have shown that parents who care for children with any chronic illness experience a high level of stress (Armstrong et al., 2010). While much

education is focused on managing the disease process and preventing exacerbations, very little time is spent working with the caregivers on stress management and stress reduction.

The use of evidenced-based practice (EBP) can improve coping skills for parents of children with SCD. EBP is the basis for decision making for best practice in healthcare. According to McCurry et al. (2009), nurses have a mandate to question current practices, test innovation, and participate in research for the common good of the patient. This project is focused on systematically reviewing the best evidence available on cognitive behavior therapy to use with patients and families with SCD for improving their coping skills for pain management. The positive social change comes from better parental support, enabling better management for improved caregiving for children with SCD.

Background of Sickle Cell Disease

SCD is an autosomal recessive blood disorder which affects red blood cells of both male and female, as one of the 22 pairs of chromosomes is defective (Myers & Eckes, 2012). Neonates and adults have different components of hemoglobin. Neonates have fetal hemoglobin (HgbF) while adults have normal adult hemoglobin (HgbA). Normal blood screen will show HgbA, but a person with sickle cell trait will reflect a HgbFS. An infant normal blood test is HgbFA, but the infant with a sickle cell trait or disease will be HgbFS (Myers & Eckes, 2012). A patient with the SCD trait carries a HgbAS while the one with HgbSS has the SCD. Two parents with the HgbAS may

produce an offspring with HgbSS. It is important to be informed of the genetic makeup of SCD and SCD trait among affected persons to determine transmission of the disease.

The hemoglobin in red blood cells (RBC) in blood is responsible for carrying oxygen throughout the body. The lifespan of a normal RBC is 120 days, while that of SCD is 10-20 days (Myers & Eckes, 2012). Hemoglobin S causes SCD, which changes the shape of the RBC causing it to sickle and making it difficult to pass through the blood vessels and capillaries. As a result, the blood flow is disrupted, and restricted blood distribution results in severe pain and vas-occlusive crisis.

Problem Statement

Parents and other caregivers of children with SCD have difficulties coping with the disease. A core role of the pediatric nurse is holistic support of parents, including their coping skills. Parents are usually in a state of helplessness and express guilt for their child being ill (Wonkam, Mba, Mbanya, Ngogang, Ramesar, & Angwafo, 2014). Lack of parental support contributes to poor family dynamics especially when other siblings are involved. Parents who are informed of other methods to cope with SCD painful crisis may be in a better position to care for their child. Support groups like the Sickle Cell Parent Support Network exist, but support on different methods of coping with painful crisis is also needed for caregiver. There is little in the literature specific to strategies that would guide nurses in the support of parents with SCD. Social cognitive therapy has been used successfully with parents of children with other chronic and life-threatening illness (Elliott, 2012).

Purpose Statement

The purpose of this project was to systematically review the literature on the use of cognitive behavior therapy (CBT) for patients and families with chronic or life-threatening illness. The outcome of the review will be used to assist the multidisciplinary team in the development of a practice protocol for parents of children with SCD. CBT has the potential to be very beneficial in assisting parents and children to cope more effectively with the stress of hospitalization, the disease, its complications, and financial implications (Wonkam et al., 2014). In a study to determine the cost benefit of CBT, Thomas and Taylor (2002) concluded that CBT appears to have immediate benefits in managing pain, reducing psychological distress, and improve coping skills with SCD (Wonkam et al., 2014).

The setting is a nationally renowned acute care children's hospital with a capacity of 116 beds. The children's hospital is in a large metropolitan area in the northeastern United States and is located within a general hospital. The hospital's mission is to advance the health of the communities it serves. Throughout the year, the hospital records about 9000 admissions for complex conditions from all over the world. SCD is a concern for the community and the hospital. The institution has had an adult SCD center for years. In 2005 the hospital established the first comprehensive pediatric center for sickle cell disease in New York. A nationally recognized hematologist with expertise in SCD leads the center. The center has also conducted extensive research funded by the National Institutes of Health on SCD. The center also offers family-centered treatment plans to assist SCD patients and families to deal with the disease while living healthier, more

normal lives. However, no pediatric program with a focus on CBT for caregivers exists in the institution.

Practice-Focused Question(s)

The gap in nursing practice is the lack of psychosocial support for caregivers and parents of children with SCD who are hospitalized with an exacerbation. This gap was identified by the nurses in this hospital setting during a discussion on improving care for children with SCD. The practice focused question is whether there is evidence in the literature on the use of CBT techniques to improve patient and family member coping skills with children who have chronic and life-threatening illness.

Parents of children suffering with SCD can benefit from psychosocial interventions by educating them about the disease process and improving coping mechanisms. Parental ability to cope may improve participation in their children's care and change the entire ambience of the environment. This systematic review is an attempt to inform clinical practice in addressing the gap in practice. Alleviating pain and discomfort while increasing comfort and coping skills is essential in the care of children with SCD and caregivers. The ability to cope with pain due to illness can yield positive mental and physical health outcomes.

Nature of the Doctoral Project

According to Titler (2010), "evidence-based practice is the conscientious and judicious use of current best evidence in conjunction with clinical expertise and patient values to guide healthcare decisions" (p.36). A systematic review of the literature on the use of SCD with families that are impacted by a child with a chronic life-threatening

illness yielded rigorous studies that can be used to inform practice with SCD children and parents. A systematic review is a comprehensive review of current research where synthesis, appraisal, and analysis of the findings are obtained to examine the best evidenced-based practice (Inoue, Khan, Mushtaq, Sanikommu, Mbeumo, LaChance, & ... Sanikommu, 2016).

I conducted this systematic review using electronic search engines to locate relevant databases. The review provided research from all levels (qualitative, quantitative, epidemiology) of evidence that were specific to the key words identified in this paper. I identified strength and the levels of the research to gather and evaluate the best evidence. Additionally, I further evaluated the outcomes of the research studies based on the specific criteria of benefit to the patient (Mazurek-Melnyk, Fineout-Overholt, Stillwell, & Williamson, 2010).

Lack of patient and family knowledge of alternate measures for coping with SCD may interfere with effective treatment interventions, the healing process, or delay in discharge (Withycombe et al., 2016). This project will use a systematic review approach which will provide the best evidence for the possible implementation of CBT for families and patients with SCD.

The capacity to absorb information is a context factor that promotes adoption of EBP (Titler, 2010). In addition, if an organization can identify, capture, interpret, share, reframe, and recodify new knowledge, it can better incorporate EBP (Titler, 2010). Eccleston, Fisher, Law, Bartlett, & Palermo (2015), looked at the effects of psychological intervention in parents of children suffering from chronic illnesses using problem solving

therapy (PST), CBT, family therapy (FT), and multi-systemic therapy (MST). Eccleston et al. looked at 47 randomized control trials (RCT's) with a total of 2985 participants. The primary outcomes assessed were parents' behavior and mental health. Included in the analysis were painful conditions, diabetes, cancer, asthma, and atopic eczema.

Eccleston et al. (2015) concluded that CBT and PST therapy that involves parents reduces children's primary symptoms, improves parent adaptive behavior and parent mental health. The multisystem assault interferes with the affected patient and family ability to cope. Patients suffering from cancer also benefit from CBT (Elliot, 2012). The use of CBT therapy may have potential implications for nursing practice as the application of this technique can improve the overall care of the family unit. This systematic review may also inform other pediatric nurses about ways to approach care in both SCD patients and others with chronic life-threatening illness.

Significance

Due to the number of children suffering with SCD and the impact on family life, exploring ways to decrease the stress associated with the disease is a significant step in improving coping skills. Patients with SCD usually develop complications which result in increased stress in dealing with the disease. According to Abel, Cho, Chadwick-Mansker, D'Souza, Houston, & King. (2015), approximately 35% patients with SCD suffer from a disease related complication like cerebrovascular accident (CVA) which affects their IQ, school absences, and decrease in activities. Abel et al. identified stress, anxiety, mood, sleep disturbances, weather, or physical activity as triggers of SCD painful episodes.

Using CBT for families and patients with SCD may benefit both children and their parents by improving coping skills that will decrease depression, decrease hospitalization and improve school attendance. Although there is limited literature on the effects of CBT for families and patients coping with SCD, there is evidence that shows its effectiveness in diseases such as diabetes, asthma, cancer, and chronic pain (Elliott, 2012).

Potential stakeholders include the health care team within the organization. Other potential stakeholders include the national, international, and local organizations that have an interest in the SCD population. The national organization is called Sickle Cell Disease Association of America (SCDAA). This organization is well-known for providing education, research, and advocacy to many patients and families affected with SCD. Other stakeholders that have a special interest in the SCD population are community-based organizations (CBO). Such organizations are placed in the community at the grass-roots level where providing education and advocacy are important. After providing information to the hospital stakeholders, information regarding the findings of the project will be disseminated to nursing staff, and education will be provided on the potential ways to utilize CBT.

Contribution to Nursing Practice

Parents of children with SCD have increased stress and difficulties dealing with the disease condition (Wonkam et al., 2014). In a study on parental coping with SCD children in Nigeria, Wonkam et al., reported 42.1% of caregivers experienced moderate to severe issues with coping ability with affected children. Wonkam et al. also reported

that the disease negatively impacted 58.2% of the families' finances. CBT has been instrumental in alleviating and improving patients' ability to cope with their disease. However, there is limited research that is done on looking directly at the effectiveness of CBT in parents' ability to cope with SCD children. Therefore, potential interventions that are nurse-directed will increase the body of knowledge to nursing, which will guide the discipline of nursing practice.

Implications for Social Change

Social change is the situation in which change comes about that is sustainable and profound. Little has been done to improve the nursing care of SCD patients and caregivers. This debilitating disease has been given less attention through research, education, and funding (ASH, 2016). Thus, there is a need to find innovative and creative treatments which can lessen the challenges that are currently seen in the SCD population. Psychosocial issues, such as coping, stress, and depression are rarely addressed in the SCD communities. The implementation of the use of CBT to assist patients and families on how to effectively cope with the disease could substantially improve the health and mental well-being of families.

Summary

SCD affects many children throughout the world. There are treatment options to manage pain and complications of the disease, but little in the literature on psycho-social management and support. The use of CBT has the potential to address this gap in practice. Parents of children with SCD are usually stressed, depressed with feelings of hopelessness, and experiencing difficulty coping. Nurses are at the forefront of caring for

those children as they witness the effects of the disease on the entire family. Parents of children suffering with SCD, children, and professional caregivers need to work collaboratively to improve the quality of life.

Advanced practice nurses and pediatric staff nurses would benefit from practice guides incorporating the use of CBT into clinical practice. A systematic literature review may identify research and trends in clinical practice. In the next section I will identify key concepts, models, and theories that formed the underpinning of this review.

Section 2: Background and Context

Introduction

Caregivers and patients suffering with SCD usually have difficulties coping with the illness. According to Wonkam et al. (2014), parents and children with SCD can benefit from CBT which assists them to cope with the disease, its complications, and financial implications. The practice-focused question is whether there is evidence in the literature that supports the use of CBT to improve patient and family member coping skills during a painful crisis. The purpose of this project is to identify the best evidence available on CBT for patients and families in children with chronic or life-threatening disease that may be utilized with sickle cell disease for improving coping skills for pain management.

Concepts, Models, and Theories

Parents or other primary caregivers of patients with SCD experience different types of stressors in various settings. SCD patients visit the emergency room (ER) and are hospitalized because of a crisis. When patients are hospitalized, the primary caregivers' stress levels increase tremendously (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010). Therefore, it is important to determine the type of stress that the individual endures and the resources available for stress management. There are three major stressors that are associated with hospitalization. Loss of parenting role, need for information, and uncertainty over recovery outcomes decrease coping and increase caregivers stress (Brousseau et al., 2010).

Melnyk, Feinstein, Moldenhouer, & Small. (2001) identified several measuring tools that can be used to identify stress and coping in parents of SCD children. For example, the Family Needs Survey (FNS) assesses the needs of parents with disabled children, and the Profile of Mood States (POMS) measures feelings, moods, and the effect of caretakers (Melnyk et al., 2001). In addition, the Sickle Cell Self-Efficacy Scale (SCSES) is a tool that measures the person's ability to deal effectively with changes.

The theory of stress and coping will guide the underpinnings of the study process. The theory was first developed by Lazarus in 1970 and was based on the cognitive, psychosocial, biological, and behavioral aspect of the individual (Bandura, 1977). The cognitive appraisal concept is the ability to see a situation from another person's point of view since people have different sensitivities, vulnerabilities, interpretations, and reactions to certain stressors (Brousseau et al., 2010). Encouraging self-efficacy is necessary to improving better coping skills. (Bandura, 1977).

Relevance to Nursing Practice

CBT is a psychosocial therapy used in psychiatry with many conditions to bring clarity and balance between thoughts and behaviors. According to Currid, Nikčević, & Spada, (2011), the use of CBT gives patients insight into their problems by understanding the relationship between thoughts, emotions, physiological sensation and behaviors. Evidence has shown that CBT is effective in the reduction of mental health problems brought along by physical health (Currid et al., 2011). CBT helps in the development of coping skills which ultimately decrease healthcare cost to patients and organizations (Currid et al., 2011).

CBT was first used with people with eating disorders; however, since that time, CBT has been used widely with people suffering from anxiety, depression, obsessive compulsive disorders, post-traumatic stress disorder, and anger issues (Hoffman & Militello, 2009). The use of CBT continues to spread through the different specialties of nursing. Since contemporary nursing practice approaches caring holistically, CBT compliments care by providing an effective evidenced-based treatment for health conditions. Nurses have identified the need for increased evidence for CBT in healthcare. Advance practice nurses' role is to meet the expectations by delivering evidenced-based treatment to increase the efficiency of CBT (Currid et al., 2011). There is a high level of satisfaction and acceptance among patients because of the treatment's usefulness when CBT is part of the treatment modality. A survey of 102 patients found that 76% were satisfied with CBT treatment, so nurses can prepare themselves to use CBT as an adjunct to conventional treatments (Currid et al., 2011).

Local Background and Context

SCD affects millions of people globally, but it is more prevalent among people from Africa, South and Central America, Saudi Arabia, India, and the Mediterranean (CDC, 2017). However, because SCD is not reportable, the true number of those affected by the disease is unknown (Hoffman & Militello, 2009). SCD is reported as the most common inherited blood disorder in the United States (Hoffman & Militello, 2009). According to Hoffman and Militello (2009), 80,151 black and 8,928 Hispanic suffer with SCD in the United States with New York (8,309), Florida (7,539), and Texas (6,765)

people recorded. SCD hospitalizes approximately 113,000 people and cost the United States \$488 million dollars annually.

The setting is a nationally renowned acute care children's hospital with a capacity of 116 beds. The children's hospital is in a large metropolitan area in the northeastern United States is located within a general hospital. The hospital's mission is to advance the health of the communities it serves. SCD is a concern for the community and the hospital. The institution has had an adult SCD center for years. In 2005 the hospital established the first comprehensive pediatric center for SCD in New York.

Role of the DNP Student

My professional context for the DNP project is to increase the knowledge of the use of CBT in the realm of management for families and patient with SCD in order to improve coping skills for families and patients with SCD in order to better manage their disease. Furthermore, I will rigorously disseminate the findings through scholarly presentations and publications. My role is also to increase awareness of alternative methods of treatment and to also discover ways to empower sickle cell patients and families to cope more effectively with the disease.

Summary

A systematic literature review of CBT may yield evidence-based research that could support the addition of CBT to nursing care for pediatric SCD patients and their families, Section three will describe the approach to the review.

Section 3: Collection and Analysis of Evidence

Introduction

The purpose of this project was to identify the best evidence available on the utilization of CBT with families and pediatric patients with chronic and life-threatening illness. This information will then inform nursing practice on the development of a protocol for incorporating CBT into the care of children and families affected by SCD. SCD is a worldwide problem that causes suffering and increased healthcare cost. SCD is prevalent among people from Africa, South and Central America, Saudi Arabia, India, and the Mediterranean (CDC, 2017). SCD is the most common inherited blood disorder in the United States. In this section, I will discuss the practice-focused questions, sources of evidence, and the analysis and synthesis of the literature.

Practice-Focused Question

The gap in nursing practice is the lack of psychosocial support for caregivers and parents of children with SCD who are hospitalized with an exacerbation. This gap was identified by the nurses in this hospital setting during a discussion on improving care for children with SCD. The practice focused question is whether there is evidence in the literature on the use of CBT techniques to improve patient and family member coping skills with children who have chronic and life-threatening illness that could be adapted for the SCD population.

Sources of Evidence

A systematic review summarizes the existing literature and then provides evidence that are high level and have been shown to be an effective best clinical practice

(Melnyk & Fineout-Overholt, 2011). A systematic review is also a type of evidenced-based strategy that is commonly used for doctoral projects. This DNP project was focused therapies which can assist with the coping skills of parents/guardians of children with SCD. The goal was to review articles using searchable keywords: sickle cell disease, cognitive behavior therapy, pain management, distress and coping, pain therapy, CBT and sickle cell, stress and coping, CBT and outcomes, CBT and theory, self-efficacy and sickle cell complications.

The Johns Hopkins Nursing Evidence-Based Practice Model (JHNEBP) was the quality improvement framework guideline for this project. The JHNEBP came about when a group of nurses, and faculty from the John Hopkins Hospital, and John Hopkins University of nursing had a goal to form the foundation for professional nursing practice (White, Newhouse, Dearholt, Poe, & Pugh, 2007). The authors have also developed a problem-solving approach to clinical decision-making. Since the inception of the tool, professionals from all disciplines have used the JHNEBP model to achieve evidenced-based practice. The systematic review will be used by the multidisciplinary team to develop a new practice guideline. The use of this guideline will help to assess parents' current coping skills, educate parents and the patient about SCD and the use of SCT techniques, and measure the impact.

The model provides guidelines, tools, description, and examples of its application. In addition, graduate programs use the JHNEBP to teach evidence-based practice to develop critical thinking skills (White et al., 2007). The JHNEBP model is also referred to as the practice question, evidence, and translation (PET) (White et al., 2007). PET is a

three-step process designed specifically to meet the needs of the practicing nurse (White et al., 2007). PET goal is to ensure that the latest research findings and best practices are quickly and appropriately incorporated into patient care to improve outcome (White et al., 2007). JHNEBP is a step-by-step tool which is easy to use and is well understood by practitioners who are new to evidenced-based practice (White et al., 2007). JHNEBP is also a more descriptive method for the bedside nurse.

Table 1

JHNEBP Evidence Rating Scale

STRENGTH of the Evidence	
Level I	Experimental study/randomized controlled trial (RCT) or meta-analysis of RCT
Level II	Quasi-experimental study
Level III	Non-experimental study, qualitative study, or meta-synthesis.
Level IV	Opinion of nationally recognized experts based on research evidence or expert consensus panel (systematic review, clinical practice guidelines)
Level V	Opinion of individual expert based on non-research evidence. (Includes case studies; literature review; organizational experience, e.g., quality improvement and financial data; clinical expertise, or personal experience)

Table 2

JHNEBP Quality Rating Scale

Quality of the Evidence		
A High	Research	Consistent results with sufficient sample size, adequate control, and definitive conclusions; consistent recommendations based on extensive literature review that includes thoughtful reference to scientific evidence
	Summative reviews	Well-defined, reproducible search strategies; consistent results with sufficient numbers of well-defined studies; definitive conclusions.
	Organizational	Well-defined methods using a rigorous approach; consistent results with sufficient sample size; use of reliable and valid measures.
	Expert Opinion	Expertise is clearly evident.
B Good	Research	Reasonably consistent results, sufficient sample size, some control, with fairly definitive conclusions; reasonable, consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence.
	Summative reviews	Reasonably thorough and appropriate search; reasonable, consistent results with sufficient numbers of well-defined studies; evaluation of strengths and limitations of included studies; fairly definitive conclusions.
	Organizational	Well-defined methods; reasonably consistent results with sufficient numbers; use of reliable and valid measures; reasonably consistent recommendations.
	Expert Opinion	Expertise appears to be credible.
C Low quality or major flaws	Research	Little evidence with inconsistent results, insufficient sample size, conclusions cannot be drawn.
	Summative reviews	Undefined, poorly defined, or limited search strategies; insufficient evidence with inconsistent results; conclusions cannot be drawn.

(table continues)

Quality of the Evidence

Organizational	Undefined, or poorly defined methods; insufficient sample size; inconsistent results; conclusions cannot be drawn.
Expert Opinion	Expertise is not discernable or is dubious.

Analysis and Synthesis

Using a systematic and comprehensive search, the DNP project included only literature from the English language. I conducted an electronic search using search engines, including CINAHL, Pub Med, Medline, OVID, Cochrane data bases, Nursing web journals, and Academic Search Premier from 2006 to 2016. The search was conducted using articles over a 10-year period, including historical journals that captured the variables of interest. Articles were identified based on the key words which include CBT, coping with SCD, CBT and coping, and self-efficacy. The journal articles selected were synthesized to reflect the integrity and quality used to gather the best evidence. Analysis was also done to further identify the statistical findings of the results.

Summary

Search engines like CINAHL, Medline and PubMed, and Cochrane provide relevant and peer reviewed articles that are in line with the practice-focused question. There continues to be a gap in nursing practice in psychosocial support for parents and other caregivers of children with SCD. The JHNEBP model served as a model for the review, by providing the guidelines necessary to identify the best evidence for clinical practice. The JHNEBP is widely used in research and highly rated in the development of

evidence-based projects. The tools provided in the JHNEBP were used to identify the strength and quality of the evidence using the rating scale, and the levels of research articles available that support the practice-focused question.

Section 4: Findings and Recommendations

Introduction

Local Background and Context

SCD affects millions of people globally, but it is more prevalent among people from Africa, South and Central America, Saudi Arabia, India, and the Mediterranean (CDC, 2017). However, because SCD is not reportable, the true number of those affected by the disease is unknown (Hoffman & Militello, 2009). SCD is reported as the most common inherited blood disorder in the United States (Hoffman & Militello, 2009). According to Hoffman and Militello (2009), 80,151 black and 8,928 Hispanic individuals suffer with SCD in the United States with New York (8,309), Florida (7,539), and Texas (6,765) people recorded. SCD hospitalizes approximately 113,000 people and cost the United States \$488 million dollars annually.

The setting is a nationally renowned acute care children's hospital located within a general hospital, with a capacity of 116 beds. The children's hospital is in a large metropolitan area in the northeastern United States. The institution established the comprehensive pediatric center for sickle cell disease in 2005.

Practice-Focused Question(s)

The gap in nursing practice is the lack of psychosocial support for caregivers and parents of children with SCD who are hospitalized with an exacerbation. This gap was identified by the nurses in this hospital setting during a discussion on improving care for children with SCD during my practicum experience.

The practice focused question is whether there is evidence in the literature that CBT improves the coping skills of patients and family member during a painful crisis. Parents of children suffering with SCD can benefit from interventions to educate them about the disease process and improving their coping mechanisms. Parental ability to cope may improve participation in their children's care.

Purpose Statement

The purpose of this project was to identify the best evidence available on CBT for patients and families with chronic or life-threatening illness. CBT has the potential to be beneficial to assist parents and children to cope more effectively with the stress of hospitalization, the disease, its complications, and financial implications (Wonkam et al., 2014).

Sources of Evidence

The study reviewed articles with searchable keywords including pediatric illness, SCD, CBT, and family coping strategies. The Johns Hopkins Nursing Evidence-Based Practice Model (JHNEBP) was the quality improvement framework guideline used for this project. The model provided guidelines, tools, description, and examples of its application. The JHNEBP model is also referred to as the practice question, evidence, and translation (PET) (White et al., 2007). The strength of the evidence was judged using the JHNEBP Evidence Rating Scale. The evidenced ranged from level one through five, with level one being the highest. The quality of the evidence indicator was the JHNEBP Quality Rating Scale ranging from high (A), good (B) to low (C).

Analysis and Synthesis

Using a systematic and comprehensive search, the DNP project included literature from the English language only. An electronic search was done using engines including CINAHL, Pub Med, Medline, OVID, Cochrane data bases, Nursing web journals, and Academic Search Premier from 2006 to 2016. The search was conducted using articles over a 10-year period to include historical journals that captured the variables of interest. Articles were then categorized based on the key words which included CBT, coping with SCD, CBT and coping, and self-efficacy.

The search yielded numerous articles under the first general search. Many of the research articles pertained to the adult population. This was narrowed down based upon a link between the pediatric population with chronic or life-threatening conditions and family coping skills. This was further narrowed to the use of social-cognitive therapy and coping skills. Articles not mentioning the keywords used in this literature review were omitted from the analysis of this project(see Appendix A).

Table 3

Search Engine Used for Literature Search Articles

Keywords	CINAHL Plus with full text	CINAHL	MEDLINE
SCD and CBT	29	0	12
SCD	0	0	9177
Stress, Coping, and Theory	1094	1929	0
CBT, SCD, and Outcomes	18	0	0
CBT, Cancer, and Children	0	4	0

Keywords	CINAHL Plus with full text	CINAHL	MEDLINE
			<i>(table continues)</i>
CBT, Chronic, and Illness	0	12	0
CBT, Chronic, and Disease	0	70	0
CBT, Nursing, and Practice	0	38	0
Parental, Coping, and Illness	0	13	18

Total:1141+2066+9207=12414

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
1/Good	Coping in Parents of Children Who Are Chronically Ill: Strategies for Assessment and Intervention. Melnyk et al., 2001	In a quasi- experimental one- group pretest- posttest study, 9 African American individuals with SCD completed 3 weekly educational sessions learning CBT methods.	The study determined that a solid framework can facilitate astute assessment and interventio ns with parent of chronically ill children	The study population was small thereby limiting the study results.

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
4/Good	Cognitive behavioral therapy in patients with sickle cell disease. <i>Creative Nursing</i> , 21(1), 38-41. Daniels, S. (2015)	Quasi one-group pretest-posttest study, 9 African American individuals with SCD completed 3 weekly educational sessions learn CBT method.	Participants demonstrated increased frequency of use of CBT methods post-intervention, including diverting attention, coping self-statements, and behavioral activities, leading to better pain control. However, quality of life and role limitation did not show significant improvement.	The sample size was small, limiting statistical analyses. A larger sample size would have resulted in more substantial support for CBT's efficacy. In addition, assessing QOL after a longer period of time would be beneficial.

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
1/Good	Keane, B., & Defoe, L. (2016). Supported or stigmatized? The impact of sickle cell disease on families. <i>Community Practitioner: The Journal Of The Community Practitioners' & Health Visitors' Association</i> , 89(6), 44-47.	Descriptive- Semi-structured interviews and questionnaires	The findings of this study are not unique and families in our region would benefit from wider support (including psychological and social) on a regular basis.	There are limits to an evaluation study of this nature. The semi-structured interviews were not audio recorded and there was a reliance on hand-written notes to form the basis of the results. Any further work in this area should consider an 'open question' format and audio recording, which would allow greater depth to the interview process. The study was limited to a small group of families in relative terms but, in the context of our

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
				<p>SCD population as a whole, is a representative view of families with a SCD child. The views of fathers are underrepresented in this study and careful consideration of this would need to be included in any future work. A larger sample size would allow for the use of sophisticated statistical analyses</p>

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
4/Good	Gold, J. I., Treadwell, M., Weissman, L., & Vichinsky, E. (2008). An expanded Transactional Stress and Coping Model for siblings of children with sickle cell disease: family functioning and sibling coping, self-efficacy and perceived social support. <i>Child: Care, Health And Development</i> , 34(4), 491-502. doi:10.1111/j.1365-2214.2008.00810.x	Ninety-seven siblings (M = 11.24 years) from 65 families who care for a child with SCD participated. Primary caregivers completed the Coping Health Inventory for Parents, the Family Relations Scale and the Child Behaviour Checklist, while siblings completed the Kidcope, the Children's Self-Efficacy for Peer Interaction Scale, and the Social Support Scale for Children.	Family processes were predictive of sibling adjustment, revealing that family coping, expressive ness and support improved adjustment, while family conflict predicted poor adjustment.	Longitudinal studies should investigate the interrelations hips between family and sibling adaptation, and the effects of these relationships on sibling adjustment. A larger sample size would allow for the use of sophisticated statistical analyses. This study utilized self-report measures, raising the additional concern that rater bias may have been introduced.

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
4/Good	Annie, K. A., & Green, J. (2015). Psychological therapies for sickle cell disease and pain. The Cochrane Database Of Systematic Reviews, (5), CD001916. doi:10.1002/14651858.CD001916.pub3	This review searched the Cochrane Cystic Fibrosis and Genetic Disorders Group Haemoglobinopathies Trials Register, which comprises references identified from comprehensive electronic database searches and the Internet, hand-searches of relevant journals and abstract books of conference proceedings. The date of the most recent search of the Group's Haemoglobinopathies Trials Register: 17 February 2015. The review looked at all randomised or quasi-randomised controlled trials comparing psychological interventions with no (psychological) intervention in people with sickle cell disease.	Twelve studies were identified in the searches and seven of these were eligible for inclusion in the review. Five studies, involving 260 participants, provided data for analysis. One study showed that cognitive behaviour therapy significantly reduced the affective component of pain (feelings about pain), mean difference -0.99 (95% confidence	Evidence for the efficacy of psychological therapies in sickle cell disease is currently limited. This systematic review has clearly identified the need for well-designed, adequately-powered, multicentre randomised controlled trials assessing the effectiveness of specific interventions in sickle cell disease.

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
			<p>interval - 1.62 to - 0.36), but not the sensory component (pain intensity), mean difference 0.00 (95% confidence interval - 9.39 to 9.39). One study of family psycho-education was not associated with a reduction in depression. Another study evaluating cognitive behavioural therapy had inconclusive results for the assessment of coping strategies, and</p>	

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
			<p>showed no difference between groups assessed on health service utilization. In addition, family home-based cognitive behavioral therapy did not show any difference compared to disease education. One study of patient education on health beliefs showed a significant improvement in attitudes towards health workers, mean difference - 4.39 (95% CI -6.45 to</p>	

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
			-2.33) and medication, mean difference - 1.74 (95% CI -2.98 to -0.50). Nonetheless, these results may not apply across all ages, severity of sickle cell disease , types of pain (acute or chronic), or setting.	

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
4/Good	Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. <i>Journal Of Pediatric Psychology</i> , 38(8), 809-828. doi:10.1093/jpepsy/jst049	PsychInfo, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature were searched according to inclusion criteria. Meta-analysis of 13 studies and qualitative analysis of 96 studies was conducted.	Caregivers of children with chronic illness reported significantly greater general parenting stress than caregivers of healthy children ($d = .40$; $p = \leq .0001$). Qualitative analysis revealed that greater general parenting stress was associated with greater parental responsibility for treatment management and was unrelated to illness duration and severity across	Some studies may not have been identified through the search methods used. Overall, the literature is largely limited in its ability to determine causality.

(table continues)

Table 4

JHNEBP Evidence Rating Scales: Strength and Quality of the Evidence

Strength /Quality	Study	Design and Sample	Results	Limitations
			illness populations . Greater parenting stress was associated with poorer psychological adjustment in caregivers and children with chronic illness.	

SCD and Family Coping with Serious Illness

Six articles met the inclusion criteria which included SCD, coping, stress, serious illness, and CBT. The analysis examined SCD and family coping with serious illnesses, SCD and family coping during pediatric illness, and SCD and family coping with SCD. The Melnyk et al. (2001) study on stress and children with chronic illness revealed that more children than originally thought are affected by a chronic illness. It is estimated that

approximately 31% of children in the United States experience a chronic illness throughout their lifespan (Melnyk, 2001). Increased stress accompanies a diagnosis of a chronic illness. Melnyk et al. (2001), categorized stress experienced by parents of children with chronic illness at the time of diagnosis, during developmental transition, with the constant healthcare needs of the child, and during exacerbation and hospitalization.

The full impact of a chronic illnesses is not evident to parents and caretakers at diagnosis. However, parents do begin experiencing stress prior to the diagnosis when they sense that something is wrong with their child. The uncertainty that accompanies the diagnosis of a chronic illness is stressful, and parents fear the loss of their child (Melnyx et al., 2001). Lack of awareness of the potential outcomes of the diagnosis and prognosis increases parents and other caretakers stress (Melnyx et al., 2001). Separation anxiety and the inability to care for the child is also extremely stressful, but the fear of death is the ultimate stressor.

Kean and Defoe (2016), designed a study to determine the sources available for children with SCD and the resources that could be implemented for family support. Approximately 300,000 babies are born with SCD worldwide in mostly low and middle-income families (Kean & Defoe, 2016). Along with the everyday challenges of SCD, the disease has been associated with societal stigmatization and substandard care. A survey of families of children with SCD 16 years and older determined that SCD was not well accepted by the community, and children were abused by community members (Kean & Defoe, 2016). This stress added to the parental feelings of isolation feelings of guilt that

they are responsible for their child's illness. Community support for families with children with SCD is limited. Families are reluctant to disclose their child illness for fear of segregation. The study concluded that a multidisciplinary teams need to come together in support of educational programs to increase awareness of the disease to decrease the stigma associated with the disease.

Annie and Green (2015) conducted a literature review to determine the effects of medical, social, and psychological interventions on families with SCD. They found a majority of articles addressed SCD with a traditional focus on palliative and symptomatic treatment. The articles pointed out that the standard of care for SCD is to address the presenting signs and symptoms in a crisis. However, psychological interventions are often overlooked and may benefit candidates by complementing traditional medicine. The study analysis summarized various conclusions on the effects of psychological interventions on people with SCD. According to Annie and Green (2015), in one study, CBT showed changes in the affective component in pain reduction, while in another, the study showed no significant difference in groups. However, the efficacy of psychological interventions on SCD has shown promising results to improve coping ability (Annie & Green, 2015).

Implications

There is limited research in the use of CBT in patients and caregivers of SCD. Several barriers contribute to the lack of use of CBT in the SCD population. According to Annie and Green (2015), reviews clearly identified the need for trials to assess the effectiveness of interventions in SCD. Since the findings of SCD, little has been done to

improve the treatment and care of the SCD patients. This debilitating disease has been given less attention through research, education, and funding (American Society of Hematology, 2016). Thus, the need to find innovative and creative treatments which can lessen the challenges that are currently seen in the SCD population. Psychosocial issues, such as coping, stress, and depression are rarely addressed in the SCD communities. The implementation of the use of CBT to assist patients and families on how to effectively cope with the disease could substantially improve the health and mental well-being of families. The positive social change comes from better parental support, enabling better management for improved caregiving for children with SCD.

The Clinical Practice Guideline (CPG) process is complex and may be time-consuming. The literature review showed limited evidence in improving coping skills with SCD with the use of CBT. Developing CPG to guide decision making process is not intended to substitute for clinical judgment American Psychological Association (APA) CPG is an important reference to emulate in developing CPG for the CBT project (Hollon, 2016). In addition, the 2014 Evidenced-Based Management of Sickle Cell Disease provided by expert panel does not include or mention any alternative modes of treatment such as CBT for the management of SCD.

The results of this systematic review will be presented to a panel of individuals with different perspective and expertise in the treatment of SCD. It is pertinent to address the patient's preferences which will guide individualized care in clinical practice. The evidence shows that there is a need for the inclusion of CBT and other alternative modalities to be part of CPG that is geared towards improving the physiological, and the

psychosocial well-being of the patient with SC, thereby improving the quality of life for these patients.

Recommendations

CBT is a talk therapy that is increasing in popularity in medicine. It is recommended by the National Institute of Health (NIH) for use in chronic illnesses like depression, anxiety, and diabetes. This literature review suggests that it can also be used in the management of SCD. As an advanced practice nurse, one can intervene by helping patients to recognize how past occurrences can influence their thinking and behaviors (Powers, Jones, & Jones, 2005). For example, by educating the entire family about the disease process, complications, its social implications, and ways to deal with a crisis is a positive approach in coping with the disease. Small group sessions / focus group that is aimed at exploring thoughts, feelings, and behaviors allow one to see the connection between cognition and behavior. By dissecting the mental issues, this allow patients and caregivers to identify the causes of their behavior and ways to manage them (Prochaska, 2006).

Nurses can assist by using a combined cognitive and behavioral approach by breaking down major problems into smaller manageable ones to cope with SCD. Prochaska (2006) stated that change can be achieved in six steps: Precontemplation, Contemplation, Preparation, Action, Maintenance, and Termination. Nurses' needs to identify specific levels of change that can be incorporated into the coping strategies that will assist the patients and parents on how to begin the coping process.

Strengths and Limitations of the Project

Strengths

The project brought clarity to the disease process, current treatment modes, and alternate management using CBT. The literature indicated that parents and caregivers showed improvement in their coping skills when caring for children with SCD and other chronic illnesses. The information gained from the systematic review can be used to educate stakeholders of the importance of maintaining health and wellness by using CBT to improve coping.

Limitations

Caring for patients with a chronic illness like SCD can be very demanding, stressful, and have increased financial implications. This project did not include other family members like the siblings who are severely affected by the disease of a loved one. Close attention should be paid to the entire family, which in turn may have a more lasting effect in the management of SCD. A systematic review of the entire family's needs would probably better assist in the approach in caring for the patients. The review was also restricted to English written articles. Non-English articles were not included thereby limiting the analysis of a broader population. The 10-year duration of the study could have also impacted findings.

Section 5: Dissemination Plan

The intent of this project was to convey to audiences like the people diagnosed with SCD, their parents, stakeholders, and the general public that there are alternate ways to deal with alleviating the burdens of the disease. CBT is one way by which parents of

SCD children can cope with the stressors that they experience, and dissemination is how the message can be conveyed to everyone affected.

Oermann and Hays (2011) described dissemination as the building of evidenced-based knowledge after examining different healthcare interventions available to the system. Project dissemination is another step in planning an evidenced-based project. The results of the literature review can be beneficial to patients with SCD and their caretakers. This may promote best practice or even possibly change standards of practice for that particular population. In order for this review to effect change and be beneficial to the SCD community, the results must be disseminated and incorporated into practice. In thinking about dissemination of information, one has to first target caretakers and then the community.

The results of this review will be shared with the key stakeholders identified in section one. This multi-disciplinary team will need to consider the evidence and recommend changes in overall practice guidelines. The Nursing Quality Council will be involved in changes to nursing practice guidelines and education for advanced practice and staff nurses in the use of CBT with SCD families.

There are several ways by which dissemination takes place. Manuscript, poster presentation, and publications are means by which a broader audience can be reached nationally and internationally to convey important messages. The yearly nursing symposium, held at the identified institution, is a convenient avenue to disseminate this research findings to healthcare stakeholders. This forum provides nurses with the opportunity to share their research projects with the wider healthcare community. The

symposium is an ideal medium for nurses to collaborate with each other to provide quality evidenced-based care for better health outcome.

Analysis of Self

Many years ago, I felt that my life had no purpose or meaning. Throughout life, I had several periods of disappointment and numerous setbacks. This was as a result of repeated mistakes that I made personally. I suffered both mentally and physically with my children bearing the brunt of the pain. I felt worthless and helpless. Finally, I came to the realization that my children were not responsible for my misfortune. After witnessing the pain and suffering that my children had to endure, I decided to fight my demons. I had to come up with a plan to devise ways to provide them with a more fulfilling life.

As a child, my dream was to become a nurse because I wanted to help people mentally, emotionally, and physically. What better profession to achieve that goal but nursing. However, I lacked the qualifications to become a nurse. I started off by becoming a nursing assistant, while perusing my high school diploma. Finally, I continued my educational path and was accepted into the nursing diploma program. Several years later, I was accepted into college to pursue the BSN program. From there, I persevered and here I am.

Scholar

Professionally, I have grown in many ways. I became a nurse, a teacher, a leader, a change maker, and a scholar. When I decided to undertake the Doctorate in Nursing Practice (DNP), I had no idea of the challenges the final project would present. I also did not know what project I would embark upon. Doing a need assessment for this project,

was my initiation into true scholarly writing. The assessment helped me identify the need for nonpharmacological approaches to SCD to assist in coping with the disease.

The analysis of the project was my biggest challenge. Finding the information was easy, but synthesizing and engaging with the contents was challenging (Ackerman & Arbour, 2016). However, I am now able to review an article searching for the why, where, when, who, and how. The project has stretched my imagination, improved my critical thinking skills, and taught me the basis of analysis. Presently, I can better dissect literary contents more thoroughly and come out with a better understanding of the literature.

Practitioner

It is challenging to assume a scholar-practitioner role. Undertaking the DNP program was a lengthy, stressful process. In the role of a practitioner, one has to juggle family, work and school. Alternating between the mindset of a practitioner and a scholar, has an impact on the writing process and the framework with which one embraces inquiry (Klocko, Marshall, & Davidson, 2015). My goal was to create a balance between being a scholar and a practitioner.

As a full time practitioner, trying to balance coursework with other daily activities can produce increased stress which can disrupt family life (Klocko et al., 2015). Meeting and fulfilling deadlines became a daily occupation. Every minute of the day was important and had to be accounted for, so no time was wasted. Better time management skills also resulted from the rigors and discipline of the program. However, the program assisted and prepared me in becoming a better practitioner and mother. Parkinson (2015)

recounted the step-by-step self-practice/self-reflection as a training strategy in CBT also assisted me in my pursuit. The support of the project chair and classmates also helped me redefine my identity as a doctoral writer.

Project Manager

Becoming a project manager at the doctoral level was the most anxiety producing adventure that I undertook. I was afraid of the unknown and the fear of failure paralyzed me. To be successful, I realized that I had to do some self-management. That approach allowed me to control and manage my emotions to learning to deal with rejection and criticism. In preparation, for project management, I read articles about techniques to control emotions, thinking, and actions. Self-management precedes people management and builds self-confidence. According to Mersino (2007), leaders should focus on themselves before they manage or lead others.

In order to be successful in any undertaking, one must also have good communication and great people skills. Improving those skills were given top priority in building my project. I was able to approach my superiors and peers building meaningful relationships that I needed to move forward. Their input, and the interest shown in my project, assisted me in the achievement of my goal. Some people are fearful of presenting to crowds, which can result in the downfall of their professional career as project manager. Campbell (2009), stated that the ability to communicate effectively is the number one criterion for promotion and advancement of professional. In the end, I took away a wealth of knowledge which included effective management skills.

Summary

Researchers have shown that chronic illness including SCD, affects many more people than previously thought (Hildenbrand, Barakat, Alderfer, & Marsac, 2015). The impact of SCD on the patients and caretakers is devastating in many ways. The disease changes the entire structure and function of the families affected. Caretakers experience increased emotional stress and difficulty coping with the situation at hand. The way families cope with the physical and psychosocial burdens of SCD influences the child and family functioning (Hildenbrand et al.,2015).

There are several traditional pharmacological methods approved to treat SCD. For example, the use of opioids, Hydroxyurea, and blood transfusion is the standard of care for the management of SCD. Bone marrow transplant, and more recently, fetal hemoglobin induction were added to the treatment regimen (Cao, 2004). These traditional treatment modes alleviates signs and symptoms of the disease, while the psychosocial aspects of the disease are being ignored.

There are nonpharmacological methods like CBT that can decrease stress and increase coping in persons affected by SCD. The use of CBT can impact the way caretakers and patients view and cope with SCD disease. Over the years, the use of CBT has increased among participants, thus decreasing painful crisis. Nevertheless, more in-depth research needs to be done to examine SCD-related stressors beyond pain (Hildenbrand et al.,2015).

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Appendix A: SCD, Pediatric, and CBT Literature Search

<i>Potential Articles Identified</i>	<i>Articles Omitted Based on the Absence of Searchable Keywords</i>	<i>Articles Used in Systematic Review</i>
<i>N=12,414</i>	<i>N=12,201</i>	<i>N=6</i>

Appendix B: IRB Approval

IRB approval number is 12-14-17-0241217