



DOCTOR OF NURSING PRACTICE (DNP) PROGRAM

A DNP PROJECT

Education Intervention to Improve Knowledge and Screening for Sickle Cell Carrier Status among African Americans of Reproductive Age

STUDENT NAME: Anthonia Ajimavo

DNP PROJECT CHAIR: Irina Benenson, DNP, FNP-C

DNP TEAM MEMBER: Sallie Porter, PhD, DNP, APN, RN-BC, CPNP, FNAP

DATE: April 2nd, 2020

Table of Contents

Abstract

Introduction

Background & Significance

Needs Assessment

Problem Statement

Clinical Question

Aim & Objectives

Review of Literature

Theoretical Framework

Methodology

Design of project

Setting

Study Population

Subject Recruitment

Consent Procedure

Risk/Harms/Ethics

Subject Cost & Compensation

Study Intervention

Outcomes measured

Project Timeline

Resources Needed/Economic Considerations

Evaluation Plan

Data Analysis

Data Maintenance & Security

Anticipated Findings

Results

Discussion

Implications for Clinical Practice

Implication for Healthcare Policy

Implication for Quality and Safety

Implication for Education

Implication for Economy

Sustainability

Conclusion

Appendices

Abstract

Introduction: Approximately 2 million people in the US have SCT per the National Heart, Lung, and Blood Institute (NHLBI; 2010). Sickle cell trait is a heterozygous carrier state and it is not a disease. People with SCT usually do not exhibit signs and symptoms of SCD (CDC, 2017). Sickle cell trait carriers live normal healthy lives, but they can pass the trait on to their offspring.

Background & Significant: African Americans of reproductive age are unaware of their sickle cell trait status. The lack of knowledge about SCT carrier status can lead to a transfer of SCT to offspring, risk of having a child with SCD, and lack of knowledge regarding increased risk for some health conditions. The aim of this study was to increase the intention of African Americans to obtain screening to know their sickle cell carrier status.

Purpose of Project: The purpose of this project was to determine if an educational intervention will increase knowledge and screening in African Americans of reproductive age.

Methods: A quasi experimental research study with a 12 item pre-post-post questionnaire. The questionnaire included the 10-item sickle cell trait knowledge questionnaire (SCTKQ) with 2 additional question of intent to screen taken at 3 different time points: pre-intervention, immediately post-intervention and 2-weeks post-intervention. The intervention is a 40 minutes educational session.

Results: The result of this project indicated that there was an increase in baseline knowledge after the implementation of an educational seminar. Although the mean score was slightly less 2 weeks post intervention compared to immediately after the intervention, it remained statistically significant; immediate post-intervention ($P = 0.002$), 2-week post-intervention ($P = 0.001$). The result of intention to obtain screening by participants did not show any statistical significance pre and post intervention ($P = 0.346$), but there was a slight increase in the number of people who intended to obtain screen; pre

intervention (N=19), immediate and 2-week post intervention (N= 26). Lastly, more participants reported taking action towards obtaining screening (N=26), compared those who reported not taking any action (N=6).

Implication to Practice: Healthcare providers can help bridge the gap in lack of knowledge and awareness of sickle cell status among African Americans of reproductive age through education, screening, and making appropriate referrals. Awareness, management and prevention of these potential health complication is important, but it is crucial to stress the reproductive health implications to persons who are SCT carriers. Healthcare providers should encourage individuals, regardless of their ethnicity, to know their SCT status.

Keywords: sickle cell trait, sickle cell disease, knowledge deficit, lack of knowledge, reproductive health, reproductive decisions, African American, blacks, and sickle cell trait screening

Education Intervention to Improve Knowledge and Screening for Sickle Cell Carrier Status among African Americans of Reproductive Age

Introduction

Sickle cell disease (SCD) is a group of inherited red blood cell disorders (Center for Disease Control and Prevention [CDC], 2017). In a person with sickle cell disease, the red blood cell forms a sickle shape that dies quickly resulting in a constant shortage of red blood cells (CDC, 2017). (SCD) is an autosomal recessive disorder and it occurs when an individual inherits sickle cell gene “S” from each of their parents. SCD affects mostly people of Sub-Saharan Africa, Spanish speaking regions in the western hemisphere (South American, the Caribbean, and Central America), Saudi Arabia, India, and Mediterranean Countries (CDC, 2017).

Sickle cell trait (SCT) is when people inherit one gene of hemoglobin “S” from one of their parents and one normal gene “A” from the other parent. People with SCT usually do not exhibit signs and symptoms of SCD (CDC, 2017). Sickle cell trait carriers live normal healthy lives, but they can pass the trait on to their offspring. The odds of people with sickle cell trait passing the trait on to their offspring depends on the carrier status of their partner.

(SCT) is a heterozygous carrier state, it is not a disease. Parents who are both sickle cell trait carriers have a 25% (1 in 4) chance of producing a child with SCD with each pregnancy. When one of the parents has SCD and the other is a sickle cell trait carrier, the risk increases to a 50% chance of having a child with SCD with each pregnancy. Sickle cell disease and SCT can be determined through a blood test such as hemoglobin electrophoresis that detects the types of hemoglobin in the bloodstream (CDC, 2017). Other tests used to determine SCD and SCT are isoelectric focusing, high-performance liquid chromatography, and DNA-based testing (Gallo et al., 2010). Hemoglobin is the

oxygen carrying protein used by red blood cells (CDC, 2017). There are different types of SCD, and the most common types are HbSS, HbSC, and HbS-beta thalassemia (CDC, 2017). HbSS is when a person inherits gene “S” from each parent. HbSS is the most severe form of SCD (CDC, 2017). HbSC is when a person inherits gene “S” from one parent and gene “C” from the other parent (CDC, 2017). HbS beta thalassemia is when a person inherits gene “S” from one parent and gene for beta-thalassemia from another parent (CDC, 2017).

In the United States (US), all infants are tested for SCD through the newborn screening (NBS) program (Gallo et al., 2010). Sick cell trait is also identified during this process of screening but not everyone is aware of their SCT status. This project focused on the lack of SCT status awareness in African Americans of reproductive age. This project measured the current knowledge of SCT and SCD with the use of a sickle cell trait knowledge questionnaire (SCTKQ). The questionnaires had two additional questions to measure the participant’s intent to screen. The study participants took the tests before and immediately after a 40 minutes educational session. The test was also repeated two-weeks post the educational intervention to determine if knowledge is retained and if any action had been taken by participants to get screened. The project hoped to increase knowledge of the population that is affected by the disease process, increase awareness of sickle cell trait status, increase screening among African Americans and impact reproductive health decisions through the informative education session.

Background & Significance

Approximately 100,000 people in the (US) have SCD, which is 1 in 500 African Americans, and 1 in 36,000 Hispanic Americans (Shepherd, 2016). Per the CDC, SCD occurs in one in every 365 black or African American births and 1 in every 13,600 Hispanic births. Approximately 2 million people in the US have SCT per the National Heart, Lung, and Blood Institute (NHLBI; 2010). About 1

in 13 Blacks or African American are born with SCT (CDC, 2017). Also, people living with SCD face 75,000 hospitalizations per year, which totals an annual economic cost of US \$475 million (CDC, 2017).

The prognosis of SCD remains poor as about 1% of the children born with SCD in the U.S. die within their first 3 years of life (Shephard, 2016). There has been advancement in the management of SCD through newborn screening (NBS) initiative, immunization for children against *Haemophilus influenza* type b and *Streptococcus pneumoniae*, penicillin prophylaxis, and education about the complications of the disease process over the years. These measures were put in place to combat the mortality rate of children with SCD. Despite these measures, the average life span of an individual with SCD has not improved beyond the fifth decade of life (Abboud, De Montalembert, Tshilolo, & Ware, 2017). According to CDC, there has been a decline in SCD-related deaths amongst African American less than 4 years old by 42% between 1999 and 2002 (D. Grosse, Olney, Yang, & Yanni, 2009). When compared to the period of 1983 through 1986, the mortality rate between 1999 through 2002 showed a 68% reduction between ages 0 through 3 years, 39% reduction between ages 4 and 9 years old, and 24% between ages 10 through 14 years (D. Grosse et al., 2009). In the US, 94% of children with SCD will survive into adulthood with the overall median age of survival at 58 years (Azar & Wong, 2016). There is currently no cure for SCD, but there are treatment options available to manage symptoms and prevent complications (Gallo et al., 2010).

In 1972, President Richard Nixon signed into the law the National Sickle Cell Anemia Control Act that included screening and counseling programs for SCD and SCT, information and educational activities, and research (Naik & Haywood, 2015). However, not until 2006 did all states in the country adopt the universal screening for SCD and other hemoglobinopathies with the last state being New Hampshire. Universal SCD screening for newborns is being practiced in all state since 2006 (Ojodu,

Hulihan, Pope & Grant, 2014). As screening is done to detect SCD, SCT is identified. Since SCT detection is not the main purpose of the newborn screening, some laboratories may not communicate the SCT findings to parents, leaving parents of children with SCT unaware of their newborn's screening results (Benenson, Porter & Vitale, 2018). Although all states notify a primary care provider when an infant test positive for SCD, there are no universal procedures to notify providers for positive SCT screenings (Kavanagh, Wang, Therrell, Sprinz, & Bauchner, 2008).

NBS is done to identify SCD, SCT is also identified in this process but may not necessarily be communicated to parents and primary care providers (Kavanagh et al., 2008). Even when SCT is identified, there are no standardized means of reporting positive SCT results to providers or families of the affected individual (Ojodu et al., 2014). In the study done by Kavanagh et al. (2018) to identify communication of positive newborn screening results for SCD and SCT, there was a higher rate of communication to primary care providers and hematologists about SCD diagnosis compared to SCT. Furthermore, the programs that communicated the positive SCT results had no way of determining whether the information reached the intended recipient (Kavanagh et al., 2008). In some states, since SCT is identified during NBS for SCD, standards for notification and documentation of SCT status have not been established (Pecker & Naik, 2018).

There have been debates about the benign state of SCT in the literature. Although the overall risk of SCT to health is low, there are some potential health concerns related to SCT. Some of the health concerns include splenic infarction, hematuria, rhabdomyolysis, renal problems, and vascular problems (Shephard, 2016). It is understood that SCT carriers have a ten-fold increase in the risk of hemorrhagic stroke (Shephard, 2016). SCT is considered a risk factor for venous thromboembolism, pulmonary embolism, proteinuria, chronic kidney disease, and exertional rhabdomyolysis (Naik et al., 2018).

Despite the concerns for the health risks linked to SCT, there is a need to address the reproductive implications that are tied to it. There is a relationship between carrier status of SCT and chances of producing an offspring with either SCT or SCD. Literatures supports that there is a limited understanding of the inheritance pattern of SCT and its reproductive implications among African Americans (Gallo et al., 2010). African Americans who are unaware of their SCT status have a high-risk for having a child with SCD if they are not informed prior to conception (Mayo-Gamble et al., 2017).

Healthy People 2020 has recognized the need to increase the number of hemoglobinopathy carriers such as sickle cell carriers, who are aware of their carrier status (Department of Health and Human Services [HHS] 2014). They support that increased public awareness of testing for hemoglobinopathy gene and carrier status will increase both the awareness for carriers and their children and it will also shed some light on its effects on health-related decisions (HHS, 2014). The NHLBI and CDC have both identified SCT as a research priority requiring more goal-oriented and rigorous approaches to SCT research as research efforts have been flawed by poor design, small sample size, and use of low-sensitivity SCT diagnostics procedures (Naik & Haywood, 2015).

An effort has been made to obtain the status of SCD and SCT in the US as it affects diverse racial population with the highest prevalence in African Americans. In a study by Therell, Lloyd-Puryear, Eckman, Mann (2015), data was collected on newborn screenings conducted in the US for SCD and SCT for 20 years from January 1991 to December 2010. The results showed there were 76,527,627 newborn screened nationwide. Of the 76,527,627 newborns within that period that were screened, there were 39,422 confirmed cases of SCD (HbSS 24,014; HbSC 12,382; and S beta Thalassemia 3026). Based on this data, the highest prevalence of SCD was in the District of Columbia, with a ratio of 1 diagnosis of SCD per 437 births (Therell et al., 2015).

In Ojodu et al., (2014) “Incidence of Sickle Cell Trait- United States, 2010”, his data revealed that the incidence of SCT between January 1991 to December 2010 was 15.5 cases per 1000 births. It is crucial to keep in mind that during that period, NBS was not fully adopted national wide, and that result might not be the most accurate representation of the SCT carrier status. Based on race, the incidence of SCT among screened newborns is 73.1 cases per 1000 births in African Americans, 6.9 cases per 1000 births in Hispanics, and 3.0 per 1000births in whites (Naik & Haywood, 2015). Although there are diverse populations affected by SCD, it has been labeled a Black disease that has led to a publicized racial stigmatization (Naik & Haywood, 2015). The data for New York State reveals that for every 1,000 births within that period, there were 22.3 cases of SCT (Therell et al., 2015). Similar to the information on SCD, the District of Columbia also had the highest incidence of SCT with a ratio of 1 per 22 births (Therell et al., 2015).

Sickle cell trait does not cause an acute crisis, but it is essential to understand the significance of its carrier status and its impact on one’s health. Its genetic transmission to offspring and association with potential health conditions is an area for education. A precise understanding of positive SCT status is imperative for at-risk individuals in other for them to understand the potential genetic transmission of SCT to offspring and also to get familiar with the rare but serious complications of SCT status (Harrison et al., 2017). Although there are no studies correlating SCT status awareness with decreased adverse health consequences, it is important to note that information about the carrier status remains beneficial. Information about SCT may be advantageous in various life situations such as when an individual is considering family planning, participating in intensive military, and or athletic training (Benenson et al., 2018). Also, SCT status disclosure can serve as an educational opportunity to enlighten individuals in making better decisions to support their health and prevent harmful circumstances (Benenson et al., 2018).

Carrier status awareness raises the need for genetic counseling, and this is an area that needs to be addressed. Despite the NBS program in the US, genetic counseling, and follow-up for individuals with SCT remains poor due to variation in policies regarding notification in different states (Naik & Haywood, 2015). There may be factors that contribute to the lack of standardized communication mechanism for SCT notification and referral to genetic counseling. Significant challenges exist in formulating effective follow-up and making it acceptable to affected families due to the pervasive stigma and discrimination associated with the condition (Harrison et al., 2017). A new strategy to communicate the genetic implications associated with having a child with SCD needs to be developed in African Americans (Mayo-Gamble et al., 2017). Identification of SCT status is an opportunity for early genetic and reproductive counseling, community empowerment, and greater patient involvement in healthcare decisions and it has been neglected (Naik & Haywood, 2015). Ojodu et al. (2014) conveyed that the ideal time for primary care providers and genetic counselors to begin educating the families of identified persons with SCT about potential health complications and reproductive consideration is immediately after NBS has been done. While genetic and reproductive counseling is important to families of identified SCT carriers, it is essential to begin education and counseling prior to conception.

Genetic and reproductive counseling should be provided by knowledgeable professionals who are able to capture the attention of the affected population. Since there have been issues of mistrust between African Americans and health care providers dated back to the Tuskegee experiment, it is vital to gain the trust of this population. Counselors and educators should be well informed as information disseminated should be consistent across the nation. In the effort to ensure comprehensive genetic and pregnancy counseling, individuals may not be informed or may be incompletely educated about their SCT carrier status that resulted in confusion about health risks and mistrust of the

underlying intentions for screening (Naik & Haywood, 2015). Educators must be knowledgeable in the information they are passing to the community in the effort to educate them, and the information shared should be the same across the nation.

Needs Assessment

There are several factors that contribute to the lack of knowledge of SCT carrier status among African Americans of reproductive age. The lack of knowledge about SCT carrier status can lead to a transfer of SCT to offspring, risk of having a child with SCD, and lack of knowledge regarding increased risk for some health conditions such as venous thromboembolism (VTE). Additionally, stigma, fear, and mistrust of the healthcare system may contribute to low rates of African American who know their SCT status. As there is increased life expectancy, there is need to address issues of reproductive health decision making, especially among women as they carry the burden to conceive, abort, or bear a child (Ross, 2015).

Global Level

According to World Health Organization (WHO; 2017), it is estimated that 5% of the global population carries the trait gene for hemoglobin disorder. Over 300,000 babies with severe hemoglobin disorders are born each year with the majority in low and middle-income countries (WHO, 2017). The majority of the people with SCT are from regions in sub-Saharan Africa, India, Middle East, Saudi Arabia, and Mediterranean Region (WHO; 2017). In response to this global issue, the WHO have implemented some strategies which were adopted by the 63rd World Health Assembly in May 2016. WHO planned to increase awareness of international community of the global burden of the disorder, promote equitable access to services, provide technical support to countries for the prevention and

management of this disorder, and promote and support research to improve quality of life for those affected (WHO; 2017).

On December 22, 2008, the United Nations General Assembly adopted a resolution that recognizes SCD as a public health problem and one of the world's foremost genetic disease (Sickle Cell Society, 2019). This resolution called for members of sickle cell society to raise national and international awareness on sickle cell each year on June 19 (Sickle Cell Society, 2019).

National Level

Per the CDC (2017), one in every 13 Black or African American individual is born with SCT. Although people with SCT are generally healthy, they have the risk of having a child with sickle cell disease or trait. The CDC (2017) also estimated that in 2010, the incidence of SCT in the US was 15.5 cases per 1000 births, ranging from 0.8 cases per 1000 births in Montana to 34.1 per 1000 births in Mississippi. There were 73.1 cases of infants with SCT per 1000 births among black newborns nationally (Ojodu et al., 2014). These numbers are quite astounding, and it speaks to the importance of raising awareness of SCT. There are many organizations nationwide that strive to advocate for people living with SCD and promote awareness through community-based programs. The Sickle Cell Disease Association of America continues to make an effort to educate the public and policymakers on SCD and SCT (<http://Sicklecelldisease.org>). Other organizations such as the Sickle Cell Disease Association of America, and the American Sickle Cell Anemia Association all promote awareness on SCD and SCT, support people living with SCD, and support research on SCD.

State Level

Per the US Census Bureau (2017), over 19 million people are residing in New York. Of the 19 million people living in New York, 14% of the population accounts for African American. Based on the data collected in 2010, there were about 22 infants per 1000 infants screened who were identified as SCT carriers in New York state (Ojodu et al., 2014). From the data collected in 2010, New York state had one of the highest incidences of infants identified with SCT. This supports the need for an increase in awareness and education of the people residing in New York. Several foundations and networks provide services to family and people living with SCD. In New York, there are dedicated sickle cell centers in most of the boroughs (i.e. Queens, Brooklyn, and the Bronx). These centers, such as Sickle Cell Awareness Foundation Corporation International, provide support, treatment, and awareness to patients, families, and the community they serve for SCD and SCT. In Florida, there is an outpatient center exclusively dedicated to the treatment of SCD and conducting innovative research for SCD (<http://fscdr.org>).

Local Level

East New York and Starrett City, Brooklyn have 176,471 residents, 53% who identify as African American and 38% as Hispanic (US Census Bureau, 2017). Healthy People 2020 acknowledged the need for increased public awareness of carrier status as it affects the health-related decision (Office of Disease Prevention and Health Promotion [ODPHP], 2019). The local chapter in Brooklyn such as the Sickle Cell Thalassemia Patients Network (SCTPN) provides mentoring, tutoring, and advocacy for teens with SCD.

All of these organizations continue to improve the quality of life of individuals living with SCD and help their families cope with the burden. Most of these organizations focus on research and treatment of SCD with minimal emphasis on prevention. There is a need to educate the community on

the genetic transmission of SCD. It is essential to provide people with the tools they need to prevent a disease. Through education, we can become a healthier community.

Problem Statement

African Americans are unaware of their sickle cell trait status. Unawareness of the SCT carrier status can lead to unknowingly producing offspring with SCT or SCD.

Clinical Question

Will a faith-based educational intervention improve sickle cell trait knowledge and intention to be screened/obtain screening results among African Americans individuals of reproductive age?

Aim & Objectives

This project aimed to increase the intention of African Americans to get screened to know their sickle cell carrier status. The objectives of this study were to:

- Increase knowledge of SCT through a 40-minute education intervention that was held at a community church serving predominantly African Americans
- Increase awareness of SCT through an educational intervention and
- Increase the intention of SCT screening by providing information on where to get screened and what screening process entails.

Review of Literature

An extensive review of the literature was done using databases PubMed, and CINAHL. The key terms used in different combination for this search included *sickle cell trait*, *sickle cell disease*, *knowledge deficit*, *lack of knowledge*, *reproductive health*, *reproductive decisions*, *African American*, *blacks*, and *sickle cell trait screening*.

Using the keywords *sickle cell trait* and *African Americans* in the search engine, CINAHL yielded 64 articles. Of the 64 sources, only eight were deemed appropriate due to their relevance to the DNP project. Further modification of the search result by limiting the publication year to a seven-year limit resulted in the elimination of one additional article. A total of seven articles applied to the research topic using the above combination.

Keywords *sickle cell trait* and *knowledge deficit* using CINAHL generated one article. This article contributed to the project as a non- research article. Another keyword combination of *sickle cell trait* and *lack of knowledge* produced five articles. Of the five articles, one article was eliminated, as it did not relate to the topic leaving four articles. Two of the four articles generated had already been previously selected, leaving two new articles to be applied.

The combination of keywords *sickle cell trait* and *carrier status* inputted in CINAHL generated sixteen articles. Of the sixteen articles, only four articles were relevant to the research topic and were within the seven-year limit. These four articles had all been generated using other keywords. Hence, no new articles were produced.

Surprisingly the combination of keywords *sickle cell trait*, *knowledge deficit*, and *African American* yielded no results using CINAHL. Using keyword *sickle cell trait* alone in CINAHL yielded 555 results. When research results were narrowed down to a seven-year timeframe, there were 333 articles left. Of these, only one new article was useful as the remainder of the articles had either been found during previous searches or were not relevant to the topic. This new article contributed to the project as the second non-research article.

PubMed was also used alongside CINAHL in generating articles to support this project. Keywords were also used in various combinations during the search. Using the keywords *sickle cell*

trait and *African American*, 13 reports were generated. None of the articles were applicable as they were either over seven years old or was not relevant to the topic. Using the keywords sickle cell trait and knowledge deficit resulted in zero results. When *sickle cell trait* and *carrier status* were used, it generated ten articles of which none of the articles were used because they either were over the seven-year limit or was not relevant to the project after reading the title and the abstract.

The last search in PubMed using the keywords *sickle cell disease* and *sickle cell trait* resulted in 549 articles. Those relevant to the topic had already been generated from CINAHL hence, no new articles were found. A total of 15 articles were used to support this project. Thirteen of the articles were research-based while the other two were an expert opinion. All of the articles were within ten years margin with most of the studies conducted in the US. The table of evidence can be found in Appendix A.

Through the search of the literature, there were some common themes identified from various pieces of literature in addressing the lack of knowledge of SCT carrier status among African Americans of reproductive age. The factors that lead to these themes were lack of knowledge of SCT and SCD, unawareness of SCT carrier status, education as a tool to increase knowledge, and some social contexts associated with sickle cell such as stigma attached to SCD. Some of these factors had either a positive or negative influence on the individual's decision to either know their sickle cell carrier status, that of their partner, or disclose their status to their partner and family members.

Lack of awareness of sickle cell trait carrier status

Sickle cell trait and SCD screening are essential in African Americans, a population affected by sickle cell disease. However, there are many barriers to status awareness and screening (Mayo-Gamble et al., 2017). Sickle cell trait status awareness is imperative to reproductive health choices as it can prevent producing a child with SCD.

African Americans may be unaware of SCT and their carrier status. Mayo-Gamble et al. (2017) report in their research of 300 participants that 58.4% (n=175) perceived sickle cell trait as an illness. Of the 175 who viewed sickle cell trait as an illness, 34.7% (n=104) felt sickle cell trait is associated with a problem with your blood, and 23.7% (n=71) felt it means you are sick. There is unawareness of sickle cell trait amongst African American as 52% of the 258 participants, and 13% of the 300 participants respectively were unaware of their sickle cell trait status (Harrison et al., 2017; Mayo-Gamble et al., 2017). In a study conducted in Ghana, “Awareness of Sickle Cell Trait Status: A cross-sectional Survey of Antenatal women in Ghana”, pregnant women’s awareness of SCD and SCT and the factors that contributes to it was evaluated and it reflected a lack of awareness of SCT carrier status. Two hundred-and sixty pregnant women were recruited and of these women, only 10% (26 women) were able to identify themselves as SCT carriers. In a similar study conducted in Northern Manhattan with two hundred and eight participants who were parents of young children (Siddiqui et al., 2012). There were fifty-eight African Americans and one hundred and fifty Dominicans in the study. More than 43% of the Dominicans were unaware of carrier status, likewise 7% of the fifty-eight African Americans were unaware of their SCT carrier status. In the same study done in Northern Manhattan, primary care providers revealed that many do not routinely check newborn screening results for sickle cell trait or perform the recommended follow-up (Siddiqui et al., 2012). This calls for a cry to health care providers to take up an active role in increasing awareness in the population affected by sickle cell.

Lack of Knowledge of SCD and SCT

General lack of knowledge of SCD and SCT is a common factor in the literature. In Obed et al. (2017), result of the two hundred and sixty pregnant women in Ghana who participated in the study by taking a questionnaire reflected a lack of knowledge of SCT as only a third of the questions were answered correctly. Furthermore, it stated that there is a gap in knowledge of Ghanaian women of childbearing age between the significance of testing for the SCT before conception and how the results could impact their family planning decision (Obed et al., 2017). Of note, a third of the Ghanaian population carry the sickle cell gene and about 2% or 15,000 babies are diagnosed with SCD each year (Obed et al., 2017). Similarly, a study done in Northern Manhattan on two separate groups of African Americans and Dominicans of reproductive age revealed that people of reproductive age lack knowledge about SCT and SCD (Siddiqui et al., 2012). There is a substantial knowledge gap about sickle cell in people of reproductive age surveyed from Dominican and African American communities in Northern Manhattan, with Dominicans substantially less knowledgeable than the African Americans (Siddiqui et al., 2012).

In Harrison, Walcott, and Warner's "Knowledge and Awareness of Sickle Cell Trait Among Young African American Adults", 258 young African Adults took the sickle cell trait knowledge questionnaire (SCTKQ) with an average score of 68%. This test score showed that participants lack an understanding of the genetic transmission of SCT and how its carriers are typically asymptomatic (Harrison et al., 2017). In addition, individuals may lack knowledge of the steps in the screening process. Screening for SCT entails individuals to have a medical provider that will order the test, explain results, and be prepared to educate and make a referral as appropriate for genetic counseling in cases of positive screening (Mayo-Gamble et al., 2017).

Even though the goal for health care providers is to increase awareness and knowledge of SCT, SCD, screening process, and its implication to reproductive health, we have to be sensitive about the delivery. Disclosure of trait status must happen in a manner that is effective and that ultimately allows affected individuals to have control over and benefit from this important health information (Harrison et al., 2017).

Education as a Tool to Increase Knowledge

Implementation of an educational intervention can be instrumental in promoting knowledge of sickle cell trait, and its reproductive health implications in the population it affects as seen in (Gallo et al., 2016; Hershberger et al., 2016; Wilkie et al., 2013). CHOICES is a web-based educational intervention that provides information about reproductive options and consequences to help those with SCD or SCT identify and implement an informed parenting plan (Wilkie et al., 2013). A randomized controlled study was done including, 234 participants in the Chicago area who had SCD or SCT. The participants either participated in the CHOICES or attention control usual care intervention (e-Book) program that provided information on reproductive health, knowledge, intention, and behavior related to SCD and SCT. The e-book is a web-based educational program that includes information provided by sickle cell program to patients, parents, and the community. The e-book group received information provided by the sickle cell program in Chicago that was reformatted into a web-based program. The purpose of this study was to compare immediate posttest effects on the two groups. Posttest score revealed higher scores for participants in the CHOICES group when compared to the e-book group. Besides the increase in knowledge, the CHOICES group showed an increase in both their intentions and planned behavior while the e-book only showed an increase in their intention but not their planned behavior.

A two-year follow-up study by Gallo et al. (2016) looked to determine if knowledge was gained and retained. Although the scores did not show any significant increase in intention and behavior scores, it did reflect a sustained increase in knowledge in both groups with a higher score in the intervention group compared to the e-book. This demonstrates the effect of educational intervention in knowledge increase on a subject matter.

In Hershberger et al. (2016), a qualitative study of the CHOICES program demonstrated increased knowledge, a new way of thinking and behaving, and rethinking parenting plans in the participants. In this qualitative study, 68 men and women who had participated in the randomized controlled trial CHOICES or e-book were interviewed to obtain their perception about parenthood and participating in the study. Participants verbalized that participating in the education intervention either the e-book or CHOICES program was helpful to their knowledge.

In a study done in Jazan region of Saudi Arabia, “120 secondary school male students participated in a study that involved implementation of an education intervention in determining its effect on the knowledge and attitude about sickle cell anemia (Kotb et al., 2019). The education intervention was designed based on findings of the focus group discussion among the study participants. The study participants included students from rural area and city dwellers. A pre and posttest was done immediately after the education intervention. The baseline assessment showed that there were gaps in the knowledge of the student while the posttest revealed an increase in knowledge scores of the students. Some of the limitations of this study was that there were no comparison group, and there was no repeated assessment to assess for knowledge retention. Although the educational intervention in this study improved knowledge, the overall attitude of the participants did not change. There is a need for frequent health education campaign to increase sensitivity and understanding of the seriousness of the disease (Kotb et al., 2019).

Nationwide Children Hospital in Ohio conducted a study where a trained educator provided in-person education to caregivers of infants with SCT (Creary et al., 2017). The participants completed a health literacy assessment and a SCT knowledge assessment (SCTKA) before and after receiving education. There was a total of 113 caregivers in this study. The study aimed to determine if an in-person SCT education would affect caregiver knowledge, identify a barrier to increase in knowledge, and determine if the knowledge gained is sustained over time. The follow-up assessment was done about six months after the education intervention. The result of the study showed that there was an increase in the SCTKA score immediately post educational intervention. Although there was an increase in knowledge score after education intervention, the knowledge might slowly decline over time (Creary et al., 2017).

A study done in Nigeria amongst the National Youth Service Corps showed that education plays a vital role in increasing knowledge amongst the at-risk population. Nation Youth Service Corps is a program designed by the Nigerian government to engage Nigerian university graduates in national building and the development of the country (nysc.gov.ng). In Asuzu et al. (2012), a total of 451 people enrolled in the National Youth Service Corps program met the inclusion criteria for the study. There were 239 participants in the intervention group and 212 participants in the control group. Both groups took the pretest, but the intervention group participated in a health education program on SCD and screening. Three months later, a post-intervention test was done on both groups. The result of the project reflected a statistically significant change ($p=0.00$) in the level of knowledge of the participants in the intervention group. The percentage of the participant who had a good level of knowledge increased by 64.1%. Providing education to the at-risk population about carrier status identification, informed reproductive health decision making, and educating them on the benefits of testing is crucial (Asuzu et al., 2012).

Health care providers can be instrumental in increasing awareness of SCT status as they are skilled to educate, screen the population affected, and make referrals for genetic counseling (Arhin, 2019; Benenson et al., 2018). Registered Nurses have the tools and experience to handle case management and patient education, and they can be used to provide appropriate reporting, case management, and follow-up of infants with SCT who are identified by newborn screening (Arhin, 2019).

Health promotion efforts can be instrumental in increasing knowledge and awareness of SCT. Targeted education could be beneficial in increasing knowledge and increasing awareness among the affected population. In the study done in Northern Manhattan, despite the high prevalence of sickle trait, most Dominicans surveyed demonstrated a low level of knowledge about sickle cell (Siddiqui et al., 2012). Community-based surveys have consistently demonstrated limited awareness and understanding of SCD and SCT among African Americans (Arhin, 2019; Benenson et al., 2018). There is a need for health promotion efforts to increase sickle cell knowledge among both at-risk groups and the public at large (Harrison et al., 2017). Health care providers are in the position to champion the effort to increase knowledge and awareness.

Stigma as a Barrier

Some of the social context attached to lack of SCT awareness is the stigma with SCD and SCT. It is essential to understand what these stigmas are and how it affects the willingness of African Americans to know their carrier status. Some of these stigmas are that African American feel unsupported by their medical providers, they experience difficulty in accessing appropriate care, and they sometimes have a difficult provider-patient relationship (Harrison et al., 2017). In addition to the physical and emotional suffering, people suffer from the stigma associated with SCD (Ross, 2015). Individuals may not be interested in knowing SCT status due to the level of stigma associated with

sickle cell (Harrison, Walcott, & Warner, 2017). Due to the stigma and discrimination attached to sickle cell, there is a significant challenge in effective follow-up (Harrison et al., 2017).

There are multiple barriers to increase knowledge and awareness including perceptions that the public views sickle cell as just a “minority” problem and false fears that sickle cell carriers are contagious (Harrison et al., 2017). Another barrier is the lack of trust in health care professionals due to previous unfair and unethical medical treatment (Arhin, 2019; Benenson et al., 2018). Additionally, racial discrimination, community fear, incomplete knowledge, and concern for social or occupational implications stigmatize screening (Naik & Haywood, 2015).

Cultural and Social Consideration

Some cultural issues identified is the inequality in reproductive and genetic responsibility as women carry the burden of making mostly the decision on reproduction. Regarding reproductive health decision, individuals have to know their SCT status and that of their partner as well. In cases when women know their status, some were unaware of their partner’s status. A contributing factor to not asking partners to get tested for SCT is lack of awareness of the availability of testing and the importance of testing, and the awkwardness and sensitivity of asking their partners to get tested to know their SCT status (Ross, 2015). Besides, some women were scared to ask their partners due to fear of the effect of discussing the topic will have on their relationship (Smith & Aguirre, 2012). Due to fear of their partners, they simply placed more value on their relationship than the risk of having a child with SCD or SCT. Perhaps the social-economic status of the at-risk population affected by SCD and SCT is also a contributing factor. In association with stigma, it is possible that men were unwilling to get tested due to the history of discrimination in terms of employment which made it difficult for their female partners to discuss the option of testing.

Theoretical Framework

A conceptual framework is a guide to an empirical inquiry that is built from a set of concepts, deemed critical to the inquiry, which are related and function as an outline for the inquiry or set of actions (White, Dudley-Brown, & Terhaar, 2016). The conceptual framework that guided this project is the ACE Star model of transformation. This framework was designed to help bridge the gap between research evidence and practice (White et al., 2016).

Kathleen Stevens and staff of the University of Texas Health Science Center in San Antonio developed the ACE Star model of knowledge transformation framework. This framework was designed to facilitate the understanding of the cycles, nature, and characteristics of knowledge. The goal of this framework is knowledge transformation, and this is defined as “the conversion of research findings from primary research results, through a series of stages and forms, to impact on health outcomes by way of evidence-based care” (White et al., 2016, p. 17).

This model uses 5-point star for the five stages of knowledge translation including (a) knowledge Discovery, (b) evidence summary, (c) translation into practice, (d) integration into practice, (e) evaluation (White et al., 2016).

The first stage is the knowledge discovery phase whereby knowledge is discovered that will help develop a plan and implement a change that is geared towards a target population or setting. This stage is simply knowledge generation. In this stage, an extensive search of the literature is carried out to elicit pertinent information relating to the phenomena of interest.

The second stage of the ACE Star model of knowledge transformation is evidence summary. Information is gathered into a single, meaningful statement about the goals of the project. This is simply the summary of the structured review of the literature. This is the process that guides the

phenomenon of interest. After the information is gathered on the topic, the information gathered helped put together the clinical question.

Translation into practice is the third stage, which involves putting together the summarized research, knowing what the recommendations are from all the literature review. This is when all the information gathered from the search of literature and reviews are synthesized to create a concise teaching PowerPoint module. This information was disseminated in a church setting to inform African Americans of reproductive age.

Practice integration is the fourth stage, and it involves bringing about a practice change in hopes of changing cultural norms (Stevens, 2004). Concerning this project, an educational intervention was implemented to educate the audience, provide information on where to get tested and what tests are necessary. Community center resources were also provided. This action stage aimed to impact people's view on the topic through knowledge sharing.

Evaluation is the final stage of the ACE star model of knowledge translation. This is the stage where the process is evaluated to determine if the purpose was served or the goal was attained. Evaluation of the process is imperative in determining the effect of process change. Evaluation was done through completed questionnaire by participants. In relation to this project, an evaluation helped in determining if the process helped in increasing knowledge, and ultimately encouraging people to take action towards obtaining screening to know their sickle cell trait status. The theoretical framework applied can be found in Appendix B.

Methodology

Design

A quasi-experimental research design was used for this project. The project involved the use of a demographic questionnaire (age, gender, race, parental status, the highest level of education attained, and income level), pretest-posttest, 2-week post-test, and 40-minutes educational intervention. The education intervention was a PowerPoint presentation followed by a question and answer session.

Setting

The project took place at an African American church in an urban area in Brooklyn, New York. This area is popularly known as East New York. The church seats over 150 people with weekly Sunday attendance of about 100 people. The church is predominantly attended by Africans but has a vibrant blend of Islanders, Hispanics, and Americans. The project was held on a non-service day; a Saturday morning. See Appendix C for the letter of cooperation.

Study Population

The study population included individuals from the church and the surrounding neighborhood. Inclusion criteria for this project were male and females between the ages of 18 to 45 years who identify as African Americans and can speak and read in English. Exclusion criteria for this project were persons with a known diagnosis of SCD or SCT.

Subject Recruitment

The project was open to members of the church and the surrounding neighborhood. Recruitment began once IRB approval was obtained. Upon approval, recruitment flyers were displayed in the information box near the entrance to the church (see Appendix D for flyer). Recruitment efforts included an announcement made by the pastor outlining contents of the recruitment flyer via the pulpit during Sunday and mid-week church service information sessions. Additional information about sickle cell education intervention were provided to the congregation after church service by the co-

investigator. Effort to recruit included distribution of recruitment flyers at the church, local neighborhood grocery stores, social media such as WhatsApp, and through snowballing by potential participants. The flyer summarizing the project included contact information (e-mail and telephone number) for any questions or concerns. Participants were recruited over 4 weeks.

This project is considered a pilot study, and due to the pilot nature of the study, no sample size justification is warranted. Regardless, the co-investigator aimed for a target sample size of 50. Using Raosoft, Inc (2004) for a priori analysis to calculate sample size having a 10% margin of error, a 90% confidence level, and a response distribution of 50%, the recommended sample size was 41.

Consent Procedure

An informed consent form was made available at the time of recruitment (see Appendix E). Copies of the consent form were provided in church each time announcement were made regarding the project. Also, the co-investigator had copies of the consent form available at all times the flyers were distributed. Participants had the option to sign consent form up until the day of the education session. The consent forms were distributed and collected only by the co-investigator. The co-investigator assumed the responsibility of explaining the content of the consent form to each interested participant. The information in the consent form includes benefits of the project, risks of the project, confidentiality, and participant's right to withdraw at any time. Co-investigator remained for one hour after services each time announcements about the project was made to answer additional questions and have consent forms signed. The co-investigator also assumed the responsibility of obtaining consent outside of the church wherever flyers were distributed.

Risk/Harm/Ethics

There was no anticipated discomfort or harm in participating in this study. Therefore, the risk to participants was minimal. Participants were informed of any new findings that may affect their decision to remain in the study if there were any. There might have been feeling of distress over potential SCT status after participation in education intervention. Additionally, there might have been feelings of shock, surprise, and sadness experienced during the project. Participants could withdraw at any time during the process. List of genetic counseling and emotional counseling centers close to the project setting were provided to participants.

All efforts were made to ensure that participant's personal information such as e-mail address, telephone number, and home address were kept safe and were only available to the co-investigator and principal investigator.

Subject Costs and Compensation

There was no cost to participants of this project. Light refreshments were provided during the education intervention. A \$10 visa gift card was given as compensation for participating in this project. Gift cards were mailed to participants' home address after the completion of the post-posttest. Some participants received their gift cards in person. The co- investigator made a second visit to the church to hand in gift cards to members of the church who participated in the project. The co-investigator ensured that all participants obtain the gift card by logging the dates the cards were sent out or handed in person to each participant. See Appendix F for visa Gift card tracking log

Intervention

Study participants were recruited for 4 weeks once IRB approval was obtained. Participants were allowed to sign consent up until the beginning of educational intervention. Once study

participants had been recruited, and consent forms had been signed and collected, the co-investigator conducted the education intervention.

Intervention Process:

1. Sign-in sheet (see Appendix G)
2. The consent forms were distributed for participants to read, review and sign
3. Demographic survey was done (10-minute) and collected (See Appendix H for demographic Questionnaire)
4. The pre-test was taken and collected (see Appendix I)
5. Immediately following the administration of the pre-test, a 40-minute educational session was conducted. (See Appendix J for education PowerPoint).
6. 20 minutes Question and Answer session
7. Participants took 15 minutes post-test (see Appendix K)

The 40 minutes education session provided baseline information on SCD, SCT, screening process, and its reproductive health implications. The pre-post-posttest encompassed the 10-item true/false sickle cell trait knowledge questionnaire (SCTKQ) and two questions to measure intention to obtain screening which totaled 12 questions that were answered on each test. The 2-week post-test was designed to evaluate both knowledge retention and effectiveness of the education intervention by measuring the actual change in behavior. The 2-week posttest could be taken through different mediums (See Appendix L for post-posttest). Participants had the option to either take it over the phone or via e-mail. All the participants took the 2-week posttest via-email. The co-investigator assumed the responsibility of ensuring that participants were reached through their preferred medium to take the test. Participant's contact information (email address and phone numbers) was collected on the sign-in sheet. Co-investigator made the phone calls and sent the e-mails two weeks after

participating in the educational intervention in efforts to have participants take the post-intervention test. Multiple e-mails and phone calls were made in effort to assure 100% participations.

Outcomes Measured

The outcomes measured are the intention to screen and increase in knowledge. The 10- item SCTKQ was taken at three different time points by the participants, and the difference in score was measured. In addition to the SCTKQ, the questions addressing intention to screen was measured to reflect if the education intervention played any role in increasing intention to screen or otherwise. SCTKQ questionnaire was tested for internal reliability with a Cronbach alpha score of 0.59. The internal reliability and validity of SCTKQ tool is low as there has been no other tool developed to compare with. The psychometric properties of the SCTKQ have not been validated; therefore, the result of the questionnaire does not reflect “low,” “medium,” or “high” knowledge. Response to the questionnaire was narrated in percentage. Permission to use this tool was obtained from the owner (see Appendix M).

Project Timeline

The timeline for this project took 7 months beginning from DNP team approval up until final DNP presentation. Proposal was approved by DNP team in September 2019 and project was submitted to IRB that same month. IRB approval was obtained in October 2019, and project was implemented in December 2019. Data collection and analysis was completed in January 2020, the final write up with revisions took 2 months and presentation to Rutgers School of Nursing was scheduled for the first week in April. See Appendix N for the project timeline.

Resources Needed

The cost of this project was solely the responsibility of the co-investigator. The resources used for the execution of this project covered recruitment flyer, educational materials, handouts, subject compensation, and refreshments. A complete breakdown of the budget cost can be found in Appendix O.

Evaluation Plan

Data Analysis

Statistical Package for the Social Science (SPSS) was used for statistical analysis of the data collected from the educational intervention. A statistician was consulted to assist in analyzing the data. Due to non-normality, a non-parametric statistical test was used. Wilcoxon Signed Ranks Test was used to analyze changes in SCTKQ score between the participants who took the tests from all the three study time points. Pre-test was compared to immediate post-test, and pre-test was also compared to 2-week post-test. The demographic data was analyzed using descriptive statistics: mean, median, and mode. The demographic data includes age, gender, race, parental status, educational level, and income level of the participants. These demographic data reflected the study participants. Results of Intention to obtain screening was analyzed in frequencies using Chi-square. The answer key to the questionnaire can be found in Appendix P.

Data Maintenance & Security

Questionnaire and consent used during the project were stored in a keypad security safe box and transported by the co-investigator. Participant's information and copies of questionnaires, gift card, and participant identifiers were stored and carried in the secured lockbox. Only the co-investigator had access to the locked box. Data collected was stored in a password-protected external

hard drive. The external hard drive was in the possession of the co-investigator. Backup storage of the data was in the co- investigator's Google drive account of which the co-investigator had sole access. Access to the materials was restricted solely to the principal investigator and co-investigator. Each questionnaire was de-identified by assigning it a numeric identifier that represented the study participants. Participant identifiers were destroyed after data collection was completed. The master list linking the participants to the random ID number was kept separately from the actual surveys. Aggregate data was kept in the Principal Investigator's office located in the School of Nursing is located at 65 Bergen street, room 1115, Newark, NJ 07107 as required for retention. Upon completion of the project, closure of the IRB process, and final writing of the manuscript, all data will be maintained for 6 years in accordance with Rutgers University guidelines.

Results

A total of 37 African American men and women were consented to participating in this project. Five people were lost to follow-up and were not included in any calculations. The remaining 32 participants completed the demographic survey, pre-test, posttest, and 2-week posttest. The demographic data collected were age, parental status, sex, race, education level, and income. Out of the 32 participants, 66% were females (N= 21), while 34 % were males (N= 11). More than half, 59%, identified themselves as a parent (N=19), while the remainder self-reported as not being parents (N=13, 41%). The majority of the participants were age 28 and older (N= 26), while others were less than 28 years of age (N=6). About 90% of the participants had college or graduate education (N=29), while about 10% had vocational education or less (N=3). Out of the 32 participants, 78% (N=25) earned over \$30,000 and 22% (N=7) earned less than \$29,000. See Table 1 for Demographic data.

Table 1
Characteristics of Participants

Variable	Frequency	Percent
Male	11	34.4
Female	21	65.6
African American	32	100
Parent	13	40.6
Non-Parent	19	59.4
Age 18- 27	6	18.8
Age 28-37	15	46.9
Age 38 - 45	11	34.4
Vocational or less	3	9.4
College or graduate	29	90.6
Less than 29K	7	21.9
Income more than 30K	25	78.1

Effect of the Intervention on Sickle Cell Trait Knowledge Questionnaire Scores

The SCTKQ pretest, posttest and 2-week posttest were analyzed using IBM SPSS version 24. The SCTKQ questionnaire consisted of 10-items to test knowledge of SCT. The highest mean score for all three time points was immediately post-intervention: pretest (M= 7.03), immediate posttest (M= 8.59), and 2-week posttest (M= 8.47). To determine whether intervention was effective in improving knowledge post intervention, pre and post intervention mean score were compared using Wilcoxon signed ranked test. The increase in mean knowledge score was statistically significant ($P= 0.002$). To determine whether intervention was effective in retaining knowledge, pre and 2-week post intervention scores were compared. Although there was still an increase in overall knowledge score, there was a slight drop in mean score from 8.59 to 8.47 compared with the immediate post intervention score. Nevertheless, the increase in knowledge 2-week post intervention was statistically significant ($P= 0.001$). Results are summarized in Table 2 and 3.

Table 2*SCTKQ Knowledge Score Pre and Immediately Post-Intervention*

	Mean Score	Standard Deviation	P-value
Pre-intervention	7.03	2.571	
Immediately post-intervention	8.59	1.898	0.002

Table 3*SCTKQ Knowledge Score Pre- and 2-week Post-Intervention*

	Mean Score	Standard Deviation	P-value
Pre-Intervention	7.03	2.571	
2-week post-Intervention	8.47	1.883	0.001

Effect of the Intervention on Intention to Screen

Questions addressing intention to obtain screening for SCT were added to each knowledge questionnaire that were taken at the three time points. A chi-square test was used to analyze frequencies of positive answers (“yes”) on intention to screen pre and post intervention, and pre and 2-week post intervention. Question 11 asked: “Do you intend to get screened to know your sickle cell trait status?” This question was the same for pre-intervention, immediately post intervention and, 2-week post intervention. The chi-square test was performed to determine whether the difference in frequency of positive answers were statistically significant. The test determined that there was no

statistically significant change in frequencies of positive answers pre and post intervention ($p = 0.346$) and pre and 2-week intervention ($p = 0.346$) on question 11. There was an increase in number of participants who intended to undergo screening to know their SCT status immediately post intervention and 2-weeks post intervention when compared to pre-intervention. The result is summarized in Table 4 below.

Table 4

Intention to Obtain Screening for SCT Status

	Frequencies (%)	P-value
Pre-intervention	(N=19), 68.8%	
Immediately post- Intervention	(N=26), 81.3%	0.346
2-week post Intervention	(N=26), 81.3%	0.346

Question 12 asked: “Have you taken any step to know your sickle cell trait status?” in the 2-week post intervention test. This question was asked to address the impact of the education intervention on action to obtain screening. The result as shown in the table below demonstrated that a higher percentage (81.3%, N =26) of the participants took a step to obtain screening compared to the number of participants (18.8%, N=6) who did not take any action. The participants were not asked about specific steps they took to obtain screening. The result is presented in Table 5 below.

Table 5*Question 12. Effect of Education on Action to Obtain Screening*

Variable	Frequency (%)
Took steps to know SCT status	N=26, 81.3%
Did not take steps to know SCT status	N=6, 18.8%

Discussion

African Americans are most commonly affected by SCT and SCD. This study guided by quasi-experimental approach demonstrated that education can help increase knowledge of SCT amongst the population it affects the most. Secondly, it demonstrated that it can also impact screening amongst these population.

The church has been instrumental in impacting a positive change in the community and supports health promotion efforts (Brand, 2017). The findings from this study showed an increase in knowledge baseline both immediately after the educational intervention and two weeks post intervention when compared to the pre-intervention scores. Although not statistically significant, there was an increase in number of participants who intended to get screened to know their SCT status immediately post-intervention when compared to pre-intervention results. Prior to intervention, there were 19 participants who intended to get screen. This number increased to 26 both immediately after the education intervention and 2-weeks after the intervention. The lack of statistical significance may be related to small sample size, that may decrease statistical power to detect differences. On the other hand, it is possible to assume that gaining knowledge about SCT and SCD may not be sufficient to take steps to complete screening. It is likely that additional barriers (not just lack of knowledge) for screening exists that were outside of the scope of this project.

The result of this project is similar to the findings from a study done in Nigeria amongst National Youth Service Corps member that demonstrated that education intervention increases knowledge of participants (Asuzu et al., 2012). In Creary et al. (2017), a trained educator provided an education intervention to caregivers of infants with SCT in Ohio. The result was very similar as it did reflect an increase in knowledge immediately post-education intervention with a decrease in knowledge over time. The finding of declining knowledge overtime proposes the need to develop knowledge retention strategies. When compared to a study done in Saudi Arabia among secondary school boys, although the education intervention did increase knowledge, it did not make a positive impact on attitude of the participants (Kotb et al., 2019).

Similarly, in the study done amongst Youth Corps members in Lagos, Nigeria, there was an increase in the number of people who screened to know their genotype after an educational intervention was implemented (Asuzu et al., 2017). In this study, 415 youth corps members participated in a health education program of which 239 members were assigned into the intervention group. SCT screening was offered free of charge after the education intervention. The data collected 3 months later demonstrated that the percentage of people who obtained screening increased by (11.9%) in the intervention group.

This project was successful as it reached all three objectives as intended. The outcome of the project exhibited an increase in knowledge, increase in number of participants who intended to obtain screening and increase in awareness of SCT. The success of the project can be tied to many factors. There was strong support from the church leadership: Pastor, health fair team, and the youth club. The setting of this project being an African American church was a facilitator for the success of the project. The African American church can address health issues in ways that are culturally and ethnically sensitive.

Limitations

There are several limitations to this project. One of the major limitations to this study is the SCTKQ used to measure level of knowledge. The questionnaire has a low internal reliability and validity. There is currently no other tool to measure sickle cell trait knowledge. Secondly, this project had a small sample size and convenience sampling was used. The recommended sample size per Raosoft, was 41 with a 10% margin of error and a 90% confidence level. There were only 32 participants who completed all the questionnaires at all three timepoints. Initially, 37 participants consented, but, 5 participants were lost to follow-up. Due to the small sample size that included mainly churchgoers, the result of this project not be generalizable to a larger African American population.

Another limitation to this study is a short follow-up time. Participants took the follow-up posttest immediately and 2 weeks after the education intervention; a longer period may have provided a better measure of knowledge retention. In addition, lack of a comparison group limits the generalizability of the study result. It makes it difficult to determine if the increase in knowledge scores and increase in number of participants willing to obtain screening was solely due to the education intervention. Lastly, this project was not able to determine what actions were taken towards obtaining screening.

Strengths

This project has the potential to evolve. The participants of this project showed interest in the topic and expressed learning new information. Due to response and feedback from participants, the project could be repeated on a larger scale.

Another strength of this project is the novel setting and the outreach design of the project. Implementing the education intervention in a non-traditional classroom setting may have added to the

uniqueness of the project. Lastly, an African American church playing an active role in health promotion strategy addressing issues that affects the community it serves may be the future of population-targeted health-care delivery.

Implications

Clinical Practice

It is known that SCT is a generally benign carrier state, it is not a disease, therefore, carriers do not experience acute vaso-occlusive crises and hemolysis. The literature suggests that there are significant but rare medical complications (rhabdomyolysis with strenuous activity, renal complications, venous thromboembolism) that can be heightened in people with SCT. Healthcare providers need to be aware of these potential health events. Healthcare providers should educate their SCT individuals on these complications and consult them on preventative measures.

Awareness, management and prevention of these potential health complication is important, but it is crucial to stress the reproductive health implications to persons who are SCT carriers. Healthcare providers should encourage individuals, regardless of their ethnicity, to know their SCT status. SCT trait people should be encouraged to disclose their status to their partners and other family members. Clinicians should refer SCT individuals for genetic counseling where they can receive in-depth personalized information on reproductive risk and childbearing options. SCT status should be documented in patient's chart and communicated to other healthcare team members. Each clinical encounter should be utilized to educate patients to reinforce important messages and to encourage good self-care.

Healthcare Policy

Since 2006, all states have adopted the NBS program that identifies SCD and SCT (Therrell et al., 2008). The NBS is not centralized, each state is responsible for its own program and there are

variations in how these programs are run from state-to-state (Therrell et al., 2008). There should be a standardized method of notifying healthcare providers and parents. The lack of this standardized method has led to a lag within the system.

The healthcare policy makers need to create policies for standardized notification of newborn SCD screening. Implementing such policy could increase awareness of SCT status and create room for discussion between health care provider and their patients. Policy improvement on the identification of SCT across the nation, adequate reporting to the primary care provider, parents, and proper documentation on patient charts is warranted. The policy should clearly state who to be notified (healthcare provider, and parents) and method of notification used.

In addition to notification of parents and healthcare providers, there should be policies put in place for follow-up care. For example, once the family and parents have been notified, there should be an office visit scheduled within a month of notification. There should be a straightforward process of referral to genetic counseling and other specialists, if needed.

Quality and Safety

Increase in disease and carrier status awareness will improve the overall health of the community. Health education and preventive measures are important in improving the health outcomes of SCT individuals and their future offspring. Health education promotes knowledge, which affects safety and quality of life of the population by reducing the incidence of SCD. Knowledge of SCT inheritance is necessary for making informed choices concerning reproductive health. Increasing number of individuals who are aware of their status and understand its reproductive consequences may possibly reduce number of children born with SCD. Educating SCT patients on rare complications of the trait and meaningful ways to avoid them may reduce incidence of these sequelae and improve health outcomes of SCT individuals.

Education

This project demonstrated that a 40-minute education session on SCT increased knowledge of the participants. Education is instrumental in increasing awareness and promoting change in the behavior of a population. There are many avenues to share knowledge, it does not necessarily have to be in a formal setting such as schools. Utilizing informal avenues such as churches, Mosques, salons, community centers can be instrumental in reaching target population.

Healthcare providers such as nurses, NPs, PAs, and MDs can also champion the task of educating the community. Healthcare providers can team up with community leaders, faith-based organization, ethnic societies in the community in order to deliver information that are culturally and racially sensitive. By collaborating with community groups, healthcare professionals can improve public awareness, and therefore, possibly reduce the incidence and the healthcare burden of SCD.

Economy

The economic burden of SCD is enormous. Educational public health programs that can promote SCT awareness and decrease the incidence of SCD may be cost saving. SCD/SCT are generally covered by health insurance. The out-of-pocket cost of testing is relatively affordable. The cost of prevention outweighs the impact of the disease on the healthcare economy. It may be more economical to channel funds towards prevention than treatment of the disease that is associated with high socioeconomic burden.

Sustainability/Plans for Future Scholarship

The project has the potential to evolve, it can be done in different boroughs in the city. It can be used as an avenue to continue to educate the community about SCT. The project can be extended into community outreach programs i.e. community health fairs, schools, and youth development programs such as YMCA, adult education centers, and other faith-based organizations. It is important to share

the knowledge and the best way to capture the intended audience is to take the program into their community.

Dissemination/Professional Reporting

The final write-up for this project will be presented at Rutgers School of Nursing as part of the requirements for the Doctor of Nursing Practice. The results of the study can be shared with local clinics, church programs, and community fairs. Professional reporting can include presentations or manuscripts for organizations such as The Sickle Cell Foundation, American Association of Nurse Practitioners, and manuscript submissions to journals such as *Journal for Nurse Practitioners*.

Conclusion

African Americans are mostly affected by SCD and SCT. It is important that this population understand complications of SCD and health implications of SCT status. Knowing SCT status will help individuals to make informed reproductive health decisions, thus, the incidence of SCD will be reduced. This project demonstrated that knowledge of SCT was improved and there was a positive impact on intention to screen as a result of the education intervention. Public education strategies, screening policies, and standardized reporting should be developed to improve healthcare outcomes of this populations.

References

- Abboud, M., Tschilolo, L., Montalembert, M., Ware, R. (2017). Sickle cell disease. *Lancet*, 311-323.
- Arhin, A. O. (2019). Knowledge deficit of sickle cell trait status: Can nurses help? *Critical Care Nursing Quarterly*, 42(2), 198-201.
- Azar, S., Wong, T. (2016). Sickle Cell Disease. A Brief Update. *Medical Clinics of North America*, 375-393.
- Benenson, I., Porter, S., & Vitale, T. (2018). Sickle cell trait: What every nurse practitioner should know. *Journal for Nurse Practitioners*, 14(9), 663-670. <http://doi:10.1016/j.nurpra.2018.07.020>
- Brand, D. J. (2017). The African American Church: A change agent for health. *ABNF Journal*, 28(4), 109-113.
- Centers for Disease Control and Prevention. 2017. Sickle Cell Disease. <https://www.cdc.gov/ncbddd/sicklecell/facts.html>
- Creary, S., Adan, I., Stanek, J., O'Brien, S. H., Chisolm, D. J., Jeffries, T., Zajo, K., Varga, E. (2017). Sickle cell trait knowledge and health literacy in caregivers who receive in-person sickle cell trait education. *Molecular Genetics & Genomic Medicine*. 5(6), 692-699.
- Gallo, A., Wilkie, D., Yao, Y., Molokie, R., Stahl, C., Hershberger, P., Zhao, Z., Suarez, M., Johnson, B., Angulo, R., Carrasco, J., Angulo, V., Thompson, A. (2015). Reproductive Health CHOICES for Young Adults with Sickle Cell Disease or Trait: Randomized Controlled Trial Outcomes over Two Years. *Journal of Genetic Counseling*, 25(2), 325-336. <http://doi:10.1007/s10897-015-9874-0>

- Gallo, A., Wilkie, D., Suarez, M., Labotka, R., Molokie, R., Thompson, A., Hershberger, P., Johnson, B. (2010). Reproductive Decision in People with Sickle Cell Disease or Sickle Cell Trait. *Western Journal of Nursing Research*, 32 (8), 1073-1090.
<http://doi:10.1177/0193945910371482>
- Harrison, S. E., Walcott, C. M., & Warner, T. D. (2017). Knowledge and Awareness of Sickle Cell Trait Among Young African American Adults. *Western Journal of Nursing Research*, 39(9), 1222-1239. <http://doi:10.1177/0193945916665089>
- Hershberger, P. E., Gallo, A. M., Molokie, R., Thompson, A. A., Suarez, M. L., Yao, Y., & Wilkie, D. J. (2016). Perception of young adults with sickle cell disease or sickle cell trait about participation in the CHOICES randomized controlled trial. *Journal of Advanced Nursing*, 72(6), 1430-1440. <http://doi:10.1111/jan.12702>
- Kavanagh, P., Wang, J., Therrell, B., Sprinz, P., & Bauchner, H. (2008). Communication of positive Newborn Screening Results for Sickle Cell Disease and Sickle Cell Trait: Variation Across States. *American Journal of Medical Genetics*, 15-22.
- Kotb, M. M., Almalki, M.J., Hassan, Y., Sharif A. A., Khan, M., Sheikh, K. (2019). Effect of Health Education Programme on the Knowledge of and Attitude about Sickle Cell Anaemia among Male Secondary school students in the Jazan Region of Saudi Arabia: Health Policy Implications. *BioMed Research International*. <http://doi.org/10.1155/2019/9653092>
- Mayo-Gamble, T. L., Barnes, P. A., Cunningham Erves, J., Middlestadt, S. E., & Lin, H.-C. (2017). ‘It means everyone should know their status’: exploring lay conceptions of sickle cell trait and sickle cell trait screening among African Americans within middle reproductive age. *Ethnicity & Health*, 23(7), 813-829. <http://doi:10.1080/13557858.2017.1295135>

- Mayo-Gamble, T. L., Middlestadt, S. E., Lin, H.-C., Cunningham-Erves, J., Barnes, P., & Jackson, P. B. (2018). Identifying Factors Underlying the Decision for Sickle Cell Carrier Screening Among African Americans Within Middle Reproductive Age. *Journal of Genetic Counseling*, 27(5), 1302-1311. <http://doi:10.1007/s10897-018-0255-3>
- Naik, R. P., & Haywood, C., Jr. (2015). Sickle cell trait diagnosis: clinical and social implications. *American Society of Hematology*, 160-167. <http://10.1182/asheducation-2015.1.160>
- National Heart, Lung, and Blood Institute. (2010). A century of progress: Milestones in Sickle Cell Disease Research and Care. <https://www.nhlbi.nih.gov/files/docs/public/blood/Tagged2NHLBISickleCellTimeline.pdf>
- Newborn Screening for Sickle Cell Disease and Other Hemoglobinopathies. <https://consensus.nih.gov/1987/1987screeningsicklehemoglobinopathies061html.htm>
- Obed, S. A., Asah-Opoku, K., Aboagye, S., Torto, M., Oppong, S. A., & Nuamah, M. A. (2017). Awareness of Sickle Cell Trait Status: A Cross-Sectional Survey of Antenatal Women in Ghana. *American Journal of Tropical Medicine and Hygiene*, 96(3), 735-740. <http://doi:10.4269/ajtmh.16-0396>
- Office of Disease Prevention and health Promotion. (2019). Blood Disorders and Blood safety. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/blood-disorders-and-blood-safety>
- Ojodu, J., Hulihan, M. M., Pope, S. N., & Grant, A. M. (2014). Incidence of sickle cell trait-United States, 2010. *MMWR Morbidity and Mortality Weekly Report*, 63(49), 1155-1158.

- Olatona, F. A., Odeyemi K.A., Onajole A.T., Asuzu, M.C. (2012). Effects of Health Education on Knowledge and Attitude of Youth Corps Members to Sickle Cell Disease and its Screening in Lagos State. *Journal of Community Medicine & Health Education*, 2:163.
<http://doi:10.4172/2161-0711.1000163>
- Pecker, L. H., & Naik, R. P. (2018). The current state of sickle cell trait: implications for reproductive and genetic counseling. *Blood Journal*, 132 (22), 2331-2338.
- Raosoft, Inc. (2004). Sample size calculator. <http://www.raosoft.com/samplesize.html>
- Ross, P. T. (2015). Motivations of women with sickle cell disease for asking their partners to undergo genetic testing. *Social Science & Medicine*, 139, 36-43.
<http://doi:10.1016/j.socscimed.2015.06.029>
- Shephard, R. J. (2016). Sickle cell trait: what are the costs and benefits of screening? *Journal of Sports Medicine and Physical Fitness*, 56(12), 1562-1573.
- Sickle Cell Awareness Foundation Corporation International. (2019, March). Mission & Services.
<https://www.scafcorpint.org/>
- Sickle Cell Disease Association of America. (2019, March). Mission & Vision.
<https://www.sicklecelldisease.org/mission/>
- Sickle Cell Thallesemia Patient Network. (2019, March). Strive Program.
<http://www.sctpn.net/1viralvoice/>
- Siddiqui, S., Schunk, K., Batista, M., Adames, F., Ayala, P., Stix, B., Rodriguez, J., McCord, M., Green, N. S. (2012). Awareness of sickle cell among people of reproductive age: Dominicans and African Americans in northern Manhattan. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 89(1), 53-58. <http://doi:10.1007/s11524-011-9618-x>

- Smith, M., & Aguirre, R. T. P. (2012). Reproductive Attitudes and Behaviors in People with Sickle Cell Disease or Sickle Cell Trait: A Qualitative Interpretive Meta-Synthesis. *Social Work in Health Care*, 51(9), 757-779.
- Stevens, K.R. (2004). ACE Star Model of EBP: Knowledge Transformation. Academic Center for Evidence-Based Practice. The University of Texas Health Science Center San Antonio. <http://nursing.uthscsa.edu/onrs/starmodel/institute/su08/starmodel.html>
- Therrell, B. L., Jr., Lloyd-Puryear, M. A., Eckman, J. R., & Mann, M. Y. (2015). Newborn screening for sickle cell diseases in the United States: A review of data spanning 2 decades. *Seminars in Perinatology*, 39(3), 238-251. <http://doi:10.1053/j.semperi.2015.03.008>
- The Foundation for Sickle Cell Disease Research. (2019, March). Our services. <https://fscdr.org/>
- U.S Census Bureau (2017). American Community Survey 1-year estimates. Retrieved from Census Reporter Profile page for NYC-Brooklyn Community District 5—East New York & Starrett City PUMA, NY <https://censusreporter.org/profiles/79500US3604008-nyc-brooklyn-community-district-5-east-new-york-starrett-city-puma-ny/>
- Wilkie, D. J., Gallo, A. M., Yao, Y., Molokie, R. E., Stahl, C., Hershberger, P. E., Zhao, Z, M Suarez, M., Labotka, R. J., Johnson, B., Angulo V., Carrasco, J., Shuey, D., Pelligra, S., Wang, E., Rogers, D., Thompson, A. A. (2013). Reproductive health choices for young adults with sickle cell disease or trait: Randomized Controlled Trial Immediate Posttest Effects. *Nursing Research*, 62(5), 352-361. <http://doi:10.1097/NNR.0b013e3182a0316b>
- World Health Organization, Sickle Cell Disease. <https://afro.who.int/health-topics/sickle-cell-disease>. Accessed April 19, 2019.

Yanni, E., Grosse, S. D., Yang, Q., Olney, R. (2008). Trends in Pediatric Sickle cell Disease- Related Mortality in the United States, 1983-2002. *Journal of pediatric*.154 (4), 541-545.
<http://10.1016/j.jpeds.2008.09.052>

Appendices

Appendix A

Table of Evidence

CLINICAL QUESTION: Will a faith-based educational intervention improve sickle cell trait knowledge and intention to be screened/obtain screening results among African Americans individuals of reproductive age?

Article #	Author, Date	Evidence Type	Sample, Sample Size, Setting	Study Findings that help answer EBP question	Limitations	Evidence Level & Quality
1	Patricia E. Hersherberger., Adata M. Gallo., Robert Molokie., Alexis A. Thompson., Marie L. Suarez., Yingwei Yao., Diana J. Wilkie. (2016)	Qualitative Study- Descriptive study done after a Randomized control trial was done	68 men and women of childbearing age participated in semi-structures interview after completing a Randomized Controlled Trial from 2012-2013. Mean age of 25 years old. # with SCD= 39 # with SCT= 29	The study revealed that educative program such as CHOICES can help increase knowledge and promote new way of thinking and behavior. Also, It helped them rethink their parenting pattern. Three themes were identified from the educational program. (a) Increase knowledge and new ways of thinking and behaving. 64%, n=9 from the e-book group verbalized “learned a lot”. 31%, n=17 from the CHOICES group also expressed that they “learned a lot”. Additional	Intentional limitation was that the participants were collected from those that participated in the CHOICES intervention and usual care (Reason being that they also wanted to understand the experience of the CHOICES group and the e-Book group. Secondly, sample was collected to urban	Level III, A High Quality

				46%, n=25 indicated a fuller educational experience. (b) Rethinking parenting plans. 78%, n=53 indicated that participating in the study helped them to rethink or revise their individual parenting plans. (c) Appraising the program and delivery. 70%, n=38 indicated that the strength of the educational program was the focus on reproductive options.	population so finding is limited.	
2	Paula Thompson Ross. (2015)	Qualitative Study- Structured interview	28 women, ages 18-52(mean 30.39). Women of varying age, reproductive statuses and socioeconomic positions.	This study revealed that the implication of having a child with SCT influenced women to ask their partners to undergo testing. Also, the concern about the physical suffering their child would go if they were to be born with SCD was a determining factor for them to know the status of their partners. 79%, n=22 of the women asked their partners to undergo genetic testing.	Self-selection bias. Also, due to the fact that health status is not static, participant's responses may have been influenced by their current health status.	Level III, B Good Quality
3	Saira Saddiqui., Kelly Schunk., Milagros Batista.,	Qualitative study- Ethnography	208 parents of young children: 150 Dominican and 58 African American	The result of this study showed that despite the prevalence of sickle cell disease in the populations that it affects, there is still a	Limitation was not discussed.	Level III, B Good Quality

	Francisca Adames., Peggy Ayala., Benjamin Stix., Jacqueline Rodriquez, Mary McCord., Nnacy S. Green. (July 6 th ,2012)			significant knowledge gap about sickle cell in people of reproductive age. 27% of Dominican parents surveyed correctly defined SCD as an inherited blood disorder compared to 76% of African Americans ($p < 0.001$). 7% of African Americans did not know their own trait compared to 43% of Dominicans ($p < 0.001$).		
4	Tilicia L. Mayo-Gamble.m Susa E. Middlestadt., Hsein-Chang Lin., Jennifer Cunningham-Erves., Priscialla Barnes., Pamela Braboy Jackson. (2018)	Cross Sectional Survey	300 Participants, ages 18-35	The study showed that there are influential factors such as fear belief, knowledge, perceived norm, perceived behavioral control that contribute to screening for Sickle cell carrier status. Perceived behavior control was more predictive of intention $p < .001$. Attitude and perceived norm $p < .001$	Convenient sample, which makes findings non-generalizable. Secondly due to study design, sequence and causation was not possible	Level III, B Good Quality
5	Sayward E. Harrison., Christy M. Walcott., and Tamara D. Warner. (2017)	Descriptive, cross sectional study	258 young African American adults.	It showed that there is limited overall knowledge of Sickle cell Trait, poor understanding of the genetic transmission of Sickle cell trait and its typically asymptomatic presentation. There were 3	3 major limitations were addressed in this study. (A) The measure used to assess knowledge "SCTKQ" which was created	Level III, B Good Quality

				<p>hypotheses for this study. (a) Young African American adults possess misinformation about SCT, including genetic transmission. (b) Majority of young African American are uncertain of their SCT status. $P < .0001$ (c) Young adult who report receiving information about sickle cell from their families display greater knowledge than those who do not. $P < .001$</p> <p>The result of the study supported the 3 hypotheses.</p>	<p>primarily for the purpose of this study as no other measure was available to assess knowledge. It had low internal reliability. (B) Participants were undergraduate African American students –it limits its generalizability to large African American population. (C) Validity of participant's self-reported trait status- majority of the participants did not know their status there are chance for false positive and false negative</p>	
6	<p>Tilicia L. Mayo-Gamble., Priscilla A. Barnes., Jennifer Cunningham Erves., Susan</p>	<p>Qualitative Study-phenomenological</p>	<p>300 African American ages 18-35 unaware of their sickle cell trait status</p>	<p>This study showed that there is lack of Knowledge of sickle cell trait and perceived importance of sickle cell screening is a barrier in a population that is affected by the disease. Categories emerged from this qualitative</p>	<p>3 limitations were identified in this study. (a) Due to use of similar words, participants did not answer the questions correctly. (b)</p>	<p>Level III, B Good Quality</p>

	E. Middlestadt and Hsein-Chang Lin. (Feb 21,2017)			<p>study in understanding the meaning of sickle cell trait and sickle cell trait screening from Lay African Americans</p> <p>Meaning of Sickle cell Trait:</p> <ul style="list-style-type: none"> - (a) perceived as an illness, (b) perceived recognition of the inheritance pattern of sickle cell trait, (c) perceived lack of knowledge of sickle cell trait, and (d) perceived importance of sickle cell trait. <p>Sickle cell trait screening:-</p> <ul style="list-style-type: none"> (a) perceived recognition that screening means getting tested for sickle cell trait, (b) perceives lack of knowledge of sickle cell trait screening, (c) perceived health benefit of sickle cell trait screening, (d) perceived importance of sickle cell trait screening, and (e) perceived barriers to sickle cell trait screening. 	Convenient sample was used. (c)The depth of the quality research restricts the generalizability of the study.	
7	Agatha M. Gallo., Diana J. Wilkie., Yingwei Yao., Robert Molokie., Christiane Stahl., Patricia E.	Randomized Controlled Trial	234 Participants with SCD (N=138) or SCT (N= 96). Ages 18-35 years old. Male =35%, 94% African American	This study showed that an educative program can help increase knowledge, intention, and behavior related to reproductive health in young adults with SCD or SCT. Compared to the e-book group the CHOICES group had significantly more	Limitations from this study are (a) since it was conducted in 1 geographical location, it is possible that the intervention could yield different	Level III, A High Quality

	Hershberger., Zhongsheng Zhao., Marie L. Suarez., Bonnye Johnson., Rigoberto., Jesus Carrasco., Veronica Angulo., Alexis A. Thompson (August 2015)			improvement in knowledge over time ($p=.004$) but not intention ($p=.18$) or behavior ($p=.69$). Also, e-book group did show significant improvement over time ($p<.001$).	effect if it was carried out in another location. (b) it is unknown if learning was hindered by cognitive impairment as this was not included as a eligibility criteria	
8	Marcella Smith & Regina T.P. Aguirre. (2012)	Qualitative Interpretive Meta-Synthesis	3 Articles	There is still little or no knowledge of SCD/SCT among high-risk population. Attitudes towards learning one's SCT status, learning one's own and partner's SCT status and consequences of not asking about a partner's SCT status are influencing informed reproductive decisions.	N/A	Level III, B Good Quality
9	Samuel Amenyi Obed., Kwaku Asah-Opoku., Serwah Aboagye, Magdalene Torto, Samuel	Cross sectional survey in Ghana	206 participants. Women at least 20 weeks gestation answered a questionnaire regarding awareness of	The general knowledge of Sickle cell disease and trait in this population is poor despite the fact that it is a population that is affected by the disease. Patient who responded that they knew about sickle cell disease	Limiting factors for this study is the knowledge level of the participants. It is possible that the participants were clear on the	Level III, C Low quality

	Antwi Oppong., and Mercy Nuamah. (2017)		their sickle cell trait status and questions to test their knowledge of sickle cell disease	scored higher than those that responded that they did not know anything ($p < .001$). Those that knew they had been tested for sickle cell trait scored higher than those that did not know whether they had been tested ($p = .004$). Those with at least secondary education scored higher on knowledge test compared to those with less education ($p = 0.004$).	difference between SCT and SCD.	
10	Diana J Wilkie., Agatha M Gallo., Yingwei Yao., Robert E Molokie., Christine Stahl., Patricia E. Hersherberger., Zhongsheng Zhao., Marie L. Suarez., Robert J. Labotka., Bonnye Johnson., Rigo Angulo., Veronica Angulo., Jesus	Randomized controlled study	234 participants with SCD. Ages 18-35 years	This study showed that an educative program can influence the knowledge, and behavior related to reproductive health in young adults with SCD or SCT. The participants in the CHOICES group had significantly higher odds of adopting a more proactive parenting plan to avoid having a child with SCD or SCT ($P = .04$) at posttest than the e-book group. Participants who received the CHOICES intervention had significantly higher knowledge scores at posttest than the e- book ($p < .001$). No significance was seen on reproductive health intention	Limitations from this study are (a) since it was conducted in one geographical location; it is possible that the intervention could yield different effect if it was carried out in another location. (b) it is unknown if learning was hindered by cognitive impairment as this was not included as a eligibility criteria. (c) Inability to	Level I, A High quality

	carrasco., David Shuey., Stephanie Pelligra., Edward Wang., Dennie T. Rogers., and Alexis A. Thompson. (2013)			on both intervention groups. The CHOICES group however dis show higher score than the e-book group ($p=.10$)	conclude on the long-term effect of CHOICES intervention	
11	Olatona FA, Odeyemi KA, Onajole AT, Asuzu MA. (2012)	Quasi- Experimental study	451 participants who were enrolled in the NYSC. 239 in the intervention group and 212 in the control group	The result of the study that there was a statistically significant change ($p=0.00$) in the level of knowledge about sickle cell disease and screening in the intervention group which reflect a positive effect of education on knowledge level.	Limitations for this study were not discussed.	Level 1, High Quality

12	Creary Susan, Adan Ismahan, Stanek Joseph, O'brien Sarah H, Chisolm Deena, Jeffries Tanica, Zajo Kristin, & Varga Elizabeth (2017)	Quasi experimental study	113 participants who were caregivers to an infant with SCT. Study was done at [REDACTED] in Ohio	The result of the study showed that caregivers' baseline SCT knowledge is low but improves with education and can decline with time.	Limitations were that it was a small, single institutional study and findings are not generalizable due to exclusion criteria (language).	Level 2, B
13	Kotb Mohammed Mahmoud, Almalki Mohammed J, Hassan Yasser, Sharif Anwar Al, Khan Maseer, & Sheikl Kamaludin (2019)	Quasi-experimental study	120 secondary school male students participated in the study conducted at the [REDACTED]	The result of showed increase in knowledge post education Intervention but there was no increase in attitude about sickle cell disease among participants	The study was limited to male student and there was no comparison group and follow-up test to measure knowledge retention and attitude overtime	Level 2, A
14	Irina Benenson, DNP, FNP-C, Sallie Porter, PhD, CPNP, and Tracy	Expert Opinion	N/A	Although there are no studies indicating that SCT status awareness decreases adverse health consequences in people with SCT, information about SCT may	N/A	A

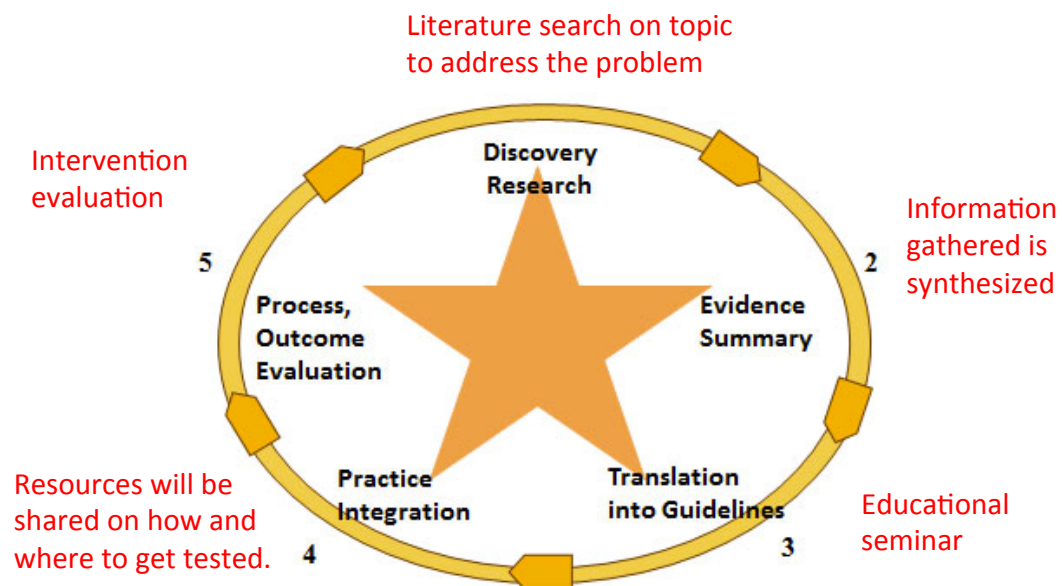
	Vitale, DNP, RN (October 2019)			be beneficial in many life situations such as family planning and participating in intensive military or athletic training. SCT status disclosure may be used as an educational opportunity to assist individuals in making better decisions to support health and avoid harmful situations		
15	Afua O. Arhin, PhD, RN (February 2019)	Expert Opinion	N/A	Effective reporting, patient education case management, and follow-up of infants with SCT who are diagnosed by newborn screening may be the best approach in curtailing the incidence of this devastating disease	N/A	A

Appendix B

Theoretical Framework

Ace Star Model of Knowledge Transformation

ACE STAR MODEL OF KNOWLEDGE TRANSFORMATION



Adapted from: (Stevens, 2004)

Appendix C



RUTGERS

School of Nursing

Letter of Cooperation

Date: 10/1/2019

Re: Letter of Cooperation for [REDACTED]

Dear Anthonia Ajimavo,

This letter confirms that I, as an authorized representative of [REDACTED], allow the Co-investigator “Anthonia Ajimavo” access to conduct study related activities at the listed site as discussed with the co-investigator as outlined below, and which may commence when the co-investigator provides evidence of IRB approval for the proposed project.

- Research site: [REDACTED]
- Funding Agency: Principal Investigator
- Study Purpose: To determine if African Americans of Reproductive age are aware of their sickle cell trait carrier status and if an education intervention will impact their intension to get screened.
- Study Activity: 1-hour educational intervention including 40 minutes PowerPoint presentation and 20 minutes Q & A session. pre-post-post knowledge and intent test.
- Subject Enrollment: Inclusion criteria: Male and female English speaking African American, ages 18-45 years old. Exclusion criteria: persons with sickle cell disease
- Site Support: Provide Space for study
- Data Management: Data will be locked and transported in a keypad secured locked box. Data will be transferred into a flash drive, and a copy will be saved in co-investigator’s google drive account.
- Anticipated End Date: January 2020

Page 1 of 2
Version 2; 10/1/2019

We understand that this site's participation will only take place during the study's active IRB approval period. All study related activity must cease if IRB approval expires or is suspended. I understand that any activities involving Personal Private Information or protected Health information may require compliance with HIPAA Laws and Rutgers Policy.

Our organization agrees to the terms and condition stated above. If we have any concerns related to this project, we will contact the principal Investigator. For concerns regarding IRB policy or human subject welfare, we may also contact the Rutgers IRB (see orra.rutgers.edu/hssp).

Regards,

*Signature**Date Signed*

*Full Name**Job Title*

Page 2 of 2
Version 2; 10/1/2019

Appendix D

Rutgers, The State University of New Jersey

Recruitment Flyer



RUTGERS
School of Nursing

Sickle Cell Trait Unawareness in African Americans. A Faith-Based Approach.

Are you an African American Male or Female?

Are you between the ages of 18 and 45?

Do you know your sickle cell trait status?

This research seeks to obtain baseline knowledge of African American on sickle cell trait and intention to test or get screened using a pre-post-posttest.

Location: [REDACTED]

Time commitment: Total of 2 hours is needed. The duration of study is 1 month. This project has 2 sessions.

Study Activity: The first session is on the day of the educational intervention. Participants are required to fill out a demographic questionnaire, partake in a pretest, PowerPoint educational session and a posttest in the first session. The second session is 2 weeks after the 1st session. You are required to participate in a 15 minutes test that can be taken over the phone or via electronic mail.

There is no cost in participating in this project. Participants will be compensated with a \$10 visa gift card for their time. The card will be mailed out after completion of the second posttest.

For more Information please contact:

Principal Investigator: Irina Benenson, DNP, FNP-C

E-mail: [REDACTED]

Co-Investigator: Anthonia Ajimavo

E-mail: [REDACTED]

Cell Phone: [REDACTED]

Version 2; 10/1/2019

Appendix E

Rutgers, The State University of New Jersey

Rutgers, The State University of New Jersey



RUTGERS

School of Nursing

Informed Consent

CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: Education Intervention to Improve Knowledge and Screening for Sickle Cell Carrier Status among African Americans of Reproductive Age

Principal Investigator: Irina Benenson, DNP, FNP-C

Co-Investigator: Anthonia Ajimavo, MSN, AGNP-C

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. The purpose of the research is to: determine if a faith-based educational intervention will increase the intention of African Americans to get screened to know their sickle cell trait status. If you take part in the research, you will be asked to partake in a total of 3 questionnaires and a one-hour education session. Your time in the study will take approximately 2 hours. 10 minutes to answer demographic questions. 15 minute each for pretest, posttest, and post-posttest. 1 hour for the education session which involves 40 minutes PowerPoint presentation and 20 minutes for question and answer. There is minimal risk in participating in this study. Possible benefits of taking part in this study may be increased knowledge of sickle cell trait and its screening process. Your alternative to taking part in the research study is not to take part in it.

The information in this consent form will provide more details about the research study and what will be asked of you if you choose to take part in it. If you have any questions now or during the study, if you choose to take part, you should feel free to ask them and should expect to be given answers you completely understand. After all of your questions have been answered and you wish to take part in the research study, you will be asked to sign this consent form. You are not giving up any of your legal rights by agreeing to take part in this research or by signing this consent form.

Who is conducting this research study?

Dr. Benenson is the Principal Investigator of this research study and Anthonia Ajimavo is the co-investigator. The co-investigator has the overall responsibility for the conduct of the research. However, there are often other individuals who are part of the research team.

Anthonia Ajimavo may be reached at cell phone: [REDACTED]; e-mail: [REDACTED]

The co- investigator or another member of the study team will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

Why is this study being done?

This study is being done to determine if there is a lack of sickle cell trait status awareness within African Americans of reproductive age and if an educational intervention will increase the intent of African Americans to get screened.

Who may take part in this study and who may not?

Inclusion Criteria: Males and Females who identify as African Americans and are between the ages of 18 and 45 who can read and speak English. Exclusion criteria: People with known diagnoses of sickle cell disease or have sickle cell trait.

Why have I been asked to take part in this study?

You are being invited to take part in this study in order to determine if an educational intervention can affect willingness of African Americans of reproductive age to get tested to know their sickle cell trait status.

How long will the study take and how many subjects will take part?

The study will last for 1 month. Your participation is required on the day of the educational intervention. Also, 2 weeks after the educational intervention to partake in a 15 minutes test that can either be taken via phone or electronic mail. This test is the 2-week posttest. The study is expected to have about 50 participants.

What will I be asked to do if I take part in this study?

As a participant, you are required to participate in the 2 sessions of this study. On the day of the first session, you will be asked to answer a demographic questionnaire, partake in a 12– item pre-posttest that will be conducted before and after the 1-hour educational intervention. The second session of this project will be conducted 2 weeks after the first session. You are required to partake in another test (known as the 2-week posttest). This will take 15 minutes to complete. This test can be taken either over the phone or via electronic mail that will be sent to your email address.

What are the risks and/or discomforts I might experience if I take part in this study?

There is minimal risk in participating in this study. There might be feeling of distress over potential SCT status after participation in education intervention. Additionally, there might be feelings of shock, surprise and sadness experienced during the project.

Are there any benefits to me if I choose to take part in this study?

The benefits of taking part in this study may be increased knowledge on sickle cell disease, sickle cell trait and screening process. However, it is possible that you may not receive any direct benefit from taking part in this study.

What are my alternatives if I do not want to take part in this study?

There are no alternative treatments available. Your alternative is not to take part in this study.

How will I know if new information is learned that may affect whether I am willing to stay in the study?

During the course of the study, you will be updated about any new information that may affect whether you are willing to continue taking part in the study. If new information is learned that may affect you after the study or your follow-up is completed, you will be contacted.

Will I receive the results of the research?

In general, we will not give any individual results from the study. The co- investigator anticipates dissemination of this study after completion.

Will there be any cost to me to take part in this study?

There will be no cost to you in participating in this study. All the costs related to this study will be the sole responsibility of the co- investigator.

Will I be paid to take part in this study?

You will be compensated for your participation in this study. Participants will receive a \$10 visa gift card for taking part in this study according to the following schedule:

- After the second post-test that will take place 2 weeks after the educational intervention
- The gift card will be mailed to participant's address provided on sign in sheet

How will information about me be kept private or confidential?

All efforts will be made to keep your personal information in your research record confidential, but total confidentiality cannot be guaranteed. Data collected will be stored on a password protected external hard drive. The hard drive will be solely in the possession of the co-investigator.

A back up storage of the data will be in co- investigator's Google drive account of which the co-investigator will have sole access. Access to the materials is restricted solely to the principal investigator and co-investigator.

What will happen to my information or biospecimens collected for this research after the study is over?

- The information collected about you for this research will not be used by or distributed to investigators for other research.

What will happen if I do not wish to take part in the study or if I later decide not to stay in the study?

It is your choice whether to take part in the research. You may choose to take part, not to take part or you may change your mind and withdraw from the study at any time.

If you do not want to enter the study or decide to stop taking part, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to co-investigator Anthonia Ajimavo.

If you decide to withdraw from the study for any reason, you may be asked to return for at least one additional visit for safety reasons.

Who can I call if I have questions?

If you have questions about taking part in this study or if you feel you may have suffered a research related injury, you can call the co- Investigator: Anthonia Ajimavo, Rutgers School of nursing. Cell phone [REDACTED].

If you have questions about your rights as a research subject, you can call the IRB Director at: Newark Health Science (973)-972-3608 or the Rutgers Human Subjects Protection Program at (973) 972-1149 Newark Health Science (973)-972-3608 or the Rutgers Human Subjects Protection

Program at (973) 972-1149

AGREEMENT TO PARTICIPATE**1. Subject consent:**

I have read this entire consent form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form and this study have been answered. I agree to take part in this study.

Subject Name: _____

Subject Signature: _____ Date: _____

2. Signature of Investigator/Individual Obtaining Consent:

Appendix F
GIFT CARD TRACKER

Participant	Date gift card sent

Appendix G

Sickle Cell Carrier Status Seminar Sign-in Form

NAME	CELL PHONE #	EMAIL ADDRESS	HOME ADDRESS

Appendix H



RUTGERS

School of Nursing

Demographic Questionnaire

Please provide your response to the following questions.

1. How old are you?
 - ☐ 18-27
 - ☐ 28- 37
 - ☐ 38 – 45
2. What is your sex?
 - ☐ Male
 - ☐ Female
3. What is your race?
 - ☐ African American
 - ☐ African
 - ☐ Caucasian
 - ☐ Hispanic
 - ☐ Asian
 - ☐ Others
4. Are you a parent?
 - ☐ Yes
 - ☐ No

5. What is your highest level of education attained?

- ☐ Less than high School
- ☐ High School
- ☐ Vocational School
- ☐ College (4-year)
- ☐ Graduate Degree

6. Income level

- ☐ Less than \$10,000
- ☐ \$10,000 to \$29,000
- ☐ \$30,000 to \$49,000
- ☐ \$50,000 or more

Appendix I



RUTGERS

School of Nursing

Sickle Cell Trait Knowledge Questionnaire and Intent Measure

PRE-TEST


DIRECTIONS: This is a questionnaire about SICKLE CELL TRAIT. Circle the best answer.

1. Sickle cell trait can turn into Sickle Cell Disease.
A. True
B. False
2. If a person has sickle cell trait, it can be passed on to their children.
A. True
B. False
3. Sickle cell trait causes lots of pain crises.
A. True
B. False
4. People with sickle cell trait have inherited a gene for sickle hemoglobin from one parent but not the other.
A. True
B. False
5. Most people with sickle cell trait live long, healthy lives.
A. True
B. False

6. If a person has sickle cell trait, all of his or her children will have sickle cell trait.
A. True
B. False
7. Sickle cell trait is only passed down through the mother.
A. True
B. False
8. People from all racial/ethnic backgrounds can be affected by sickle cell trait.
A. True
B. False
9. Sickle cell trait causes many medical problems for most affected individuals.
A. True
B. False
10. Sickle cell trait results in many deaths each year.
A. True
B. False
11. Do you intend to get screened to know your sickle cell trait status?
A. Yes
B. No
12. Have you ever thought of finding out your sickle cell trait status?
A. Yes
B. No

Appendix J

Educational Seminar PowerPoint Slides



RUTGERS
THE STATE UNIVERSITY
OF NEW JERSEY

Sickle cell trait status awareness

**Sickle Cell Disease and Sickle Cell Trait in the
African American Community**

ANTHONIA AJIMAVO, MSN, AGNP-C



Content

- What is sickle cell disease?
- What is sickle cell trait?
- Who is affected by sickle cell trait/disease?
- How do you get sickle cell disease?
- Implications of sickle cell disease
- Implications of sickle cell trait
- Screening tests
- Important facts about sickle cell disease and sickle cell trait
- Living with sickle cell disease
- How sickle cell disease can be prevented?
- Questions and answers

School of Nursing



Goals & Objectives

- **GOALS**
 - Educate participants on sickle cell disease and sickle cell trait
 - Discuss the importance of screening
 - Increase screening for sickle cell trait
- **OBJECTIVES**
 - Participants will understand the difference between SCD and SCT
 - Participants will understand the health risks of SCD
 - Participants will understand the importance of screening for SCT
 - Participants will understand the related health risk of SCT
 - Participants will understand the reproductive implications of SCT

School of Nursing

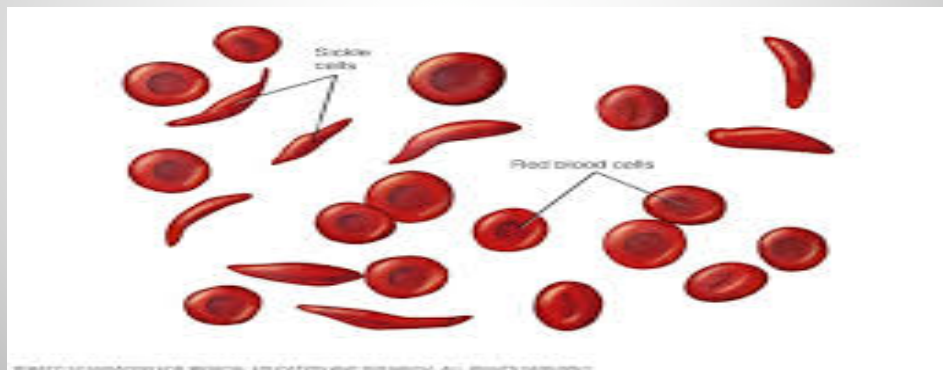
Definitions

- What is hemoglobin?
 - A protein that allows red blood cells to carry oxygen to all parts of the body
 - Can be abbreviated as Hgb or Hb
 - There are different types of Hb: HbA, HbS, HbC
- What is a red blood cell?
 - They are types of cells in the body that carries oxygen in the blood
 - Red blood cells contain hemoglobin
 - Normal red blood cells are round and flexible as they move through small vessels

School of Nursing

What is Sickle Cell Disease?

- Sickle cell disease is a group of inherited red blood cell disorder (CDC, 2017).
- Red blood cells have a sickled shape and there is constant shortage of red blood cell due to short red blood cell life (CDC, 2017).



School of Nursing

Sickle Cell Disease

- The red blood cell become hard and sticky looking like a farm tool called a sickle.
- Sickled red blood cells becomes inflexible and may **block small blood vessels (called vaso-occlusion)**. The blockage of blood vessels causes **pain and decrease oxygen supply to different organs**
- Sickled red blood cells are fragile and are destroyed prematurely. It cause a constant **shortage of red blood cells (anemia)**



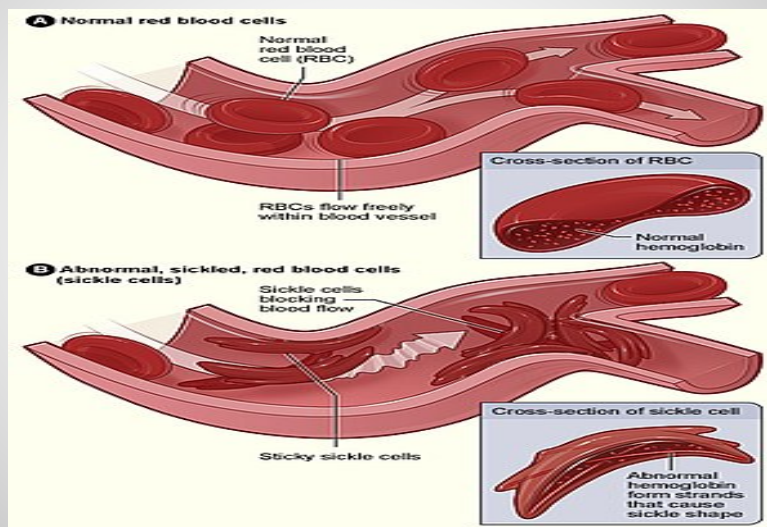
School of Nursing

Types of Sickle Cell Disease

- There are several types of SCD; the major types are discussed below
 - A. HBSS- This is when a person gets two sickle cell gene “s” from each parent. This is the most severe form of the disease. This form is called *sickle cell anemia*
 - B. HBSC- This is when a person gets a sickle cell gene “S” from one parent, and another abnormal hemoglobin “C” from the other parent. This is a milder form of SCD.
 - C. HBS Beta Thalassemia- This is when a person inherits a sickle cell gene “S” from one parents and one gene for beta thalassemia from another parents.

School of Nursing

Normal and Sickled Red Blood Cells



School of Nursing

Who is affected by Sickle Cell Disease?

- Sickle cell disease occurs more often among people from parts of the world where malaria is or was common. It is believed that people who carry the sickle cell trait are less likely to have severe forms of malaria (CDC, 2017).
- SCD affects mostly people of Sub-Saharan Africa, Spanish speaking regions in western hemisphere (South American, the Caribbean and Central America), Saudi Arabia, India, and Mediterranean Countries i.e. Turkey and Greece (CDC, 2017).

School of Nursing



Sickle Cell Disease- Statistics

- 100,000 people in the U.S. have SCD (CDC, 2017).
- SCD occurs in 1 in every 365 African Americans (CDC, 2017).
- SCD occurs in 1 in 13, 600 Hispanic-Americans (CDC, 2017).
- About 1% of children with sickle cell disease die during their first 3 years of life (Shephard, 2016).
- On average, people with sickle cell disease live 30 years less than people without sickle cell disease
- In the US, 94% of children with SCD will survive into adulthood with the overall median age of survival at **58 years** (Azar & Wong, 2016).
- There is currently **no cure** for SCD but there are treatment options available to manage symptoms and prevent complications (Gallo et al., 2010).

School of Nursing



Health problems in people with Sickle Cell Disease

- **Anemia**
- **Vaso-occlusive crisis** - sudden pain episode that can last for long period of time
- **Acute chest syndrome**- occurs when there is blockage of blood to the lungs. This can be life threatening.
- **Infections, sometimes life-threatening**
- **Stroke**
- **Blood clots in deep veins of the legs (DVT)**
- **Blood clots in the lungs (PE)**
- **Kidney damage**
- **Chronic leg ulcers**
- **Eye damage and blindness**

School of Nursing

Health problems in children with Sickle Cell Disease

- **Priapism** – A sustained painful erection lasting 4 or more hours (Azar & Wong, 2016)
- **Hand-Foot Syndrome** (Dactylitis)- blockage in blood vessels to the extremities causing swelling in the hand and feet
- **Acute stroke**- neurologic decline due to intracranial ischemia or hemorrhage (Azar & Wong, 2016)



School of Nursing

Treatment of Sickle Cell Disease

- Currently, **there is no cure** for sickle cells disease
- Treatment is to reduce complications of sickle cell disease:
 - Vaccinations
 - Antibiotic therapy for infants and young children
 - Hydroxyurea – medication that reduce number of painful crises
 - Pain medications
 - Blood transfusions

There are ongoing research on cure for SCD in Stem cell transplant and Gene therapy. Not everyone with SCD is a candidate for these options.

School of Nursing


 RUTGERS

Sickle cell trait status awareness

Sickle Cell Disease

<https://youtu.be/iTm7jHIZAic>

School of Nursing

 RUTGERS

Sickle cell trait status awareness

What is Sickle Cell Trait?

- Sickle Cell Trait is when a person inherits one sickle cell gene from one parent and one normal gene from the other parent
 - Sickle Cell Disease occurs when a person inherits two sickle cell genes , one from each parent
- Sickle Cell Trait is a “**carrier state**”, **not a disease**

School of Nursing



Sickle Cell Trait- Statistics

- About 2 million people in the United States have sickle cell trait (NHLBI, 2010).
- 1 in every 13 Blacks or African American have Sickle cell trait (CDC, 2019)
- 1 in 100 Hispanic Americans is born with SCT (CDC, 2019)

School of Nursing



Health Concerns in people with Sickle Cell Trait

- Most people with SCT **do not have any symptoms** of SCD, although—**in rare cases**—people with SCT might experience complications (damage to the spleen, kidneys and eyes)
- In **their extreme form**, and **in rare cases**, the following conditions could be harmful for people with SCT:
 - Increased pressure in the atmosphere (which can be experienced, for example, while scuba diving)
 - Low oxygen levels in the air (which can be experienced, for example, when mountain climbing, exercising extremely hard in military boot camp, or training for an athletic competition).
 - Dehydration (for example, when one has too little water in the body)
 - High altitudes (which can be experienced, for example, when flying, mountain climbing, or visiting a city at a high altitude)

School of Nursing



Rare Complications of Sickle Cell Trait in Athletes

- Some people with SCT have been shown to be more likely than those without SCT to experience heat stroke and **muscle breakdown** when doing intense exercise, such as competitive sports or military training under unfavorable temperatures (very high or low) or conditions. Studies have shown that the chance of this problem can be reduced by avoiding dehydration and getting too hot during training

School of Nursing



Reproductive Implication of Sickle Cell Trait

The most important thing to know about having Sickle Cell Trait is that you could have a child with Sickle Cell Disease if your partner also has Sickle Cell Trait!!!

School of Nursing



Sickle cell trait status awareness

What is the chance to have a child with Sickle Cell Disease if you have Sickle Cell Trait?

- If both parents have SCT, there is a 50% (or 1 in 2) chance that any child of theirs also will have SCT, if the child inherits the sickle cell gene from one of the parents. Such children will not have symptoms of SCD, but they can pass SCT on to their children.
- If both parents have SCT, there is a 25% (or 1 in 4) chance that any child of theirs will have SCD. There is the same 25% (or 1 in 4) chance that the child will not have SCD or SCT.

School of Nursing



Sickle cell trait status awareness



School of Nursing

Sickle Cell Trait Video

- <https://www.youtube.com/watch?v=MDepyJP5oOI>

School of Nursing

Newborn screening for Sickle Cell Disease

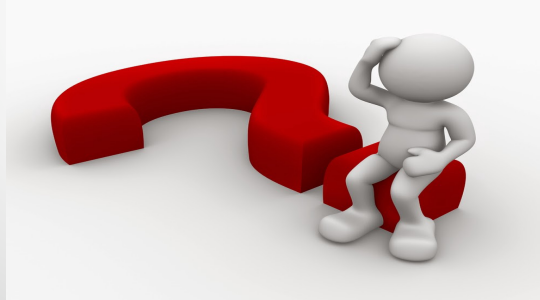
- Adopted in 1987 a consensus was reached to screen all new born in the United State for SCD and other hemoglobinopathies
- All 50 states in the United States offer SCD screening at birth
- SCT is identified in the process of screening for SCD
- **Not everyone is informed** about their SCT status (no standard protocols of informing)



School of Nursing

Problem

- Many African American of reproductive age are unaware of their Sickle Cell Trait status
- If you don't know your Sickle Cell Trait status you may **unknowingly** increase the chances of having children with Sickle Cell Disease



School of Nursing

Sickle Cell Trait

- Why should you care?
 - SCT and SCD affects mostly people of African descent
 - There are about 2 million people living with SCT
 - There is need to shift focus from treatment of SCD to prevention of SCD
- Why should you know your status?
 - It empowers you to make informed reproductive health decision
 - It makes us an informed population
- What is the end goal?
 - To increase the number of African Americans who know their SCT status
 - To prevent or reduce the prevalence of SCD
- Is it that important?
 - It is a preventive measure, that can lead to a better quality of life.

School of Nursing

Steps to Take



School of Nursing

- First step – know your Sickle Cell Trait status
- Ask your health care provider if Sickle Cell Trait test results are documented in your chart
- If there is no Sickle Cell Trait test results in your chart, ask to perform a screening test

Testing

- A screening test allows to measure the different types of hemoglobin in your blood
- It allows to distinguish between SCD and SCT

Types of Tests:

- Hemoglobin electrophoresis
- HPLC- High performance liquid chromatography
- IEF- Isoelectric focusing



School of Nursing



What do I do next?

- Where can I get screening test?
 - At the clinic or hospital
- How do I begin the process?
 - Speak to your health care provider if you are unaware of your SCT status or if you are unsure about your carrier status
- What are the costs?
 - If you have health insurance, it should be covered by your insurance
 - If you don't have health insurance coverage, ask about the cost of the blood test before proceeding.

Free screening! Take advantage of free screening provided by some local organization by visiting their websites for events.

School of Nursing



Next step.....

- If you have SCT, request genetic counseling to better understand your risk
- If in a relationship, disclose your status to your partner and to other family members
- Encourage your partner and family members to get screened
- If positive screen, know your choices of having children. This choices include having children, adopting, or using more advanced options

School of Nursing



Facts

- Sickle Cell Disease is an inherited disorder of hemoglobin
- Sickle Cell Trait is a carrier status, not a disease
- Sickle Cell Trait can not become sickle cell disease
- Most people with sickle cell trait live long and healthy lives
- Sickle Cell Trait increases a risk of having children with Sickle Cell Disease that is incurable conditions, with multiple health problems
- Sickle cell trait can be seen in people of different ethnic background
- All states in the United State screen all babies for Sickle Cell Disease

School of Nursing




Community Resources

There are various organizations that provide support and services to people and families living with SCD. Some of these organizations are listed below:

- Sickle Cell Disease Association of America.
- Sickle Cell Awareness Foundation Corporation International.
- Sickle Cell Thalassemia Patient Network.
- The Foundation For Sickle Cell Disease Research

School of Nursing




RUTGERS

Sickle cell trait status awareness

World sickle Cell Awareness Day

July 19th Every year

School of Nursing



RUTGERS

Sickle cell trait status awareness

National Sickle cell Awareness Month

**September is Sickle Cell
Awareness Month**

School of Nursing



Sickle cell trait status awareness

Prevention

SICKLE CELL CARRIER STATUS AWARENESS AND SCREENING

School of Nursing



Sickle cell trait status awareness

QUESTION & ANSWER

School of Nursing

Appendix K



RUTGERS

School of Nursing

Sickle Cell Trait Knowledge Questionnaire and Intent Measure

IMMEDIATE POST-TEST

DIRECTIONS: This is a questionnaire about SICKLE CELL TRAIT KNOWLEDGE. Circle the best answer.

1. Sickle cell trait can turn into Sickle Cell Disease.
A. True
B. False
2. If a person has sickle cell trait, it can be passed on to their children.
A. True
B. False
3. Sickle cell trait causes lots of pain crises.
A. True
B. False
4. People with sickle cell trait have inherited a gene for sickle hemoglobin from one parent but not the other.
A. True
B. False
5. Most people with sickle cell trait live long, healthy lives.
A. True
B. False

6. If a person has sickle cell trait, all of his or her children will have sickle cell trait.
A. True
B. False
7. Sickle cell trait is only passed down through the mother.
A. True
B. False
8. People from all racial/ethnic backgrounds can be affected by sickle cell trait.
A. True
B. False
9. Sickle cell trait causes many medical problems for most affected individuals.
A. True
B. False
10. Sickle cell trait results in many deaths each year.
A. True
B. False
11. Do you intend to get screened to know your sickle cell trait status?
A. Yes
B. No
12. Will you take a step to know your sickle cell trait status?
A. Yes
B. No

Appendix L



RUTGERS

School of Nursing

Sickle Cell Trait Knowledge Questionnaire and Intent Measure

POST-POST TEST

DIRECTIONS: This is a questionnaire about SICKLE CELL TRAIT KNOWLEDGE. Circle the best answer.

1. Sickle cell trait can turn into Sickle Cell Disease.
A. True
B. False
2. If a person has sickle cell trait, it can be passed on to their children.
A. True
B. False
3. Sickle cell trait causes lots of pain crises.
A. True
B. False
4. People with sickle cell trait have inherited a gene for sickle hemoglobin from one parent but not the other.
A. True
B. False
5. Most people with sickle cell trait live long, healthy lives.
A. True
B. False

6. If a person has sickle cell trait, all of his or her children will have sickle cell trait.
A. True
B. False
7. Sickle cell trait is only passed down through the mother.
A. True
B. False
8. People from all racial/ethnic backgrounds can be affected by sickle cell trait.
A. True
B. False
9. Sickle cell trait causes many medical problems for most affected individuals.
A. True
B. False
10. Sickle cell trait results in many deaths each year.
A. True
B. False
11. Do you intend to get screened to know your sickle cell trait status?
A. Yes
B. No
12. Have you taken any step to know your sickle cell trait?
A. Yes
B. No

Appendix M

RUTGERS
School of Nursing

Permission to use SCKTKQ

[REDACTED]
Fri 4/12/2019 9:50 AM

Anthonia Ajimavo

Hello Anthonia,
Yes you have my permission. Thanks for your interest in my work and best of luck with your study!

[REDACTED]

Rutgers, The State University of New Jersey

Rutgers, The State University of New Jersey

Appendix N



RUTGERS
School of Nursing

Project Timeline

PLAN	TIMELINE
Proposal draft submission to new team	July 21 st , 2019
DNP implementation PowerPoint submission	July 26 th , 2019
DNP Team presentation	September 2019
DNP Team approval	September 11 th , 2019
IRB Submission	September 20 th , 2019
IRB Approval	October 2019
Recruitment	November 2019
Implementation	2 nd week of December 2019
2-week post implementation follow-up	End of December 2019
Data collection and analysis	January 2020
Final write up	February & March 2020
Rutgers School of Nursing presentation	April 2nd 2020
Graduation	May 2020

Appendix O



RUTGERS
School of Nursing

Estimated Project Cost

Materials	Cost
Educational materials i.e. pencils, flash drives	\$50.00
Handouts (Printing consent form)	\$150.00
Subject Compensation	10 x 32 = \$320.00
Refreshments	\$100.00
Stamped envelopes	\$25.00
Total	\$645.00

Appendix M

RUTGERS
School of Nursing

SICKLE CELL TRAIT KNOWLEDGE QUESTIONNAIRE ANSWER KEY

1. Sickle cell trait can turn into Sickle Cell Disease.
(False)
2. If a person has sickle cell trait, it can be passed on to their children.
(True)
3. Sickle cell trait causes lots of pain crises.
(False)
4. People with sickle cell trait have inherited a gene for sickle hemoglobin from one parent but not the other.
(True)
5. Most people with sickle cell trait live long, healthy lives.
(True)
6. If a person has sickle cell trait, all of his or her children will have sickle cell trait.
(False)
7. Sickle cell trait is only passed down through the mother.
(False)
8. People from all racial/ethnic backgrounds can be affected by sickle cell trait.
(True)
9. Sickle cell trait causes many medical problems for most affected individuals.
(False)
10. Sickle cell trait results in many deaths each year.
(False)