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SICKLE CELL DISEASE AWARENESS INTERVENTION FOR PARENTS AND CAREGIVERS

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SICKLE CELL DISEASE AWARNESS INTERVENTION FOR PARENTS AND CAREGIVERS

Sherice Paton DNP(c), MSN RN

Abstract

Sickle Cell Disease (SCD) is an inherited hematologic disorder that overwhelmingly affects people of African lineage. In the United States, approximately 100,000 children have been born with the disease and suffer from complications associated with the disease. Children with SCD are seen in the emergency department an average of three times each year (CDC, 2016). The cost of treatment for each patient with SCD is approximately $500,000.00 annually (Cochrane, 2016). One out of every thirteen infants in the USA are born with sickle cell trait (SCT).

Despite the magnitude of children affected by this disorder and the complications involved there is no standardized course of action related to awareness. The purpose of this evidence-based project is to increase awareness for parents and caregivers of children diagnosed with SCD.

Nola Pender's health promotion model was utilized to for this project. The methodology was a quasi-experimental one-group, pretest-posttest design to show the relationship between providing SCD education pre and post intervention. This study could be beneficial as a resource tool for family and caregivers.

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Chapter 1

Introduction

Background of the Problem

Sickle Cell Disease (SCD) is an inherited hematologic disorder that is seen in people from the sub-Saharan area in Africa, Hispanic regions in the western hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy). In the United States, approximately 100,000 children have been diagnosed SCD, and 1 out of every 13 children are diagnosed with having the Sickle Cell Trait (SCT). These patients often struggle with managing the disease process and the lifelong complications associated with the disorder. In addition to a significantly higher infant mortality rate. Patients with SCD are seen at hospitals on average of three times a year. The average length of stay for pediatric patients is approximately three days with an average cost of one million US dollars annually(Cochrane, 2016). Some patients with SCD do not have access to outpatient care and are forced to use the emergency room as their only treatment option. Others are unaware of the resource and new technology available to them on an outpatient basis.

According to the Centers for Disease Control and Prevention (CDC), the life expectancy of a male with SCD is 42, and the life expectancy of a female with SCD is 48. In order to improve the quality of life of individuals with SCD, it is important to increase awareness of the disease process, prevention, and treatment.

When SCD is not managed correctly, patients can suffer both physical and psychological complications, including severe pain and suffering, depression, and time away from family. Some of the major complications include cerebrovascular accident (CVA), Deep Vein Thrombosis (DVT), Pulmonary Embolism (PE), Splenic Sequestration, loss of vision, infection,

depression, suicidal ideations, and feelings of loneliness. Patients often also experience the negative impact of time missed from work, school, and social events (Lyon & Taylor, 2016). Because the disease impacts individuals in a myriad of ways, it is important to take a holistic approach to care that extends beyond the patient's physical well-being.

SCD is a lifelong illness; this means parents and caregivers need to be empowered to care for a child with this diagnosis. Parent and caregiver awareness regarding the disease process, crisis prevention, and genetic counseling could decrease complications and undo stress, as well as prevent crises and reduce the frequency of hospital admissions for the patient. Awareness and counseling can also be beneficial to averting SCD diagnoses for future generations (Pandarakutty et al., 2019).

Parents and caregivers should understand the disease process in terms of pain management, crisis prevention, signs and symptoms of acute crisis, and life-threatening complications that require immediate attention. Patients also need to be educated in order to cut down or prevent complications. This awareness and education is invaluable and should continue throughout the lifespan as technology and treatment options change (Pandarakutty et al., 2019).

Despite the prevalence of this condition as well as the diverse and vulnerable population that it most often affects, there are no standardized guidelines for providing patients with information about SCD and the implications of the disorder during regularly scheduled appointments. Based on this deficit, this evidence-based project will provide pre and posttest analysis regarding SCD knowledge.

Nola Pender's Health Promotions Model (HPM) was utilized as a resource tool to implement the change. Pender's HPM describes health as "a positive dynamic state not merely the absence of disease"(Wilson, 2021). Pender's HPM focuses on increasing a client's level of

well-being. It describes the multi-dimensional nature of individuals as they interact within their environment to pursue health and wellness as it relates to this vulnerable population. It is a middle range theory that focuses on enhancing improving health status and quality of life in vulnerable populations such as children with Sickle Cell Disease (SCD). The model describes significant factors that may predict health status and quality of life (QOL) in vulnerable populations (Wilson, 2021).

The Johns Hopkins Nursing Evidence-Based Practice Model (JHNEBP) was utilized as a quality improvement Evidence-Based Practice (EBP) framework for this project. The model utilizes a three-step process called PET: practice question, evidence, and translation. The goal of the model is to ensure that the latest research findings and best practices are quickly and appropriately incorporated into patient care.

Statement of the Problem

Approximately 100,000 infants in the United States have been born with SCD and 1 out of every 13 are diagnosed with SCT within the United States (Kato et.al, 2018) These patients are part of a diverse and vulnerable population that often struggle with managing the disease process and the lifelong complications associated with the disorder. In addition to a significantly higher infant mortality rate, patients with SCD are seen at hospitals on average of three times a year. The average length of stay for pediatric patients is approximately three days with an average cost of approximately one million US dollars annually (Cochrane, 2016). Some patients with SCD do not have access to outpatient care and are forced to use the emergency room as their only treatment option. Others are unaware of the resource and new technology available to them on an outpatient basis.

When parents and caregivers are not properly educated about a child's diagnosis, there is an increase in the likelihood of complications such as physical, emotional, and financial difficulties associated the diagnosis (CDC, 2016).

In order to manage SCD properly, parents and caregivers should be aware of complications associated with traveling to high altitudes and managing a pain crisis, as well as the importance of staying hydrated and incorporating frequent rest periods when engaging in sports and exercise. Awareness of these complications can decrease or prevent the probability of complications. Increased knowledge about the effects of having SCD/SCT will provide parents, caregivers, and patients an opportunity to make informed decisions regarding their health. However, if awareness is not provided, there will be no reduction in the recurrence of the disease or complications. (Housten et al., 2016).

Purpose

The purpose of this SCD evidence-based project is to provide awareness for parents and caregivers with a child diagnosed with SCD. When SCD is not managed correctly, children can suffer both physical and psychological complications to include a crisis, severe pain and suffering, depression, and time away from family and loved ones. Some of the major complications include cerebrovascular accident (CVA), Deep Vein Thrombosis (DVT), Pulmonary Embolism (PE), Splenic Sequestration, loss of vision, infection, depression, suicidal ideations, and feelings of loneliness. Parents caregivers and patients can also experience the negative impact of time missed from work, school, and social events (Lyon & Taylor, 2016). It is important to focus on holistic care and not just the physical well-being of patients.

Parents and caregivers should have resources available (support groups, access to SCD websites, etc.) as well as an awareness of pain management, crisis prevention, and signs and

symptoms of acute crisis. They need a clear understanding of both life-threatening complications that require immediate attention and how to prevent infection. This awareness and education is invaluable and should continue throughout the patient's lifespan.

The life expectancy for males with SCD is 42 years of age. Females with SCD have an expected lifespan of 48 (CDC, 2020). It is important to ensure good outpatient management for the SCD population to implement preventative measures that could possibly increase their life expectancy in addition to increase quality of life (Press.et al., 2018).

The risk of mortality for children diagnosed with SCD increases with age. The estimated rates of mortality worldwide were 15% for infants, 36% for children < 5 years of age, and 43.3% < 10 years of age (CDC,2020).

The practice focused question is: Would an online class offering awareness about SCD for parents and caregivers of children diagnosed with the disease increase awareness about SCD? To determine the effectiveness of this intervention pre and post test scores were measured. This allowed an assessment of pre-initiative versus post-implementation rates.

Definition of Terms

AA (AA): an American of African and specifically of black African descent.

CDC*: Centers for Disease Control and Prevention*

Genetic Counseling: The process of providing information and support to people who have or may be at risk for genetic disorders (National Institute of Health, 2016).

Healthcare Effectiveness Data and Information Set (HEDIS): used by providers to develop a strategy to evaluate the quality of care provided performance data to identify opportunities for improvement, monitor the success of quality improvement initiatives, track improvement, and provide a set of measurement standards that allow comparison with other plans. Data allow identification of performance gaps and establishment of realistic targets for improvement

Primary Care Manager (PCM): a healthcare provider responsible for providing you all routine, non-emergency, and urgent health care. If they can't provide care, they will refer you to a specialist.

Renal Medullary Cancer (RMC): A malignant epithelial tumor, arising from the collecting duct epithelium. RMC is a very aggressive form of cancer.

Sickle Cell Disease (SCD): A group of inherited red blood cell (RBC) disorders that involves a mutation of the RBC. The mutation causes the RBC to appear sickle in form and can cause a multitude of complications. Types of SCD include HbSS, HbSC, HbS beta thalassemia, HbSD, HbSE, and HbSO (CDC, 2016).

Sickle Cell Trait (SCT): When a person inherits one sickle cell gene ("S") from one parent and one normal gene ("A") from the other parent. Types of SCD are C and S trait.

Need for the Project

In the United States there are approximately 100,000 children have been born and suffer from SCD. However, 1 out of every 13 are diagnosed with SCT within the United States. The life expectancy for males is 42 years of age and 48 years for females. *SCD* can cause severe and life-threatening complications resulting in physical, emotional and financial distress (CDC, 2016). Many patients lack the awareness regarding the disease process to make informed decisions regard their health care and lack the information needed to make responsible decisions regarding family planning. Patients have reported receiving little or no awareness regarding their disease process after being diagnosed. Others are unaware that they have the trait or that it was a genetic disease when they received their diagnosis. Providing consistent standardized awareness and genetic counseling will increase awareness of the disease process and decrease complications associated with the disease leading to healthier outcomes and informed decisions about their healthcare as well as future generations (CDC, 2020).

Significance of the Problem

Approximately 100,000 Children have been diagnosed SCD and 1 out of every 13 are diagnosed with SCT within the United States. These patients often struggle with managing the disease process and the lifelong complications associated with the disorder. Patients with this SCD are seen in the emergency department on average of three times a year. Some patients with SCD do not have access to outpatient care and are forced to use the emergency room as their only treatment option. Others are unaware of the resources and new technology available to them on an outpatient basis. The average cost of treatment for a patient with SCD is approximately One million US dollars per year (Cochrane, 2016). These Emergency Department visits, in

addition to admissions, are costly both financial and physically. However, often times these hospital visits are preventable with good outpatient management, awareness, and genetic counseling. The life expectancy for males is 42 years of age and 48 years for females (Dawsey, 2015). It is important to ensure good outpatient management for the SCD population to implement preventative measures that could possibly increase their life expectancy in addition to increase quality of life.

When SCD is not managed correctly children can suffer both physical and psychological complications to include a crisis, severe pain and suffering, depression, and time away from family. Some of the major complications include cerebrovascular accident (CVA), Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE) Splenic Sequestration, loss of vision, infection, depression, suicidal ideations feelings of loneliness, related to the disease process in addition to time missed from work, school and social events (Lyon & Taylor, 2016). It is important to focus on holistic care not just the physical well-being in the outpatient management SCD awareness and the impact on the rate of SCD screening and genetic counseling. It is important to ensure patients are provided with consistent awareness as well as genetic counseling to allow patients to make informed decisions regarding their healthcare and their offspring's healthcare. This will also decrease and/or help to prevent complications.

Assumptions

There are five assumptions for this project. The first assumption is that stakeholders will request SCD resources. This is based on Nola Pender's Health Promotion Model. Pender's model suggests individuals have experiences that affect subsequent actions. These experiences affect the need for specific knowledge and influence the motivational significance. Health-promoting behaviors should result in improved health, enhanced functional ability, and better

quality of life at all development stages. (Wilson, 2021). These variables can be modified through nursing actions. Health-promoting behavior is the desired behavioral outcome and is the endpoint in the Health Promotion Model. It is the idea that individuals have the natural ability for self-care, and healthcare has a duty to focus on affecting that ability (Younas, 2017). Pender's believed that quality of life could be improved by the prevention of problems before they arise resulting in health care dollars could be saved by the promotion of healthy lifestyles. The second assumption is that stakeholders be given opportunities to for health literacy regarding SCD awareness. The third assumption is that there would be a positive correlation between awareness and higher SCD post intervention scores. The fourth assumption is SCD awareness measures would be documented and reinforced. This would allow other healthcare professionals to easily access teaching needs and provide the necessary information. The fifth assumption is that providing education regarding SCD will prevent complications and increase awareness.

Summary of the Problem

Approximately 100,000 children have been born with SCD and 1 out 13 are diagnosed with SCT in the United States (CDC, 2016). The estimated rates of mortality for children with SCD worldwide were 15.3% for infants, 36.4% (33.4-39.4) for children< 5 years old, the percentage increases to 43% by 10 years of age.

Important information about SCD is not regularly provided to the patients or family members (CDC, 2016). Although mandatory counseling is often completed for infants, continued awareness isn't consistently provided to the patient and/or loved ones throughout the life span. Opportunities to educate loved ones during regularly schedule appointments with Primary Care Manager (PCM) are often missed.

Due to the limitations and assumptions listed above, the main objective for the intervention is to determine if providing a synchronous online class regarding SCD awareness would results in an increase in awareness regarding SCD. By utilizing awareness as a resource tool about SCD and possible complications, patients and caregivers can have the necessary knowledge to make informed decisions regarding this disease process. It will also allow the stakeholders to be proactive in addition to providing the tools necessary to make informed decisions and improve health outcomes. In the Chapter 2, relevant literature related to the dynamics of SCD is discussed covered.

Chapter 2: Literature Review

Introduction

PICO

P = Population/Patient/Problem Parents of children with sickle cell.

I = Intervention: A 50-minute class utilizing an online platform for community-based education

C= Comparison: Pretest-posttest design

O= Outcome: Increased knowledge as demonstrated by increasing awareness to parents of children with Sickle cell. Topic: Improving quality of life,

Approximately 100,000 Americans are diagnosed SCD and 1 out of every 13 are diagnosed with SCT within the United States (Kato et.al, 2018). These patients are part of a diverse and vulnerable population that often struggle with managing the disease process and the lifelong complications associated with the disorder. In addition to a significantly higher infant mortality rate. Patients with this SCD are seen at hospitals on average of three times each year. The average length of stay for pediatric patients is approximately three days with an average annual cost of approximately of one million dollars. (Bou-Mourn et al., 2018). Some patients with SCD do not have access to outpatient care and are forced to use the emergency room as their only treatment option. Others are unaware of the resources and new technology available to them on an outpatient basis to help manage this disease.

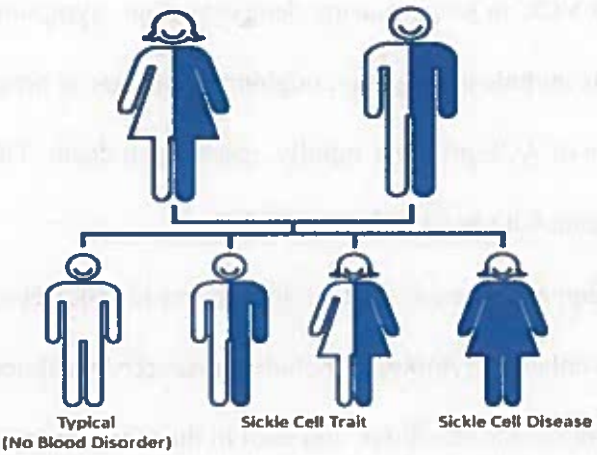
Pathophysiology

SCD is a group genetic disorder involving red blood cells (RBC). RBCs are needed to carry oxygen (O_2) throughout the body. It is an autosomal recessive disorder discovered by James B. Herrick in 1910 (Obeagu, 2018). The most common form of SCD found in the United States of America is Homozygous HbS Disease (HbSS), which is the severest form of the disease.

Normal RBCs live approximately 120 days. They are round and flexible, allowing for effortless passage through the vascular system. In a patient with SCD, the RBCs have a much shorter life cycle. The cells are shaped like sickles or crescent moons, which is how the disease got its name. These cells are also tacky and not flexible. This results in the RBCs having difficulty traveling through the vascular system, especially through the smaller blood vessels. This causes delays or lack of oxygenation due to slow or occluded blood flow to specific areas of the body (Obeagu, 2018). For a child to inherit SCD, both their mother and father must have the trait. If only one parent passes the sickle cell gene to the child, that child will have the SCT. Individuals with SCT inherit a sickle cell gene from one parent, and a normal gene from the other parent. Most people with SCT do not have any symptoms associated with SCD and live normal, healthy lives. However, the trait can be passed on to future generations (Benenson, Porter, & Vitale, 2018).

Figure 1

SCD Inheritance, 2020



In the United States, it is mandatory for infants to be screened for SCD. Most infants do not experience symptoms of SCD right away as they are protected by increased levels of a protein known as fetal hemoglobin. Fetal hemoglobin is replaced by sickle hemoglobin around the 5th month of life, which causes the cells to sickle. Swelling in the hands and feet are usually the first noticeable signs of SCD, and are often accompanied by fever, acute pain, and decreased movement of the extremities. This is called Hand-Foot Syndrome, or Dactylitis. As the cells begin to sickle they often get wedged in the blood vessels, obstructing the blood flow to and from the extremities.

A hallmark sign indicating the onset of a sickle cell crisis is pain. Pain is the most common problem experienced by people diagnosed with SCD. Medical attention is often required resulting in visits to the emergency room and/or hospitalization (Abboud, 2020). The pain is usually associated with a Vaso-Occlusive Crisis (VOC) in the blood vessels. The pain can

start suddenly, and the intensity of the pain ranges from mild to severe with a sudden onset lasting from a few hours to several days. Other complications include Acute Chest Syndrome (ACS) and Splenic Sequestration. Both complications can be life-threatening and require hospitalization.

ACS is primarily due to VOC in lungs causing deoxygenation. Symptoms can mimic pneumonia, but other symptoms include chest pain, coughing, shortness of breath, difficulty breathing, and fever. Symptoms of ACS progress rapidly, resulting in death. This is the most common cause of death in patients with SCD (Abboud, 2020).

Splenic Sequestration happens when a large number of sickle cells get trapped in the spleen and cause it to suddenly enlarge. Symptoms include unexpected weakness, pale lips, increased heart rate and respiration, extreme thirst, and pain in the stomach (specifically on the left side).

Prevention

Although a sickle cell crisis is inevitable, there are ways to decrease the occurrence such as preventing dehydration, avoiding high risk areas (airplanes, high altitudes, and hot and cold climates) as well as preventing infection. Staying hydrated is one of the most important ways for a patient with SCD to prevent a crisis. The loss of body fluids causes the blood to be more concentrated, increasing the likelihood of VOC. Common causes of dehydration are vomiting, diarrhea, fever, and exercise. People with SCD should drink fluids frequently, and their urine should be light yellow in color. If the urine starts getting darker, patients should increase their fluid intake. Patients should also drink fluids pre and post work out or with any exertion, and they should increase their fluid intake if suffering from a fever or infection. Those affected by SCD should also avoid extreme temperatures (both hot and cold) as well high altitudes (cities,

flying, and mountains). High altitudes have lower O_2 levels and can result in an increase in sickled cells. Common communicable diseases can also be hazardous for children with Sickle Cell Disease. The best defense against infection is prevention. Frequent hand washing with soap and water is best way for patients with SCD to keep bacteria at bay. If soap and water is not available, healthcare professionals recommend the use of hand sanitizer. Patients with SCD should also receive all scheduled immunizations, as well as an annual influenza vaccine (Mary & Beevi, 2018).

Pain should be treated at the onset. For acute mild pain, the use of over-the-counter medications NSAIDS such as ibuprofen/Advil may be useful as well as resting, distractions, meditation and guided imagery. . Pain relievers such as acetaminophen/Tylenol can also be utilized. Tylenol and Ibuprofen can also be alternated. It is important to ensure children and teens < 20years of age are not given aspirin, which can cause Reye syndrome. For mild to severe pain a prescription for strong medication such as opioid analgesics may be required. A pain management plan should be created to aid in the management of chronic pain (Mary & Beevi, 2018).

Treatment and Management

Treatment of SCD crisis requires aggressive care and is focused around rapid hydration, pain management, and treating the underlying cause. Standard protocols, if treated at a health care facility should include obtaining I.V access immediately and initiating IV fluids. A rapid pain assessment should be conducted in addition the prompt administration of pain medication. O_2 should be administered to maintain O_2 saturation, and supportive care. Antibiotics and blood transfusion may be required to correct the situation. If not treated early and aggressively, organ damage and death can occur (Mary & Beevi).

Parent and caregiver education/ Counseling/ Support Groups

Parents and care givers are responsible for providing care of children diagnosed with SCD. The extent of care can be overwhelming. Education for them should include Basic knowledge about the disease process, common problems, complication, prevention, caregiver role strain, and self-care for the caregiver as well as resources and support groups.

Review of Medication Therapy for the Prevention of Sickle Cell Crisis

This research study discussed the use of three medications (hydroxyurea, L-glutamine, and (Crizanlizumab) in the treatment of related SCD pain episodes. The research was conducted by four credible researchers with graduate degrees in pharmacy. The researchers have a wealth of knowledge regarding the medication being researched. The researchers provided an abstract that is clear and concise with an overview of the material presented. The research was conducted through the University School of Pharmacy in Hendersonville NC. The investigators are credible and have clear knowledge of the information that is presented. The research conducted was a randomized, double-blind, placebo controlled MSH trial. This study enrolled 299 adult patients; the age criteria was >18 years with a diagnosis of SCD. The participants reported at least three crisis events in the year prior to the beginning of the research. The participants received either one of the three listed medications or a placebo (Riley et. al, 2018).

The article is well organized with medications broken down into sections. The research problem is clearly identified. It is also clearly stated and appropriate for the completed research. It is undetermined if the participants were adequately informed about the research project. However, the IRB granted full board permission due to the use of FDA regulated drugs utilized in the trials (Riley et. al, 2018). Some of the resources utilized for this research is greater than 5 years old. Some of the data for Hydroxyurea were from 1991 (Riley et. al, 2018). The

terminology was not always clear or understandable. Some of the acronyms that were utilized were not previously explained. The researchers also explained the reliability and validity of the research in detail. The research does discuss the need for further research as Hydroxyurea was the only medication studied in the past. The article generated additional questions that need to be considered regarding the use of other medications in the treatment of SCD. The references in this study were cited appropriately.

This article is beneficial to the project that will be conducting as it researches the effects of three different medications and whether the medications were effective in preventing SC complications from occurring in participants > 18 with SCD.

Coping with Pain in the Face of Healthcare Injustice in Patients with SCD

The researchers conducted a descriptive comparative study. The study included adult participants with a SCD diagnosis in an outpatient setting. The participants completed the PAINReportIt Healthcare Justice Questionnaire, as well as a Coping Strategies Questionnaire-SCD. The research involved a total of 52 participants. This study was conducted in Illinois. The sample size could have been larger. Inclusion criteria involved participants with a diagnosis of SCD who had been prescribed opioids for pain control during a crisis. The participants also had to be able to speak English and had to be at least 18 years of age. Exclusion criteria include being legally blind patients or having a disability that would prevent a participant from completing the questionnaire. The Institutional Review Board (IRB) of an urban public university in Illinois permitted the researchers to complete exempt level research (Ezenwa, et.al, 2017). According to the study, all participants were satisfactorily informed about the research prior to signing written informed consent forms. The credentials of the researchers are not clear. It is not known if they had sufficient knowledge of the research topic.

The research question was clearly stated and is appropriate. The primary resources utilized for this research is less than 5 years old. The references are listed appropriately. The data was clear and concise.

This research is beneficial as the number one reason for admissions related to SCD complications is severe pain. Pain can be an indictor of other issues therefore it is important to understand the participant's perspective and perceptions of pain.

Awareness Needs of Adults Living with SCD in the U.S. and Jamaica

The researchers completed qualitative research via a pilot study. The researchers involved in this study were registered nurses and advanced practice nurses with more than 5 years of experience caring for patients with SCD (Jordan, 2016). There was enough data collection to interpret the results of this study. The research included 200 adults with a diagnosis of SCD within the United States and Jamaica. The study received IRB exempt level approval. The questionnaire utilized by the researchers was distributed with a disclosure statement attached. All participants voluntarily agreed to the conditions of the study (Jordan, 2016).

The reliability and validity were addressed during this research. The references were cited correctly, and the resource utilized were less than 5 years old. The hypothesis was clearly stated, and the research supported the hypothesis. Limitation such as funding and small sample size due to lack of funding were discussed.

This study is helpful to this project as it discusses the awareness needs of patients with SCD from their perspective. It is important for patients with SCD to discuss their perceptions of the disease and what they believe the effects of their disease process encompasses (Jordan, 2016).

The 10-Item SCD Severity Measure (SCDSM-10): A Novel Measure of Daily SCD Symptom Severity Developed to Assess Benefit of GBT440, an Experimental HbS Polymerization Inhibitor

The research for this study was qualitative in nature. This study was based on a 1-on-1 open-ended concept as it relates to elicitation interviews (Savavge, et. al. 2018). The study involved a total of 56 adults as well as 10 adolescents (between the age of 12 and 63 years of age) with SCD & SCT in the US and UK. The participants involved were patients currently receiving hydroxyurea. 64% of the participants were female. The other 46% were male (Savavge, et. al. 2015). Only 1 to 42 had a Vas-Occlusive Crisis (VOC) in the preceding year necessitating urgent care. The research revealed that 74% of the participants reported having a characteristic "good" day versus 26% of the participants stated they had a crisis also known as a" bad day" (Savavge, et. al. 2015). This research was conducted by the American Society of Hematology in Washington D.C. The reliability and validity were addressed during this research. The references were cited correctly, and the resource utilized were less than 5 years old. The sample size could have been larger as it included patients from both the US and UK. The hypothesis was clearly stated, and the research supported the hypothesis. Limitation such as funding and small sample size due to lack of funding were discussed. The study received IRB approval prior to the study. The participants were informed and signed consents prior to the research being conducted.

This research is beneficial as it relates to the effects the use of hydroxyurea plays in the role of preventing SCD complications. This could be an important tool in patient awareness in preventing crisis.

Lived Experienced of Patients with SCD about Disease Management

The researchers conducted this qualitative research study involving eleven patients with SCD. In this study seven of the participants were female (64% of the participants)and three males (27%). The study explored the experiences of SCD patients as it relates to the management and control of pain during a crisis. This study was partly funded by a deputy of research of Ahvaz Jundishapur University of Medical Sciences as well as Ahvaz, Iran (Bauman, et.al, 2016). The hypothesis related was directly related to the research. The reliability and validity were addressed during this research. The references were cited correctly, and the resource utilized were less than 5 years old. The hypothesis was clearly stated, and the research supported the hypothesis. References were cited appropriately. Limitation such as funding and small sample size due to lack of funding were discussed.

Prevention of Morbidity in SCD & SCT- Qualitative Outcomes

This research study involves simple descriptive, data comparative, and correlational statistics utilized to interrupt the data (Howard, et. al, 2015). The research was conducted over 29 days as a qualitative research study. The order of each intervention was decided through randomization (Howard, et. al, 2015). The participants involved included ten adults (> 18 years) and 10 children (between 8 and 18 years of age). The researchers will obtain informed consent with permission from the institutional policies (UK ethical committee) as well as European/US Federal guidelines (Howard, et. al, 2015). Consents were signed by either the participant and /or participant's parent or guardian (Howard, et. al, 2015). The participants were asked to provide journals in an online diary. They were also asked to complete QOL questionnaires, complete lab studies, in addition to biochemistry studies (Howard, et. al, 2015). The adults were also asked to

complete pulmonary function test. The researchers had verifiable credentials as experienced psychologist.

The study was funded by the National Institute of Health Research (NIHR. Phase two). The reliability and validity were addressed during this research. The references were cited correctly, and the resource utilized were less than 5 years old. The hypothesis was clearly stated, and the research supported the hypothesis. It is also clearly stated and appropriate for the completed research.

Specifying SCD Interventions

This research study involved eight academic sites. Each site had two participants per site. The research was conducted over a two-year period. Data was collected in an online survey. This study was approved by the Washington University in St. Louis Human Research Protection Office. The funding was provided by SCD implementation Consortium with additional funding by US Federal Government, as well as the National Heart Lung and Blood Institute and the National Institute on Minority Health and Health Disparities (Howard, et. al, 2015). The hypothesis was cleared stated, and the research supported the hypothesis. It is also clearly stated and appropriate for the completed research. The validity and reliability were clear and concise. The references were cited correctly, and the resource utilized were less than five years old. The hypothesis was clearly stated, and the research supported the hypothesis. It is also clearly stated and appropriate for the completed research.

This research is important as it discusses useful interventions that can be useful in the awareness of patient with SCD. Hopefully preventing crisis.

Drugs for Preventing Red Blood Cell Dehydration in People with SCD

This research reviewed 51 studies at different facilities. However, only three met the inclusion criteria; the study involved 524 patients with SCD between the ages of 12 and 65 (Nagalla, S., & Ballas, 2018). These studies were conducted over 6 months. A quasi-randomized controlled trial of medications was utilized to rehydrate sickled RBCs versus a placebo (Nagalla, S., & Ballas, 2018). The study does not note IRB approval. It also does not discuss obtained consents. However, the information is clear and concise. The study included enough participants but was short. The study could have also included additional facilities. The researchers noted that phase II of the research concluded early due to pain related issues. The study failed to show a significant decrease in pain related to SCD complications. However, the researchers were able to see a reduction in the amount of pain perceived during a crisis (Nagalla, S., & Ballas, 2018). The references were cited correctly, and the resource utilized were less than 5 years old. The hypothesis was clearly stated, and the research supported the hypothesis of this. It is also clearly stated and appropriate for the completed research. The validity and reliability were clear and concise.

The studies are valuable to my research as it is needed to assess the efficiency of this therapy for patients with SCD. It also demonstrates patient's perception of pain. This study was selected due to the large number or participants compared to other research studies. I would reference other studies that researched similar research as there is no evidence of patient consents.

Improving Sickle Cell Transitions of Care through Health Information Technology

This research study investigated the benefits of electronic health records in the transitions between inpatient and outpatient care for SCD patients. The researchers utilized focus group with 94 participants. It involved 34 patients, 31 parents and guardians /caregivers, 22 parents and caregivers, and seven IT developers for a total of 94 participants. The participants received $50 cash for their participation. Each site obtained local IRB approval as well as approval from the Office of Management. Funding was approved and provided the Agency for Healthcare Research and Quality (Frost, et.al, 2016). Some of the data collected was collected prior to the study but is still within the 5-year time frame. The references were cited correctly.

The researchers had verified credentials. The hypothesis was cleared stated, and the research supported the hypothesis. It is also clearly stated and appropriate for the completed research. The validity and reliability were clear and concise.

This article is important to this study as it involves the use of electronic health records. This is a useful tool in empowering patients to take control of their health by accessing, reviewing, and sharing medical information during their outpatient appointments. The research was clear and concise (Frost, et.al, 2016).

Adapting Medical Guidelines to be Patient-Centered using a Patient-Driven Process for Individuals with SCD and their Caregiver's

This study was conducted with 64 participants diagnosed with SCD and their caregivers with various demographics. The researchers utilized community forums. The researcher obtained IRB approval from Vanderbilt University Medical Center (VUMC) with funding from the patient centered outcomes research institute (PCORI), National Center for Advancing Translational Sciences and the National Heart, Lung, And Blood Institute. The funder was not

involved in the design of this study, or the gathering, analysis, and/or the results of the data. (Cronin, et.al, 2018). Informed consent was waived for this IRB-exempt, as it is HIPAA-compliant (Cronin, et.al, 2018). The hypothesis was clearly stated, and the research supported the hypothesis. The researcher credentials listed and are appropriate for this study. The references were cited correctly, and the resource utilized were less than 5 years old. The hypothesis was clearly stated, and the research supported the hypothesis and appropriate for the completed research. The validity and reliability were clear and concise.

This study is important as it explains the caregiver role in the prevention of SCD complications in the outpatient setting (Cronin, et.al, 2018). This research also focuses on the importance of the caregiver as a vital role in the prevention of SCD complications.

Effectiveness of Clinical Decision Support Based Intervention in the Improvement of Care for SCD Patients

This research study involved a total of 20 patients with a SCD diagnosis (47 patients in the family medicine as well as 24 assigned to the internal medicine clinic). This study utilized a quasi-experimental design to research the efficiency of the CDC tool. This tool utilizes best-practice alert (BPA) in addition to healthcare awareness. The study group involved three Family Medicine Clinics (FMC) at the University of Florida where the CDS tool. The control group consisted of three Internal Medicine Clinics (IMC), also at the University of Florida. The IMC did not have access to the CDS tool. The research was collected over one year (6-month preintervention and a 6-month intervention), from March 2016-March 2017 (Mainous, et.al, 2018). The hypothesis was not clear and requires more explanation. The investigators are credible and have clear knowledge of the information that is presented. The validity and reliability of this research was clear and concise. The data was also clear and concise. The

references were cited correctly, and the resources utilized were less than 5 years old. This research can be useful in linking outpatient awareness between different Primary care managers either in family medicine clinic or Internal medicine clinic.

Genetic Counseling

This study discussed the several occasions when patients should have been offered genetic counseling and the opportunity was either missed or neglected. This resulted in the patient missing an important opportunity to be educated about SCD & SCT. The primary goal this research was to increase awareness, provide information of the benefits of genetic counseling as well as screening to prevent SCD, and to offer critical guidance (Taylor et al., 2014). The investigators noted that only 16% of people of childbearing age were aware they had SCT, and only 37% of parents and guardians were informed of their infant's SCT diagnosis after the newborn screening was completed. The study was unable to determine if the 37% of parents and guardians that received the results understood the implications, or if the information was shared with the diagnosed patients later in life. This information is crucial for patients to make critical decisions needed in regard to family planning (p. 1495). The researchers suggested providers and family members be notified of the results of the newborn screen in addition to updating medical records to reflect the test results. Genetic counseling was also highly recommended for patients affected with SCT and SCD. The main limitation of the study is that it is a Level VII study (Melnyk & Fineout-Overholt, 2010). The findings of their study supported this project as the findings exemplified the current gaps in the management of patients living with SCD & SCT.

Summary of the Review of Related Literature

The purpose of this project is to increase awareness about SCD to parents and caregivers. Research showed that awareness and genetic counseling for this vulnerable population could help reduce the incidence of SCD complications and better quality of life. The literature reviewed related to a need for this study. In the next chapter, Chapter 3: Methodology, the information specifically related to SCD for this project will be discussed, along with the background and context of this research project.

Chapter 3: Methodology

The purpose of this SCD evidence-based project is to provide awareness for parents and caregivers with a loved one diagnosed of SCD. When SCD is not managed correctly, patients can suffer both physical and psychological complications to include a crisis, severe pain and suffering, depression, and time away from family. Some of the major complications include cerebrovascular accident (CVA), Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE) Splenic Sequestration, loss of vision, infection, depression, suicidal ideations feelings of loneliness, related to the disease process in addition to time missed from work, school and social events (Lyon & Taylor, 2016). It is important to focus on holistic care and not just the physical well-being of the patient. SCD patients can be viewed drug abuser or drug seeking as they usually present to the ED in severe pain. This can complicate their access to treatment, but most pain control issues can be managed on an outpatient basis. The required care can be accessed even in rural areas via home health nurses and telehealth visit with specialist equipped to manage SCD patients.

Project design

The pretest and posttest consisted of a questionnaire (see Appendix A). The questions are based on criteria developed by Housten, et al. (2016) to assess whether participants are aware of critical information regarding SCD. This questionnaire will also assess the participants' understanding of SCD as it relates to children. The posttest questionnaire will be the same as the pretest and will be used to determine if the participants' SCD knowledge improved based on the information provided. Utilization of the pretest/posttest method will be used to assess the change in participants' knowledge. The information received from the

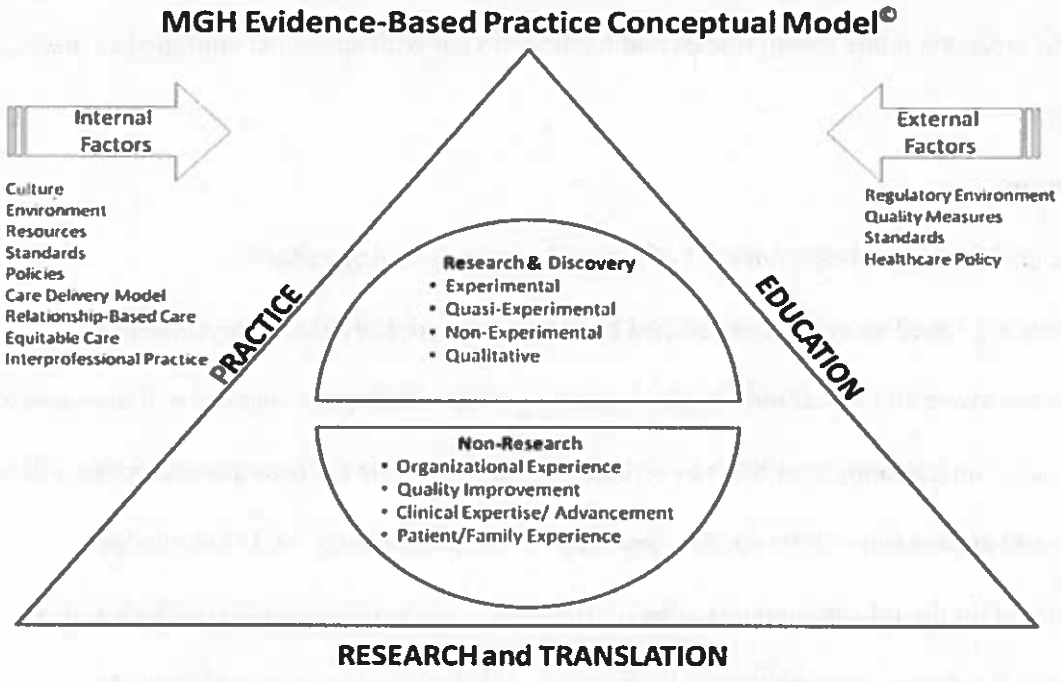
participants can benefit other SCD & SCT patients, as well as healthcare providers, to achieve successful patient outcomes.

Theoretical Framework

For the project initiative, The Johns Hopkins Nursing evidence-based practice model (JHNEBP) will be utilized as a quality improvement EBP framework for this project. The model uses a three-step process known as PET: practice question, evidence, and translation. It also provides guidelines, tools, description, and illustrations. The utilization of this model ensured best practices guidelines can be incorporated into patient care (Alexander, 2018). The goal is to utilize EBP, establish best practices, and incorporate them in efforts to improve outcomes.

Figure 2

JHNEBP Conceptual Model



Adapted from Johns Hopkins Nursing Evidence-Based Practice Conceptual Model (2012)

Nola Pender's Health Promotion Model (HPM) will be utilized as the theoretical framework for this project as it complements the JHNEBP model. Pender's theory is a middle range theory that focuses on improving health status in addition to the Quality of Life (QOL) in vulnerable populations such as children living with SCD. This model refers to significant factors that can predict health status and QOL. It describes health as a "positive dynamic state not just the absence of disease" (Matthie & Jenerette, 2017).

Pender's HPM is focused on maximizing the patient's level of well-being. It is the multidimensional nature of persons as they interact within their environment to pursue health (Matthie & Jenerette, 2017).

Pender's HPM focuses on three areas: individuality and life experiences, behavior-specific cognitions and affect, as well as behavioral outcomes. Pender's HPM believes that everyone has distinct personal characteristics and life experiences that have a direct correlation to subsequent actions. The variables can be altered and improved through EBP and nursing engagement to achieve the desired behavioral outcome. This can ultimately result in behaviors such as improved health, enhanced life expectancy, and better overall quality of life. Behavioral demand is directly influenced by competing demand and preferences, which can disrupt expected outcome.

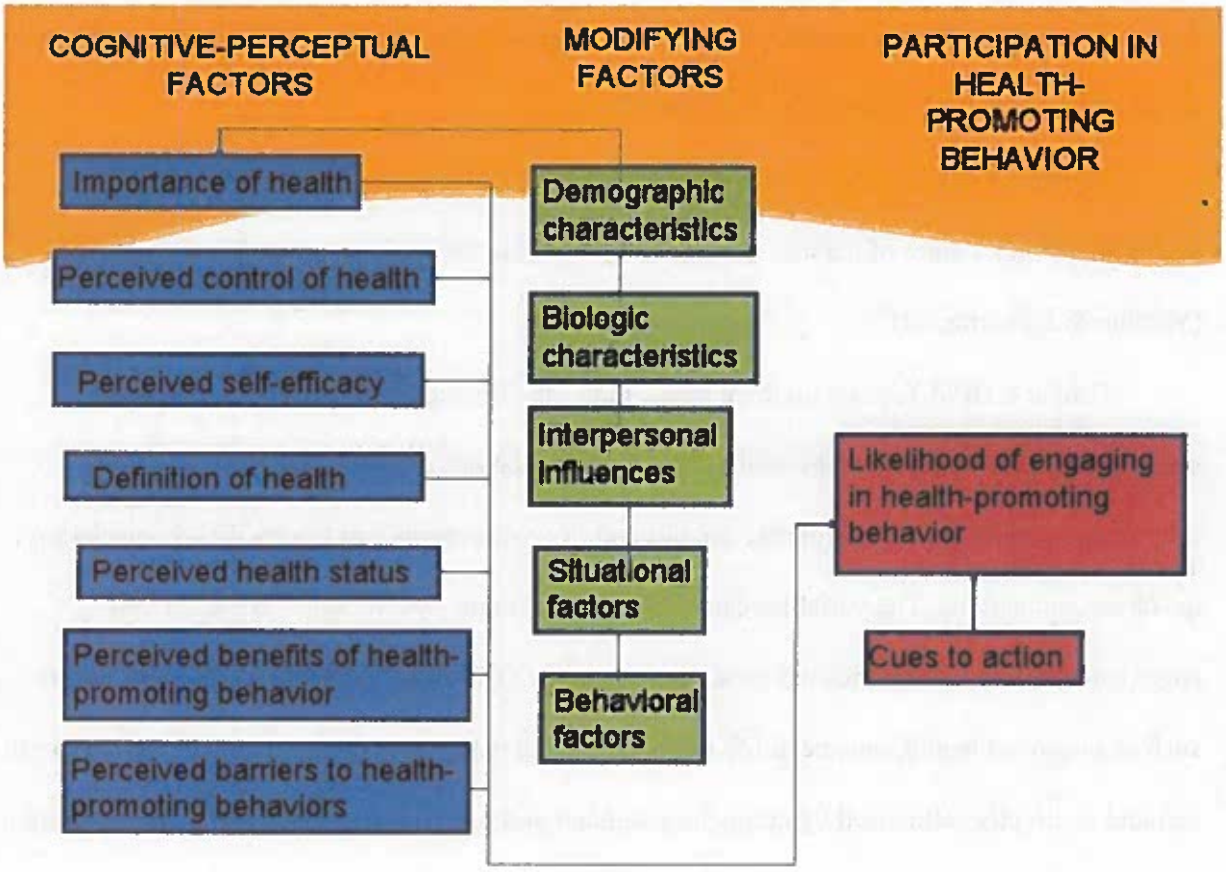
There are four assumptions in Pender's HPM:

1. People seek to actively regulate their personal behavior.
2. People interact with the environment, gradually altering their environment as well as being transformed over time.
3. Nurses contribute to the patient's interpersonal environment, which employs influence on patients over their lifespan.

4. Self-initiated change of an individual's environment is essential to changed behavior.

Figure 3

Nola Pender's Health Promotion Model



Setting

The project will be conducted online via a Zoom platform within the United States. The project will involve parents, guardians and caregivers with a child diagnosed with SCD. The pretest/posttest answers will be completely anonymous. This will allow the participants an opportunity to be open and honest about their experiences without fear of reprisal or retaliation

for providing unambiguous responses as noted in other types of research methodologies. HIPAA rights will be protected in accordance with federal guidelines.

A convenience sample from parents, guardians and caregivers will be used to identify potential candidates to participate in this project.

Sample

The target population of this study will be parents, guardians, and caregivers who are involved in the care of a child diagnosed with SCD. The subjects have to be at least18 years of age. Each participant must be able to read and comprehend the English language. Participants will be provided with anonymity throughout the process. SCD patients <18 years of age, pregnant, or unable to read or comprehend English will not be used for this project. Invitations will be sent via e-mail to a convenience sample of participants meeting the inclusion criteria. 40 participants will be identified as possible candidates for this study. The project will be conducted over an 8-week period with the selected participants.

Ethical Considerations

Institutional Review Board from Edinboro University approved the project. CITI training was completed to ensure the investigator is proficient in research ethics, regulatory oversight, and accountable conduct. Adherence to the Health Insurance Portability and Accountability Act (HIPAA) will be implemented to ensure patient privacy. Informed consent will be acquired from all participants before carrying out this project. No participant names or other identifiers will be used in the summary of the research to ensure anonymity. The information from this study will be stored in a password protected file to ensure participants' privacy is protected.

Time Schedule

This project will be conducted over 8 weeks or until sample size is reached with the participants that meet the inclusion criteria.

Summary of Methodology

A pretest-posttest design will be used for this study. Prior to initiating this project, approval from the Clarion and Edinboro IRB as well as CITI course completion will obtained as well as consent from the IRB, and the participants. Participants' privacy and anonymity will be maintained in accordance with HIPAA guidelines. The data will be analyzed and interpreted using Intellectus Statistics.

Chapter 4: Analysis and Discussion

Introduction

This chapter provides discussion of the results of the pre- and post-test knowledge surveys. This includes descriptive as well as statistical analysis. A two-tailed paired samples t-test was conducted to examine whether the mean difference between the pre-test scores and post-test scores was significantly different from zero. Participants' demographic information, survey scores, and means before and after intervention are included.

Outcomes will be discussed to determine the program's effectiveness in increasing knowledge regarding SCD. Should the intervention results be statistically significant for effective and positive change in knowledge, further teaching can be incorporated to translate knowledge into practice utilizing Nola Pender's HPM to engage the community. Limitations and future directions will be identified.

Results & Analysis

Demographic Variables

Prior to the implementation of this project, participants registered for the 50-minute synchronous educational session and submitted demographic information that provided an overall description of the project's aggregate sample. Table 1 is a summary of the participants' demographic information. 40 participants completed the pre- and post-test surveys regarding SCD. Means, medians, frequencies, percentages, and ranges were used to describe key characteristics of the 40 participants in the sample. Most participants were female (82.5%) in the 30-39 age group and identified as AA. 80 % of the participants lived in Georgia (Figure 5), 50% of all participants were parents followed by guardians (22.5%) teachers (17.5%), and other caregivers (10%). 55% of participants stated they received previous education regarding SCD, while only 20% stated it was related to children. 100% of the participants stated they learned

from this intervention. Parents' scores were higher in both pre/posttest scores than the other participants, followed by guardians. While 92% would like additional resources as it relates to children with SCD.

Table 1

Demographics Variables of participants (N=40)

Variable	*n*	%
Gender		
Male	7	17.75
Female	33	82.50
Role		
Parent	20	40.00
Guardian	9	22.50
Teacher	7	17.50
Other	4	10.00
Previous experience with SCD		
Yes	33	82.25
No	7	17.75
Previous education on SCD		
Yes	22	55.00
No	18	45.00
Age(years)		
16 (18-29)	16	40.00
11(30-39)	11	27.50
6 (40-49)	6	15.00
4 (50-59)	4	10.00
3 (60 and above)	3	7.50
Race		
African American/Black	23	57.50
Caucasian/White	9	22.50
Latino/Hispanic	4	10.00
Asian/Pacific Islander	2	5.00
Other	2	5.00

Note. Due to rounding errors, percentages may not equal 100%.

Figure 4

Participants by Category

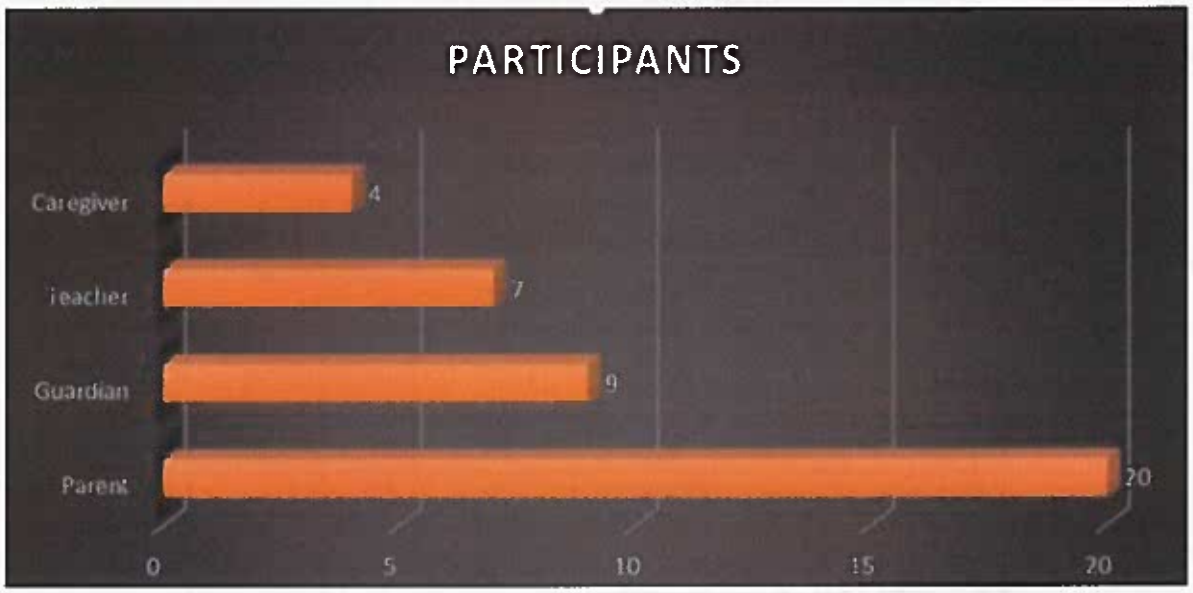
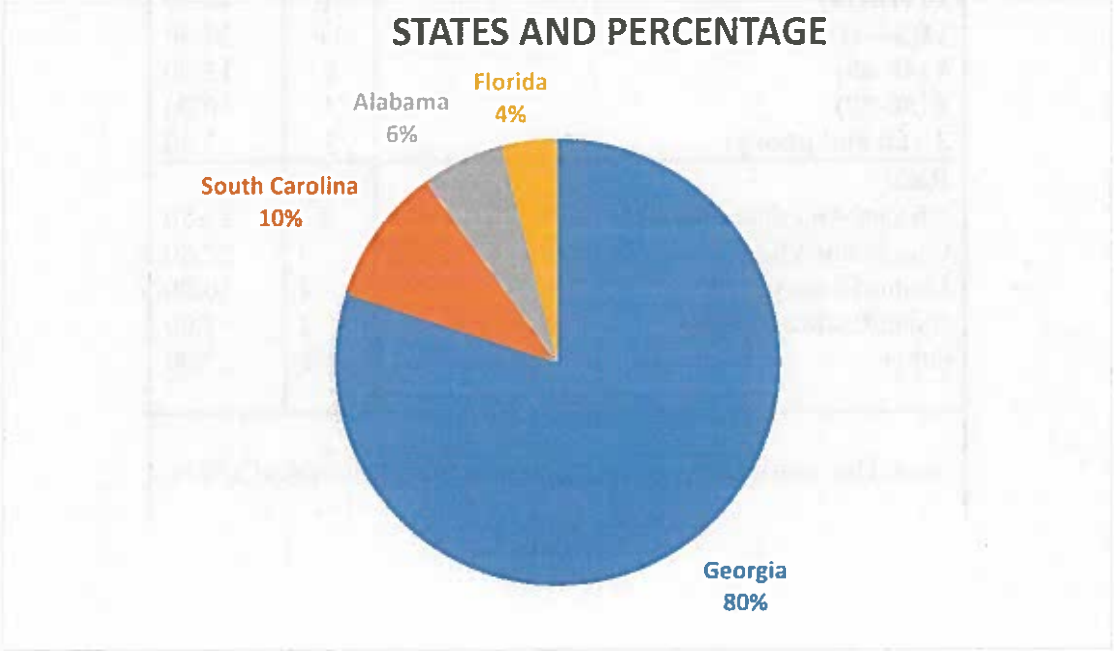


Figure 5

Participants' Location by State



Sickle Cell Awareness Knowledge Survey Scores

The primary focus of this educational intervention was to compare the knowledge of

Sickle Cell Disease reflected by a change in pre- and post-test survey outcomes. The data was retrieved by the primary investigator from Intellectus Statistics spreadsheet report. Each participant's score was calculated and graphed to illustrate the knowledge scores before and after the educational session. The pre- and post-test knowledge survey means (Table 3) were then calculated using Intellectus Statistics function, and a paired t-Test (Table 3) was conducted using participants' knowledge scores and Intellectus Statistics' data analysis function. Table 3 shows the mean knowledge scores.

Assumptions

Normality. A Shapiro-Wilk test was conducted to determine whether the differences in pre-test scores and post-test scores could have been produced by a normal distribution (Razali & Wah, 2011). The results of the Shapiro-Wilk test were not significant based on an alpha value of .05, $W = 0.95$, $p = .055$. This result suggests the possibility that the differences in pre-test scores and post-test scores were produced by a normal distribution cannot be ruled out, indicating the normality assumption is met.

Homogeneity of Variance. Levene's test was conducted to assess whether the variances of pre-test score and post-test scores were significantly different. The result of Levene's test was significant based on an alpha value of .05, $F(1, 78) = 37.91$, $p < .001$. This result suggests it is unlikely that pre-test scores and post-test scores were produced by distributions with equal variances, indicating the assumption of homogeneity of variance was violated.

Results

The result of the two-tailed paired samples *t*-test was significant based on an alpha value of .05, $t(39) = -20.29$, $p < .001$, indicating the null hypothesis can be rejected. This finding suggests the difference in the mean of pre-test score and the mean of post-test score was

significantly different from zero. The mean of pre-test score was significantly lower than the mean of post-test score. The results are presented in Table 2 . A bar plot of the means is presented in Table 3.

Table 2

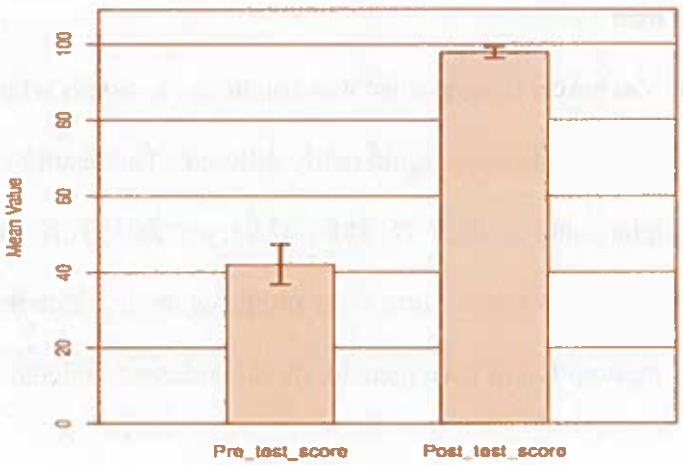
Two-Tailed Paired Samples t-Test for the Difference between Pre-test score and Post-test score

Pre-test score		Post-test score				
M	*SD*	*M*	*SD*	*t*	*p*	*d*
42.00	17.13	97.75	4.80	-20.29	< .001	3.21

Note. N = 40. Degrees of Freedom for the *t*-statistic = 39. *d* represents Cohen's *d*.

Table 3

95.00% CI Error Bars



Discussion

The project illustrates the effectiveness of online interventions to increase the knowledge of SCD as it relates to children. This was confirmed by a significant statistical difference in pre-test and post-test scores. The results yielded an ($p < 0.001$) increase in knowledge (an average of 55.75%). Furthermore, the project is evidence that online platforms can be effectively utilized to provide educational programs (such as SCD) during a pandemic.

Nola Pender's Health Promotion Model (HPM) in conjunction with JHNEBP were utilized to provide best practice guidelines for stakeholders involved in the care of children with SCD. Participants were given information and resources that can be used to implement change by understanding the disease process, prevention, and complications. Although 55% of participants stated they received previous education, 100% stated they learned from this intervention. Additionally, 92% would like additional resources as it relates to children with SCD.

Research and Practice Implications

The findings from this project support the use of the SCD educational intervention as an approach to decrease knowledge deficits and improve knowledge for caregivers of children diagnosed with SCD, which could ultimately result in fewer complications related to the disease process. The findings also suggest that utilizing the educational intervention could promote continued utilization of online platforms during a pandemic to increase awareness and interventions to promote SCD education for caregivers.

Implications include opportunities for further research which could encompass a larger group of parents and caregivers in a variety of settings throughout the United States. Implementing this project with a larger audience of parents and caregivers will permit a broad

view of the results, as well as greater understanding of how the project impacts children diagnosed with SCD. Further research should also be conducted to evaluate and reinforce retained knowledge related to the intervention one-year post intervention, which could not be incorporated due to the limited scope and time constraints of this project.

Limitations

There are limitations to this study related to the small group size and the target audience. However, it still possible to translate the data collected from the participants to develop programs to meet the needs of larger groups.

Another limitation was the limited timeframe for implementation and evaluation as well as the reliability and validity of the survey instrument. There was also audio, video, and/or connection issues for a few participants. A small number of participants reported having to sign back into the session due to connection issues, which could have impacted their experience and learning. Some had to switch from their computer to their due to audio/visual concerns. Another limitation of this study is that the generalizability of this research may have been reduced as the project was limited to parents and caregivers of children diagnosed with SCD. The last limitation was this study was conducted in the Southeastern region in the United States with participants fluent in English.

Recommendations

This project demonstrated the importance of educating caregivers about children with SCD. Additional research is need with larger groups in various settings throughout the United States. This will allow stakeholder an opportunity for early interventions which can prevent complications, hospitalizations and/or death (Adegbolagun, et al 2022). Recommendations for practice include incorporation of the educational intervention as part of the healthy people 2030

initiative, as well as providing educational guidance for caregivers in daycare and schools in efforts to provide early detection of symptoms and prevent life threatening complications.

Conclusion

Researchers have shown that, in the long-term, the impacts of SCD extend far beyond the child who is directly affected. The impact of SCD on children, their parents, and their caregivers is devastating in several ways. Having a child diagnosed with SCD ultimately changes the entire structure and dynamics of a family's everyday life, and the ways in which caregivers cope with the physical and psychosocial burdens of SCD influences the child's outcome (Adegbolagun, et al 2022).

This project demonstrates the effectiveness of the educational intervention in increasing the health literacy among parents and caregivers involved in the care of children living with SCD. This project also demonstrated an effective way to increase knowledge deficits via an online platform during a pandemic.

A review of the findings suggests a need for the implementation of educational programs to strengthen the knowledge and awareness of SCD for parents and caregivers. Since children are not always under the direct care of their parents, it is important that teachers, daycare workers, and other stakeholders are equipped with knowledge regarding children with SCD in order to prevent life threatening complications and to improve their quality of life (Adegbolagun, et al 2022).

Increased knowledge is a change agent that may ultimately improve the health, safety, and well-being of children living with this disease as it relates morbidity and mortality. It can ultimately save millions in costs related to hospitalizations, medication, rehab, and time off

work. This project showed that an online platform is an effective tool to increase knowledge and has the potential to encompass a larger audience globally.

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Appendices

Appendix A:

Pre- & Post-Test Knowledge Survey Questions

Pretest/ Post test

1. True or False: Sickle is contagious and can be spread from person to person
2. True or False: Sickle cell Disease is inherited
3. True or False Children with sickle cell disease cannot take immunization
4. True or False: Babies born with SCD do not survive to adulthood
5. True or False: There is no cure for Sickle Cell disease
6. True or False: Only African Americans get Sickle Cell Disease
7. True or False: Sickle cell trait is mild form of sickle cell disease
8. True or False: Sickle cell disease affects how blood cells travels in the body.
9. True or False: Children with Sickle cell disease can have swelling and pain in their hands and feet.
10. True or False: Children with sickle cell disease often take daily doses of penicillin until 5 years of age.

Appendix B

Clarion IRB Committee Letter

Institutional Review Board, Clarion University

RE: IRB Application No. N/A (Sickle Cell Disease Awareness Intervention for Parents and Caregivers)

Principal Investigator(s) Sherice Patton

As acting Chair of Clarion University of Pennsylvania's IRB, I have reviewed the above IRB application. The proposed project meets the IRB's guidelines for evidence-based projects and, as such, does not require IRB review.

Jennifer L. Boyer
Jennifer L. Boyer, JD, PhD

March 21, 2022
Date

Appendix C

CITI Certificate

CITI PROGRAM

This is to certify that:

SHERICE PATTON

Has completed the following CITI Program course:

CITI Good Clinical Practice
(Curriculum Group)
CITI Good Clinical Practice
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

Dwight D. Eisenhower Army Medical Center

Completion Date 11-Mar-2019
Expiration Date N/A
Record ID 24720957

Not valid for renewal of certification through CME.

CITI
Collaborative Institutional Training Initiative

This GCP training contains all of the required CITI Program modules from the GCP for clinical trials with investigational drugs and medical devices (IAS, FDA Region Version 2. This IOI is GCP Investigator Site Training meets the Minimum Criteria for IOI GCP Investigator Site Personnel Training identified by Therapeutic Goods Administration as necessary to enable mutual recognition of GCP training among trial sponsors.

Verify at www.citiprogram.org/verify/?wc9408198-2530-480b-9653-eda9cad9c76e2-24720957