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The role of healthcare providers in using the knowledge of sickle cell trait to mitigate health problems in African American Clients.

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The role of healthcare providers in using the knowledge of sickle cell trait to mitigate health problems in African American Clients.

A Scholarly Project Presented to the Faculty of the
Nicole Wertheim College of Nursing and Health Sciences

Florida International University
In partial fulfillment of the requirements
For the Degree of Doctor of Nursing Practice

By

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Abstract

Background: Sickle cell trait (SCT) for long has been regarded as a benign condition and as such healthcare providers do little to nothing to mitigate adverse health problems associated with sickle cell trait. An effective approach to improving health outcome for those with SCT is to educate providers on SCT, its complications and management. This study is aimed at evaluating the effectiveness of an educational intervention on providers' knowledge, attitude and practice regarding sickle cell trait.

Method: A quasi experiment study was conducted in Jackson Health System on 30 providers belonging to internal medicine team to evaluate their pre and post knowledge, attitude and practice towards SCT.

Result: Out of 30 providers recruited for the study, 21 completed both the pretest and posttest questionnaire giving a response rate of 70%. The overall score improved after the educational intervention, however the overall mean score for pretest and posttest was not significantly different ($p = 0.223$). There was a significant difference ($p = 0.045$) between the knowledge mean score for pretest and posttest. Attitude scores for pretest and posttest were not significantly different ($p = 0.545$). A similar finding was obtained for practice score (P-value 0.604).

Conclusion: Educational intervention was effective in improving knowledge, attitude and practice of providers regarding sickle cell trait. Therefore this effort must be sustained through continuous education within the institution to increase awareness towards sickle cell trait among healthcare providers especially for new hires.

Key Words: *Health care providers, African Americans, mitigation, Knowledge, attitude, practice, sickle cell trait, genetic counseling, Rhabdomyolysis, status, screening*

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Introduction/Problem Statement

Sickle cell Trait and other sickle cell disorders disproportionately affect African and Americans (CDC 2020). There is a lack of awareness of SCT and limited number of providers are screening their African American patients for SCT. Very

often many African American patients and their health care providers do not know their sickle cell trait status and are also unaware that SCT has some adverse health implications like sudden death, rhabdomyolysis and chronic kidney disease. This knowledge gap exist because SCT status is not transferred during transition from pediatric to adult care and does not exist in patients' medical record. It is also not part of history taking during initial encounter between patient and provider. Many African American youths are actively involved in sports which predispose them to exertional rhabdomyolysis and sudden death. And quite often we see or hear about black athletes collapsing during sporting activities or during military training. If an individual is identified to have SCT measure can be taken to avoid dehydration, heat stroke and muscle breakdown during exercise. It can also reduce the incidence of sickle cell disease through genetic counseling. Sickle cell trait is no longer a benign condition as previously thought, therefore individuals who carry such traits should be evaluated on regular basis and given the large number of people with SCT, it is important that providers be aware of these associations. Awareness of SCT status by patient, families and treating provider is very important.

Background

People with sickle cell trait even though they do not suffer serious medical problems are often neglected and no action is taken to treat their potential medical conditions before they progress into more serious health problems. There is a misconception that SCT poses no serious health problem because individuals with SCT do not usually manifest any visible symptoms as seen with sickle cell disease and as such individuals

are often not screened (Mainous et al 2015). This problem is further compounded by lack of awareness of SCT status by both patients and providers. Sickle cell trait occurs in all 50 states of the United States but prevalence is disproportionately very high in States with high black populations. Even though national mandatory newborn screening has been instituted, yet government and some philanthropic organizations who sponsor research into treatment and prevention of other diseases like HIV/AIDS, tuberculosis, diabetes and osteoporosis have failed to attach same importance to sickle cell disease and sickle cell trait. There are advertisement on television or billboards educating black community about health implications of sickle cell trait. The mandatory sickle cell disease and sickle cell trait screening for every newborn black babies does not go far enough. Very often the data collected is not communicated to PCP when patients transition to adolescents/adults. As many as 1.5% of babies born in the United States (15.5 cases per 1000) have SCT (Ojodu et al 2014). Ojodu et al (2014) also reported that there are no standardized methods or protocols for alerting families or healthcare providers to this information, educating them about the potential health outcomes that might be associated with the condition, or counseling them about the impact that this might have on the family's future reproductive choices. By including educational materials and providing genetic counseling at the same time that families are given positive SCT results, the occurrence and public health burden of SCD might be reduced. Because people with SCT are at risk of having a child with sickle cell disease if their partner also has SCT or one of several other abnormal hemoglobin genes, it is important to properly inform them of their status and educate them about possible health problems and reproductive considerations (CDC 2020). Such knowledge will inform genetic counseling, effect disease modifying measures, mitigate complications associated with SCT when caught early, reduce morbidity and mortality in African Americans reduce health care

cost and increase advocacy for sickle cell disease related disorders (Houston et al 2016).

Problem Identification

Sickle cell disease is an inherited disease that affects the hemoglobin. The disease distorts red blood cell into sickled or crescent shape which impedes blood flow to the rest of the body. This blockage of blood flow leads to some serious health problems including strokes, infections and episodes of pain called crises. Sickle cell disease apart from causing significant morbidity and mortality in affected individual also affects them socially due to a lot of stigma associated with this condition. Sickle cell disease also has significant impact on the healthcare and economy of many countries (Gardner 2018). When an individual inherits one sickle cell gene and one normal gene, the individual has sickle cell trait which is a carrier state of sickle cell disease. Carrier state is characterized by the presence of about 40% HbS, absence of anemia, hematuria and inability to concentrate urine (Maakaron 2020). Carriers even though they do not have the symptoms of sickle cell disease pose threat to SCD because they have the capacity to pass on this trait to their children. If both parents are carriers of sickle cell trait, there is a 25% chance that they will have a child with sickle cell disease. People with sickle cell trait are often neglected because they show no visible symptoms. Many African American patients do not know their sickle cell trait status and neither do their providers. According to Creary et al (2017) only 16% of individuals in their childbearing age who have SCT have knowledge of their status. This is a serious problem because sickle cell trait has serious health implications for African Americans. Sickle cell trait status is often missing in their medical records because it is not included in routine history taking during emergency room or office visits. People with SCT are often not screened because they are "not sick". This is a huge gap in practice which must be bridged for better health outcome for African

Americans who seek health care. Not knowing the SCT status for African American clients has great public health implications for African Americans. Evidence has shown that SCT has clinical sequelae such as exercise related injury, heat stroke, sudden death, muscle breakdown during exercise (CDC 2016), renal complications, venous thromboembolism, pregnancy related complications such as preeclampsia and risk of having a child with sickle cell disease due to lack of genetic counseling (CDC 2020).

Scope of the Problem

Sickle cell traits affects about 300 million individuals worldwide and one third of this number are in sub Saharan Africa (EL Ariss et al 2016). Gibson et al (2016) also reported a prevalence of 25% in some parts of Africa and 60% in Saudi Arabia. According to Maakaron (2020) Sickle cell trait and sickle cell disease are common in individuals whose ancestors come from Africa, Mediterranean region (Turkey, Greece, and Italy), Middle East (Saudi Arabia) and South Asia (India). Because of forced and voluntary migration from areas with high prevalence such as Africa, India and Middle East, SCD and SCT is now found all over the world and both the incidence and prevalence will continue to increase in Western world (Maakaron 2020, Ashorobi et al 2021). In the United States SCD and SCT disproportionately affect blacks. The prevalence of SCT in the United States is 9% among African Americans and 0.2% among Caucasians (Gibson et al 2016). According to CDC (2020), approximately 3 million people has SCT in the United States nearly all of them African Americans and many are unaware of their status. As many as 1.5% of babies born in the United States (15.5 cases per 1000) have SCT (Ojodu et al 2014). 1 in 13 black or African American babies is born with sickle cell trait (CDC 2020). Ojodu et al (2014) in their study of the incidence of SCT in the United States reported that every State and ethnic population has people living with SCT and the overall incidence in the 44 participating States was 15.5 per 1000 newborns. They also

reported that incidence varied greatly from State to State with Montana having the lowest occurrence of 0.8 per 1000 newborns screened and Mississippi with the highest 34.1 per 1000. Florida stands at 25.9 per 1000 newborns. Among ethnic groups blacks had 73.1 and Hispanics 6.9.

There is no sex predilection for SCD and SCT since they are not X-linked diseases.

The male to female ratio is 1:1 (Maakaron 2020)

Consequences of the Problem

Sickle cell trait was previously thought to a benign condition. Studies have shown that SCT poses serious health risk. Under conditions of low oxygen like high altitude, extreme exercise and high intensity physical training SCT may become a pathologic risk factor (Maakaron 2020). Other complications associated with SCT include rhabdomyolysis, splenic infarct, renal malignancy, thromboembolic disorders, and hematuria (Tantawy 2014). All of these lead to increased morbidity, mortality and lifestyle changes in black population. People with SCT are at risk of having a child with sickle cell disease which is associated with huge financial burden to the patients and their families as well as substantial cost to the society. Singh et al (2014) reported that in 2004 United States spent \$488 million from 113,000 hospitalizations for sickle cell related illnesses. Huo et al (2018) put the estimated incremental economic burden of SCD at \$2.98 billion per year in the United States. Breakdown of this cost shows that 57% went to inpatient cost, 38% outpatient and 5% was out-of-pocket expenses paid by the patient Since sickle cell disease is a lifelong condition and there is presently no cure, this cost will only continue to rise. The only way to curtail these excessive healthcare cost is through early diagnosis and treatment for individuals with sickle cell trait and those with sickle cell disease.

Significance of this Problem

Sickle cell trait is not a completely benign condition, rather it is indeed a risk factor for certain serious health disorders. If SCT individuals are denied routine

check-ups, there will be increase in morbidity, mortality and changes in lifestyles in black population. Quality of life will therefore be affected. Healthcare cost will continue to skyrocket due to hospitalizations and disability. It is imperative to thrust sickle cell status to limelight in order to give affected individuals best health outcome by providing best medical advice and treatment to affected individuals. Also it is important to break the cycle of transmission since two individuals with SCT have 25% of having a child with sickle cell disease. This can be achieved through genetic counseling. Health care providers must educate their African American patients and offer screening if status is unknown. This can reduce both the incidence and prevalence of SCT and SCD. It is important to implement SCT screening not only for newborns but for every individual whose status is unknown (Ashorobi et al 2021). Memish et al (2011) in a study done in Saudi Arabia reported that a decrease in the number of individuals with SCT marrying another carrier due to premarital screening and genetic education.

Review of the Literature

Sickle cell disease is a lifelong inherited genetic disorder caused by sickling of red blood cells. Individuals with sickle cell disease exhibit significant morbidity and mortality. Symptoms include chronic anemia, acute chest syndrome, stroke, splenic and renal dysfunctions, pain crises and susceptibility to bacterial infections. SCD includes the lifelong challenges of managing the chronic illness while accessing and navigating the health care system. The burdens of the disease can affect all aspects of the lives of individuals with SCD to include physiological, psychological and social wellbeing (Jenerette et al 2011).

Sickle cell trait (SCT) is an inherited blood disorder that affects millions of people worldwide. It is a carrier state for sickle cell disease considered to be a benign condition. People with SCT are asymptomatic and do not show any of the symptoms usually associated with sickle cell disease. Even though these carriers are not “sick”, they are at risk for serious health complications such as exertional injury, sudden death, chronic kidney disease and venous thromboembolism (Benenson et al 2018). Knowledge and awareness of these potential health complications associated with SCT is paramount both for the provider and the patient. This will help inform appropriate medical interventions and genetic counseling early in order to reduce morbidity and mortality and ensure best clinical outcome for people with SCT. This is why the main objective of this study is to call attention to this group of people who are often neglected by providers until serious health problem ensues. The study also seeks to make healthcare providers who attended to at risk population aware of the health risk posed by SCT and to emphasize the importance of screening and genetic counseling. Benenson et al (2018) also emphasized that SCT screening should be carefully documented and communicated to affected individuals and their providers. Even though newborn screening is mandatory, this information is often not transferred when these individuals transition to adolescents or adulthood because there is no systematic way of doing so. Because of this gap in practice neither the patient nor healthcare providers know the SCT status of their clients. In order to provide evidence-based care to African Americans and other at risk populations, providers must be aware of the SCT status of their clients, potential health complications and routine management of individuals with SCT (Benenson et al 2018). This can only be possible through screening of all individuals whose SCT status are unknown starting during the initial encounter. The result should be part of the patients’ medical record

In addition to medical problems and complications, people with SCD also experience psychosocial problems; stigmatization and labeling based on presumptions on the nature of the disease. Even though sickle cell disease is a genetic disorder, racism often play a big role in terms of healthcare equity, hindered accesses to care and less funding support (Power-Hay et al 2020). Bulgin et al (2018) also reported that sickle cell patients can experience bias for different reasons including race, minority status, disease and socioeconomic status, delayed growth and recurrent acute pain. This stigmatization may begin in childhood, the magnitude which is never assessed until adolescence and adulthood (Okechukwu et al 2020). Jeanerette et al (2015) noted that young adults with SCD are at risk for health related stigmatization due to many challenges of the disease. People with SCD have suffered devaluation, judgement and social disqualification of these individuals based on a health-related condition (Weiss et al 2006). Pain is the hallmark feature of sickle cell disease. Almost all people with sickle cell disease have painful episodes called crisis. This can last from hours to days. Crisis can cause pain in the lower back, legs, joints and chest. Some people have one episode every few years, others have many episodes each year and these crises can be severe enough to warrant hospitalization. This is when the ordeal starts. Ezenwa et al (2016) noted that people with sickle cell disease experience stigma because frequency of their acute healthcare utilization and chronic use of opioids for pain management. Many health care workers including doctors and nurses do not understand what it means for a sickler to be in crisis. This lack of knowledge makes it almost impossible for these patients to receive adequate and timely treatment. The goal of treatment should be to manage and control symptoms and to limit the number of crises. According to Jenerette et al (2011), health related stigma is increasingly becoming a major health issue that should receive more attention. They went further to say that young adults with sick cell disease are at risk for health-related stigmatization due to many challenges of the disease. Stigmatization adds to the

burden of individual and family affected by sickle cell disease and is associated with adverse health outcomes (Ezenwa et al 2016). Satorious (2006), reported that stigma evokes negative attitudes and feelings which may affect the type of care these people receive., like receipt of timely and quality health care. Stigma has a significant impact on the health and well-being of sickle cell patients. Health related stigma can have a deleterious affect across the lifespan on the individual being stigmatized (Jenerette et al 2011).

Stigmatization is the main reason college athletes and American Society of Hematology are opposed to the mandatory sickle cell trait screening required by The National Collegiate Athletes as prerequisite to athletic participation. American Society of Hematology because of this ethical concerns recommends that universal precautions that would protect all student athletes should be in place instead of revealing the sickle cell trait status of student athletes (Ferrari et al 2015).

Sickle Cell Disorder Screening

Progress has been made in newborn screening since it was made mandatory in the United States. Every State in the United States, the District of Columbia and U.S territories mandates sickle cell disease for all newborn babies (Maakaron 2020). When it became apparent that sick cell disease can no longer be ignored as a significant public health problem, the United States congress in 1972 passed the National Sickle Cell Anemia Control Act which authorized education, screening, counseling, research and treatment programs for sickle cell disease (U.S Congress 1972). United States and other high income countries have instituted mandatory newborn screening for SCD and for all at risk individuals which has contributed to mitigation of mortality and morbidity associated with these disorders. In sickle cell

endemic countries like Nigeria which leads the world in sickle cell disease prevalence, such national newborn screening is still lacking. Because of this about 70-90% of babies born with sickle cell die before age 5, only a small number of affected infants and children make it to adolescence (Grosse et al 2011), and most of these deaths occur before cases are diagnosed (Oron et al 2020). This is in contrast to high income countries where more than 90% of individuals with SCD reach adulthood. Uyoga et al (2019) reported that this dismal statistic of high mortality and morbidity in sub Saharan Africa can be prevented or reduced by early diagnosis and supportive care. Fraiwan et al (2019) reported that about 70% of deaths can be prevented with early diagnostic and treatment plans. In order to improve the health outcome of patients with SCD and SCT successful screening, education, follow-up and management programs must be implemented (de Montalembert et al 2019). Oron et al (2020) also suggested that a major barrier to sickle cell prevention is lack of large-scale newborn screening. Nnodu et al (2020) are of the opinion that newborn screening should be integrated into existing primary health care. For meaningful preventive care to occur there must be in existence a structured plan for early diagnosis and patient tracking (Fraiwan et al (2019).

Very often in the United States, the story ends with screening of newborns. Little or no effort is made towards communicating the findings to providers when these babies transition to adults. As a result many who carry sickle cell trait are unaware of their status. This has led to a steady increase in the incidence of sickle cell disease since these people at risk are not being offered any education or genetic counseling to make informed reproductive choices. Sox (2013) reported that the biggest challenges facing NBS are timely follow-up and implementation of comprehensive care. Also Kavanagh et al (2008) noted that wide variation in reporting of screening results has led to delays in early intervention. El-Haj et al (2018) noted that there is no mechanism of linking NBS systems with clinical data

system. In order to facilitate transfer and exchange of information between NBS program and clinical providers, medical record must be linked with NBS program (Wang et al 2011). There are immigrants with unknown sickle cell status living in the United States. Because there is no mandatory NBS from their home countries, these immigrants and their offerings are also not screened in the United States until they become sick. Routine screening of migrants from sickle cell endemic areas will help reduce morbidity and mortality associated with SCD and ultimately save lives and health care costs (American Society of Hematology 2019). They also recommended that ED physicians should be educated to identify and quickly treat individuals with acute sickle cell disease related events.

Call to Action

Even though so much has been done in term of diagnosis and pharmaceutical therapies to reduce the burden of sickle cell disease on patient and family a lot still has to been done in terms of palliative and curative care to enhance quality of life (Siddiqi et al 2013). People with sickle cell disease have less access to comprehensive team care than people with other genetic disorders like hemophilia and cystic fibrosis. There is a great shortage of health care providers interested in and experienced in caring for individuals with sickle cell disease, there are very few who wants to accept Medicaid, coupled with lack of a standardized treatment guidelines (Stone 2015). The combination of being both black and poor for the majority of children with SCD in the United Sates presents a distinct set of challenge (DeBaun 2012). More education and training is needed for effective emergency medicine, emergency nursing and hospital care. Genetic education and counselling should be enhanced through mass public education campaign. Just like other chronic disease like HIV/AIDS, diabetes and hypertension, sickle cell should also be advertised on television, radio, social media and other public communication outlets. If the public know that two carriers cannot marry and that a carrier cannot marry a Sickler because of the chances of

having a child with sickle cell disease, both the incidence and prevalence of the disease will be greatly reduced. Blood and bone marrow transplant which is the only cure for this disease should be made affordable. As at now only a very small number of people with sickle cell disease are able to be transplanted.

Research and clinical trials have received very little attention as far as sickle cell disease is concerned. Research is needed in the areas of stem cell, gene therapy and editing and alternative donor transplants. Research on patient experiences has revealed several themes that resonate among individuals with sickle cell disease and caregivers. These include: mistrust and not being treated with respect, poor pain management, being stigmatized as drug seekers and drug addicts and not being included in decision making regarding their health.

Epidemiology of Sickle Cell Trait

Sickle cell Trait is a benign state of sickle cell disease occurring in over 300 million people worldwide. It is recognized globally to be of great public health importance because of its reproductive and clinical significance (Pecker et al 2018). According to CDC (2020) sickle cell disease and SCT affect particularly individuals whose ancestors came from Sub-Saharan Africa, South and Central America, the Caribbean, Saudi Arabia, India and Mediterranean countries such as Turkey, Greece and Italy. In at least 40 countries sickle cell disease prevalence varies between 2 and 30% (Adam et al 2019). In Nigeria for example an estimated 150,000 babies are born annually with sickle cell disease (Fraivan et al 2019). In the United States, approximately 100,000 individuals have sickle cell disease. In Americans 3 million individuals have sickle cell trait affecting 8-10% of African American population (CDC 2020). Sickle cell disease occurs among 1 out of every 365 black of African American births. Sickle cell disease occurs among about 1 out of every 16,300

Hispanic-American births. About 1 in 13 African American babies is born with sickle cell trait

In 2010 it was estimated that over 60, 000 infants were born in the United States with SCT according to the national Newborn Screening 10-year Incidence Report. The incidence of SCT in participating States was 15.5 per 1000 newborn overall, 73.1 among black newborns and 6.9 among Hispanic newborns (Ojodu et al 2014). Since only 44 States participated in this study, the incidence rate could have been higher if all the 50 States participated. In this same study Florida had an incidence of 25.9 cases per 1, 000 infants screened. A study by Reeves et al (2019) in Michigan showed that blacks were disproportionately affected by SCD and SCT. In a period of 1997-2014 they reported 592 SCA births and 33404 SCT in black children representing 86.3% of SCA and 80% SCT cases respectively.

Why Providers must know the Sickle Cell Trait of their Clients.

Sickle cell trait although considered benign has significant health and social implications. In malaria endemic areas, SCT protects carriers against malaria caused by Plasmodium falciparum (Lansche et al 2018). This notwithstanding, SCT is a risk factor for some adverse health outcome such as exertional rhabdomyolysis, sudden death, chronic kidney disease, venous thromboembolism, preeclampsia and sickle cell disease (Naik et al 2018). These health problems emphasize the importance of comprehensive clinical and genetic evaluation to identify causes of health complications reported in individuals with sickle cell trait (Sambuughin et al 2018). Because of these health complications associated with SCT, evidence supports that SCT may not be a benign condition after all (Nath et al 2020). Increasing knowledge about these clinical outcomes can help inform genetic counseling, early treatment and recommendations (Pecker et al 2018). Primary care providers can play a vital role in early diagnosis and management of SCD and SCT. In order to make a significant

impact on disease burden and economic burden of these disorders more attention is needed at primary care level (Galadanci et al 2014). Sickle cell disorders have continued to proliferate in sub-Saharan regions like Nigeria because there is no organized primary health care delivery system. According to Galadanci et al (2014) management of sickle cell disorder in Nigeria is still suboptimal and they call for a concerted effort to improve primary health care delivery system in the country. Here in the United States primary care providers must double their effort to improve the health outcome of patients with sickle cell disorders through awareness of the existence of these disorders in their patients.

SCT and Exertional Rhabdomyolysis/Sudden Death

Sickle cell trait though benign is a risk factor for exertional rhabdomyolysis particularly with dehydration and hot weather (Nelson et al 2016). Nelson et al (2016) in a 4 year study of 48000 active duty black U.S soldiers reported incident rate of exertional rhabdomyolysis of 12% and 0.8% for soldiers with SCT and those without SCT respectively. Sickle cell disease significantly elevates the risk for exertional rhabdomyolysis and sudden death especially among athletes and military trainees (Nelson et al 2016). Providers should be aware of this risk due to high profile deaths involving rhabdomyolysis in athletes and military personnel. Nelson et al (2018) concluded in their study that SCT was significantly associated with higher risk of exertional rhabdomyolysis, but was not associated with higher risk of death. Harmon et al (2012) reported exertion related deaths among black football players participating in NCAA. Also Kark et al (1987) reported that SCT by a factor of 20-30 was a significant risk factor in sudden and unexplained deaths among black military recruits. Because of this significant risks, many organizations like the NCAA and military require a mandatory SCT screening prior to exposure to demanding physical

training. This adoption of a universal screening protocol by NCAA and the military has raised some concerns by organizations like American Society of hematology association as they argue that it may lead to stigmatization and discrimination (Thompson 2013).

Risk for Chronic Kidney Disease

Although sickle cell trait is often seen as being benign, carriers are at risk for renal manifestations and complications such as impaired urinary concentration, asymptomatic hematuria and papillary necrosis (Key et al 2010). Naik et al (2017) suggested that hemoglobin variants including SCT have a role in kidney disease in blacks. Naik et al (2014) also suggested that sickle cell trait may be an important and unrecognized risk factor for renal disease in black population. Sickle cell trait and sickle cell disease have been associated with faster kidney function decline in African American patients (Nath et al 2020, Olaniran et al 2019). As reported by Munter et al (2012), African Americans have a disproportionately higher risk of chronic kidney disease progression to end stage renal disease when compared to whites and Asian Americans. In a study by Naik et al (2014) of 15,97s of people that identified themselves as African American, 1,245 were identified as carriers of SCT. The study also showed that the incidence of CKD was significantly higher (20.7%) in carriers of SCT than in noncarriers. In this study Naik et al (2014) concluded that among African Americans in these cohorts, the presence of SCT was associated with an increased risk of CKD, decline in eGFR, and albuminuria, compared with noncarriers. These findings suggest that SCT may be associated with the higher risk of kidney disease in African Americans.

SCT and Pregnancy Complications

SCT has been linked with various adverse outcomes in pregnancy, ranging from maternal complications such as elevated risk of bacteriuria to potentially life-

threatening entities such as pre-eclampsia and prematurity (Wilson et al 2020).

O'Hara et al (2020) postulated that for a pregnant woman being SCT positive is a risk factor for pregnancy related hypertensive disorders showing that SCT has adverse effect on reproductive health. In their retrospective study of 25,020 enlisted active service women which comprised of 84% black women, they reported 30.4% of overall pregnancy related hypertensive disorders attributable risk due to SCT status and that those with SCT had higher health care utilization rates for all pregnancy related hypertensive disorders including preeclampsia and eclampsia. These women should be identified early in pregnancy in order to prevent these complications (Hamdi et al 2006).

Hamdi et al (2006) studied pregnancy outcome in women with SCT. They reported that incidence of anemia, abortion and neonatal death was significantly high among women with SCT and therefore concluded that these women need increased and special care during pregnancy, labor, puerperium and surgery. Taylor et al (2006) also evaluated the obstetric outcomes and pathologic findings in pregnant women with SCT. They reported a shorter average pregnancy duration and low birth weight, acute ascending amniotic infection and meconium histiocytosis in subjects with SCT. They also identified a significantly higher fetal death among women with SCT when compared to the control group (3.5% vs 9.7%).

Sickle Cell Trait, Genetic Counseling and Sickle Cell Disease Prevention

Sickle cell disease is a disorder which can be prevented or even eradicated through adherence to genetic counseling among subjects with SCT who are considering having children. There is no cure at present for sickle cell disease the only way to reduce the risk of transmission and prevent the health burden associated with sickle cell disease is to make informed reproductive choices (Asgharian et al 2010). Galadanci et al (2014) proposed the following as ways of reducing the devastating effects of sickle cell disorders in Nigeria, training of healthcare workers, awareness

and education, early diagnosis, health surveillance and referrals to specialists. Mayo-Gamble et al (2019) reported that there is consistently insufficient knowledge about the genetic inheritance pattern of SCD among people with sickle cell trait (SCT). Premarital counseling is very advantageous in reducing both the incidence and prevalence of SCT and SCD by targeting intending couples of high risk marriage and offering them genetic counseling prior to conception (Alswaidi et al 2009). It is very beneficial to invest in strategies that will reduce the mortality, morbidity, prevalence and incidence of sickle cell disease. Some countries where sickle cell disease is endemic have developed a very efficient genetic counseling and testing for hemoglobinopathies. Success has been made in this regards in some Mediterranean countries like Greece, Cyprus and Italy (Cao et al 2002). In some countries like Nigeria and Cyprus religious organizations play very important role in this respect offering premarital genetic counseling to at risk couples with very remarkable results (Cowan 2009, Ezugwu et al 2019). In Nigeria members of Roman Catholic faith are required to attend a pre-marriage course prior to wedding and this includes SCT screening and genetic counseling (Ezechukwu & Chukwuka 2004). Even though premarital counseling by religious bodies has raised some ethical issues namely intrusion into marriage as opined by Ezugwu et al (2019), providers should not be deterred from offering genetic counseling to SCT carriers who are thinking of having children because of ethical concerns. This is because the health, social and economic burden of sickle cell disease is enormous and far outweighs the ethical issues raised. Ezechukwu and Chukwuka (2004) are of the opinion that this practice should be encouraged and strengthened because of success it has achieved. Nnaji et al (2013) in their study of sickle cell disease in Southeastern Nigeria reported that 2/3 of their respondents will call off their marriage if there was risk of their offspring inheriting sickle cell anemia.

Individuals with SCT even though they are just carriers of SCD are at risk of having children with sickle cell disease when they make babies with another SCT carrier. Pre-conception counseling is therefore of essence in order to help individuals make an informed reproductive decisions and choices and this will also have remarkable impact on the epidemiology of the disease (Aneke & Okocha 2016).

Premarital counseling has been shown to have a great advantage in reducing the prevalence of this disorder over newborn screening because premarital genetic counseling is aimed at primary prevention while newborn screening addresses secondary or tertiary prevention (Tamhanker et al 2008). It would be beneficial to identify SCD carriers and at risk couples and educated them on patterns of inheritance of SCD and health risks associated with SCD. According to Rance et al (2018), education regarding sickle cell disease knowledge and genetic implications may help women to make informed decisions regarding pregnancy. Increasing SCT awareness through testing and proper education especially in practice settings will help mitigate against the sequelae of SCT and perhaps decrease the incidence of sickle cell disease. The application of SCT guidelines in practice can help educate patients and their families which will help improve clinical outcomes for black patients through implementation of modifiable factors. Proper implementation of SCT practice guidelines will reduce the economic and social burden of SCT and sickle cell disease both for the patient and the society. Aneke and Okocha (2016) suggested that it is imperative to invest in w

Management Considerations for Individuals with Sickle Cell Trait

Most providers do not know the sickle cell status of their African American patients. Even some patients and their families do not know their status due to poor reporting system (Taylor et al 2014). This should be established during initial encounter between the provider and the patients. Benenson et al (2018), postulated

that for provider to provide an evidence based care to their patients with SCT, they must be very conversant with the screening, health complications and routine management of these patients. Sickle cell screening should be initiated immediately in those individuals whose status is not known. Despite widely performed newborn screening, there are individuals who were born before the mandatory newborn screening and also there may be immigrants who were not screened in the countries of their birth and many may be unsure of their screening results due to lack of standardized reporting system (Vichinsky 2020). Also there is no standard way of reporting SCT results when clients transition from babies to adulthood from one provider to another. Information about SCT status of client seeking clearance for sporting activities, competitive athletes and participation in other strenuous training is very important. This information will help the provider in providing adequate teaching to the client, review and reinforce healthy practices such as adequate hydration to prevent adverse health events like rhabdomyolysis, exertional fatigue and sudden death associated with SCT (Vichinsky 2020). Also the use of any supplement that can exacerbate hypernatremia and dehydration should be discourage and should not be prescribed to individuals engaged in strenuous physical activities (Vinchinsky 2020)

Providers should conduct appropriate laboratory testing for their patients whose SCT status is known to detect early signs of kidney disease and renal cancer which has been associated with SCT in African Americans. Laboratory tests which will detect persistent albuminuria/proteinuria and serum creatinine should be ordered and evaluated. Increased incidence of albuminuria often occur in individuals with SCT (Sood et al 2019). Patients should be taught to seek prompt medical help for hematuria and SCT carriers with unexplained and persistent hematuria should be further investigated for renal complications using imaging (Benenson et al (2018).

This will help the provider make appropriate referrals for further investigation of the condition.

Pregnant individuals with SCT should be closely monitored throughout the duration of the pregnancy and beyond. Sickle cell trait is associated with pregnancy related hypertensive disorders such as preeclampsia and eclampsia and have increase health care utilization (O'Hara et al 2020. Wellenstein et al (2019) found an association between SCT and adverse pregnancy outcomes such as hypertension, small for gestational age, diabetes and preterm delivery. Providers should refer their clients with sickle cell trait who seek to have children to genetic counseling in order to make appropriate reproductive choices. Vinchinsky (2020) advised that communication of a positive SCT screening result must be accompanied by appropriate counseling.

Individuals with SCT should also be educated that they cannot donate blood for general blood supply (Vinchinsky 2020). Individuals who are SCT carriers at risk for venous thromboembolism and therefore should be taught signs and symptoms to recognize and report to their providers immediately. During air travel they should be advised to move frequently and anticoagulation should be considered during surgery and illnesses which can predispose an individual to thromboembolic events (Benenson et al 2018).

Knowledge Gap;

Sickle cell disease and sickle cell trait have continued to be unsurmountable problems due to lack of awareness and knowledge about these two disorders. Some individuals with SCT do not know their status and even their healthcare providers are also not aware of the SCT status of their patients. Efforts are not being made to educate black communities on health implications of SCT through television advertisements as seen with other health conditions such HIV/AIDS, obesity and asthma. There is no public health awareness education on SCT and SCD and as such

both prevalence and incidence of these diseases have continued to increase in black communities. Knowledge gap also exist during transition from pediatric to adult care due to lack of a standardized protocol of communicating sickle cell status from one provider to another. This lack of communication also exists between patients and providers because provider often do not collect information on SCT status from their patients during initial encounter. There is no routine check-ups for individuals with SCT which will help detect serious health conditions like chronic kidney disease early and sudden death which occur sometimes in black athletes. Studies have shown that SCT is no longer considered a benign condition.

Proposal of Solution

In order to prevent the health sequelae associated with SCT and prevent the occurrence of sick cell disease, the following actions must be taken:

Standardized reporting method: Result of newborn screening should be reported using a scandalized method and such results should be passed on to the next provider when the patient transitions to adolescent/adult care.

Genetic counseling: This will lead to reduction in both the incidence and prevalence of SCD assuming carriers make informed reproductive choices. According to Ashorobi et al (2021) it is very essential that carriers of sickle cell trait are given access genetic counseling making it possible for them to be we informed regarding the fact that their offspring has the potential to inherit sickle cell disease. Genetic counseling should be made available to individuals with SCT who are in childbearing age. They will be educated on their status and implication for reproductive choices. It is assumed that this will help them make informed choice. According to Ashorobi et al (2021), genetic counseling has been shown to reduce the percentage of SCT and SCD.

Inclusion in medical record: Sickle cell trait status should be included in initial patient assessment and form part of patient permanent medical record. Sick cell trait status should be initiate during the first encounter between an African American patient and his/her health care provider. The result of the screening should me made part of the patients permanent medical record and should be made available to other providers who may seek the patient's medical record. This process will facilitate sharing knowledge of a patient's SCT status among health care providers.

Public Education: Mass public health education should be regularly done through radio and TV ads. Television ads can be used to educate the population about SCT, its health implications and precautionary measures. Enhancing and expanding the knowledge of basic aspect of SCT and SCD are very important in disease management and prevention. Knowledge of SCT will be very significant in helping people make better choices which will improve their overall health outcome. Creamy et al (2017) reported that only 38.1% of their study population have baseline knowledge of sickle cell trait prior to being educated about SCT. After receiving proper education 90.3% achieved better education. It is therefore imperative that people with SCT and SCD should be educated about the inheritance of SCD, partner testing, genetic counseling and prenatal diagnosis.

Routine follow-ups: All people with sickle cell trait should have routine follow-up tests and labs to detect serious conditions early and apply proper management protocols. This can be included in the annual physical examination. Primary care providers should initiate and monitor laboratory results in all persons with SCT. This will enhance preventative care and prompt referral to specialists.

Purpose/PICO Clinical Questions/Objectives

Purpose: The purpose of this project was to alert providers of the gap in knowledge and practice concerning SCT in African American Patients and potential health risks that African Americans are exposed to when their sickle cell trait (SCT) is unknown.

The project also assessed the providers' knowledge, attitudes and practices concerning sickle cell trait.

PICO clinical question: Will educational Intervention to providers lead to change in practice and best health outcome for African Americans with sickle cell trait?

- **P:** How will providers and African Americans utilize SCT knowledge?
- **I:** What can providers do to improve health using knowledge of SCT?
- **C:** How will change in practice by providers improve health outcome?
- **O:** going forth will African Americans with SCT have better health outcome?

Research Objectives

The project in addition to calling the attention of providers to this gap in practice also investigated:

- If the provider knows the SCT status of their African American patients, if yes does patient know?
- If SCT status is part of patient history taking during initial encounter
- If providers are routinely screening their African American patients for SCT
- If providers are utilizing the evidence base data that SCT poses serious health risks for African Americans to guide management and treatment of illnesses
- If those with SCT are routinely evaluated for SCT complications.
- For providers who do not routinely screen their patients, they were asked if they will incorporate SCT screening of African American patients to their practice
- The study also persuaded providers to screen patients of unknown SCT status and to offer appropriate genetic education to SCT patients and monitor them routinely for signs of serious complications.

Search Strategy

An extensive and comprehensive review of peer reviewed articles that highlighted sickle cell trait, its complications and management strategies was done. The following databases were utilized: the Cochrane library database, Cumulative Index to Nursing and Allied Health Literature (CINHAL), Medline, National Institute of Health, Center for Disease Control and Prevention and World Health Organization. Key search terms include sickle cell trait, SCT complications, Providers' knowledge, attitude and practice of SCT, Sickle cell trait management strategies, genetic counselling and SCT prevention. Only articles published in English Language were accessed.

Definition of Terms

Sickle cell Trait: Inheritance of one gene for normal hemoglobin and one for sickle cell hemoglobin. It is a genetic carrier state

Health care Provider: an individual who is licensed or otherwise authorized by State to provide health care services.

Genetic counseling: Getting information about how genetic disorders such as sickle cell disease might affect you individually and your family.

Rhabdomyolysis: A breakdown of muscle tissue that releases a damaging protein (myoglobin) into the blood which can damage the kidneys.

Sickle Cell Screening: Testing a person's blood for abnormal types of hemoglobin.

SCT Status: Knowing if one is a carrier of sickle trait.

Practice Question

The main objective of this study was to raise awareness about sickle cell trait and health problems associated with it among healthcare providers. The practice question therefore is "would an educational intervention for providers lead to an

increase in knowledge of sickle cell, change in attitude and practice among providers”? In order to answer this question a pretest-intervention-posttest research design was used to study the knowledge, attitude and practice of providers regarding SCT.

Conceptual Underpinning and Theoretical Framework of the Project

An implementation framework, Knowledge to Action framework (KTA) will be used to examine the role that providers play in creating awareness of SCT and its health implications. The KTA framework is used to guide knowledge translation into practice (Crockett 2017). The KTA framework which consists of two iterative process, knowledge creation and action cycle was developed in Canada in the 2000s by Graham and his colleagues to solve the problem of confusing multiplicity of terms used to describe the process of transforming knowledge into action (Graham et al 2006). According to WHO (2021), solution to some clinical problems may be found in already existing knowledge. It is important to synthesize existing research data and to contextualize the resulting knowledge prior to implementation (WHO 2021). The knowledge of sickle cell trait already exist. The problem is that this knowledge is not translated into action to prevent health complications associated with SCT. This project seeks to identify this gap in knowledge and practice and offer solutions to close this gap, hence ensuring best health outcome for African American patients with SCT. Sickle cell trait disproportionately affect African Americans, however awareness by providers and patients is often lacking. Based on KTA framework this study will involve:

1. Problem identification (investigate of providers are aware of the SCT status of their black patients.
2. Creation of awareness, coaching and persuasion
3. Outcome evaluation.

Because KTA framework is iterative and dynamic it is often used in research in healthcare and academic settings to solve problem targeted at patients, the public, nursing and applied health professionals (Field 2014). As the process of KTA is iterative, not only can it inform, components of the action cycle also feedback to inform knowledge creation (WHO 2021). Xu et al (2020) in their study of intervention to improve the quality of care transition for joint arthroplasty patients concluded that KTA framework provides a logical and valuable tool for clinical work. Their results also showed that using the KTA framework for joint arthroplasty patients helped improve care transition.

Methodology

Introduction

This QI project will be used to effect changes in the way providers treat and manage patients with SCT. Measures to monitor were selected, interventions to implement were chosen and possible strategies to effect these changes were identified. Effort is in the pipeline to adapt these changes to JHS, identify and deal with barriers that may affect the adaptation of these changes. At the end of the project Plan, Do, Study, Act (PDSA) will be used to push this initiative until all the providers have been educated. The purpose of this project was to explore providers' knowledge, attitude and practices regarding sickle cell trait and to raise awareness that SCT is not a benign condition. Also the project sought to find out if an educational intervention will lead to change in practice among healthcare providers. This is because SCT has sequelae of health complications. Evidence from literature showed that little to nothing is being done as far as SCT and its management are concerned. Increased awareness of SCT among providers and their patients is very paramount. The current gap in knowledge and practice must be bridge by using evidence based practices in the management of individuals with SCT.

Study Design

The study made use of a quantitative pretest-intervention-posttest one group design to explore and gain an in-depth information on what providers know and how they manage individuals with sickle cell trait.

Approach and Rationale.

The study was done using a quantitative quasi-experimental design of one group pretest-posttest design. The study participants came from internal medicine team of Jackson Health system. There was no randomization of study participants and there was no control group. The study participants were subjected to the same treatment and assessment. This design allowed for the assessment of educational intervention that was applied to the study population. The study is exploratory which will help provide a detailed information about providers and sickle cell trait. A pretest- intervention-posttest design was considered the best research design to study providers' knowledge, attitude and practice regarding sickle cell trait and its complications. Pretest-posttest design as a form of quasi-experimental design allowed for uncomplicated assessment of an intervention applied to the study participants. The design made it possible to determine if educational intervention will lead to a change in practice.

Setting and Location

The study was carried out at Jackson Memorial Hospital. Jackson Health System is a non-profit tertiary care teaching hospital and the major teaching hospital of the University Of Miami School Of Medicine. Its organizational structure helped me achieve the goals of this project. Jackson Health System being a county hospital provides high quality care to everyone irrespective of insurance status. Most minority patients who do not have health insurance are issued a Jackson Card which enables

them to access health care. Jackson takes care of the vast majority of black patients with sickle cell disease and their families and has a dedicated center for sickle cell patients. Dr. Thomas Harrington, a specialist in sickle cell disorders follows most sickle cell patients who come to Jackson Memorial Hospital for their health care needs. This makes Jackson Memorial Hospital an ideal place to carry out this project. Jackson health system has hospitalist team. Hospitalists provide general medical care to hospitalized patients. They lead the hospital medical team, coordinating care for inpatients. Hospitalists see patients for the duration of a hospital stay. If the patient has a chronic condition that requires multiple stays, the hospitalist may see them more frequently. The study population for this project were the Hospitalist at Jackson Memorial Hospital.

Study Population

The target population for this study was the hospitalist providers of Jackson Memorial Hospital, medical doctors, nurse practitioners and physician assistants, of all genders. Thirty participants participated in the study. The inclusion criteria are being a member of hospitalist at JMH and English speaking. Exclusion criteria was non-speakers of English language. English language was the only language that was used for this project.

Recruitment and Consenting.

Recruitment was done electronically through the medical director of the Hospitalist. Email letter was used to recruit participants comprising of 30 providers medical doctors, nurse practitioners and physician assistants. The recruitment letter (Appendix C) explained the purpose, benefits and conditions for participation. Consent for participation was obtained by asking the participants to click yes to be taken to the study questionnaire. The recruitment letter also explained to the

participants that they will not be compensated for participating in the study and also that they would not incur any cost.

Sampling

Data was collected using non-probability or convenience sampling method in order to make the process less cumbersome. Basic data and trends regarding sickle cell trait and its management were collected without the complications of using a randomized sample.

Convenience sampling was done using a structured questionnaire for data collection. Convenience sampling is very easy to carry out and may generate useful data and information that would have been impossible with probability sampling techniques which require more formal access to lists of populations (Etikan2016, Laerd dissertation 2020). Participants were recruited until saturation was reached

Sample Size.

Thirty providers were recruited for this study. A good maximum sample size is usually 10% as long as it does not exceed 1000 (Davis 2021). There are about 200 members of internal medicine teams throughout Jackson Health System and 10% of that is 20. Sample size of 30 exceeds the 10%. A t-test can be done with much less than 30 participants.

Duration of Data Collection

Approval for this project was obtained from Florida International University IRB and Jackson Health System Nursing Research and Evidence Based Practice Council as well as Council of Chief Nursing Officers of Jackson Health System (Appendices A, B) The project ran for three months. Participants were allowed to exit the study at any time since participation was entirely voluntary.

Data Collection

A pretest-posttest design was used for data collection .A pretest-posttest questionnaire was created and uploaded to a software Qualtrics (Appendix D). After participants gave their consent they were taken to the study site to complete a pretest questionnaire in order to collect baseline data. After three weeks a PowerPoint presentation containing Evidence based facts about sickle cell trait and its management was sent to participants. After two weeks the participants were prompted to return to the study site to complete the post-test portion of the pretest-posttest survey. Change from intervention applied was measured by comparing pre-intervention data to post-intervention data. In order to draw valid conclusion same respondents took part in both the pretest and posttest surveys.

Intervention/Instrumentation

Two instruments were used for this study namely a structured questionnaire and a power point of educational intervention. The pretest and posttest questionnaire has 31 questions (appendix D) divided into three sections, knowledge, attitude and practice. The questions were developed from findings from the extensive literature review done. The use of pretest-posttest method made it possible to determine if educational intervention made any impact on knowledge, attitude and practices of the providers.

Educational Intervention

An educational power point was developed which summarizes information about SCT and its management (appendix E). The educational intervention was expected to last 10 minutes. Included in the power point are information about SCT, complications associated with SCT, evidence based management practices and recommendations that will ensure best health outcome for individuals with SCT.

Data Analysis

Data coding and analysis was be done using Qualtrics/SPSS coding software. All data analysis were done using SPSS. Results of the pre-test and post-test surveys were scored with percentage and a mean score calculated. The scores were organized according to a topic domain and were compared for improvement. Descriptive statistics was used to primarily describe the data collected explaining how many respondents undertook the desired behavior, what range of answers were, description of central tendency and the spread of the data. The results of the pretest and posttest were analyzed for significant difference using paired t-test.

Project Evaluation

The study was designed with accepted principle with research method which was clear and feasible. The research question, which was “would an educational intervention lead to a change in practice and best health outcome for African Americans with sickle cell trait” was very clear and well defined at the beginning of the project. Both the instrument used for the study and the study design were designed to answer the research question.

Sample size was representative of the study group. More than 10% of the study population participated in the study. According to Davis (2021) a good maximum sample size is usually around 10% of the population as long as this does not exceed 1000. More than 10% of the Internal medicine teams of JHS participated in the study. Appropriate research design was applied to this study. The design allowed for the same intervention and assessment to be applied to the same group. It was able to measure change resulting from intervention by comparing the pretest data to the posttest data.

Quasi experimental design lacks randomization and therefore it does not eliminate the problem of confounding variables. Quasi experimental design makes it possible to

know with some level of confidence whether a particular intervention caused a change.

SPSS was used for data coding and analysis. This is an appropriate data analysis software for this type of study to compare pretest information to the posttest information.

Discussion and conclusion were consistent with the study results. Ethical standards were met throughout this study. Informed consent was obtained. Participants were accurately informed of the purpose, methods, risks and benefits of the study. They were giving the opportunity to make a voluntary decision about whether to participate in the study. Respect of human dignity, confidentiality and privacy were taken into consideration. The participants were not exposed to any risk or harm. Answers to the research question will contribute to improving the health of African Americans with sickle cell trait by improving management protocol. To make sure this study was ethically acceptable before it started approval from FIU IRB and JHS Nursing Research and Evidence Based Council was obtained.

Protection of Human Subjects

No risk to participants occurred during this study. Participants did not provide any personal identifier, no personal information was collected. Explanations were provided to participants electronically periodically and as needed. This was highly adequate to collect information required for this study. It was not possible for me to associate a participant to the study and it was not possible for anyone to be link back to his/her answers. The questionnaire which was used for data collection was only assigned numbers which did not represent any individual or information from the participants. Consent was obtained electronically and data collected was stored electronically in my personal desktop computer which is password protected. My computer is not shared with any other individual.

Benefit to Society

This study will create awareness of SCT and its health risks. Given the large number of people with SCT it is important that healthcare providers be aware of these associations. This will help providers to target activities and programs that will result in improvement in health outcome for African Americans. This awareness will also lead to reduction in the prevalence of sickle cell disease through appropriate genetic counseling since SCT has important reproductive consequences with a risk of having a child with sickle cell disease. Reduction in incidence of sickle cell disease will lead to reduction in morbidity and mortality associated with sickle cell disease and hence reduction in healthcare costs.

Results/Interpretation of findings

The purpose of this project was to alert health care providers about the gap in knowledge and practice concerning sickle cell trait, provide evidence based practice measures to properly manage those with sickle cell trait and to study providers' knowledge, attitude and practice concerning sickle cell trait.

A convenience sampling approach was used for data collection. The project was conducted over a period of three months and a total of 30 health care providers were recruited for this study. Data analysis was done using paired t-test that compared changes in the mean scores between pretest and posttest data. All data analysis was done using SPSS 24.0

Demographic Characteristics

Overall, twenty-one (70%) respondents completed both pre- and post-intervention questionnaires and were included in the analysis. Thirteen of the respondents were

males (61.9%) and 8 (38.1%) were females. Three (14.3) of the respondents identified as Black or African American, 4 (19%) white, 12 (57.1%) Hispanic, while two participants (9.5) identified as others. Eleven of the 21 (52.4%) respondents were MDs, 8 (38.1%) NPs and 2 (9.5%) PAs. Most of the participants had 1-3 years of experience (15/21, 71%), while three each (14%) had 4-7 years and greater than 10 years of experience. Details of participants' characteristics are presented in Table 1.

Table 1.
Participants' Characteristics

Characteristic	Frequency (%)
Gender	
Male	13(61.9)
Female	8 (38.1)
Ethnicity	
Black or African American	3 (14.3)
White	4 (19)
Hispanic	12(57.1)
Other	2 (9.5)
Experience (Years)	
1-3	15 (71)
4-7	3 (14)
>10	3 (14)
Profession	
MD	11 (52.4)
NP	8 (38.1)
PA	2 (9.5)

Total score pre vs post intervention

From the 30 healthcare providers recruited for this study only 21(70%) successfully completed both the pretest and posttest. Table 1 shows the healthcare providers' demographic characteristics. The pre-intervention KAP score of the respondents showed some improvement in the posttest score after the educational intervention was applied. To determine whether or not the intervention had an impact on participants' overall score on the survey, participants' total scores were compared using the paired

t-test (table2). The mean score pre-intervention was 83.0(SD 15.5) and the mean score post-intervention was 88.4(SD22.6). Although the mean total score was higher post-intervention, this difference was not statistically significant (mean difference =5.4, $p=0.223$)

Table 2.
Total (Overall) Scores Pre- vs. Post-Intervention (Paired T-Test)

Pre-Intervention	Post-Intervention	P-value
Mean 83.0 (SD 15.5)	Mean 88.4 (SD 22.6)	0.223

Knowledge score pre vs post intervention.

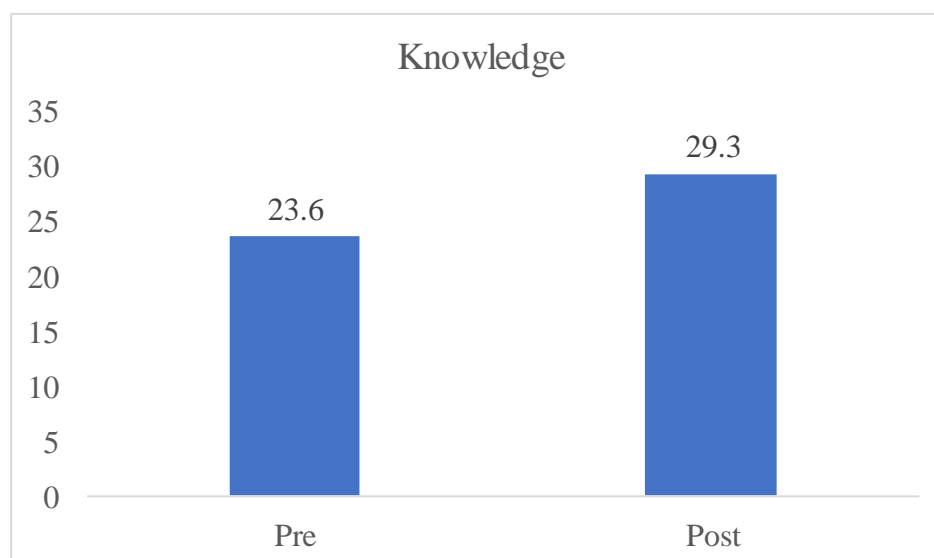
Following the educational intervention knowledge scores significantly improved.

Participants' knowledge of SCT scores were compared using the paired t-test (table 3). The mean score pre intervention was 23.6 (SD 5.4) and the mean score post intervention was 29.3 (SD 7.1). There was a significant increase in knowledge scores when comparing pre and post intervention (mean difference =5.7, $p=0.045$).

Table 3.
Knowledge Scores Pre- vs. Post-Intervention (Paired T-Test)

Pre-Intervention	Post-Intervention	P-value
Mean 23.6 (SD 5.4)	Mean 29.3 (SD 7.1)	0.045

Figure 1



Attitude score pre vs post intervention

Most healthcare providers showed positive attitude towards SCT pre and post intervention. Almost 100% of the respondents believed that SCT is of public health importance and that the public should be educated on the health and reproductive implications of SCT. To determine whether or not the intervention had an impact on participants' attitude towards SCT, participants' attitude scores were compared using the paired t-test (table 4). The mean attitude score pre-intervention was 37.3 (SD8.8) and the mean attitude score post intervention was 36.3 (SD 10.8). However when the mean attitude scores pre and post intervention were compared using paired t-test, there was no significant difference (mean difference =1.0, $p=0.545$).

Figure 2

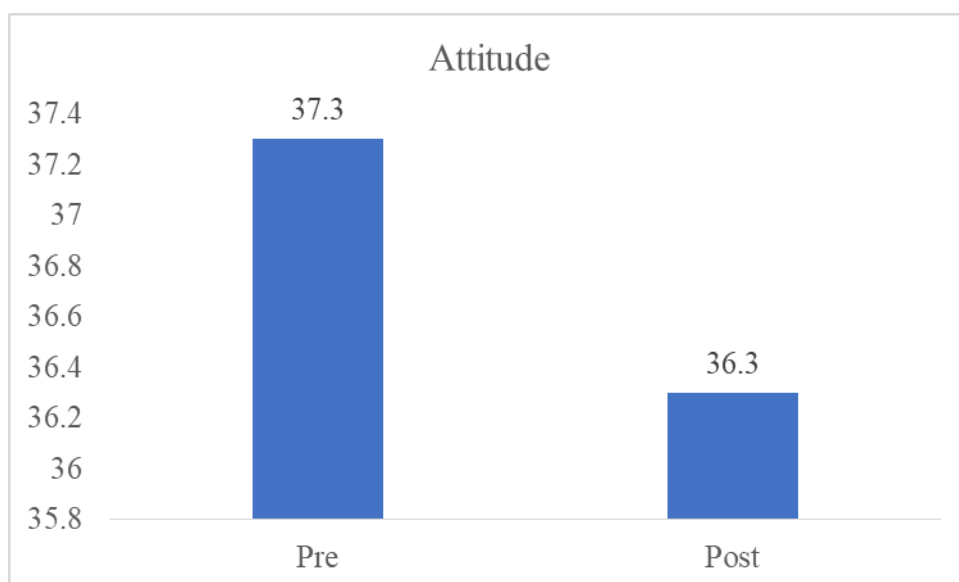


Table 4.
Attitude Scores Pre- vs. Post-Intervention (Paired T-Test)

Pre-Intervention	Post-Intervention	P-value
Mean 37.3 (SD 8.8)	Mean 36.3 (SD 10.8)	0.545

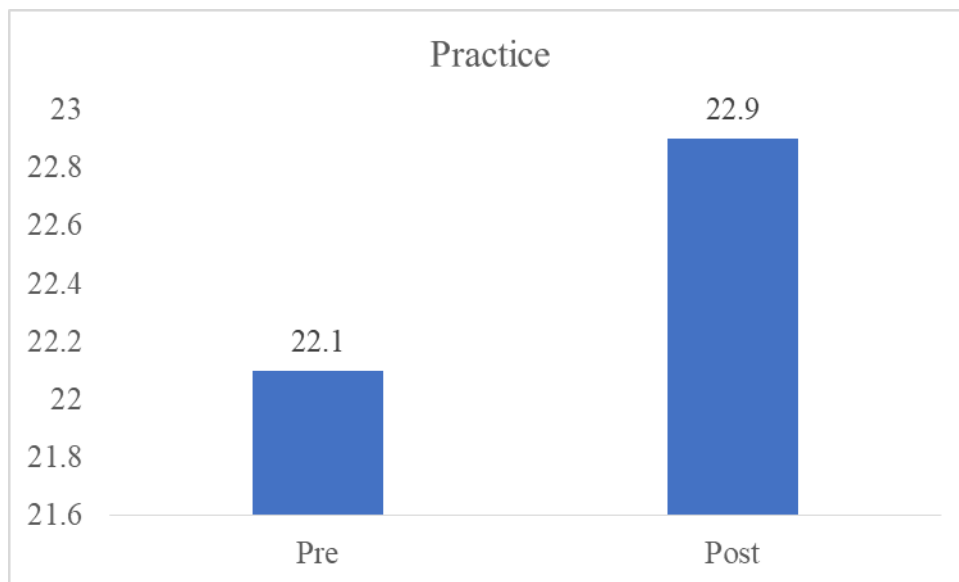
Practice score pre vs post intervention

100% of the providers see black patients regularly in their practice but only 50% of them know the SCT status of some of their patients. The results collected for practice for pretest and posttest were almost similar and 90% also said that they will be more proactive in managing their patients with SCT. Most of the respondents (85%) for both pretest and posttest strongly agree that SCT should be included in the patients' medical record. There was no significant difference in the practice of the providers

Table 5.
Practice Scores Pre- vs. Post-Intervention (Paired T-Test)

Pre-Intervention	Post-Intervention	P-value
Mean 22.1 (SD 4.4)	Mean 22.9 (SD 5.6)	0.604

Figure 3



Discussion

How results compare to review of literature

Even though the knowledge of SCT improved among healthcare providers after the educational intervention, unfortunately in reality the actual management of people with SCT is still deficient. This may be attributed to lack of established clinical protocol to manage patients with SCT. This can also be attributed to the fact that some providers pre-intervention considered SCT a benign condition. Nath et al (2020) pointed out that SCT should no longer be considered a benign condition. SCT under conditions of low oxygen such as high altitude may become a pathologic risk (Maakron (2020)). Sickle cell trait has clinical sequelae such as exercise related injury, heat stroke, sudden death, muscle breakdown (CDC 2016), renal complications (Naik et al 2018), venous thromboembolism (Benenson et al 2018), pregnancy complications (Tantawy 2014) and risk of having a child with sickle cell disease due to lack of screening and genetic education (CDC 2020). These health problems emphasize the importance of comprehensive clinical and genetic evaluation to identify causes of health complications reported in individuals with SCT (Sambuughin et al 2018). The gap between knowledge and practice was also evident when 66.67% of the providers know that black athletes and military trainees are at risk of sudden death from muscle breakdown due to SCT, yet only 58% of the respondents strongly agree that black athletes and military trainees should be first screened for SCT before issuing clearance for these individuals to participate in strenuous activities and 58.33% do not screen their patients of unknown SCT status and 58.33% also do not obtain family history of sickle cell disorders from their black patients. Mainous et al (2015) reported that people with SCT are often not screened because such individuals do not usually manifest any visible symptoms as seen in people with sickle cell disease. This is why educating the providers is extremely important to bridge this gap between knowledge of SCT and practice among providers. Galadanci et al (2014) pointed out that in order to curb problems associated

with SCT attention is needed at primary care level. Benenson et al (2018) suggested that in order to provide evidence based care to at risk population providers must be aware of the SCT status of their clients, potential health complications of SCT and routine management of individuals with SCT. It is also important for providers to know that they should implement SCT screening not only for newborns but for everyone whose status is unknown (Ashorobi et al 2021). The importance of screening is further buttressed by report of Memish et al (2011) who reported a decrease in the number of individuals with SCT marrying another carrier due to premarital screening and genetic education. Benenson et al (2018) also emphasized that SCT screening should be carefully documented and communicated to affected individuals and their providers.

Most people with SCT and their families do not know their SCT status neither do their providers. In this study only 8.33% know the SCT status of all their black patients, 41.67% do not have SCT status in their patients' medical record and only 16.67% obtain this data during initial patient encounter. This has been attributed to poor reporting system (Taylor et al 2014) and lack of standardized methods or protocols for alerting families and healthcare providers about SCT status (Ojodu et al 2014). CDC (2020) emphasized that providers must know their clients' SCT status and people with SCT should be properly informed of their SCT status and they should also be educated about possible health problems and reproductive considerations. Vinchinsky (2020) advised that communication of a positive SCT screening result must be accompanied by appropriate counseling.

This study reemphasized that educating the providers will change practice for better and improve the way individuals with SCT are treated and managed. The study demonstrated the significance of making evidence based facts about disease management available to healthcare providers. Factors such as unawareness of health risks, lack of knowledge SCT management considerations and negative attitude

negate proper and adequate management of individuals with SCT. These problems can be minimized or totally removed through provision of adequate training and access to updated information on SCT. Gonzalez-Formoso et al (2020) in a randomized study using educational intervention in family and community service to improve safety culture reported that educational intervention given to Residents was effective in improving patient safety culture. Also Farha et al (2018) reported that following an educational intervention knowledge and perception score of providers regarding pharmacovigilance significantly improved. In their study providers showed an overall low knowledge score (7.8%) pre-intervention but showed a remarkable increase (67.9%) post-intervention. This is in agreement with the findings of this study, the mean score for knowledge improved after the educational intervention and the difference in the mean scores for pretest and posttest were found to be statistically different.

Knowledge of healthcare providers regarding SCT will have major impact on the practice and management of SCT patients. If well-educated on the disease process and management there will be a positive drive towards better management practices regarding SCT, hence improving the health outcome of those with SCT. Also providers' attitude towards a disease plays an important role in affecting healthcare providers practice and management of diseases. Inadequate Knowledge, awareness and perception ultimately affect practice. Abu Harmour et al (2017).

What was learned from the QI project

Lessons learned from this project include:

- People with SCT do not receive adequate care since more than 50% of the providers consider SCT a benign condition.

- Even though 100% of the providers treat black clients, more than 50% of them do not know the SCT status of their patients.
- Providers must be made aware that SCT is not a benign condition and they must be educated on how to manage patients with SCT using Evidence Based strategies in order to mitigate serious health problems in these patients.

Limitations of the project:

The study made use of a quasi-experimental design which lacked both randomization and a control group. Validity of the study is difficult to achieve as the design has inherent flaws such as lack of sample randomization. All aspects of this project were done online. When the questionnaire was sent to the providers some did not receive it because it went to their junk/spam mails instead of their inbox and I did not realize this until it was too late. Thirty percent of the providers completed either only the pretest or the posttest and as such their responses were not included in the final analysis. These definitely must have affected the findings of this study.

Implications for Advance Practice Nurse:

Advance Practice nurses can champion how the findings of this QI project will influence clinical practice and policy changes to mitigate health problems associated with SCT. This will create a more transparent and sustainable healthcare service to which nurses are the change makers. Making people with SCT aware of their status is essential in reducing both the incidence and prevalence of SCD through genetic counseling. Providers will make it part of practice to collect information about sickle cell disorders during initial patient encounter, screen all their black patients for SCT if status is unknown and refer those with SCT for genetic counseling especially those in child bearing age. These measures will reduce incidence of sickle cell disease and prevent the morbidity, mortality and cost associated with sickle cell disease.

Equipping providers with knowledge of SCT will improve how SCT is managed. Sickle cell trait will no longer be treated as a benign condition by providers. With providers being proactive through patient and family education, early referral to genetic counseling, routine laboratory testing and checking SCT status before issuing clearance for participation to sporting activities providers will be mitigating health problems associated with SCT in their African American clients. Knowing the connection between SCT and sudden death in athletes and military trainees will help prevent sudden death in these through anticipatory precautionary measures to prevent dehydration and subsequent rhabdomyolysis. Early laboratory testing will also help prevent chronic disease, venous thromboembolism, hematuria and other disease sequelae associated with SCT.

According to Melander et al (2020) the healthcare system can benefit immensely from a well-designed and meaningful project through improved service delivery, patient outcomes and use of evidenced-base practice in routine care. They are also of the opinion that DNP project will help reduce gaps in practice, promote scholarships and foster the emergence of innovations. Papham et al (2015) also reported that DNP projects has the ability to ensure improvement in patient and system outcomes as well as lead to optimization of health trajectories

How this project will change practice

This project will change practice if providers start collecting their patients' SCT status during initial encounter, making it part of medical record and communicates such results to other providers during transfer/transition of care. This will ensure early management and continuation of care for patients with sickle cell trait. This will help

mitigate adverse health problems in African American patients and ensure best health outcome for them.

Recommendations for future studies

Future research is needed to actually go into patients' medical records to see if providers are adhering to recommendations suggested in this QI project like collecting SCT status during initial patient encounter and making it part of patient's permanent medical record.

Conclusions

Providers KAP is very essential for effective management of clients with SCT. SCT awareness among providers and clients will help reduce morbidity and mortality associated with sickle cell disorders.

SCT is not a benign condition

More attention should be paid to SCT because of its clinical sequel

Practice modalities can be modified to mitigate health problems. Gaps in practice must be bridged for best health outcome for those with SCT.

Plan for Dissemination:

A research study will only be complete if the study findings are disseminated. Sharing study findings with other nurses, interdisciplinary colleagues, policy makers and the public is very paramount for the advancement of nursing science. Sharing a DNP project findings gives one the opportunity to advance the art and science of nursing. This can influence clinical practice, nursing education, health policies and research.

Dissemination Goals.

The goals for disseminating the findings of this DNP QI project include:

To increase the reach of evidence by making providers are that SCT is no longer considered a benign condition and that it is associated with sequelae of serious health problems.

By exposing the evidence based management of SCT, the project will be increasing the ability to use and apply evidence to practice.

Internal Dissemination

Results of this project will be made available to JHS leadership. Hopefully it will be accepted, standardized and incorporated into policy and procedure of the hospital.

External Dissemination Channels

The three Ps of project dissemination will be used to disseminate the findings of this project, posters, presentations and papers. An abstract will be submitted to the Sickle Cell Association of America for presentation during their annual conference.

A poster presentation will be submitted to the Florida Nurses Association annual conference and finally the results of this project will be published in a peer reviewed journal. The results will also be made available to the medical director of JM Hospitalist for dissemination to members.

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Appendix A



Office of Research Integrity
Research Compliance, MARC 414

MEMORANDUM

To: Dr. Eric Fenkl
CC: Stella Udechukwu
From: Maria Melendez-Vargas, MIBA, IRB Coordinator *WV*
Date: July 13, 2021
Protocol Title: "The role of health care providers in using knowledge of Sickle Cell Trait to mitigate health problems associated with sickle cell trait among African American Clients"

The Health Sciences Institutional Review Board of Florida International University has approved your study for the use of human subjects via the **Expedited Review** process. Your study was found to be in compliance with this institution's Federal Wide Assurance (0000060).

IRB Protocol Approval #: IRB-21-0301 **IRB Approval Date:** 07/13/21
TOPAZ Reference #: 110034 **IRB Expiration Date:** 07/13/24

As a requirement of IRB Approval you are required to:

- 1) Submit an IRB Amendment Form for all proposed additions or changes in the procedures involving human subjects. All additions and changes must be reviewed and approved by the IRB prior to implementation.
- 2) Promptly submit an IRB Event Report Form for every serious or unusual or unanticipated adverse event, problems with the rights or welfare of the human subjects, and/or deviations from the approved protocol.
- 3) Utilize copies of the date stamped consent document(s) for obtaining consent from subjects (unless waived by the IRB). Signed consent documents must be retained for at least three years after the completion of the study.
- 4) **Receive annual review and re-approval of your study prior to your IRB expiration date.** Submit the IRB Renewal Form at least 30 days in advance of the study's expiration date.
- 5) Submit an IRB Project Completion Report Form when the study is finished or discontinued.

HIPAA Privacy Rule: N/A

Special Conditions: N/A

For further information, you may visit the IRB website at <http://research.fiu.edu/irb>.

MMV/em

Appendix B



June 10, 2021

Stella N. Udechukwu
Jackson South Medical Center
3 Towers
9333 SW 15th St
Miami, Florida 33157

Dear Ms. Udechukwu,

This is to confirm that I have reviewed your request to recruit perspective participants from Jackson Memorial Hospital for your DNP quality improvement study titled, *"The role of healthcare providers in using the knowledge of sickle cell trait to mitigate health problems in African American clients."*

Jackson Health System supports its staff who seek to advance their personal and professional growth as we believe this will be beneficial to our patients, staff and organization in the long run.

This letter serves as our intent to support in your quality improvement endeavors, pending approval from your School's Institutional Review Board (IRB). As this is a proposed quality improvement study, we require a letter stating that this study is exempt based on the definitions provided in the U.S. Department of Health and Human Services Code of Federal Regulations found at 45 CFR 46.102. As soon as you are granted a Waiver of IRB Review from your institution of study, please share with me, and we can proceed with the approval process for you to conduct your quality improvement study at Jackson Memorial Hospital.

I wish you success with the IRB. We are excited to support you in this scholarly work. If there is anything more that I can do, please feel free to contact me.

Sincerely,

A handwritten signature in black ink that reads "Bridgette Johnson".

Bridgette Johnson, PhD, APRN
Director, Clinical Practice & Regulatory Compliance
Chair, Nursing Research Council
(305) 585-8361
Bridgette.johnson@jhsmiami.org



Nursing Research & Evidence Based Practice Council

September 17, 2021

Dear Stella,

This letter is to inform you that your DNP Quality Improvement Project titled: “ **The role of healthcare providers in using the knowledge of sickle cell trait to mitigate health problems in African American clients**” has been reviewed and approved by the Nursing Research & Evidence-Based Practice Council and the CNO Council at Jackson Health System (JHS).

The next step in the approval process will be to contact the JHS Office of Research for approval.

Should you have any questions please feel free to contact me.

Sincerely,

Bridgette Johnson

Bridgette M. Johnson, PhD, APRN, CDE
Director of Clinical Education
Co-Chair, Nursing Research & Evidence-Based Practice Council
(305) 585-8361
Bridgette.johnson@jhsmiami.org

cc: Carol Biggs, MBA-HA, DHSc
Chief Nursing Executive
Jackson Health System

cc: Katuska Barbery, MBA
Director of Clinical Research
JHS Office of Research
Jackson Health System

Appendix C

FIU IRB Approval:	07/13/2021
FIU IRB Expiration:	07/13/2024
FIU IRB Number:	IRB-21-0301



Participation Invitation Letter

My name is Stella Udechukwu, a DNP student from Florida International University conducting a study aimed at raising awareness about sickle cell trait (SCT). I am studying the role of healthcare providers in using the knowledge of sickle cell trait to mitigate health problems in African American clients. I will do this by studying providers' knowledge, attitude and practice with regards to SCT in order to improve health outcomes of those with SCT. I am kindly requesting your participation in this project which will greatly benefit individuals with sickle cell trait.

The study will involve completing a questionnaire and reading a PowerPoint presentation on sickle cell trait. Participation is completely voluntary and you may withdraw from the study at any time.

This study is completely anonymous and you will not be required to provide your name or any other identifying information. You will not be compensated for participating. No risk to you is anticipated. Please indicate your consent to participate by clicking the link below. By clicking the link, you understand and acknowledge that your consent is given to participate in this study. Click the survey link to begin.

Your participation will help create awareness about sickle cell trait while reducing the health risks associated with sickle cell trait, the incidence of sickle cell disease and healthcare costs. If you have questions now or later you may contact me at: sudec001@fiu.edu or 3054011665

Thank you for your time and participation.

Sincerely,

Stella N. Udechukwu

Appendix D

Questionnaire/Survey Project

Questionnaire for Healthcare Providers

I am a DNP student from FIU conducting a study which is aimed at raising awareness about Sickle cell trait (SCT) I am carrying out an evaluation of some of medical providers to study their knowledge, attitude and practice with regards to SCT in order to improve health outcome for those with SCT. Thank you for taking the time to fill in this questionnaire; it should only take 10 minutes. Your answers will be treated with complete confidentiality, you will be entirely anonymous. If you have any questions about this questionnaire, I will be glad to answer that.

I am

MD

NP

PA

I have been in practice for

1-3 years,

4-7years

8-10 years

Greater than 10 years

Section A Knowledge

1. How will you rate your knowledge of sickle cell disorders: (please tick one)

Poor

Fair

Good

Very good

Excellent

Not sure

2. Sickle cell disorders predominately affect which population (please tick one)

Hispanics

Blacks

Caucasians

Native Americans

Don't know

3. Is sickle cell trait is a benign condition?

- Yes
No

4. People with sickle cell trait are at risk for (please tick all that apply).

- Rhabdomyolysis
Sudden death
Thromboembolism
Kidney disease
stroke
Anemia

5. When two people with SCT make baby, their chance of having a child with SCD is (please tick one)

- 100%
75%
50%
25%
Not sure
0%

6. Which of the following is sickle cell trait genotype? (please tick one)

- Hb SC
Hb as
Hb ss
Hb SD
Hb aa

7. All black newborn babies are screened for sickle cell disorders?

- Yes
No
Not sure

8. Which of the following is true regarding SCT and blood donation (please tick One)

- SCT carriers can donate blood to general population
- They can donate blood to people with SCD
- They cannot donate blood to cancer patients
- Don't know

9. There is increased risk of thrombosis with hormonal birth control in those with SCT.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

10. Athletes and military trainees with SCT are at risk of (Pick all that apply)

- sudden death
- Exertional rhabdomyolysis
- Dehydration
- Hemorrhage

Section B Attitude

11. Do you believe that SCT is of Public Health importance?

- Yes
- No

12. The public should be educated on SCT through public mass media: (please tick one)

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Disagree

13. Every black patient should be screened for SCT and the result communicated to them

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Disagree

14. How important is it for a provider to know the SCT status of their black patients?

- Very important
- Quite important
- Not very important
- Not at all important

15. Knowledge of SCT status by both patient and provider will lead to a better health outcome for the patient.

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Disagree

16. Patients with SCT should be made aware of the reproductive implication, risk of having a child with SCD

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Disagree

17. Referral for genetic counselling should be included in the management protocol for patients with SCT

- Strongly agree
- Agree

- Neutral
- Strongly disagree
- Disagree

18. Knowing that SCT is no longer a benign condition, should clinicians be more proactive in screening their black patients for SCT?

- Yes
- No

19. Routine monitoring of those with SCT is very important to avert serious health problems

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Disagree

20. Do you believe that there is stigma attached to sickle cell disorders and this may prevent disclosure of SCT status by patients?

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Disagree

Section C Practice

21. Do you see black patients on regular basis?

- Yes
- NO

22. How many of your black patients do you know their SCT status?

- All of them
- Some of them
- None of them

23. Does any of your black patients have their SCT status in their medical record?

- No

Yes

24. Do you agree that SCT status should be included in patient's permanent medical record

Strong agree

Agree

Neutral

Strongly disagree

Agree

25. Is it part of your practice to obtain SCT status during initial encounter while obtaining medical history?

No

Yes

26. Do you ask your patients for family history of sickle cell disorders?

Yes

No

27. Do you screen your black patients for SCT if their status is unknown?

Yes

No

28. SCT status should be communicated to other providers during transition/transfer of care.

Strongly agree

Agree

Neutral

Strongly disagree

Agree

29. Black patients who seek clearance for sports or military training should be screened for SCT

Strongly agree

Agree

Neutral

Strongly disagree

Agree

30. Will you routinely monitor your patients with SCT for other health complications if this has not been your practice?

- Definitely
- Maybe
- It is already part of my practice
- No

31. Do you agree that genetic counselling is important in the eradication of sickle cell disease?

- Strongly agree
- Agree
- Neutral
- Strongly disagree
- Agree

Thank you very much for taking the time to complete this questionnaire.

If you have any other comments, please add them below:

Health care providers educational intervention

Strategies to mitigate health risks associated with sickle cell trait

Why this Intervention is Important

- Many providers have insufficient knowledge about the health sequel associated with SCT in black people e.g. sudden death, DVT, preeclampsia etc.
- In order to mitigate these potential health problems and improve the quality of care provided to people with SCT, there is a clear need for healthcare providers to increase their knowledge of SCT and complications associated with it.
- Increasing knowledge among healthcare providers—including adult primary care providers, pediatricians, nurses, advanced practice providers, and community hospital providers—can help more patients access evidence-based treatments and high-quality care.
- Despite widely performed newborn screening, some individuals who were born before routine screening implementation or immigrants from countries without screening may not have been screened at birth. Many others may not be aware of their SCT status because of inconsistency in reporting.

Background

- Sickle cell trait (SCT) is a hemoglobin genotype AS.
- It was previously regarded as a benign condition.
- Individuals with SCT may have rare health conditions
- Under extreme conditions a person with SCT can experience some of the same problems as a person who has sickle cell disease.
- Sickle cell disorder has a profound impact, not just on the patient, but on the whole family dynamics and society in general.
- Every action must be taken to mitigate adverse effects of SCT

Epidemiology of SCT in USA

- Sickle cell disease (SCD) is a disease that disproportionately affects blacks.
- Persons from the Caribbean and Central and South America carry the trait gene in about 4% of the population
- In the United States, approximately 100,000 people have sickle cell disease, and 2 million people have sickle cell trait.
- In the United States, SCT is found in nearly 3 million individuals, constituting 7% to 9% of the African American population.
- SCD occurs among about 1 out of every 365 Black or African-American births.
- SCD occurs among about 1 out of every 16,300 Hispanic-American births.
- About 1 in 13 African American babies is born with sickle cell trait (SCT).
- Sickle cell trait (SCT) is one of the most common hemoglobin mutations in the world.

Complications Associated with SCT

- Chronic Kidney disease
- Renal medullary carcinoma
- Asymptomatic hematuria
- Exertional rhabdomyolysis/exercise induced complications
- Sudden death
- Dehydration
- Heat stroke
- Splenic infarct
- Venous thromboembolism
- Reproductive risks/risk of having a baby with sickle cell disease

Complications Associated with SCT

- Sickle cell trait is a risk factor for a few adverse health outcomes, such as pulmonary embolism, kidney disease, and exertional rhabdomyolysis.
- Blacks, compared with whites, have an increased risk of progression to end-stage renal disease (ESRD). SCT is strongly associated with risk of progression to ESRD in blacks.
- Sickle cell trait (SCT) and hemoglobin C trait, have a role in kidney disease in blacks (Naik et al 2017)

Reproductive Complication

- . . . SCT has been linked with various adverse outcomes in pregnancy, ranging from maternal complications such as elevated risk of bacteriuria to potentially life-threatening entities such as pre-eclampsia and prematurity. (Wilson 2020).
- knowledge of sickle cell trait is important in many settings such as preconception counseling to prevent the risk of having a baby with sickle cell disease.
- Two people with SCT have 25% chance of having a baby with sickle cell disease.

SCT implication for Athletes and Military Trainees

- Sickle cell trait (SCT) has been associated with an increased risk of sudden death in athletes during strenuous exercise.
- In August 2010, the National Collegiate Athletic Association (NCAA) began requiring athletes to be screened for SCT, provide proof of SCT status, or sign a waiver and launched an educational campaign for athletes, coaches, and medical staff.

Role of Healthcare Providers in Mitigating Health Risks Associated with SCT

- Information about SCT may 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
- Therefore, providers should offer SCT screening to asymptomatic adolescents and adults who may benefit from this information.
- Due to the large number of SCT individuals, providers should be aware of these potential health sequelae.
- Providers should encourage SCT individuals to disclose/redisclose their carrier status at every health care encounter, including primary care, emergency department visits, sports and surgical clearance.

Role of Healthcare Providers in Mitigating Health risks Associated with SCT

- Know your patients' SCT status.
- Obtain SCT status during initial encounter and history taking.
- Screen all your black patients for SCT if status is unknown.
- All black individuals seeking clearance for sports and military training must be screened for SCT and the result communicated to them
- Include SCT status in patient's permanent medical record.
- Educational materials to raise awareness of SCT should be readily available and given to black patients during hospital/office visits.

Role of Healthcare Providers in Mitigating Health Risks Associated with SCT

- Appropriate transition of care is crucial SCT status should be communicated from one provider to another during transition of care.
- Screen patients with SCT for kidney diseases with serum creatinine and urine albumin at least once a year.
- For asymptomatic hematuria exclude renal neoplasm glomerular disease especially for persistent gross hematuria which represent a higher for urologic malignancies and renal cell carcinomas.
- For athletes and military trainees advocate for universal precaution.
- Anticipatory intervention to prevent dehydration and hyperthermia during intensive physical training should be enforced for those with SCT.
- SCT status is very important for black females on hormonal birth control since there is an increased risk of thrombosis.

Role of Healthcare Providers in Mitigating Health Risks Associated with SCT

- Inform your patients with SCT about risk of VTE about frequent ambulation during air travel.
- Consider anticoagulation during surgery and for your immobile patients
- Encourage individuals with SCT to disclose their status to reproductive partners.
- Blood from donors with SCT is generally not given to individuals with sickle cell disease because it will be more difficult to reach the appropriate target hemoglobin percentage.
- Refer all individuals with SCT for genetic counseling.

Conclusion

- If healthcare providers become more proactive in managing individuals with SCT many health complications will be averted.
- Individuals with SCT will have a better quality of life and a better health outcome.
- Man hour labor loss due to illnesses and visits to emergency rooms will be greatly reduced.
- This will lead to reduction in health care cost which is a huge gain for the society in general.

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DNP Table of Evidence

Author/Date	Theoretical framework	Research Focus	Methodology	Findings that help answer EBP question	Conclusion
Aneke & Okocha 2016	None	How will genetic counseling and testing reduce prevalence of sickle cell disease?	Review of Databases	Current utilization of genetic counseling in Nigeria is unacceptably low.	Need for massive education of the population to increase understanding of SCD and need for voluntary testing.
Asghrian et al 2010	None	How do people with SCD & SCT face challenges of making informed reproductive decision?	Qualitative study using focus groups	Findings enhance the need for reproductive education.	Educational intervention necessary to aid in making informed reproductive decision.
Ashorobi et al 2021	None	Is sickle cell trait a benign condition?	Literature Review	Adverse conditions associated with SCT	SCT is not completely benign and patients should be managed aggressively.
Benenson et al 2018	None	Adverse conditions associated with SCT	Review of evidence	SCT associated with renal complications, thromboembolism, rhabdomyolysis, and sudden death.	Through appropriate screenings and interventions NPS can mitigate health problems associated with SCT.
Creary et al 2017	None	SCT knowledge and health literacy in caregivers	Qualitative focus group training	Awareness of SCT improved with in person education intervention	Knowledge of SCT improved with educational intervention.
Crockett 2017	KAT	Knowledge to action in research	Analysis of KAT framework	KAT provides practical and systematic method to research	KAT increases validity and rigor of research.
Etikan et al 2016	None	Comparison of convenience sampling and purposive sampling.	Review of articles	No method is better than the other.	Choice of technique depends on nature and type of research.

Ezechukwu et al 2004	None	Pre-marriage counseling as a tool for sickle cell disease awareness in Nigeria.	Qualitative research, using questionnaire,	Pre-marital screening and genetic counseling very common among Roman Catholics.	Such premarital screening should be encouraged and expanded to schools.
Ezenwa et al 2016	None	Is there an association between stigma and physical and emotional symptoms in patients with SCD,	Descriptive comparative study.	There is association of stigma with fatigue, anger, anxiety and depression in patients with SCD.	Further studies needed to help inform strategies to reduce stigma in these vulnerable group.
Ferrari et al 2015	None	SCT screening of Collegiate athletes, ethical reasons for reform.	Analysis of ethical concerns	NCAA and Collegiate community must address the shortcomings of the current screening program.	Universal precaution should be implemented for the benefit of student athletes.
Field et al 2014	KTA	Using Knowledge to action framework in practice.	Citation analysis and systematic review.	KTA framework can be applied to healthcare and academic settings with projects targeting patients and general public.	When KTA is part of knowledge translation it guides action in ways that ensure theory fidelity.
Fraihan & Hassan 2019	None	Advancing Healthcare outcome for SCD management in Nigeria using Mobile Health Tools	Pilot population study.	System capable of generating information for all cases of SCD, track hospital visits, appointments, lab tests	Increased access to diagnosis and treatment for all people with sickle cell disorders is very important to their survival.
Galadanci et al 2014	None	Common and available management practices for SCD in Nigeria.	Questionnaire survey	Existence of variable and poor utilization of standards of care practices for SCD patients in Nigeria.	The care of people with SCD is still suboptimal in Nigeria and urgent need to address the problem especially at primary care level.
Gibson & Rees	None	Complications	Commentary/ex	SCT is linked to	Sickle cell trait

2016		of sickle cell trait	pert opinion	splenic infarction at high altitudes, venous thromboembolism, renal damage and exercise collapse.	is not a benign condition.
Hamdi et al 2002	None	Assessment of pregnancy outcomes in women with SCT.	Labor room records, patient files and computerized files.	The incidence of abortion and neonatal deaths in previous pregnancies was significantly increased among women with SCT.	Pregnant women with SCT need special care and attention during pregnancy, labor, puerperium and surgery.
Harmon et al 2012	None	SCT as a cause of sudden death in NCAA athletes	Review of causes of all cases of sudden death in NCAA student athletes from January 2004 to December 2008.	The risk of exertional death in football players with SCT was 37 times higher than in players without SCT	Exertional death in athletes with SCT occurs at a higher rate than previously appreciated.
Housten et al 2016	None	Assessment of the feasibility of community based SCT education and testing intervention.	Mixed-methods cross sectional study.	Community base SCT testing can be successfully implemented and may increase knowledge of SCT status.	Screening will increase the number of people who know their status.
Janzen et al 2016	KTA	Will use of KTA improve outcome for stroke patients?		KTA was able to change clinical practice and promotes use of EBP in stroke rehab	KTA lead to improved EBP in stroke rehabilitation.
Kark et al 1987	None	SCT as a risk factor for sudden death in military trainees	Analysis of autopsy and clinical records of 2 million trainees from 1977 to 1981.	Military trainees with SCT have a significantly increased risk of sudden death during physical training.	There is association between SCT and sudden death with physical training.
Kavanagh et al 2008	None	Communication of positive newborn screening for SCD and trait.	Survey research	Wide variation exists in stakeholder notification of NBS screening results for SCD and trait by birth location.	This variation may affect effectiveness of NBS programs.

Key et al 2010	None	Sickle Cell Trait complications.	Review of evidence	SCT is a risk factor for certain adverse health outcomes.	Research to better characterize the consequence of SCT is needed to providing better counseling on any associated health risks.
Maakaron 2020	None	Sickle cell anemia workup	Newsletter and perspective from expert opinion.	Morbidity, frequency of crisis, degree of anemia and organ system involvement vary considerably from individual to individual.	Providers must follow the existing evidence-based guidelines on screening, diagnosis and management of complication of SCD.
Mainous et al 2015	None	Study of family physician's attitude towards SCD management.	Analysis of survey conducted by the Academic Family medicine Educational Research Survey.	Only 20.4% of the respondents felt comfortable with treatment of SCD.	Family physicians are generally uncomfortable with managing SCD patients
Mayo-Gamble et al 2019	None	Perspectives of adults with SCT on information needed to make informed reproductive decision.	Descriptive qualitative study that involved focus groups composed of purposive sampling.	Highlighted unmet information needs for African Americans with SCT.	Inability of effective communication within medical and personal settings about SCT status.
Memish et al 2011	None	To assess burden of SCD and the frequency of at risk marriage detection and prevention.	Retrospective Review, premarital couples attending premarital and genetic clinics with marriage proposals between 2004 and 2009.	The frequency of voluntary cancellation of marriage proposals among at risk couples showed more than 5 fold increase between 2004 and 2009.	Premarital screening markedly reduced the number of at risk marriages which may considerably reduce the genetic disease burden.

Munter et al 2012	None	Racial differences in the incidence of chronic kidney disease.	Prospective cohort study.	In this 20 year study incidence of CKD was higher in African Americans than whites.	African Americans are four times more likely to develop ESRD than whites due to various risk factors including SCT.
Naik & Derebail 2017	None	Sickle hemoglobin related nephropathy.	Review of evidence.	Renal dysfunction is among the most common complication of sickle cell disease.	Early knowledge will provide opportunity for early intervention.
Naik et al 2017	None	Risk of ESRD in Blacks.	Cohort study	SCT is strongly associated with risk of progression to ESRD in Blacks.	Has great implication for genetic counseling of SCT carriers.

