2017

Sickle Cell Trait and Genetic Counseling

Tricia Salmon Anderson
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral study by

Tricia Salmon Anderson

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Mary Verklan, Committee Chairperson, Nursing Faculty
Dr. Janine Everett, Committee Member, Nursing Faculty
Dr. Geri Schmotzer, University Reviewer, Nursing Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2017

Abstract

Sickle Cell Trait and Genetic Counseling

by

Tricia Salmon Anderson

MS, Walden University, 2014

BS, Macon State College, 2010

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Nursing Practice

Walden University

August 2017

Abstract

Sickle cell trait (SCT) is a very prevalent disorder in the United States, especially among African Americans or people of African descent. However, even with the prevalence of the disorder, there are no standardized guidelines for providing patients with information about SCT and the implications of the disorder at physicals and well-check visits. The purpose of this evidence-based project was to increase awareness for African American patients 18–44 years old in the practice setting about SCT and to provide options for testing and genetic counseling. Kotter's contemporary change theory was used as a guide to implement the new practice approach. A quasi-experimental, single-group, pretest-posttest-only design was used to explore the relationship between providing consistent SCT education and the impact on the rate of SCT screening and genetic counseling. A total of 71 patients participated in the program. The analysis showed a significant ($p < 0.001$) mean difference of 18.16 points from the preintervention SCT and genetics test mean, which indicated that the intervention was successful in raising SCT and genetics knowledge scores among the target population. The results demonstrated that the implementation of SCT education in the practice setting can enhance social implications related to SCT awareness and opportunities for SCT testing and genetic counseling. The implementation of SCT clinical guidelines can help to increase awareness about SCT and improve the overall population health and reduce the financial burden affiliated with care of those with sickle cell disease and SCT complications.

Sickle Cell Trait and Genetic Counseling

by

Tricia Salmon Anderson

MS, Walden University, 2014

BS, Macon State College, 2010

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Nursing Practice

Walden University

August 2017

Acknowledgments

I would like to first thank my family; friend, Callie Keys; and mentor, Dr. Michele Sewell for their continued support and encouragement. Your support has enabled me to push through obstacles and has fueled my drive for completing my DNP project.

I also want to sincerely thank Dr. Mary Verklan for her ceaseless guidance and dedication to improve the project. Your guidance and knowledge has helped me to work harder and has made the process throughout my practicum less challenging and more rewarding. Thank you all for your commitment and your support.

Table of Contents

List of Tables

List of Figures

Section 1: Sickle Cell Trait and Mandatory Education

Introduction

Sickle cell disease (SCD) can be a debilitating disorder and poses devastating health and psychological effects for both patients and families alike. Like SCD, sickle cell trait (SCT) has been found to have serious health complications, and even though rare, SCT complications can be fatal (Housten, Abel, Lindsey, & King, 2016). However, even with the tremendous negative health impact of the SCT, many patients, families, and healthcare professionals do not fully understand the ramifications of the disease process (Mainous et al., 2015). To raise awareness, certain states have mandated that newborns are screened at birth for SCT and SCD (Centers for Disease Control and Prevention (CDC), 2016). However, going forward through life, the objective of the newborn screening, which is to increase awareness to decrease incidence, is not reinforced to individuals identified with SCT at birth. The goal of this project was to bring awareness of the need for consistent SCT education, the need for an individual to know their SCT status, and the need to provide genetic counseling in the family practice setting. In Section 1, I will discuss the introduction, background and context, problem and purpose statement, project objectives, the nature and framework of the project, the significance, assumptions, limitations, and delimitations of the problem.

Background

At this time of the study, in the project site primary care setting, the patient population likely to be affected by SCT was not routinely educated and tested for trait status. Thus, the opportunity to emphasize the importance of genetic counseling to help

decrease the incidence and allow a medium for an informed decision in this population was missed. During well-check visits to the clinic, the information was not routinely provided, as there were no mandates, guidelines, or alerts in the electronic health record that would prompt the provider to do so. In addition, due to the misconception that SCT poses no threat to the health of the patient and because it is asymptomatic, testing was not routinely offered (see Mainous et al., 2015). Lack of awareness of both the patient and the provider related to the importance of an individual knowing their SCT status may have also influenced why testing was not done. However, recent discoveries that SCT may have other serious health implications such as increased risk for heat stroke, rhabdomyolysis, sudden death from over-exertion, and kidney cancer may help to highlight the importance of testing (CDC, 2016).

Currently, in the United States those with SCT can be found in every state; however, there is an increased prevalence of SCT in states with a higher population of Blacks, who are more likely affected by the SCT disorder (Ojodu, Hulihan, Pope, & Grant, 2014). Ojodu et al. (2014) found that “in 2010, data from the Mississippi newborn screening program (NBSP) showed that Mississippi had the highest incidence of newborns positive for SCT at 34.1 per 100 births; while Montana had the lowest at 0.8 per 100 births” (p. 1158). The incidence of the disease has decreased over the years, and the mortality rate has improved; however, there is still room for improvement (CDC, 2015). According to U.S. Department of Health and Human Services (UDHHS; 2016), "in 1973, the average lifespan of a person with SCD in the United States was only 14 years; currently, it is about 40–60 years" (para. 2). The improvement in life expectancy is

credited to the advances in the diagnosis and care of SCD (UDHHS, 2016).

Despite the improvement in SCD management, SCT management, education, and the importance of genetic counseling has fallen short, and tremendous gaps in care exists in today's health care systems (Housten, Abel, Lindsey, & King, 2016). In 1972, the National Sickle Cell Anemia Control Act was implemented to help decrease SCT/SCD through mandatory newborn screening and counseling programs (UDHHS, 2016). However, the newborn screening and counseling programs has had "limited success informing individuals at-risk for SCT of their status and providing inheritance education before having children" (Housten et al., 2016, p. 2). Even though there is universal screening across the United States, children that were identified with SCT at birth rarely retain that knowledge in adulthood (Housten et al., 2016). Guidelines recommended by the National Institute of Health (2016) suggest that infants identified with SCT at birth may not understand the implications of SCT in childbearing years if the education is not reinforced. In addition, informed decisions regarding SCT status are less likely to be made by young adults with SCT status if their parents do not understand the importance of trait education (Housten et al., 2016). Therefore, it would be prudent to provide the at-risk population with ongoing SCT education in primary care settings.

The family practice setting where the project was conducted was a small practice that has a 98% Black patient population. Approximately 50% of the patients may have migrated from other regions such as the Caribbean. On an average day in the practice, there are 10–15 patients presenting for routine visits and three for physical assessments. Information about SCT was rarely, if ever, discussed. For patients to make informed

decisions about their reproductive health, consistency was needed when providing education about SCT and implications for disease. During the routine visits and physicals, a brief education about SCT was provided and options for testing and genetic counseling were explored.

Problem Statement

One in every 12 Blacks and 1 in 100 Hispanics in the United States has SCT (Housten et al., 2016). Despite the family practice project site population being 98% Black, when looking through the medical records, I found no documentation of SCT status. With the high percentage of African Americans presenting to the practice, I expected to see consistent documentation of SCT status and the necessary counseling. When patients do not know their SCT status, the chance of having children with SCD increases due to a lack of appropriate genetic counseling (Housten et al., 2016). In addition, the patients may not be aware of the life-threatening conditions that are associated with SCT. According to the CDC (2016), people with SCT have difficulties with high altitude, may experience a pain crisis, and need to stay hydrated and have frequent rest periods when engaging in sports and exercise. If an individual is not aware of their SCT status, they are less likely to engage in appropriate measures to stay healthy (Housten et al., 2016). With increased knowledge about the effects of having SCT, it is believed that patients will opt for more SCT screening and subsequent genetic counseling (Housten et al., 2016). Conversely, if information about SCT and genetic counseling continues to be inconsistently provided, there will be no decrease in the incidence of the disease (Housten et al., 2016). In addition, the opportunity for patients to improve their

health and make informed decisions regarding reproduction will be lost.

Purpose

The purpose of the project initiative was to improve awareness of the Black and ethnic minority patient's understanding of their SCT status, newly discovered complications from having SCT, and options for genetic counseling to prevent SCT complications. To accomplish this increase in awareness, routine education about SCT was provided in the family practice setting and health records were updated to reflect the patient's SCT status. Even though there are no mandates to have consistent SCT education, there is a necessity to update and provide accurate information to the target population. In the past patients were told SCT was asymptomatic, now it is time to undo prior teachings and provide the necessary guidance to ensure positive health outcomes and awareness.

Project Objectives

The primary objective of this DNP project was to increase awareness about the implications of having SCT and provide options for testing and genetic counseling. With the at-risk population receiving the information routinely, informed decisions about family planning and proactive SCT precautionary measures may take place. The objective was accomplished by providing a brief educational program about SCT. I developed an educational program to inform patients at nonemergent visits about SCT of the ramifications of not knowing their SCT status and the options for testing and subsequent genetic counseling. To determine the impact of the educational program, I conducted a measurement of the total number of patients who requested SCT testing and

further genetic counseling.

Practice Question

The practice focused question was: Would the use of routine education about SCT with the Black population in the family practice setting increase SCT testing and requests for genetic counseling? To determine if SCT testing increased after the education, I measured new testing rates against the prior year. The same approach was used with genetic counseling. In this manner, I could make a comparison with pre-initiative or project rates versus after implementation rates.

Frameworks for the Project

My goal of increasing public awareness about SCT and newly discovered associated complications warranted a theory or model that brings about strategic change. The most appropriate theoretical model for the selected problem was Kotter's contemporary change theory (CCT). The CCT involves several steps that helped me implement the new practice approach systematically. I used the CCT for the project initiative as the steps that were involved helped to bring about the changes in the clinical setting with reduced resistance. Figure 1 is a visual map of the CCT model as depicted by Burden (2016).

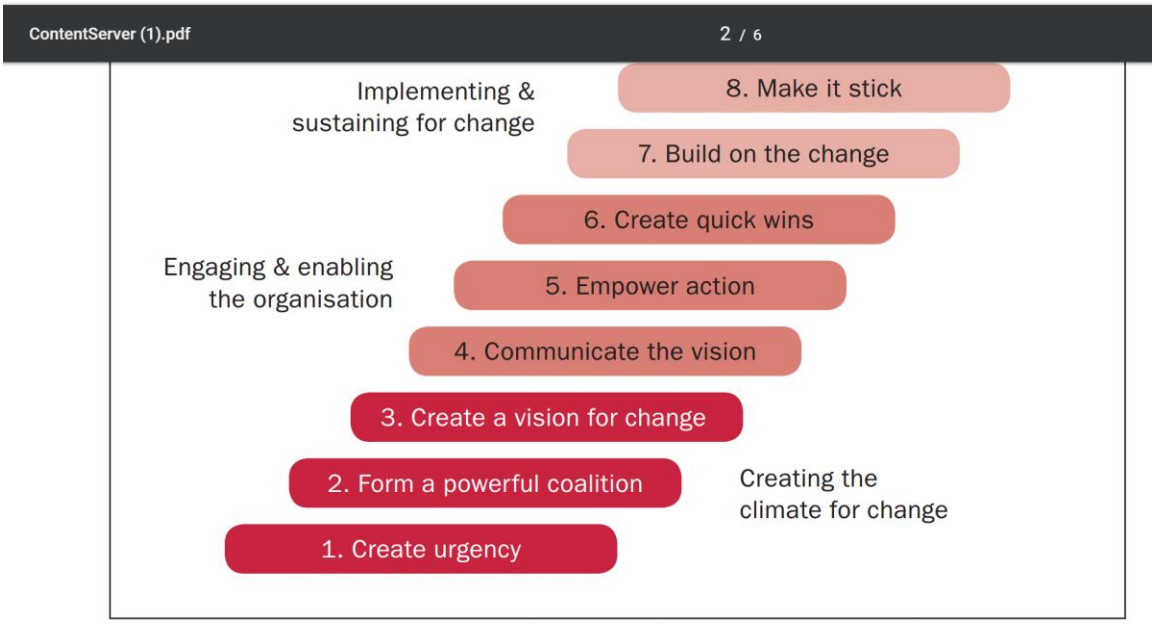


Figure 1. Visual map of the CCT model

The CCT was developed from the business and management field (Burden, 2016). Even though this theory is not originally from nursing, it can be used to implement new practice guidelines in the nursing field. I created a guiding coalition that identified key stakeholders at the project site, who were convinced about participating in the project to increase its impact. In this project, the above eight steps were applied to effectively implement the necessary changes within the practice settings. For example, when applied to this project, Steps 1 and 2 of CCT show the immediate need to begin educating the patient about SCT and the need to know their status. I will provide a more detailed explanation of the CCT model in Section 2.

Nature of the Project

To determine the effectiveness of SCT education, I used a quasi-experimental

design, one-group pretest-posttest-only quantitative approach. This approach provided me with insight about how SCT is perceived by the patient and if they possessed knowledge about the complications of SCT. The pretest post-test approach facilitates questioning about SCT status and whether the target population understood genetics and SCT disorders. The best way for me to determine the target population's needs as they relate to SCT was to obtain their baseline understanding and knowledge on the issue.

The tests and SCT education were administered by the providers at the project initiative site. The completed pre- and posttests were then collected by the providers and stored in a locked file cabinet in a private office. I then analyzed the data from the pre- and posttests using paired *t* tests via SPSS 24.0 to determine the impact of the SCT education.

Definitions

For the purposes of this paper, I used the following definitions of these terms:

Electronic Medical Record (EMR): Is a digital version of the paper chart that contains all of a patient's medical history from one practice (National Coordinator for Health Information Technology, U.S. Department of Health and Human Services, 2016, para).

Genetic counseling: The process of providing information and support to people who have or may be at risk for genetic disorders, in this case, relating to SCT and SCD (National Institute of Health, 2016).

Renal medullary cancer (RMC): A malignant epithelial tumor, arising from the collecting duct epithelium. RMC is a highly aggressive cancer with an extremely poor

prognosis (Shetty & Matrana, 2014).

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

Sickle cell trait (SCT): When a person inherits one sickle cell gene ("S") from one parent and one normal gene ("A") from the other parent. Types of SCT are C and S trait (CDC, 2016).

Assumptions, Limitations, and Delimitations

Assumptions

My main assumption in this project was that when patients receive education about SCT, they would be compelled to determine their SCT status. The assumption that patients would request SCT testing was based on the self-care theory. Self-care is a human function where someone purposefully engages in activities that improve or maintain well-being (Peters & Templin, 2010).

My second assumption was that there would be a positive correlation between the consistent education given to patients and higher SCT testing rates. My third assumption was that a SCT education prompter would be embedded in the EMR and information would be provided routinely with care. Embedded information within EMR systems would allow providers to easily and consistently provide the information to the target population. My fourth assumption was that an increased awareness of SCT status and

resultant complications would encourage the target population to ask for genetic counseling to improve reproductive health decisions. My fifth assumption was that providers would be willing to provide consistent education about SCT that is accurate and up to date. Lastly, to ensure that the information was accurate and up to date, I also assumed that providers would review the latest guidelines and recommendations.

Limitations

One of the main limitations of this project related to a lack of computerized prompters during the physical examinations and well-check visits to remind providers to provide SCT education. Another limitation was the lack of control over diagnostic testing as the practice contracted the work with an outside laboratory, and the results were not promptly and consistently provided after the screening was done. The third limitation was the individual patient's motivation to determine their trait status. Patient motivation varied dependent on educational background and previous experience of that patient with SCT. The final limitation was related to staff buy-in and involvement. I viewed staff involvement as a limitation because the implementation of the project disrupted the workflow and had a significant impact on the clinical staff. Therefore, to minimize the impact of the DNP project implementation, it was imperative to get the team to feel ownership of the project and buy into the vision of making the change in this patient population.

Delimitations

Given that the project initiative was implemented in a small family practice setting, results from the project initiative may only be applicable to that population or

other populations with similar traits in a primary care practice setting. In addition, the mix of patients that presented to the family practice were not fully representative of the perceived target population. For example, there were more patients at the higher end of the defined age range and more females. Thus, replication of the project will warrant the same mix of patients, which may be difficult to achieve.

Significance of the Project

The significance of the problem under study relates to recent discoveries regarding SCT and the impact on a person's health. Complications, such as hematuria and renal cell carcinoma, require consistent documentation of the patient's SCT status and options for testing (CDC, 2016). Providing current state of the science information to the target population will not only help to decrease the incidence of the SCD and increase awareness of SCT complications, it will also provide a dialogue for effective management strategies and surveillance for problematic symptoms.

In the family practice setting, consistent education and screening will not only increase the patient's awareness of SCT, it will also equip them with the tools to remain vigilant for SCT complications. If patients are not aware of their SCT status, they may overlook early warning signs and symptoms of related complications. For example, a patient with hematuria may not be aware that it could be a precursor to RMC versus a urinary tract infection (CDC,2016). Likewise, patients with SCT who sustain a trauma to the eye have an increased risk of developing glaucoma as compared to someone without SCT (CDC, 2016).

Reduction of Gaps

SCT education was inconsistently provided in the family practice setting where this project took place. The mandatory or routine SCT education approach that I developed as the project in this study provided consistency. The standardized approach I developed to addressing SCT could result in the development of clinical practice guidelines (CPGs). According to White and Dudley-Brown (2012), “CPGs are official recommendations made by recognized authorities regarding screening and management of certain disorders" (p. 67). Therefore, with increased genetic counseling and patients being aware of their SCT status, informed decisions about reproduction can be made that may likely decrease the incidence of SCD. In addition, patients were educated about possible symptoms or complications of SCT and were put in a position to be more proactive in their care and possess the ability to recognize early symptoms.

Breaking the trend of ignoring SCT education required commitment and dedication from both patients and providers. The CDC (2016) provided a tool kit for both patients and providers to understand the complications of SCT and to increase awareness. With increased public awareness, initiatives and further research on SCT can take place. Currently, there are legislative bills and social campaigns to raise awareness, so it is only prudent for the medical community to increase their education and involvement with SCT as well.

Implications for Social Change

A social change can be defined as making a positive impact in the community and or society that changes a person’s perspectives, behaviors, and cultural norms (Maney,

2012). In the selected target population, consistent education about SCT can help to improve health outcomes and transform how SCT is viewed locally and nationally. With increased knowledge regarding SCT, members of the community will be aware of symptoms to look for and what questions to ask regarding their status. In addition, continued community awareness will not only lead to more SCT testing, it will also increase genetic counseling, which will ultimately improve the health of future generations.

The implementation of the project not only transformed the views of the target population, but also the health care providers involved. The new findings about SCT can help to change societal views and norms and facilitate a paradigm shift in the management of the target population. The change in the views and management of SCT would result from health care providers, such as physicians and advanced practitioners, providing consistent SCT education. With consistent SCT education, there would be enhanced communication between providers as it related to disclosing the patient's SCT status and ensuring documentation in the health records. With an increase in provider involvement and awareness, I believe that other providers would be encouraged to change their management of SCT, leading to an increase in awareness across all spectrums of healthcare.

Summary

Approximately 1 in every 365 Black children are born with SCD in the United States (CDC,2016). SCT incidences are even higher; however, critical information about the disorder is not routinely provided to the populations at-risk (CDC, 2016). Even

though there is mandatory testing at birth across the United States, the results are inconsistently provided to families and primary care providers (PCP), and the opportunity to increase awareness about the disorder and debilitating effects are often missed. Therefore, to combat the current challenges, my main objective with this evidence-based project (EBP) was to determine if a standardized approach in educating patients translates to higher SCT testing and genetic counseling. Through consistent education about SCT and possible complications, Blacks can have the necessary knowledge to make informed health care decisions. Consistent education at physicals will also facilitate the opportunity for providers to look at how they manage SCT and make the necessary changes to improve health outcomes in the target population. Utilizing a standardized education approach in addressing SCT will help to reduce the current gaps in care and serve as a catalyst for social change, as the views of the target population and providers will be changed. The next section will discuss the current literature related to the dynamics of sickle cell trait.

Section 2: Literature Review

Introduction

The purpose of this project was to provide consistent SCT education to increase awareness among Blacks and change the current practices in the primary health care settings. I measured the effects of consistent SCT education based on the requests for SCT testing and genetic counseling. Current research showed that education and genetic counseling could help reduce the incidence of SCD and prompt patients with serious complications related to SCT (Smith & Aguirre, 2012). In addition to SCT education, the project provided a platform for consistent SCT testing and updates in the EMR that will help to increase awareness in the medical society and subsequently translate into positive health outcomes for patients. While the studies I reviewed showed a need to change current practices due to SCT complications, there was a lack of evidence that showed how consistent education in the primary care setting can make a difference overall. However, the literature overwhelmingly showed that SCT can be asymptomatic and precautions were needed in educating the target population. In Section 2, I will discuss my search strategy for literature review, specific and general literature about SCT, the theoretical and conceptual framework, and background and context for the project.

Search Strategy

I conducted the review of literature using the following databases: the Cochrane Library database, Cumulative Index to Nursing and Allied Health Literature and Medline simultaneous search, National Institute of Health, and CDC. Key search terms for the research included *SCT education, SCT complications, and SCT genetic counseling.*

Boolean search strings included sickle cell trait AND education, sickle cell trait AND complications, and *sickle cell trait AND genetic counseling*. My aim with the literature review was to conduct a comprehensive search of peer-reviewed studies that highlighted complications of SCT, the role of genetic counseling in management of SCT, and education strategies.

In the specific literature subsection, I will discuss the current complications associated with SCT and demonstrate the need to change current practices to address concerns. My initial search of the terms SCT AND complications yielded 1,341 articles, and from which I narrowed the search using the modifiers: full text, research article, and scholarly peer reviewed. Other modifiers that I used included studies in the last 10 years from 2006–2016, age range 18–44, exclusion of children, and the English language. A total of 87 articles were left after the modifiers were applied. Twenty-seven articles were eliminated due to duplication of information that was presented. I also excluded another 25 due to the sample population being pregnant woman, six other articles were excluded because the content was not applicable to the project initiative, and another 15 were excluded due to information on SCD rather than SCT. The search terms, genetic counseling and SCD, with the same modifiers yielded eight articles. Five of those articles were eliminated due to no access to full text version, information with pregnant women, and variations of SCD and not SCT. Finally, a search with the terms, SCT and education, yielded 12 articles; I excluded 8 again due to SCD information and SCD point-of-care testing. At the end, 19 articles were included in the final literature review.

Theoretical and Conceptual Framework

For the project initiative, I used the Kotter's CCT as the theoretical framework. The theory involved several key steps that help to systematically implement a new practice approach (White & Dudley-Brown, 2012). The steps of the CCT model include establishing a sense of urgency, creating the guiding coalition, developing a vision and strategy, and communicating the vision (White & Dudley-Brown, 2012). After communicating the vision, the next steps include introducing the change to empower a broad base of people to act, generate short wins and consolidate gains, and the production of even more change (White & Dudley-Brown, 2012). The last step of the CCT is to institutionalize new approaches in the practice to ground the changes in the culture and make them sick (White & Dudley-Brown, 2012, p. 53).

Establishing a sense of urgency was necessary to compel the staff at the family practice project setting to include SCT education during well-care visits and physicals. To accomplish the sense of urgency, I discussed critical information about SCT complications and provided educational materials to staff. The next phase in the CCT model involved building a coalition. Collaboration with the major stakeholders, such as the local sickle cell foundation and sickle cell center, was beneficial and helped to propel the project initiative. Other stakeholders, such as representatives from the target population, providers, and staff at the project site, were also recruited. Once the coalition was formed, the next steps involved developing a vision and strategy and communicating the vision to the local community and the staff at family practice. Taking the above-mentioned approach ensured that I collaboratively developed the vision and strategy with

identified stakeholders.

Finally, last steps of the CCT model were introducing the change, empowering a broad base of people to act, generating short wins, consolidating gains, and then institutionalize new approaches (White & Dudley-Brown, 2012, p. 53). I accomplished the introduction of change through the implementation of the SCT education program. Empowerment and short wins were accomplished by facilitating open communications with all stakeholders and being transparent with the program; the open communication and transparency created a sense of ownership for all parties involved. Consolidating gains will be completed using the impact evaluation method after each education session with patients. A final summative evaluation of the program was institutionalized using any specified improvements noted from the evaluation.

Specific Literature

SCT Complications

Previous researchers have outlined the seriousness of SCT and found that current practices and management are outdated. Using a retrospective design, Nelson et al. (2016) investigated 47,944 Black soldiers in the U.S. Army on active duty with SCT to determine the relationship between SCT and risks of exertional rhabdomyolysis and death. They found that those with SCT had a significantly higher risk of exertional rhabdomyolysis as compared to those without SCT. Limitations to their study were that the findings could only be generalized to Black soldiers; however, the findings of the study supported the theory the SCT is not asymptomatic.

SCT has been linked not only been to exertional rhabdomyolysis, but also to

sudden death, chronic renal dysfunction, and venous thromboembolism (CDC, 2016). In a systematic study by Key, Connes, and Derail (2015), the researchers discussed the various complications of SCT in developed countries and called for a methodical approach in managing SCT. Their systematic review showed the link between SCT and the adverse outcomes of exertional rhabdomyolysis, sudden death, chronic renal dysfunction, and venous thromboembolism. The researchers called for further research to explore preventive measures to reduce the burden of these uncommon but potentially morbid complications in affected individuals (Key et al., 2015, p. 5). The results of their study further strengthened the notion that SCT can be associated with serious health complications and supported my objective with this project to effect change in current management strategies of SCT.

In their study, Bucknor, Goo, and Coppolino (2014) examined the frequency of thromboembolism, pulmonary embolism (PE), ischemic stroke, renal disease (acute, chronic), coronary artery disease, and congestive heart failure in patients with sickle cell trait. According to Bucknor et al., (2014):

> A total of 13,964 adult African Americans registered in the Kaiser Permanente Northern California (KPNC) health system (Oakland, CA, USA), were included in the study based on laboratory and diagnostic code data for the years 1995-2008: 2642 with sickle cell trait, 11,183 with normal hemoglobin (Hb) and 139 with sickle cell disease (p. 28).

They determined that patients with SCT were more likely to have chronic kidney disease (CKD) and PE in comparison to those that did not have SCT. One strength of

their study was that it had a large sample population. Limitations as described by the researchers related to the possibility of human errors from the manual laboratory and diagnostic code used to establish SCT diagnosis because it was a retrospective study. The results of their study contributed to this project as it showed the established link between SCT, PE, and CKD.

SCT Education

The repeated calls for education to combat SCT complications and increase population and provider awareness was noted by Koopmans, Koopmans, and Ross, (2012). The researchers discussed a lack of consistent SCT education to the target population among providers. In their study, surveys were sent to members of the American Academy of Pediatrics Section on Young Physicians to evaluate SCT education during residency, current newborn screening (NBS) follow-up practice, and awareness of the National Collegiate Athletic Association policy. Of 871 eligible participants, 355 (41%) completed the survey. The results indicated that "despite formal SCT education, a significant number of pediatricians do not verify NBS results or counsel about the medical implications of SCT" (Koopmans et al., 2012, p. 299). Therefore, the findings of their study exemplified why a consistent or standardized approach in educating about SCT was warranted in this project. With a standardized or mandated approach of SCT education, providers will be compelled to discuss the complications with the target population.

In their study, Folsom et al. (2015) highlighted the importance of consistent SCT education to help prevent complications. Their investigation was conducted using

middle-aged African Americans that participated in a prospective, population-based cohort study, the Atherosclerosis Risk in Communities Study, between 1987 through 2011 for incident hospitalized PE. They discovered that subjects with SCT carried a two-fold increased risk of PE as opposed to those who did not have SCT. The information presented in their study could be classified as Level VI (Melnyk & Fineout-Overholt, 2010). Limitations of their study were related to the population size and make up and the findings cannot be generalized to the overall population. However, insights from their study strengthened the argument for change in current practice for SCT. Folsom et al. further stated that "as clinical complications of sickle cell trait are elucidated, there is a need for ongoing process to inform individuals about SCT status, and provide genetic counseling to provide an accurate assessment of risks, dispel myths, and offer reproductive recommendations" (p.7). I used the findings from their study to support the project initiative by showing stakeholders why SCT education is warranted.

Genetic Counseling

There continues to be missed opportunities to educate the population about SCT in the era of genomic medicine. Taylor, Kavanagh, and Zuckerman (2014) discussed the perpetually missed opportunities to educate the general population about SCT. The main objective of their article "was to call attention to the unfulfilled promise of genetic screening to prevent SCD and to recommend necessary steps" (Taylor et al., 2014, p. 1495). The researchers noted that a community-based survey revealed that only 16% of respondents of child bearing age knew their SCT status and that only 37% of SCT positive results from the NBS were reported to parents. Of those parents that did get the

SCT screening results, “it is not known whether they understand the implications or remember to share them with the affected child during adolescence to inform future reproductive decisions” (Taylor et al., 2014, p. 1495). The authors proposed that SCT results be sent directly to providers and families and that the results should be automatically updated in the health records. Genetic counseling was also recommended for those affected with SCT. The major limitation of the study was that it is a Level VII (Melnyk & Fineout-Overholt, 2010). The findings of their study supported this project as the findings exemplified the current gaps in SCT management.

General Literature

SCT is one of the most prevalent inherited disorders across the world (Abedian, Howard, Rawle, & Thomas, 2010). Despite the increased prevalence, there is still a lack of awareness about SCT complications amongst medical providers and the general patient population. The decreased awareness of SCT complications has also contributed the lack of consistent SCT education and genetic counseling in the primary care settings (Housten et al., 2016). According to Smith and Praetorius (2015), the key prevention for SCT is education and increased public awareness. Currently, there is a lack of informed reproductive decisions and a gap in knowledge about SCT among the high-risk population. On the provider side, there are misconceptions about the disorder and lack of confidence in providing genetic counseling and screening alternatives that perpetuates the problem of a lack of reinforced education. Gallo et al. (as cited by Smith and Aguirre, 2012) reported an interview where “a female Hispanic participant with SCT said that her medical provider told her that SCD was an ‘African American disease’” (p. 765).

While it will be impossible to eliminate SCT, the incidence of the disease can be substantially decreased with mandatory education about SCT, its ramifications, and benefits for knowing individual trait status (Housten et al., 2016). Complications associated with SCT have caused many universities and sports programs to implement SCT screening and educational programs for athletes and their families. Lee and Marks (2014) argued that the "The National Collegiate Athletic Association (NCAA) sickle cell trait disclosure requirement could be used as a helpful educational tool" to discuss symptoms related to SCT (p. 17).

Smith and Aguirre (2012) noted that the most practical way to combat SCT is related to identifying individuals with SCT, and educating them to make informed reproductive decisions. To strengthen the approach as mentioned above, the education should be mandated across all spectrums of health care that are involved with primary and preventive care. The current literature shows that more research is needed to investigate effective education strategies for the general population (Key, Connes, & Derail, 2015).

Sickle cell trait research is underfunded when compared to other genetic disorders, such as cystic fibrosis and muscular dystrophy (Smith & Praetorius, 2015). According to Smith and Praetorius (2015) "in 2004 the National Institutes of Health (NIH) spent $128 million on cystic fibrosis that affects 30,000 people (mostly White), however, it only spent $90 million on SCT and SCD which affects more than 80,000 (mostly African American)" (p. 608). The underfunding of research for SCT also contributes to the prevalence of the disease and the lack of standardized preventive

education strategies.

Background and Context

According to Hodges and Videto (2011), creating an effective and efficient program requires the utilization of assets and assessment of needs associated with the target population and their environment. In the project practice setting SCT education is not a part of the template for physicals and well-check visits even though there is a large African American patient population. SCT disproportionately affects African Americans, and even though there are mandated laws for screening at birth, a large segment of the population does not know their SCT status. Even with the surmounting evidence that SCT can have significant complications, there are no legislations to ensure that the target population get the necessary education. In addition, there no legislation in the State that calls for further research to explore SCT and the complications.

Summary

The evidence demonstrated in the literature review exemplifies that SCT can have serious complications such as exertional rhabdomyolysis, chronic kidney disease, thromboembolism, PE, renal cell carcinoma and sudden death. Even with the mandated NBS program there are tremendous gaps in current care and management of SCT. There are also perpetually missed opportunities to improve education not only in the target population, but also for medical providers. Consistent education and genetic counseling are proposed strategies to help decrease the incidence of SCT and affiliated complications. Utilization of a theoretical framework such as the Kotter's CCT can help to facilitate the necessary changes need in the family practice setting. Overall the findings

of the literature review strengthened the objective of the project and demonstrate why it is critical to improve health outcomes in the target population. The next section will discuss the methodology used for the project initiative.

Section 3: Methodology

Introduction

The purpose of this project initiative was to determine whether consistent SCT education would result in increased requests for SCT testing and genetic counseling. With increased SCT testing and status update, there should be increased awareness in the target population that will likely result in complications of SCT being averted. The results of my literature review suggested that further education and prevention strategies are needed to reduce the current gaps in care and management of SCT. With the project initiative, I examined the effect that consistent SCT education at the well-visits and physical examinations of young adult Black patients has on their SCT testing rates and genetic counseling. In Section 3, I will discuss the approach and rationale, project design and methods, population and sampling approach, data collection methods, instrumentation and data analysis, the steps that I took to ensure protection of human subjects, and the reliability and availability of the data. I will also discuss the overall evaluation method of the project.

Approach and Rationale

I used a quasi-experimental design to examine the association between consistent SCT education to the Black patients between the ages of 18–44 years who presented to the practice project site. The primary objective of the project initiative was to determine if the intervention of education about SCT has an impact on patients' requests for SCT testing and genetic counseling. The quasi-experimental research design allowed my exploration and determination of the causal relationship between the consistent education

and subsequent rates for genetic counseling and SCT testing. According to Grove, Burns and Gray, (2013), "the quasi-experimental design facilitates the search for knowledge and examination of causality in situations in which complete control of a study design is not possible" (p. 231). Specifically, I used the quasi-experimental design with no control groups, often referred to as the one-group, pretest-posttest-only design. The SCT education, the independent variable, was provided and rates for SCT testing and genetic counseling were the outcome measures.

Population and Sampling

The target population of the study were Black women and men, 18–44 years of age, who presented to the primary family practice setting where I conducted the project initiative. The inclusion criteria included participants of African or Black ethnicity, who were not diagnosed with SCD. Exclusion criteria included patients that had a documented history of SCD and SCT, patients that were not within the age range of 18–44 years, and patients who were not of a Black ethnicity.

I obtained a convenience sample from the Black patients between the ages of 18–44 years who presented to the practice for well-check visits and physical examinations. Approximately 100 patients were initially estimated to participate in the program. However, due to the mix of patients that presented only 71 ended up participating.

Data Collection

Prior to implementation of the project, I obtained approval from the Walden University Institutional Review Board (IRB) and permission from the family practice site. The project ran for approximately ten weeks, with a total of 71 participants.

Educational materials from the CDC about SCT education were printed for distribution during the education session (see Appendix A). I then placed the printed educational materials in all examination rooms for easy access. The family practice scheduling calendar was examined at the beginning of each week to determine which days' patients were scheduled for physical examinations and well-check visits. After the practice schedule was reviewed, I identified eligible Black patients who did not have a documented history of SCT or SCD by reviewing the charts in the EMR. If the patient had a documented history of SCT or SCD, they were excluded from the study. Other inclusion criteria included being able to understand and read English. All patients that were Black and met eligibility criteria were contacted via the telephone to explain the project initiative and ask for their consent to participate in the project.

When the patient presented to their appointment, the front office staff of the practice provided them with the pretest (see Appendix B). The pretest items were structured questions to determine if the patient knew their SCT status and included questions about genetics. The pretest was in paper and pencil form and was completed in the waiting area by the participants. When completed, the pretest was placed in a folder labeled pretest and kept at the front desk. The patients were then asked to create a five-digit identification number and place that number on the pretest. The purpose of the patient creating an identification number was to match the pretest with posttest, as the same number was used on that patient's posttest. Using a five-digit identification number helped to reduce duplication of the same number by another participant.

Once the patient was in the examination room, they had the presenting complaint

attended to, after which the provider presented the SCT education (see Appendix C). The education was approximately ten minutes in duration and covered the information about SCT complications, such as hematuria, renal cell carcinoma, hyphema, exertional rhabdomyolysis, exercise-related problems, and risk for SCD. Information about the importance of genetic counseling in preventing SCD was also provided to the participants. The SCT education was provided in the examination room by the medical providers and/or me and was then documented in the EMR as preventive education. I provided an in-service presentation to all medical providers the week before the implementation of the project initiative to ensure consistency in the delivery of the SCT education. The providers delivering the education also provided the participant with a print out of the information to go over during the education.

The participants completed the posttest immediately after the education, while the provider was in the room (see Appendix B). The posttest items were the same as the pretest. The patient was asked to place the same identification number on the posttest once it was completed and to place post-test in an envelope. After the posttest was completed, the patients were asked by the provider and/or myself to indicate whether they wanted SCT testing and genetic counseling. If the patient indicated that they would like SCT testing and had insurance, the testing was conducted on site at a later scheduled appointment as indicated by the patient. For the patient who indicated that they would like SCT testing but did not want to do it through insurance or were uninsured, information for the Sickle Cell Foundation was provided, as the foundation provided discounted SCT testing for $40.00 and free genetic counseling. The patients were also

given the handout from the CDC toolkit for review at home (see Appendix A).

At the end of the day, the pretests and posttests were matched via the identification number, and both were kept in their designated folders in a file cabinet in a locked private office until the completion of the project for further analysis. The identification number and information were stored separately in a code book only accessible by me. The data that I collected from the project site were the responses on the pretest and posttest and requests SCT testing and genetic counseling results. All participants that had SCT testing done on site were provided with their results on a subsequent visit and had their health records updated accordingly.

Instrumentation

SCT and Genetic Counseling Pretest and Posttest

Both the pretest and posttest were composed of 10 questions (see Appendix B). The questions were developed by Housten et al. (2016) to assess whether the participants knew critical information about SCT and to indicate whether they wanted SCT testing and understood genetics. The questions I used in the pretest identified the participant's baseline understanding about SCT and their current knowledge and thoughts about genetics. The posttest items were the same and determined if the SCT education changed the participants' beliefs. Utilization of the pretest/posttest method helped me to ensure that the target population received the necessary information to ask for genetic counseling and SCT testing.

SCT Education

I developed a pamphlet that summarized the information about SCT and SCT

complications (see Appendix C). The information from the pamphlet was from the CDC SCT toolkit (see Appendix A). The SCT educational session lasted approximately 10 minutes and was a verbal face-to-face session in the examination room. The SCT education included information about SCT complications such as renal cell carcinoma, exertional rhabdomyolysis, glaucoma post-hyphema, exercise-related complications in athletes, diabetes complications, splenic infarction, and thromboembolism. The importance of genetic counseling was also discussed with the participants to demonstrate how it can help to improve reproductive health decisions.

Protection of Human Subjects

To ensure that human subjects were protected, before I initiated the project the study was reviewed by the Walden University IRB for approval. The IRB approval number for this study was 02-22-17-0390678. Permission from the family practice site was also obtained. I maintained strict adherence to the Health Insurance Portability and Accountability Act to ensure patients privacy was protected. Informed consent was obtained from all participants before implementation of the project initiative. I also developed a code book or participant list with patient names and corresponding identification numbers. The identification number was placed on the pretest and posttest by the participants to ensure that the information was matched correctly. The participant list with patient's names and data collected from the pretest and posttest were stored in separate secured cabinets in a private office in the practice setting and was accessed only by me. In addition, any data that would be published will contain any patient identifiers. The computers I used during the project were password protected and had an up-to-date

firewall and antivirus software.

Data Analysis

The practice-focused question was: Would the use of routine education about SCT to the Black minority population in the family practice setting increase SCT testing and requests for genetic counseling? I conducted data analysis using paired *t* tests that compared the changes in responses to each question between the pre- and posttest data. All analysis was conducted using SPSS 24.0. Statistical significance was met with *p* values ≤ 0.05.

Reliability

The structured pretest and posttest that I used in the project initiative was developed by Housten et al. (2016). The tests were utilized to determine the feasibility of a community-based SCT testing and counseling program in a previous study (see Housten et al., 2016). Using a structured approach helped to increase reliability as it is consistent. According to Grove, Burns, and Gray (2013), "reliable instruments enhance the power of the study to detect significant differences or relationships occurring in the population under study" (p. 389). Because the questions I asked the participants before and after the education were the same, there was less chance of variability based on the instrument.

Validity

Validity refers to whether the instrument measures what it is intended to measure in the study (Terry, 2015). My use of a structured pretest and posttest tool helped to provide objective information that measured the impact of the SCT education effectively

and matched the objectives of the project (see Grove et al., 2013). However, Housten et al. (2016) did not conduct the Cronbach alpha in the development of the pretest/posttest tool. Operationalizing the objectives of the study helped to increase validity and the chance that the data collected would match the objectives.

Project Evaluation Plan

To be able to determine the effectiveness and impact of this study, the evaluative process was incorporated from the beginning of the project initiative to assist me in determining the need for adjustment or reevaluation of strategies. According to White and Dudley-Brown (2012), "evaluation should provide information for dialogue and planning related to applicability and sustainability and future needs" (p. 233). The main evaluative method involved the measurement of the number of patients who requested SCT testing and further genetic counseling after receiving education regarding SCT. My main objective with the practice initiative was to increase and facilitate awareness about the implications of having SCT through an educational intervention in the primary care setting. With consistent education about the SCT, I believed that there would be an increase in SCT testing and requests for genetic counseling. Results of many studies showed that lack of consistent education is the major contributing factor for higher incidence of SCT (Smith & Aguirre, 2012). Therefore, I anticipated that routine education related to SCT would increase awareness of the complications of SCT, which would then increase requests for testing and genetic counseling. Friis and Sellers (2014) described the impact evaluation as the measurement of "whatever changes the program creates in the target population's knowledge, attitudes, beliefs or behaviors" (p. 400). Per

Hodges and Videto (2011), “impact evaluation is the measurement of the extent to which the program has caused the intended short-term changes in the target population” (p. 209). The impact model helped me to determine whether education about SCT and associated complications increased SCT testing and genetic counseling in the target population.

Summary

Ensuring the project methods, population sampling, data analysis, and data collection methods are carefully constructed are critical to ensure the reliability and validity of the project results (Hodges &Videto, 2011). The aforementioned steps are also crucial as they can negatively affect the generalizability of the results. Protection of the human subjects and all of their privacy and protected health information was also an integral part of the project implementation process. Prior to initiation of the project, I obtained approval from the Walden IRB and during the project maintained strict adherence to Health Insurance Portability and Accountability Act regulations to ensure protection for the human subjects. The main objective of the project initiative was to determine the causal relationship between the consistent education and subsequent rates for genetic counseling and SCT testing. I used a quantitative research approach with a quasi-experimental design as it allowed for exploration and comparison between the variables.

I selected Black patients between the ages of 18 to 44 to participate in the project initiative. The EMRs at the practice setting were used to identify eligible patients who did not have a history of SCT or SCD. Once the patient presented to their appointment, either

a physical or well check visit, the pretest was given to determine their baseline knowledge of SCT and the recent complications. After the providers addressed the visit complaint, a brief educational session about SCT was provided and the posttest administered. To ensure consistency with the education that was provided, I gave the providers an inservice of the educational content and how to present the information to the patients. I measured the results of the pretest and posttests using the paired *t* tests via the SPSS to determine the changes in response after the SCT education. To determine the effectiveness of the program, I used an impact evaluation approach. The participants were also asked to indicate whether they wanted SCT testing and genetic counseling after the SCT education was completed. The responses of the SCT testing and genetic counseling were used as the main evaluative items to determine whether the project objective was met. The next section includes the findings and implication of the project initiative.

Section 4: Findings, Discussion, and Implications

Introduction

The purpose of the project initiative was to improve awareness of Black patients' understanding of their SCT status, newly discovered complications from having SCT, and options for genetic counseling to prevent SCD and SCT complications. A brief educational program was provided, by either me or the provider, for Black patients aged 18–44 years in the family practice setting. A pretest was provided to the participants before the education to serve as a baseline assessment, and the posttest was administered after to determine if there was any change in responses. As an overall evaluative tool, patients were also asked to indicate whether they wanted SCT education and genetic counseling. After 10 weeks, I analyzed the data from the project initiative using the paired *t* test method. The results showed that there was an increase from pretest and posttest intervention with $p < 0.001$. There was also increase in the requests for genetic counseling and SCT testing as opposed to the practice's prior year 2016 request rates. In Section 4, I will discuss the findings, implications, recommendations and limitations of the study. Section 4 will also include an analysis of self.

Evaluation/Findings and Discussion

The practice focused question was: Would the use of routine education about SCT to the Black minority population in the family practice setting increase SCT testing and requests for genetic counseling? The objective of this DNP project was to increase awareness about the implications of having SCT and provide options for testing and genetic counseling.

The providers and I conducted SCT and the importance of genetic counseling educational sessions at the project initiative practice setting. I used a convenience sampling approach based on the patients that presented to the practice setting meeting eligibility requirements. The project was conducted over a period of 10 weeks and a total of 71 patients participated. Data analysis was conducted using paired *t* tests that compared the change between the pre- and posttest data. All analysis was conducted using SPSS 24.0. Statistical significance was met with p values ≤ 0.05. I also obtained the percentage of the participants that requested SCT testing and genetic counseling to compare with the practice setting prior year (2016) rates. Of the 71 participants, 46 (64.8%) identified as female and 25 (35.2%) identified as male. The average participant's age was 31.54 ($SD = 7.450$, $n = 71$) years old, with the most senior being 44 and the most junior being 18 for a range of 26 years.

When asked if they would be interested in SCT testing, 57 (80.3%) participants reported "Yes" and 14 (19.7%) reported "No." When asked if they would be interested in receiving genetic counseling, 56 (78.9%) reported "Yes" and 15 (21.1%) reported "No." Therefore, there was an overall increase in requests for SCT and genetic testing with consistent SCT education as opposed to the practice prior year rates in 2016, which was zero with no consistent SCT education. With this positive change, the project objective of increasing SCT testing and genetic counseling requests was met.

I evaluated pre- and posttest response changes on the SCT education assessment tool in the target population by asking 10 questions that assessed whether the participants knew their SCT status whether or not they wanted SCT testing, and understood genetics

(see Appendix B). The questions were scored as 1 for correct and 0 for incorrect and then summed, divided by 10, and multiplied by 100 for both the SCT education pretest and posttest. This calculation put the score on a 100-point scale (ratio). When samples are related, such as with a pretest and posttest, and the dependent variable difference of comparison is ratio, then a paired samples *t* test is used (Freedman, Pisani, & Purves, 2011).

There was a significant mean difference of 18.16 points from the preintervention (pretest) to the postintervention (posttest) of the SCT education at $p < 0.001$. Based on the increase in scores, the intervention was successful in significantly raising SCT and genetics knowledge scores in the overall target population (see Figure 2). Essentially if compared to a standard college grading, before the education participants' average score was a C and after intervention scores were raised to an A. The results of the project initiative further strengthened the argument made in the literature review that there is a knowledge deficit in the likely affected population about SCT and the importance of genetic counseling (see Folsom et al., 2015).

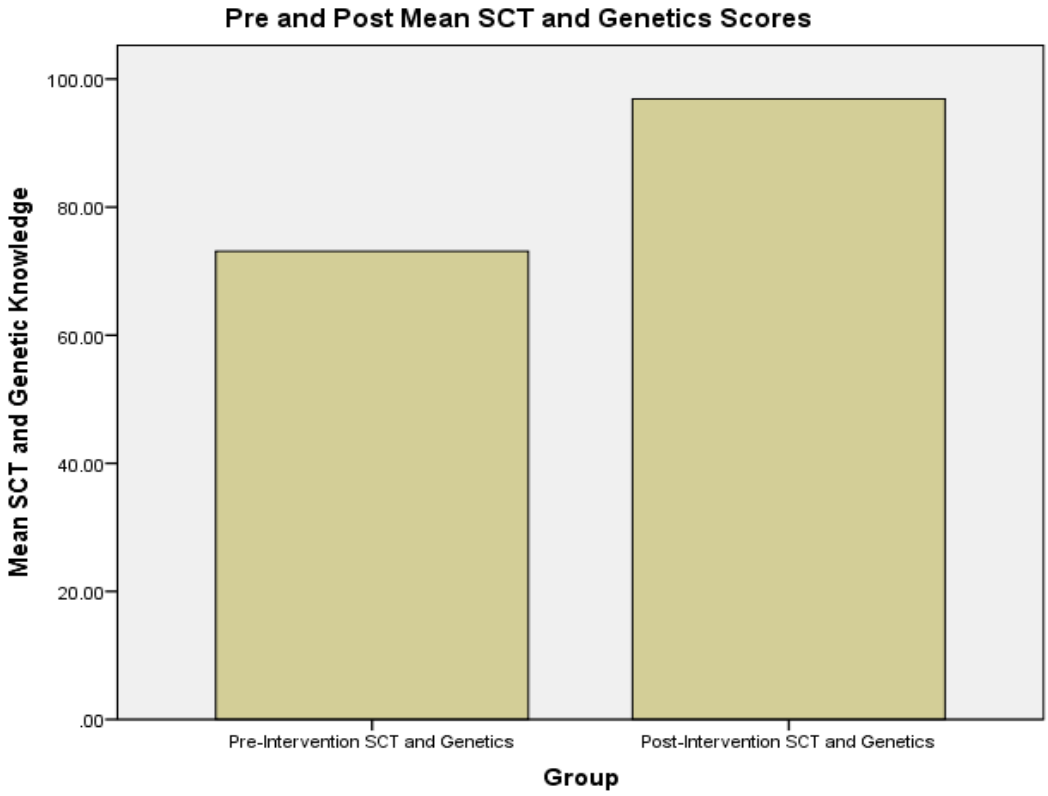


Figure 2. SCT and genetics mean scores.

Table 1 provides further analysis of the SCT pretest and posttest scores. On the pretest, the median score was 75.91, and the median score rose to 94.08 on the posttest after the SCT education. Therefore, there was 18.16 jump from the preintervention assessment as compared to the postintervention assessment. This increase in the overall scores on the posttest exemplifies that SCT education was warranted in the target population. The significant improvement in the posttest scores also aligns with recommendations in the literature review. According to Folsom et al. (2015),

> clinical complications of sickle cell trait are elucidated, thus there is a need for an ongoing process to inform individuals about SCT status, and provide genetic

counseling to provide an accurate assessment of risks, dispel myths, and offer reproductive recommendations. (p. 7)

Table 1. *Paired Samples Statistics of SCT and Genetic Pre-and Posttest Responses*

	M	*N*	*SD*
Pre-Intervention SCT and Genetics	75.91	71	12.714
Post-Intervention SCT and Genetics	94.08	71	8.379

When I conducted the paired differences in the pretest and post-test SCT responses, the results were statistically significant at $p < 0.001$. Table 2 shows the differences between the participants' SCT and genetics pretest responses as compared to the posttest responses. The mean difference between the SCT pretest and posttest responses was 18.16, as the participants scored 94.08 on the SCT posttest and 75.91 on the SCT pretest. I analyzed the data at a 95% confidence interval, with a *df* (*n*-1) was 70.

Table 2. *Paired Samples Test of SCT and Genetics Pre-and Posttest Responses*

	Mean	*SD*	95% CI		*t*	*df*	*p*
	Difference		Lower	Upper			
Pair 1							
Pre-Intervention SCT and Genetics – Post-Intervention SCT and Genetics	-18.16	12.90	-21.22	-15.11	-11.861	70	.000

I also analyzed pretest and posttest SCT Questions 6, 7, and 9 to examine SCT concepts more closely using paired samples tests. The questions were:

6. You can have SCT and not even know it.

7. People with SCT can become ill or die if they exercise too hard.

9. If one parent has SCD, all children will at least have trait.

Table 3 shows the analysis between pretest and post-test responses for Questions 6, 7, and 9. Questions 6 and 7 looked at the participants' knowledge about SCT and SCT complications, whereas Question 9 looked at the participants' knowledge about genetics related to SCT. There was a mean difference of 5.6 points from the pretest on Question 6 to the posttest at $p = .045$ (see Table 3). While the results of Question 6 were not

statistically significant, it showed that there were some knowledge deficits in the target population about SCT.

Next, Question 7 had a significant mean difference of 63.4 points between the pretest and the posttest responses with $p < 0.001$ (see Table 3). Question 7 explicitly examined the knowledge about SCT complications such as exercise induced illness, exertional rhabdomyolysis, or death. On the pretest SCT education test, 37% of the participants responded correctly, and on the posttest 100% responded correctly. Nelson et al. (2016) found that there was a positive correlation between SCT and exertional rhabdomyolysis and death. Therefore, people with SCT had a significantly higher risk of exertional rhabdomyolysis as compared to those without SCT. The results of this data analysis showed serious knowledge deficits in the target population as they relate to SCT and exercise-related complications like exertional rhabdomyolysis and death.

Finally, there was a significant mean difference on Question 9 from the pretest to the posttest with $p < 0.001$ (see Table 3). With Question 9, I again looked at whether the participants understood SCT genetics. Responses to Question 9 demonstrated the participants' SCT genetic knowledge. My analysis of Questions 6, 7, and 9 further showed that the SCT trait education was effective in improving the population's knowledge about SCT and the importance of genetic counseling.

Table 3

Paired Samples Statistics on Question 6, 7, and 9

		M	*N*	*SD*
Q6	You can have sickle cell trait and not even know it.	94.0	71	2.32
	You can have sickle cell trait and not even know it.	100.0	71	0.000
Q7	People with sickle cell trait can become ill or die if they exercise too hard.	37.0	71	4.85
	People with sickle cell trait can become ill or die if they exercise too hard.	100.0	71	0.000
Q9	If one parent has sickle cell disease, all children will at least have trait.	54.0	71	5.02
	If one parent has sickle cell disease, all children will at least have trait.	80.0	71	4.01

	Paired Differences							
	M	*SD*	*SEM*	95% CI Difference Lower	Upper	*t*	*df*	*p*
Pair 1 You can have sickle cell trait and not even know it.	-.056	.232	.028	-.111	-.001	-2.044	70	.045
Pair 2 People with sickle cell trait can become ill or die if they exercise too hard	-.634	.485	.058	-.749	-.519	-11.007	70	.000
Pair 3 If one parent has sickle cell disease, all children will at least have trait.	-.268	.533	.063	-.394	-.141	-4.227	70	.000

The Kotter CCT model served as a theoretical framework for the practice change. Each step was used to generate the necessary changes, and motivate the stakeholders. After the implementation and analysis of the project initiative, the results were presented to the medical director to show the impact of the SCT project initiative. With proven results that there was a knowledge deficit about SCT and importance of genetic counseling the changes in the practicum setting were likely to become permanent. The results of the study also exemplified that there was a need for change about SCT in the national arena. Rather than only mandatory newborn screening, there should be a national effort to educate the population and provide a national database for SCT results for follow through with medical providers. There should also be policies and or legislations passed to explore the growing complications related to SCT.

Discussion of Findings in the Context of the Literature

The findings of the project initiative showed that there is a knowledge deficit in the target population as it relates to SCT and genetics. Housten et al., (2016) believe that the decreased awareness of SCT complications has contributed to a lack of consistent SCT education and genetic counseling in the primary care settings. The results of the project exemplify that the target population requires SCT education and options for genetic counseling. Therefore, given the results, it would be recommended that SCT education and genetic counseling be offered in the primary care setting. The results were supported by the evidence in the literature review that consistent SCT education was needed. Smith and Praetorius (2015) noted that the key prevention for SCT is education and increased public awareness. The consistent SCT education during the project

initiative showed a significant increase from the participants' baseline understanding of SCT to post SCT education understanding. The improvement in SCT education and complications was specifically demonstrated in Question 7 pre-and posttest responses. In addition, there was an increase in the request for genetic counseling and SCT testing in the target population. Overall, the results of the project initiative showed that consistent SCT education can improve the target population awareness of SCT complications, and increase request for SCT testing and genetic counseling.

Implications

Practice

The findings of the practice improvement initiative illustrate that there is a knowledge deficit in the target population as it relates to SCT and genetics. The results exemplify that the target population requires SCT education and options for genetic counseling. Given the results of the project it would be recommended that SCT education and genetic counseling be offered in the primary care setting consistently. Providing consistent SCT education can help to bridge the current gap in the current care and knowledge among patients and healthcare professionals (Folsom et al., 2015). Ensuring consistency in SCT education can also pave the way for more accurate and up-to-date research (Housten et al., 2016).

Research

The results of the project initiative aligned with the current evidence that there is a lack of knowledge about SCT in the target population. However, given that the project initiative was focused on patients age 18-44 years, it would be beneficial that future

studies be geared at younger children and adolescents. Thus, future research can look explicably at the relationship between consistent SCT education in the annual child wellness visit, and requests for genetic counseling. The approach of SCT education in child well checks is based on the fact that even though there is mandatory newborn screening program across the nation, results from the screens are not accessible to primary care providers (Ojodu et al. 2014). Lack of automated results to providers help to contribute to current lack of SCT education and reinforcement to families affected. Thus, it would be recommended that a state or national database like the immunization system be designed for SCT and SCD results, so that providers and families can have easy access.

Policy

In addition to a national registry for SCT/SCD, more government guided research about SCT would be proposed. There is currently limited knowledge about exactly how SCT leads to complications such as renal medullary cell carcinoma, splenic infarct and rhabdomyolysis etc. Thus, there should be health care policy and legislation that provides funding and mandate for further research to determine the cause and likely solution. According to Smith and Praetorius (2015) SCT trait research is underfunded when compared to other genetic disorders, such as cystic fibrosis and muscular dystrophy. Smith and Praetorius (2015) also highlighted that “in 2004 the National Institutes of Health (NIH) spent $128 million on cystic fibrosis that affects 30,000 people (mostly White), however, it only spent $90 million on SCT and SCD which affects more than 80,000 (mostly African American)” (p. 608). The underfunding of research for SCT

therefore continues to contribute to the prevalence of the disease and the lack of standardized preventive education strategies. Enacting policies that increases SCT research and mandated SCT education will ultimately lead to positive social changes in the target population and society on a hold.

Social Change

Improving SCT and genetic counseling education in the general population has positive social implications. SCT once considered asymptomatic now have serious to fatal complications that most of the population is incognizant of. Implementing consistent SCT and genetics education can help to increase awareness in not only the target population, but for the general population. The project initiative showed the positive relationship between SCT education and the requests for SCT testing and genetic counseling. According to Housten et al., (2016), the newborn screening and counseling programs across the United States has had "limited success informing individuals at- risk for SCT of their status and providing inheritance education before having children" (p. 2). Thus, implementing consistent SCT education in primary care settings can help to educate the population about SCT complications. Consistent SCT education also provide a medium for the population to understand the importance of knowing their SCT status in regardless of race, and options of genetic counseling.

Strengths and Limitations of the Project

The limitations of the study relate to the small sample size and the mix of patients that presented to the practicum site. It was initially proposed that one hundred participants would be recruited. However, the practice site had a lower than normal

number of patients in the project age range scheduled during the project period. Thus, the sample size was reduced to 71 participants and may not be a true representation of the general population. However, even with this limitation, the results showed that consistent SCT education was warranted. Many of the participants admitted to being oblivious about SCT complications, and indicated that they would like to know their SCT status and receive further genetic counseling.

Other strengths of the project related to the patient's ability to have a one on one dialogue with the provider giving the education. The one on one dialogue allowed participants to explore the importance of genetic counseling. Participants could ask further questions to understand the dynamics of SCT, and what role genetics played in the disorder. The opportunity for the participants to ask questions, and clarify any confusion likely increased the participants request for further SCT testing and genetic counseling.

Analysis of Self

Scholar

Scholarly inquiry is one of the fundamentals of being a DNP prepared nurse. As a scholar practitioner, I am able to help translate the latest evidence into practice. I am also better prepared to look at systems and processes and determine whether they are compliant to the latest recommendations and or guidelines. DNP Essential II allows us as scholar practitioners to understand the dynamics of systems thinking. According to Kelly (2011), "systems thinking is a discipline for seeing the whole, and a framework for seeing interrelationships, patterns and interconnectedness that makes each situation unique" (p.

22).

Practitioner

As a DNP prepared practitioner, I am able to model the professional standards and inspire others to practice at the highest level. Also, in the future I can use the DNP essentials as guideline and a foundation for further professional growth. Practice of the DNP essentials can help to improve positive population health outcomes. Therefore, as a scholar-practitioner I am positioned to effect change and be a strong leader for years to come. Leadership skills are vital in the field of nursing, in fact the Institute of Medicine (IOM) recommends that organizations facilitate nursing leadership. Nurses are the largest group of healthcare professionals, and the insights that can be gained from nursing leadership can help to improve patient health outcomes tremendously (IOM, 2009). In addition, as a DNP prepared nurse, I am able assume vital roles in the healthcare system that can enable me to become a leader of change, assist with direct development positive heath policies, and incorporate the latest evidence into practice.

Project Manager

While project management can be tedious, the skills are necessary to introduce new practice change. The skills learned from the implementation of the project initiative can be used in other healthcare settings to garner support for change and champion quality improvement projects. It is critical to understand the dynamics of project management; this importance was highlighted during the implementation of the project initiative. As a project manager, I was able to see the importance of utilizing a business plan as a framework for conducting the project, and discussing key elements necessary

for implementation with identified stakeholders. According to Kettner, Moroney, and Martin (2017), it is imperative the project managers or program planners understand each step or process of project planning, as they are critical to successful program planning. With the project initiative, I was able to understand the dynamics of program planning steps, which included planning, designing, implementation and evaluation. Application of the program planning steps throughout the project help me to manage effectively and meet the project objective.

Professional Development

During this DNP journey, it was realized how important it is as a DNP graduate to be actively involved in the health care society. As a DNP graduate, it is imperative to not only translate evidence into practice but also promote and develop policies to promote such evidence. Thus, it is necessary to proactively seek opportunities in the political arena that improve healthcare for the population on a whole. Nursing professionals should have a seat at the table where the decisions are made that impact the general public as well as their profession. Therefore, as a DNP graduate the role is to inspire others to become engage on all levels. DNP Essential V exemplifies how the DNP graduate can influence the health care society. According to the American Association of Colleges of Nursing (AACN) (2006), “the engagement in the process of policy development is central to creating a health care system that meets the needs of its constituents” (p. 13). The engagement in political process is one area where the DNP graduate can make a significant contribution in improving our current healthcare system. The same hold true for influencing legislative changes and research for SCT and

complications, and improve the target population health and awareness.

Summary

The purpose of the project was to increase awareness about SCT and the importance of genetic counseling. Analysis of the results indicated a significant mean difference of 18.16 points from the preintervention SCT education test mean to the post-intervention test mean at $p < 0.001$. Sickle cell trait disproportionately affects African Americans in the United States. Newly found complications of SCT may be rare but clearly can have fatal consequences. However, the general population and health care society are not fully informed about these complications and a knowledge deficit persists in the target population. Thus, it is imperative to raise awareness about SCT, SCT complications and the need for genetic counseling in not only the target population but also society on a hold. Given the increasing interracial marriages and relationships, studies have shown that other ethnic groups are also affected by SCT and may also have serious complications. It is time for SCT education to be a part of wellness visits to not only help to increase awareness but to improve the population health and avert a major crisis. Overall completing the DNP project has been an exciting yet difficult process. The DNP project however showed me the importance of improving the population health, and how to implement change in a practice setting. I am thankful to Dr. Verklan for her guidance and support in navigating the tasks and difficulties of completing the DNP project. I can surely say that the experience of the DNP project has ignited a flame to continue to fight for change in the management and education of SCT to improve the

population health and make a positive social change. In the next section, the dissemination plan for the project initiative will be discussed.

Section 5: Scholarly Product for Dissemination

Introduction

The results of this DNP project showed that there was a need for consistent SCT education and genetic counseling in the target population in the primary care setting. To improve the SCT education compliance at the project site, I will present the results of the project initiative to the medical directors to depict the importance of SCT education at their organization. Highlighting the knowledge deficit about SCT and the importance of genetic counseling in the target population at the project initiative site will hopefully encourage the providers to continue SCT education sessions. The results of the project will also be used as a model to improve the practice approach in providing SCT education among providers at the organization. The next step of dissemination will be publishing the manuscript of the project. It is imperative to not only increase awareness in the target population but also in providers. According to Koopmans et al. (2012), there is a lack of consistent SCT education to the target population among providers due to misconceptions about the disorder and lack of confidence in providing genetic counseling. Thus, the manuscript will also be submitted to *The Journal for Nurse Practitioners* for consideration of publication. Publication in the above journal would help increase awareness among providers in both nursing and the medical field.

Title: Sickle Cell Trait and Genetic Counseling

Tricia Salmon-Anderson

Dr. Mary Verklan

Dr. Janine Everett

Purpose: To examine the effect of routine education about SCT within the Black population in the family practice setting on the requests for SCT testing and genetic counseling.

Method: A quasi-experimental design was used to examine the association between consistent SCT education to the Black patients between the ages of 18–44 years who presented to the practice. The project measured the participants using a pre- and postimplementation tool. 71 one patients participated in the project initiative.

Findings: There was a significant mean difference of 18.16 points from the preintervention SCT education test (M = 75.91, SD = 12.714) to the postintervention test (M = 94.08, SD = 8.37) at t (70) = -11.861, $p < 0.001$. This means that the intervention was successful in significantly raising SCT education in the target population as reflected in the scores.

Conclusion: The findings of the study implicate that there is a knowledge deficit in the target population as it relates to SCT and genetics. The results exemplify that the target population requires SCT education and options for genetic counseling. Given the results of the project it would be recommended that SCT education and genetic counseling be offered in the primary care setting.

Sickle cell trait (SCT) is a very prevalent disorder in the United States especially among ethnic minority populations such as African Americans or people of African descent. However, even with the prevalence of the disorder there are no standardized guidelines for providing patients with information about SCT and the implications at physicals and well-check visits.

Problem Statement

One in every 12 Blacks and one in 100 Hispanics in the United States has SCT (Housten, Abel, Lindsey, & King, 2016). Despite the family practice population being 98% Black, when looking through the medical records the documentation of SCT status was nonexistent. With the high percentage of African Americans presenting to the practice, one would expect to see consistent documentation of SCT status and the necessary counseling. When patients do not know their SCT status the chance of having children with SCD increases due to a lack of appropriate genetic counseling. In addition, the patients may not be aware of the life-threatening conditions that are associated with SCT. According to the Center for Disease Control and Prevention (CDC; 2016), people with SCT have difficulties with high altitude, may experience pain crisis, and need to stay hydrated and have frequent rest periods when engaging in sports and exercise. If an individual is not aware of their SCT status, they are less likely to engage in appropriate measures to stay healthy. With increased knowledge about the effects of having SCT, I believe that patients will opt for more SCT screening and subsequent genetic counseling. Conversely, if information about SCT and genetic counseling continues to be inconsistently provided, there will be no decrease in the incidence of the disease. In

addition, the opportunity for patients to improve their health and make informed decisions regarding reproduction will be lost.

Study Purpose

The purpose of the project initiative was to improve awareness of the Black and ethnic minority patients' understanding of their SCT status, newly discovered complications from having SCT, and options for genetic counseling to prevent SCT complications. To accomplish this increase in awareness, routine education about SCT was provided in the family practice setting and health records were updated to reflect the patient's SCT status. Even though there were no mandates to have consistent SCT education, there is a necessity to update and provide accurate information to the target population. In the past patients were told SCT was asymptomatic, now it is time to undo prior teachings and provide the necessary guidance to ensure positive health outcomes and awareness.

Research Design

I used a quasi-experimental design to examine the association between consistent SCT education to the Black patients between the ages of 18–44 years who presented to the practice. The primary objective of the project initiative was to determine if the intervention of education about SCT had an impact on patients' requests for SCT testing and genetic counseling. The quasi-experimental research design allowed me to explore and determine the causal relationship between the consistent education and subsequent rates for genetic counseling and SCT testing. According to Grove, Burns and Gray, (2013), "the quasi-experimental design facilitates the search for knowledge and

examination of causality in situations in which complete control of a study design is not possible" (p. 231). Specifically, the quasi-experimental design with no control groups was utilized, often referred to as the one-group, pretest-posttest-only design. The SCT education, the independent variable, was provided and rates for SCT testing and genetic counseling were the outcome measures.

Population and Sampling

The target population of the study were Black women and men, between 18–44 years of age who presented to the primary family practice setting where I conducted the project initiative. The inclusion criteria included participants of African or Black ethnicity, who were not diagnosed with sickle cell disease. Exclusion criteria included patients that had a documented history of SCD and SCT, patients that were not within the age range of 18–44 years, and patients who were not of a Black ethnicity. A convenience sample was obtained from the Black patients between the ages of 18–44 years who presented to the practice for well-check visits and physical examinations. Approximately 100 patients were initially estimated to participate in the program. However, due to the mix of patients that presented only 71 ended up participating.

Data Collection

Prior to implementation, I obtained approval from the Walden University Institutional Review Board (IRB) and permission from the family practice site before initiation of the project. The project ran for approximately ten weeks, with a total of 71 participants. Educational materials from the CDC about SCT education were printed for distribution during the education session (see Appendix A). I then placed the printed

educational materials in all examination rooms for easy access. The family practice scheduling calendar was examined at the beginning of each week to determine which days patients were scheduled for physical examinations and well-check visits. After the practice schedule was reviewed, I identified eligible Black patients who did not have a documented history of SCT or SCD by reviewing the charts in the EMR. If the patient had a documented history of SCT or SCD, they were excluded from the study. Other inclusion criteria related to being able to understand and read English. All patients that were Black and met eligibility criteria were contacted via the telephone to explain the project initiative and ask for their consent to participate in the project.

When the patient presented to their appointment, the front office staff provided the pretest (see Appendix B). The pretest items were structured questions to determine if the patient knew their SCT status and included questions about genetics. The pretest was in paper and pencil form and was completed in the waiting area by the participants. When completed, the pretest was placed in a folder labeled pretest and kept at the front desk. The patients were asked to create a five-digit identification number and place that number on the pretest. The purpose of the patient creating an identification number was to match the pretest with posttest, as the same number was used on that patient's posttest. Utilizing a five-digit identification number helped to reduce duplication of the same number by another participant.

Once the patient was in the examination room, they had the presenting complaint attended to, after which the provider presented the SCT education (see Appendix C). The education was approximately ten minutes in duration and covered the information about

SCT complications, such as hematuria, renal cell carcinoma, hyphema, exertional rhabdomyolysis, exercise-related problems, and risk for SCD. Information about the importance of genetic counseling in preventing SCD was also provided to the participants in these sessions. The SCT education was delivered in the examination room by the medical providers and/or me and was then documented in the EMR as preventive education. I provided an in-service to all medical providers the week before the implementation of the project initiative to ensure consistency in the delivery of the SCT education. The providers delivering the education also provided the participant with a print out of the information to go over during the education.

The posttest was completed by the participants immediately after the education, while the provider was in the room (see Appendix B). The posttest items were the same as the pretest. The participant was asked to place the same identification number on the posttest once it was completed and to place posttest in an envelope. After the posttest was completed, the patients were asked by the provider and/or myself to indicate whether they wanted SCT testing and genetic counseling. If the participant indicated that they would like SCT testing and had insurance, the testing was conducted on site at a later scheduled appointment as indicated by the patient. For the participant who indicated that they would like SCT testing but did not want to do it through insurance or were uninsured, information for the Sickle Cell Foundation (SCF) was provided, as the foundation provided discounted SCT testing for $40.00 and free genetic counseling. The patients were also given the handout from the CDC toolkit for revision at home (see Appendix A).

At the end of the day, I matched the pretest and posttest via the identification

number, and both were kept in their designated folders in a file cabinet in a locked private office until the completion of the project for my further analysis. The identification number and information were stored separately in a code book only accessible by me. The data collected from the project site were the responses on the pretest and posttest and requests for SCT testing and genetic counseling results. All participants that had SCT testing done on site were provided with their results on a subsequent visit and had their health records updated accordingly.

Data Analysis

The practice-focused question was: Would the use of routine education about SCT to the Black minority population in the family practice setting increase SCT testing and requests for genetic counseling? The objective of the DNP project was to increase awareness about the implications of having SCT and provide options for testing and genetic counseling.

SCT and the importance of genetic counseling educational sessions were conducted at the project initiative setting. A convenience sampling approach was utilized based on the patients that presented to the practice setting meeting eligibility requirements. The project was conducted over a period of ten weeks and a total of seventy-one patients participated. Data analysis was conducted using paired *t*-tests that compared the change between the pre- and posttest data. All analysis was conducted using SPSS 24.0. Statistical significance was met with p values ≤ 0.05. The percentage of the participants that requested SCT testing and genetic counseling was also obtained to compare with the practice setting prior year (2016) rates. Of the 71 participants, 46

(64.8%) identified as female and 25 (35.2%) identified as male. The average participant's age was 31.54 (SD = 7.450, n = 71) years old, with the most senior being 44 and the most junior being 18 for a range of 26 years.

When asked if they would be interested in SCT testing, 57 (80.3%) participants reported "Yes" and 14 (19.7%) reported "No." When asked if they would be interested in receiving genetic counseling, 56 (78.9%) reported "Yes" and 15 (21.1%) reported "No." Therefore, there was an overall increase in requests for SCT and genetic testing with consistent SCT education as opposed to the practice prior year rates in 2016, which was zero with no consistent SCT education. With this positive change, the project objective of increasing SCT testing and genetic counseling requests was met.

Pre- and posttest responses changes on the SCT education assessment tool in the target population were evaluated by ten questions that assessed whether the participants knew their SCT status, and if they wanted SCT testing, and understood genetics (Appendix B). The questions were scored as 1 for correct and 0 for incorrect and then summed, divided by ten and multiplied by 100 for both the SCT education pretest and posttest. The calculation put the score on a 100-point scale (ratio). When samples are related such as with a pretest and posttest, and the dependent variable difference of comparison is ratio, then a paired samples t-test is used (Freedman, Pisani, & Purves, 2011).

There was a significant mean difference of 18.16 points from the preintervention (pretest) to the postintervention (posttest) of the SCT education at $p < 0.001$. Based on the increase in scores the intervention was successful in significantly raising SCT and

genetics knowledge scores in the overall target population (Figure 1). Essentially if comparing to a standard college grading, before the education participants average score was a C and after intervention scores were raised to an A. The results of the project initiative further strengthen the argument in the literature review that there is a knowledge deficit in the likely affected population about SCT and the importance of genetic counseling (Folsom et al., 2015).

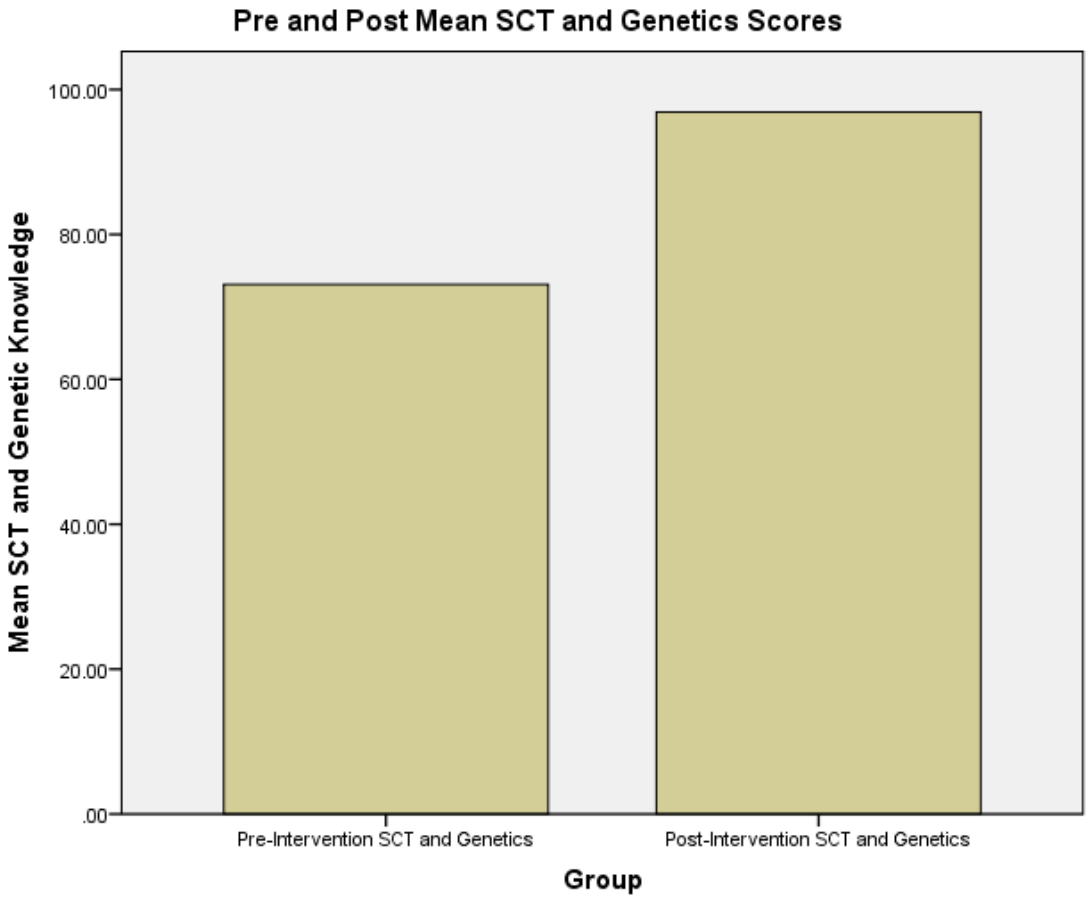


Figure 1. SCT and genetics mean scores.

Table 1 provides further analysis of the SCT pretest and posttest. On the pretest

the median score was 75.91, and the median score was 94.08 on the posttest after the SCT education. Therefore, there was 18.16 jump from the preintervention assessment as compared to the postintervention assessment. The increase in the overall scores on the posttest exemplifies that SCT education was warranted in the target population. The significant improvement in the post-test scores also aligns with recommendations in the literature review. According to Folsom et al. (2015) "clinical complications of sickle cell trait are elucidated, thus there is a need for an ongoing process to inform individuals about SCT status, and provide genetic counseling to provide an accurate assessment of risks, dispel myths, and offer reproductive recommendations" (p. 7).

Table 1

Paired Samples Statistics of SCT and Genetic Pre-and Post-Test Responses

	M	*N*	*SD*
Pre-Intervention SCT and Genetics	75.91	71	12.714
Post-Intervention SCT and Genetics	94.08	71	8.379

When the paired differences in the pretest and posttest SCT responses was conducted the results were statistically significant at $p < 0.001$. Table 2 showed the differences between the participants SCT and genetics pretest responses as compared to the posttest responses.

Table 2. *Paired Samples Test of SCT and Genetics Pre-and Posttest Responses*

	Mean	*SD*	95% CI		*t*	*df*	*p*
	Difference		Lower	Upper			
Pair 1							
Pre-Intervention SCT and Genetics – Post-Intervention SCT and Genetics	-18.16	12.90	-21.22	-15.11	-11.861	70	.000

Pretest and posttest SCT Questions 6, 7, and 9 were analyzed to examine SCT concepts more closely using paired samples tests. The questions were:

6. You can have sickle cell trait and not even know it.

7. People with sickle cell trait can become ill or die if they exercise too hard.

9. If one parent has sickle cell disease, all children will at least have trait.

Table 3 shows the analysis between pretest and post-test responses for Questions 6, 7, and 9. Questions 6 and 7 looked at the participants' knowledge about SCT and SCT complications, whereas Question 9 looked at the participants' knowledge about genetics related to SCT. There was a mean difference of 5.6 points from the pretest on Question 6 to the posttest at $p = .045$ (see Table 3). While the results of Question 6 were not statistically significant, it showed that there were some knowledge deficits in the target population about SCT.

Next, Question 7 had a significant mean difference of 63.4 points between the pretest and the posttest responses with $p < 0.001$ (see Table 3). Question 7 explicitly examined the knowledge about SCT complications such as exercise induced illness, exertional rhabdomyolysis, or death. On the pretest SCT education test, 37% of the participants responded correctly, and on the posttest 100% responded correctly. Nelson et al. (2016) found that there was a positive correlation between SCT and exertional rhabdomyolysis and death. Therefore, people with SCT had a significantly higher risk of exertional rhabdomyolysis as compared to those without SCT. The results of this data analysis showed serious knowledge deficits in the target population as they relate to SCT and exercise-related complications like exertional rhabdomyolysis and death.

Finally, there was a significant mean difference on Question 9 from the pretest to the posttest with $p < 0.001$ (see Table 3). With Question 9, I again looked at whether the participants understood SCT genetics. Responses to Question 9 demonstrated the participants' SCT genetic knowledge. My analysis of Questions 6, 7, and 9 further showed that the SCT trait education was effective in improving the population's knowledge about SCT and the importance of genetic counseling.

Table 3

Paired Samples Statistics on Question 6, 7, and 9

		M	*N*	*SD*
Q6	You can have sickle cell trait and not even know it.	94.0	71	2.32
	You can have sickle cell trait and not even know it.	100.0	71	0.000
Q7	People with sickle cell trait can become ill or die if they exercise too hard.	37.0	71	4.85
	People with sickle cell trait can become ill or die if they exercise too hard.	100.0	71	0.000
Q9	If one parent has sickle cell disease, all children will at least have trait.	54.0	71	5.02
	If one parent has sickle cell disease, all children will at least have trait.	80.0	71	4.01

	Paired Differences							
	M	*SD*	*SEM*	95% CI Difference Lower	Upper	*t*	*df*	*p*
Pair 1 You can have sickle cell trait and not even know it.	-.056	.232	.028	-.111	-.001	-2.044	70	.045
Pair 2 People with sickle cell trait can become ill or die if they exercise too hard	-.634	.485	.058	-.749	-.519	-11.007	70	.000
Pair 3 If one parent has sickle cell disease, all								

children will at least have trait.	-.268	.533	.063	-.394	-.141	-4.227	70	.000

The Kotter CCT model served as a theoretical framework for the practice change. Each step was used to generate the necessary changes, and motivate the stakeholders. After the implementation and analysis of the project initiative, the results were presented to the medical director to show the impact of the SCT project initiative. With proven results that there was a knowledge deficit about SCT and importance of genetic counseling the changes in the practicum setting were likely to become permanent. The results of the study also exemplified that there was a need for change about SCT in the national arena. Rather than only mandatory newborn screening, there should be a national effort to educate the population and provide a national database for SCT results for follow through with medical providers. There should also be policies and or legislations passed to explore the growing complications related to SCT.

Discussion

The findings of the study implicate that there is a knowledge deficit in the target population as it relates to SCT and genetics. The results exemplify that the target population requires SCT education and options for genetic counseling. Given the results of the project it would be recommended that SCT education and genetic counseling be offered in the primary care setting. In addition, future studies should be geared at younger children and adolescents and have SCT be a part of the annual wellness visit. Even though there is mandatory newborn screening program across the nation, the results from

the screens are not accessible to primary care providers. Thus, it would be recommended that a state or national database like the Georgia Registry of Immunization Transactions and Services (GRITS) system be designed for providers and families.

Conclusion

SCT disproportionately affects African Americans in the United States. Newly found complications of SCT may be rare but clearly can have fatal consequences. However, the general population and health care society are not fully informed about these complications and a knowledge deficit persists in the target population. Thus, it is imperative to raise awareness about SCT, SCT complications and the need for genetic counseling in not only the target population but also society on a hold. Given the increasing inter-racial marriages and relationships, studies have shown that other ethnic groups are also affected by SCT and may also have serious complications. It is time for SCT education to be a part of wellness visits to not only help to increase awareness but to improve the population health and avert a major crisis.

References

Abedian, M., Howard, J., Rawle, H., & Thomas, V. (2010). A qualitative study of perceptions of using prophylactic penicillin in patients with sickle cell disease. *Primary Health Care, 20(7),* 26–31.

American Association of Colleges of Nursing. (2006). *The essentials of doctoral education for advanced nursing practice*. Retrieved from http://www.aacn.nche.edu/publications/position/DNPEssentials.pdf

Bucknor, M. D., Goo, J. S., & Coppolino, M. L. (2014). The risk of potential thromboembolic, renal and cardiac complications of sickle cell trait. *Hemoglobin*, *38*(1), 28-32. doi:10.3109/03630269.2013.832689

Burden, M. (2016). Using a change model to reduce the risk of surgical site infection. *British Journal of Nursing*, *25*(17), 949-955.

Center for Disease Control and Prevention. (2016). Sickle cell trait toolkit. Retrieved from http://www.cdc.gov/ncbddd/sicklecell/toolkit.html

Folsom, A. R., Tang, W., Roetker, N. S., Kshirsagar, A. V., Derebail, V. K., Lutsey, P. L., ... Cushman, M. (2015). Prospective study of sickle cell trait and venous thromboembolism incidence. *Journal of Thrombosis and Haemostasis*, *13*(1), 2-9. doi:10.1111/jth.12787

Freedman, D.A, Pisani, R., & Purves, R., (2011). *Statistics* (4th ed.). New York, NY: W. W. Norton.

Friis, R. H., & Sellers, T. A. (2014). *Epidemiology for public health practice* (5th ed.). Burlington, MA: Jones & Bartlett Learning.

Grove, S., Burns, N., & Gray, J. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (7th ed.). St. Louis, MO: Saunders Elsevier.

Harris, A. D., McGregor, J. C., Perencevich, E. N., Furuno, J. P., Zhu, J., Peterson, D. E., & Finkelstein, J. (2006). The use and interpretation of quasi-experimental studies in medical informatics. *Journal of the American Medical Informatics Association*, *13*(1), 16–23.

National Coordinator for Health Information Technology, U.S. Department of Health and Human Services. (2016). What is an electronic medical record (EMR)? Retrieved from https://www.healthit.gov/providers-professionals/electronic-medical-records-emr.

Hodges, B. C., & Videto, D. M. (2011). *Assessment and planning in health programs* (2nd ed.). Sudbury, MA: Jones & Bartlett Learning

Housten, A. J., Abel, R. A., Lindsey, T., & King, A. A. (2016). Feasibility of a community-based sickle cell trait testing and counseling program. *Journal of Health Disparities Research and Practice*, *9*(3), 1.

Institute of Medicine. (2009). (US) roundtable on evidence-based medicine. Leadership commitments to improve value in healthcare: Finding common ground: Workshop summary. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK52843

Kelly, D. L. (2011). *Applying quality management in healthcare: A systems approach* (3rd ed.). Chicago, IL: Health Administration Press.

Kettner, P. M., Moroney, R. M., & Martin, L. L. (2017). *Designing and managing*

programs: An effectiveness-based approach (5th ed.) Thousand Oaks, CA: Sage.

Key, N. S., Connes, P., & Derebail, V. K. (2015). Negative health implications of sickle cell trait in high income countries: from the football field to the laboratory. *British Journal of Haematology*, *170*(1), 5-14. doi:10.1111/bjh.13363

Koopmans, J., Ross, L., Koopmans, J., & Ross, L. F. (2012). Identification and management of sickle cell trait by young physicians. *Journal of The National Medical Association, 104*(5-6), 299-304.

Lee, L. M., & Marks, P. (2014). When a blood donor has sickle cell trait: Incidental findings and public health. *Hastings Center Report, 44*(4), 17-21. doi:10.1002/hast.327

Mainous, A., Tanner, R., Harle, C., Baker, R., Shokar, N., & Hulihan, M. (2015). "Attitudes toward management of sickle cell disease and its complications: A national survey of academic family physicians." Anemia. Article ID 853835.

Maney, G. M. (2012). *Strategies for social change*. Minneapolis, MN: University of Minnesota Press.

Marquis, B. L., & Huston, C. J. (2012). *Leadership roles and management functions in nursing: Theory and application* (Laureate Education, Inc., custom ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.

Melnyk, M., Mazurek, B., & Fineout-Overholt, E. (2010). *Evidence-based practice in nursing & healthcare: A guide to best practice*. Philadelphia, PA: Lippincott Williams & Wilkins.

National Institutes of Health. (2008). Meeting summary: Population-based carrier

screening for single-gene disorders: Lessons learned and new opportunities. Retrieved from: http://www.genome.gov/27026048

National Institutes of Health. (2016). Genetic counseling. Retrieved from https://medlineplus.gov/geneticcounseling.html

Nelson, D. A., Deuster, P. A., Carter, R. III, Hill, O. T., Wolcott, V. L., Kurina, L. M., & Carter, R. (2016). Sickle cell trait, rhabdomyolysis, and mortality among U.S. Army soldiers. *New England Journal of Medicine*, *375*(5), 435-442. doi:10.1056/NEJMoa1516257

Office of Disease Prevention and Health Promotion. (2016). Blood disorders and blood safety. Retrieved from https://www.healthypeople.gov/2020/topics-objectives/topic/blood-disorders-and-blood- safety

Ojodu, J., Hulihan, M. M., Pope, S. N., & Grant, A. M. (2014). Incidence of sickle cell trait - United States, 2010. MMWR: Morbidity & Mortality Weekly Report, 63(49), 1155-1158.

Peters, R., & Templin, T. (2010). Theory of planned behavior, self-care motivation, and blood pressure self-care. *Research & Theory for Nursing Practice*, *24*(3), 172-186. doi:10.1891/1541-6577.24.3.172

Shetty, A., & Matrana, M. R. (2014). Renal medullary carcinoma: A case report and brief review of the literature. *Ochsner Journal*, *14*(2), 270–275.

Smith, M., & Aguirre, R. (2012). Reproductive attitudes and behaviors in people with sickle –cell disease or sickle cell trait: A qualitative interpretive meta-synthesis. *Social Work in Health Care*, *51*(9), 757-779

Smith, M., & Praetorius, R. (2015). The challenges and opportunities associated with sickle cell disease prevention, education, and management. *Social Work in Public Health*, *30*(7), 592-612.

Taylor, C., Kavanagh, P., & Zuckerman, B. (2014). Sickle cell trait--neglected opportunities in the era of genomic medicine. *Jama*, *311*(15), 1495-1496. doi:10.1001/jama.2014.2157

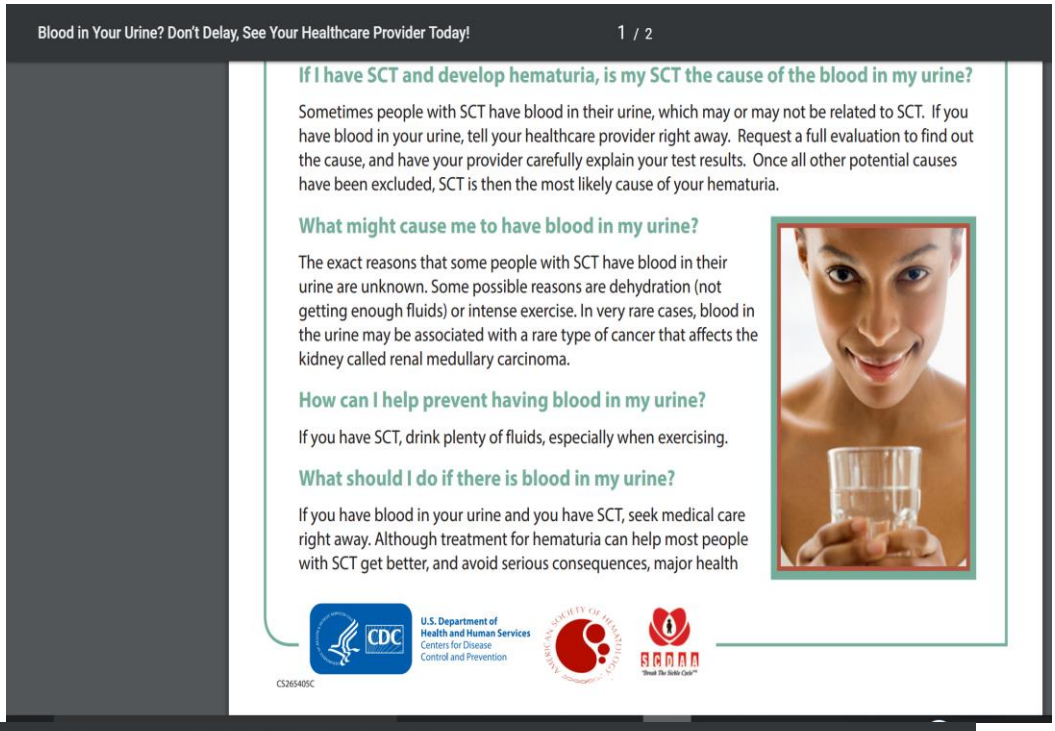
Terry, A. J. (2015). Clinical research for the doctor of nursing practice (2nd ed.). Burlington, MA: Jones & Bartlett Learning.

U.S. Department of Health and Human Services. (2016). What is sickle cell disease? Retrieved from http://www.nhlbi.nih.gov/health/health-topics/topics/sca

White, K. M., & Dudley-Brown, S. (2012). *Translation of evidence into nursing and health care practice.* New York, NY: Springer.

World Health Organization. (2016). Sickle-cell disease and other hemoglobin disorders. Retrieved from http://www.who.int/mediacentre/factsheets/fs308/en/

Appendix A: Additional Information for Patients to Take Home



Blood in Your Urine? Don't Delay, See Your Healthcare Provider Today! 1 / 2

If I have SCT and develop hematuria, is my SCT the cause of the blood in my urine?

Sometimes people with SCT have blood in their urine, which may or may not be related to SCT. If you have blood in your urine, tell your healthcare provider right away. Request a full evaluation to find out the cause, and have your provider carefully explain your test results. Once all other potential causes have been excluded, SCT is then the most likely cause of your hematuria.

What might cause me to have blood in my urine?

The exact reasons that some people with SCT have blood in their urine are unknown. Some possible reasons are dehydration (not getting enough fluids) or intense exercise. In very rare cases, blood in the urine may be associated with a rare type of cancer that affects the kidney called renal medullary carcinoma.

How can I help prevent having blood in my urine?

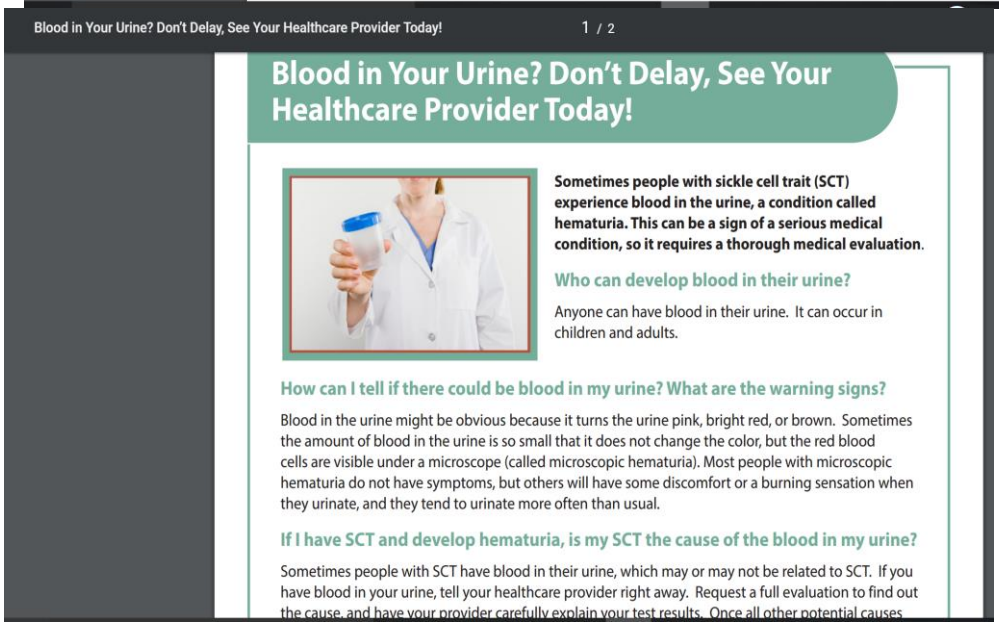
If you have SCT, drink plenty of fluids, especially when exercising.

What should I do if there is blood in my urine?

If you have blood in your urine and you have SCT, seek medical care right away. Although treatment for hematuria can help most people with SCT get better, and avoid serious consequences, major health

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

CS265405C



Blood in Your Urine? Don't Delay, See Your Healthcare Provider Today! 1 / 2

Blood in Your Urine? Don't Delay, See Your Healthcare Provider Today!

Sometimes people with sickle cell trait (SCT) experience blood in the urine, a condition called hematuria. This can be a sign of a serious medical condition, so it requires a thorough medical evaluation.

Who can develop blood in their urine?

Anyone can have blood in their urine. It can occur in children and adults.

How can I tell if there could be blood in my urine? What are the warning signs?

Blood in the urine might be obvious because it turns the urine pink, bright red, or brown. Sometimes the amount of blood in the urine is so small that it does not change the color, but the red blood cells are visible under a microscope (called microscopic hematuria). Most people with microscopic hematuria do not have symptoms, but others will have some discomfort or a burning sensation when they urinate, and they tend to urinate more often than usual.

If I have SCT and develop hematuria, is my SCT the cause of the blood in my urine?

Sometimes people with SCT have blood in their urine, which may or may not be related to SCT. If you have blood in your urine, tell your healthcare provider right away. Request a full evaluation to find out the cause, and have your provider carefully explain your test results. Once all other potential causes

Sickle Cell Trait and Damage to the Spleen: Get the Facts!

People with sickle cell trait (SCT) are generally healthy and rarely have problems with their spleens. However, some people with SCT experience a serious condition called splenic infarct, the death of tissue in the spleen.

What is a spleen?

The spleen is an organ in the upper far left part of your abdomen, to the left of your stomach. It contains white blood cells that fight germs. Your spleen also helps control the amount of blood in your body, and it destroys old and damaged blood cells. Tissue death in the spleen or other damage to the spleen could cause your body to lose some of its ability to fight off infections.

What could cause the tissue of my spleen to die?

Tissue death in the spleen, called splenic infarct, is due to a lack of blood flow or a lack of oxygen in the tissues of the spleen.

I have SCT. Could I develop splenic infarct?

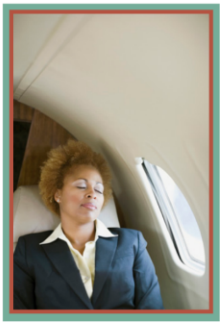
Sickle Cell Trait and Damage to the Spleen: Get the Facts. 1 / 2

Possibly. Although splenic infarct is very rare, it occurs more often in people with SCT.

What might increase my risk for developing splenic infarct?

Splenic infarct occurs more often among people with SCT

- At high altitudes (greater than 1100 meters, or 3600 feet, above sea level);
- Who have severe dehydration (not drinking enough fluids); and/or
- Who engage in very high-intensity physical activity.



What are warning signs that could signal a problem with my spleen?

Symptoms of tissue death in the spleen include

- Sudden onset of pain in the upper left side of the abdomen that does not go away (pain may also be felt in the left shoulder);
- Chest pain with breathing;
- Nausea; and
- Fever.

CDC U.S. Department of Health and Human Services Centers for Disease Control and Prevention

CS265405F

Sickle Cell Trait and Damage to the Spleen: Get the Facts. 2 / 2

Yes. You can safely travel in airplanes because modern aircraft are pressurized.

In addition, you can safely travel to, and exercise at, high altitudes when taking the precautions listed below.

What steps can I take to avoid having tissue death in my spleen?

You can

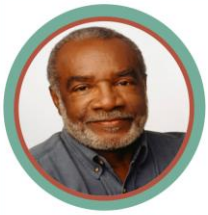
- Stay hydrated by drinking more water than usual;
- Pace yourself with frequent rest while exercising, particularly at high altitudes; and
- Start out exercising slowly, and gradually build up to the desired amount of exercise in order to give your body time to adjust; this is particularly important after recent arrival in an area at high altitude.

What should I do if I think I could have a problem with my spleen?

If you experience pain on the upper left side of your abdomen that does not go away, seek medical attention immediately. Inform your care provider that you have SCT. If you are at high altitude, ask to be transported to a lower altitude, if you are stable.

Eye Problems and Sickle Cell Trait: Learn How You Can Help Protect Your Vision. 1 / 2

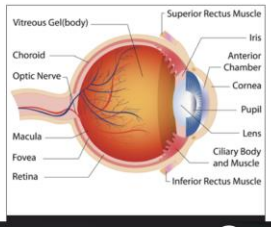
Learn How You Can Help Protect Your Vision



People with sickle cell trait (SCT) who experience an eye injury are more likely to develop eye problems including bleeding in the eye followed by a buildup of pressure inside the eye. This can lead to blurry vision or loss of vision, and may even cause permanent eye damage. Therefore, if you have SCT and have suffered an eye injury, it is important that you get checked out right away by an eye specialist who can closely monitor your care.

My doctor said I'm at risk for glaucoma post-hyphema? What's that?

Hyphema is the presence of blood in the fluid-filled space inside the eye between the clear covering of the eye (the cornea) and the colored part of the eye (the iris). This space between the cornea and iris is called the anterior chamber of the eye.



This bleeding, or hyphema, into the anterior chamber may follow an eye injury. Hyphema is rare, but it is serious.

Glaucoma, or increased pressure within the eye, can occur after hyphema. It is called glaucoma post-hyphema.

If you have SCT and have experienced an eye injury, you are

monitored closely by an eye specialist, called an ophthalmologist.

How can I tell if I have glaucoma post-hyphema? What are the warning signs?

Hyphema occurs after trauma or injury to the eye. The symptoms of hyphema include pain, discomfort and difficulty seeing in bright light, and vision changes, such as blurred or decreased vision, or total loss of vision. Following hyphema, if the vision problems do not go away with treatment, it may be due to either a buildup of pressure inside the eye (glaucoma) or more bleeding.

I have SCT. What should I do if I think I may have glaucoma post-hyphema

If you experience eye trauma or injury, you should seek immediate medical attention in an emergency department and let the treating healthcare provider know that you have SCT and have experienced eye trauma.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

CS265405A

If I have SCT and I develop bleeding in my eye, is there anything I can do to prevent further damage?

Yes! People who experience bleeding in the eye can help

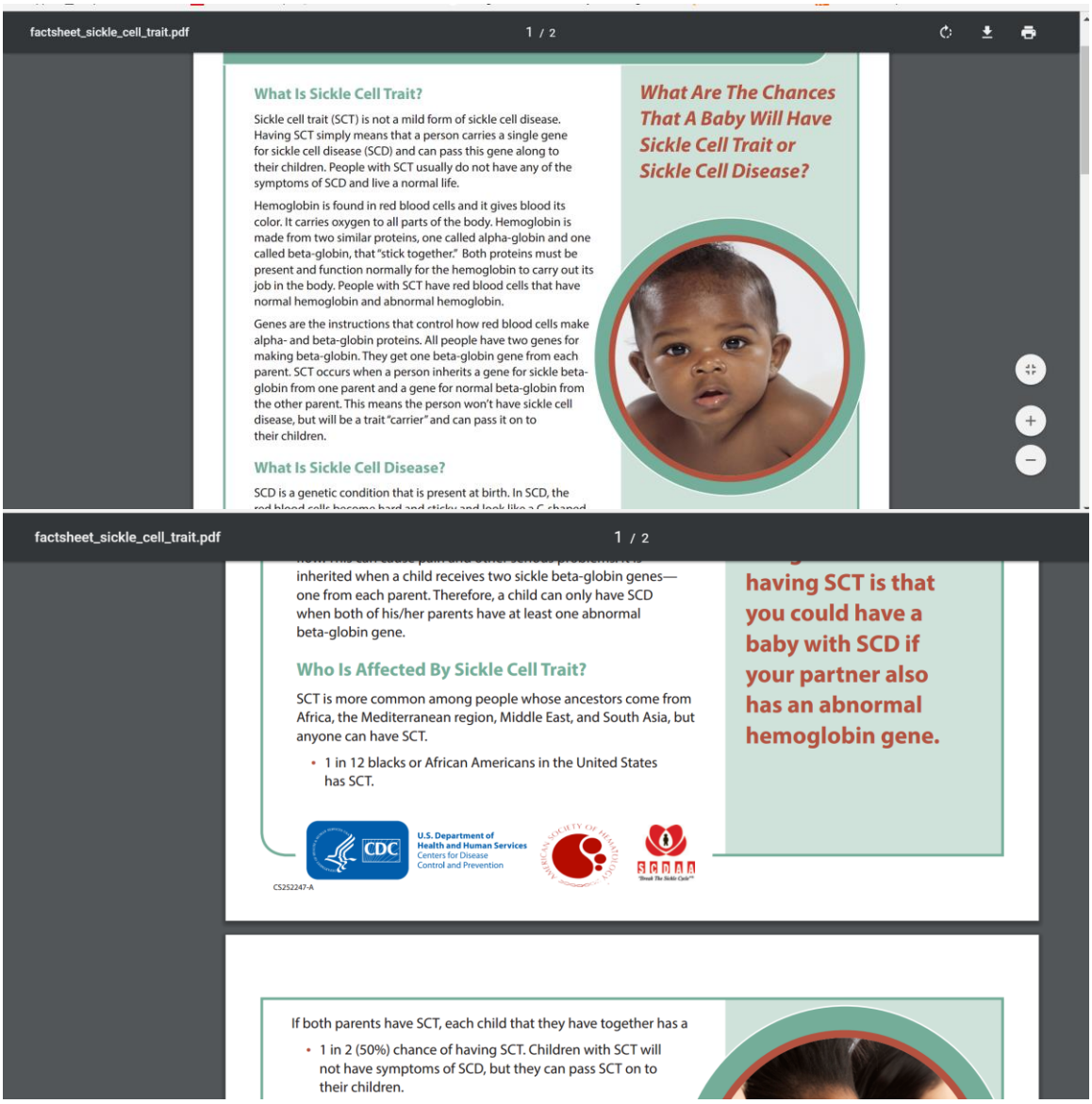
If I have SCT and I develop bleeding in my eye, is there anything I can do to prevent further damage?

Yes! People who experience bleeding in the eye can help prevent further damage by

- Limiting their physical activity;
- Avoiding situations that could lead to further eye trauma;
- Wearing eye protection on their injured eye (an eye patch with a shield); and
- Getting prompt medical care from an ophthalmologist.

Where can I get more information about eye problems and SCT?

For more information about hyphema and glaucoma post-hyphema, visit the web pages of the American Association for Pediatric Ophthalmology and Strabismus at http://www.aapos.org/terms/conditions/58.


factsheet_sickle_cell_trait.pdf
1 / 2
What Is Sickle Cell Trait?
Sickle cell trait (SCT) is not a mild form of sickle cell disease. Having SCT simply means that a person carries a single gene for sickle cell disease (SCD) and can pass this gene along to their children. People with SCT usually do not have any of the symptoms of SCD and live a normal life.
Hemoglobin is found in red blood cells and it gives blood its color. It carries oxygen to all parts of the body. Hemoglobin is made from two similar proteins, one called alpha-globin and one called beta-globin, that "stick together." Both proteins must be present and function normally for the hemoglobin to carry out its job in the body. People with SCT have red blood cells that have normal hemoglobin and abnormal hemoglobin.
Genes are the instructions that control how red blood cells make alpha- and beta-globin proteins. All people have two genes for making beta-globin. They get one beta-globin gene from each parent. SCT occurs when a person inherits a gene for sickle beta-globin from one parent and a gene for normal beta-globin from the other parent. This means the person won't have sickle cell disease, but will be a trait "carrier" and can pass it on to their children.
What Is Sickle Cell Disease?
What Are The Chances That A Baby Will Have Sickle Cell Trait or Sickle Cell Disease?
factsheet_sickle_cell_trait.pdf
1 / 2
inherited when a child receives two sickle beta-globin genes—one from each parent. Therefore, a child can only have SCD when both of his/her parents have at least one abnormal beta-globin gene.
Who Is Affected By Sickle Cell Trait?
SCT is more common among people whose ancestors come from Africa, the Mediterranean region, Middle East, and South Asia, but anyone can have SCT.
• 1 in 12 blacks or African Americans in the United States has SCT.
having SCT is that you could have a baby with SCD if your partner also has an abnormal hemoglobin gene.
CDC
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
CS252247-A
If both parents have SCT, each child that they have together has a
• 1 in 2 (50%) chance of having SCT. Children with SCT will not have symptoms of SCD, but they can pass SCT on to their children.

several types of SCD. Sickle cell anemia is a serious medical condition.

- 1 in 4 (25%) chance that they will not have SCD or SCT.

If one parent has SCT and the other parent has another abnormal hemoglobin gene (like hemoglobin C trait or beta-thalassemia trait), each of their children has a

- 1 in 2 (50%) chance of having SCT.
- 1 in 4 (25%) chance of having SCD (not sickle cell anemia). These other types of SCD can be more or less severe depending on the specific abnormal hemoglobin gene.
- 1 in 4 (25%) chance that they will not have SCD or SCT.

If only one parent has SCT, each of their children has a

- 1 in 2 (50%) chance of having SCT.
- 1 in 2 (50%) chance that they will not have SCT.

What Health Problems Might Occur in People with Sickle Cell Trait?

Most people with SCT do not have any health problems caused by sickle cell trait. However, there are a few, rare health problems that may potentially be related to SCT. For example, if people with SCT have pain when traveling to or exercising at high altitudes, they should tell their healthcare provider. People with SCT and eye trauma should seek out medical attention and inform the physician about the trait status. People with SCT should drink plenty of water during exercise. People with SCT should contact and inform their doctor if they notice blood in their urine. To find out more about SCT and to get specific answers to your questions, call your healthcare provider.

How Will A Person Know If He Or She Has Sickle Cell Trait?

To find out if you have SCT, your doctor needs to order a blood test. If you find out you and/or your loved one has SCT, talk to your healthcare provider and/or a genetic counselor about what that means. It is important that you know what SCT is and how it can affect you and your family.

For more information visit: www.cdc.gov/sicklecell

factsheet_sickle_cell_trait.pdf 2 / 2

What Health Problems Might Occur in People with Sickle Cell Trait?

Most people with SCT do not have any health problems caused by sickle cell trait. However, there are a few, rare health problems that may potentially be related to SCT. For example, if people with SCT have pain when traveling to or exercising at high altitudes, they should tell their healthcare provider. People with SCT and eye trauma should seek out medical attention and inform the physician about the trait status. People with SCT should drink plenty of water during exercise. People with SCT should contact and inform their doctor if they notice blood in their urine. To find out more about SCT and to get specific answers to your questions, call your healthcare provider.

To find out if you have SCT, your doctor needs to order a blood test. If you find out you and/or your loved one has SCT, talk to your healthcare provider and/or a genetic counselor about what that means. It is important that you know what SCT is and how it can affect you and your family.

For more information visit: www.cdc.gov/sicklecell

Page 2 of 2

Eye Problems and Sickle Cell Trait: Learn How You Can Help Protect Your Vision. 1 / 2

monitored closely by an eye specialist, called an ophthalmologist.

How can I tell if I have glaucoma post-hyphema? What are the warning signs?

Hyphema occurs after trauma or injury to the eye. The symptoms of hyphema include pain, discomfort and difficulty seeing in bright light, and vision changes, such as blurred or decreased vision, or total loss of vision. Following hyphema, if the vision problems do not go away with treatment, it may be due to either a buildup of pressure inside the eye (glaucoma) or more bleeding.

I have SCT. What should I do if I think I may have glaucoma post-hyphema

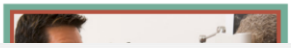
If you experience eye trauma or injury, you should seek immediate medical attention in an emergency department and let the treating healthcare provider know that you have SCT and have experienced eye trauma.

CDC U.S. Department of Health and Human Services Centers for Disease Control and Prevention

CS265405A

If I have SCT and I develop bleeding in my eye, is there anything I can do to prevent further damage?

Yes! People who experience bleeding in the eye can help



Get Screened to Know Your Sickle Cell Status. 1 / 2

TO FIND OUT WHETHER YOU OR YOUR LOVED ONE

has sickle cell disease (SCD) or sickle cell trait (SCT), blood tests must be done to screen for these conditions. Arming yourself with this information is referred to as knowing your sickle cell status.

Both SCT and SCD are conditions that are genetically inherited or passed down from your parents.

What is sickle cell screening?

Screening for sickle cell means testing a person's blood for abnormal types of hemoglobin:

- Hemoglobin is a substance inside the red blood cell that delivers oxygen to all organs in the body.
- There are many types of altered hemoglobin, but people with SCD or SCT make a form of hemoglobin which is abnormal and it is called hemoglobin S or sickle hemoglobin.
- A blood test for hemoglobin S or sickle hemoglobin can tell you if your hemoglobin is normal, you have SCD or SCT (carrier status) or if you have another type of abnormal hemoglobin.

Why should I (or my child) get screened for sickle cell?

- Getting screened to know your sickle cell status is extremely important at child-bearing age because SCD and SCT can be passed down to children through their parents' genes (Visit http://www.cdc.gov/ncbddd/sicklecell/facts.html for more information).
- Knowing if you have sickle cell trait is important because you

- All newborns should be screened for sickle cell, even if they look healthy. If left undetected and untreated, SCD can lead to severe health problems and even death, early in childhood.

When should sickle cell screening occur?

At birth:

- Newborn babies should be screened for sickle cell status (SCD or SCT), as early as 24-48 hours after birth.
- In the U.S. (all 50 states and the District of Columbia), babies are screened for sickle cell status as part of the newborn screening program.
- A positive newborn screening test means your baby likely has a condition reported but you need more testing by your baby's doctor to know for sure.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

CS252243-A

cannot turn into the other. SCD causes many disabling symptoms like anemia (causes a person to feel tired, weak or short of breath), severe pain, or even stroke. SCT does not make you sick. In fact, screening tests might show that you have SCT and yet you usually never have physical symptoms.

In adulthood:

- Screening for sickle cell status may be done as part of the care you and your partner receive before or during pregnancy, or after your baby is born.

What tests should be done?

The best tests to tell you whether you or your child is at risk for having SCD or SCT are:

- Complete blood count (CBC) – this test screens for anemia, a condition that occurs when not enough oxygen is delivered to the cells of the body due to the presence of abnormal hemoglobin

AND;

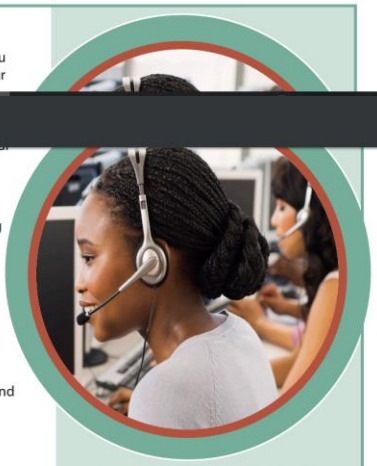
- Hemoglobin electrophoresis, high performance liquid chromatography (HPLC), or DNA testing which may be used to find out the type of hemoglobin present in a person's blood.

What tests should not be used?

- Results from sickle cell solubility tests may be misleading and SHOULD NOT be used to determine sickle cell status.

Where can I get tested?

- All infants born in the United States after 2006 should have their newborn screening information as part of his or her medical record, including sickle cell status. Contact your child's physician for more information.
- Ask your physician, local health-clinic, or community based sickle cell disease organization for testing locations near you.
- You may also contact the Sickle Cell Disease Association of America (SCDAA) at (800) 421-8543 or visit their website at www.sicklecelldisease.org to find testing locations in your community.



Where can I find more information about sickle cell disease and sickle cell trait?

For more information about sickle cell, visit: http://www.cdc.gov/ncbddd/sicklecell/index.html

inherited when a child receives two sickle beta-globin genes—one from each parent. Therefore, a child can only have SCD when both of his/her parents have at least one abnormal beta-globin gene.

Who Is Affected By Sickle Cell Trait?

SCT is more common among people whose ancestors come from Africa, the Mediterranean region, Middle East, and South Asia, but anyone can have SCT.

- 1 in 12 blacks or African Americans in the United States has SCT.

having SCT is that you could have a baby with SCD if your partner also has an abnormal hemoglobin gene.

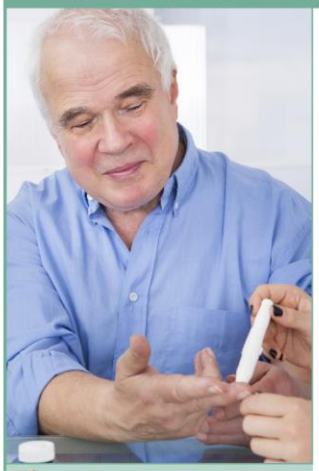
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

CS252247-A

If both parents have SCT, each child that they have together has a

- 1 in 2 (50%) chance of having SCT. Children with SCT will not have symptoms of SCD, but they can pass SCT on to their children.

What You Should Know About Diabetes Tests if You Have Sickle Cell Trait



If you have sickle cell trait (SCT), the hemoglobin A1C test used to test and monitor diabetes (a potentially lifelong disease in which you have high levels of sugar in your blood) may give false results which can affect the care you receive from your healthcare provider. The good news is other tests and test methods are available that will give you accurate results you can trust. Knowing that you have SCT and letting your doctor know will help your doctor choose the right A1C test for you.

What is an A1C test?

A1C is a blood test used to:

- provide information about a person's average level of blood sugar, called blood glucose, over the past 3 months.
- help diagnose type 2 diabetes, the most common type of diabetes.
- help diagnose prediabetes, a condition when your blood sugar is higher than normal but not high enough to be called diabetes.
- monitor your condition if you have diabetes.

Where can someone get more

What You Should Know About Diabetes Tests if You Have Sickle Cell Trait 1 / 1

Where can someone get more information on SCT, diabetes and abnormal A1C?

Centers for Disease Control and Prevention (CDC) http://www.cdc.gov/diabetes/basics/index.html and http://www.cdc.gov/ncbddd/sicklecell/traits.html

Sickle Cell Disease Association of America (SCDAA) http://www.sicklecelldisease.org/

American Society of Hematology (ASH) http://www.hematology.org/Patients/Anemia/Sickle-Cell-Trait.aspx

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) http://www2.niddk.nih.gov/

American Diabetes Association (ADA) http://www.diabetes.org/

CS258998A

- monitor your condition if you have diabetes.

How are the results of the A1C test affected by SCT?

If you have SCT, the A1C test might give false results, depending on the A1C test method used. These false results could lead to you being undertreated or overtreated for diabetes.

What should I do if I have SCT and an abnormal A1C test?

If you have SCT, make sure your doctor is aware of your trait status and knows that it might affect your A1C test results. Your doctor can perform other tests or arrange for your A1C test to be done by a method that gives accurate results.

CDC Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities

AMERICAN SOCIETY OF HEMATOLOGY

SCDAA "Break The Sickle Cycle"

Athletes: Don't Get Sidelined by Sickle Cell Trait! Play it Safe with These Helpful Tips! 1 / 2

Play it Safe with These Helpful Tips!

Participating in regular physical activity is one of the most important things you can do for your health. This is true for everyone, including those with Sickle Cell Trait (SCT). You just have to be aware of the warning signs and complications of exercise-related illness, listen to your body, and take steps to protect yourself. Below are answers to some commonly asked questions about SCT, participation in sports, exercise related illness, and what to do to stay safe and healthy while engaging in physical activity.

Should people with SCT be allowed to play sports?

Absolutely! People with SCT can safely participate in all sports provided they take a few general precautions, such as

- Drinking enough water;
- Taking breaks when needed; and
- Not overdoing it, especially when starting a new exercise program.

While most people with SCT participate in sports without problems, there have been occasional serious complications and even deaths associated with dehydration, overheating, and other avoidable situations. All athletes should be aware of the warning signs of exercise-related illness and know what to do if they experience any of these signs or symptoms.

Athletes: Don't Get Sidelined by Sickle Cell Trait! Play it Safe with These Helpful Tips! 1 / 2

dehydration, overheating, and other avoidable situations. All athletes should be aware of the warning signs of exercise-related illness and know what to do if they experience any of these signs or symptoms.

Are there conditions that increase the risk of exercise-related illness among people with SCT?

Scientific information specific to SCT is currently limited. However, the conditions that increase the risk of exercise-related illness for athletes with SCT appear to be the same as those that increase the risk for athletes who do not have SCT and include

- Significant and sudden increase in exercise intensity;
- Failure to adjust gradually to new environmental conditions like higher altitude, increased heat, or higher humidity;
- Exercising when ill or dehydrated (lack of fluids); and
- Drug, alcohol or stimulant use.

CS258998A

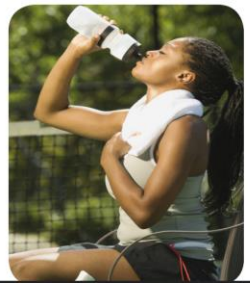
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

Athletes: Don't Get Sidelined by Sickle Cell Trait! Play it Safe with These Helpful Tips! 2 / 2

exercise-related illness?

Athletes with SCT should take the same precautions that can prevent exercise-related illness as athletes who do not have SCT. To prevent exercise-related illness, you should

- Obtain a physical examination before beginning an exercise program;
- Make a plan with a coach/fitness trainer before beginning an exercise program;
- Begin conditioning exercise gradually;
- Set your own pace;
- Stay hydrated by drinking plenty of water;
- Refrain from consuming high caffeine energy drinks and other stimulants;

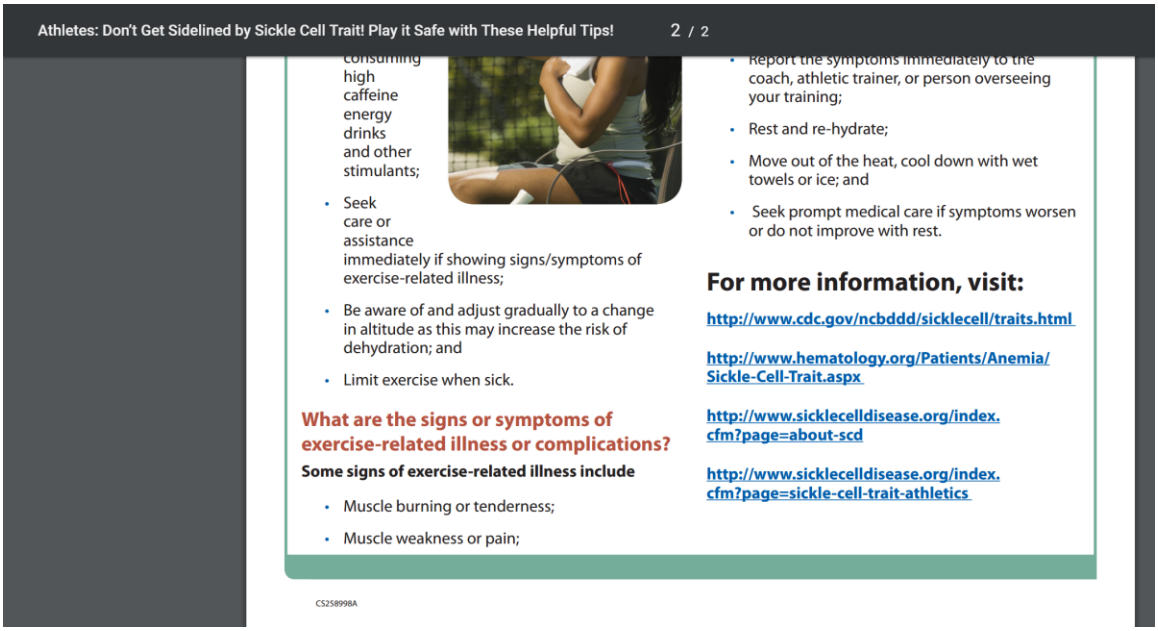


- Rapid breathing without wheezing;
- Feeling overheated;
- Inability to cool, reduced sweating at rest; and
- Prolonged exhaustion or fatigue.

What should you do if you experience any of these signs or symptoms while exercising?

If you display any of the signs or symptoms of distress above, you should

- Immediately stop exercising;
- Report the symptoms immediately to the coach, athletic trainer, or person overseeing your training;
- Rest and re-hydrate;
- Move out of the heat, cool down with wet towels or ice; and



Retrieved from

Center for Disease Control and Prevention. (2016). Sickle cell trait toolkit. Retrieved from http://www.cdc.gov/ncbddd/sicklecell/toolkit.html

Appendix B: Pretest and Posttest Measure

Sickle Cell Genetics Quiz

1. Traits like hair color and height are inherited from our parents. True False
2. Traits are passed from parents to children on genes. True False
3. A baby's sex is determined by genes from the mother. True False
4. Diseases can be passed down from parents to children. True False
5. Sickle cell disease and sickle cell trait are the same. True False
6. You can have sickle cell trait and not even know it. True False
7. People with sickle cell trait can become ill or die if they exercise too hard. True False
8. Both parents must have sickle cell disease for their baby to have the disease. True False
9. If one parent has sickle cell disease, all children will at least have trait. True False
10. If both parents have sickle cell trait, all children will have trait. True False

Retrieved from

Housten, A. J., Abel, R. A., Lindsey, T., & King, A. A. (2016). Feasibility of a community-based sickle cell trait testing and counseling program. *Journal of Health Disparities Research and Practice*, *9*(3), 1.

Appendix C: SCT Education

Recommendations

1. Get tested
2. Get Genetic Counseling
3. Know your SCT status
4. Make sure your health records are up to date with your SCT status

Ask your Doctor for SCT testing
&
Schedule a free genetic counseling session at the Georgia Sickle Cell Foundation.
Telephone: 404-755-1641

Complications Includes

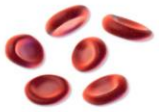
1. Blood in your urine
2. Kidney cancer
3. Muscle breakdown
4. Glaucoma
5. Sickle cell disease
6. Spleen damage
7. Sudden death from exercise related problems

YOUR LOGO HERE

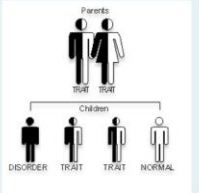
Sickle Cell Trait

Do you know your status?

Sickle cell trait is when a person inherits one sickle cell gene ("S") from one parent and one normal gene ("A") from the other parent (CDC, 2016). Sickle cell is sometimes without symptoms but can sometimes have rare but fatal complications.



Red Blood Cells



Normal red blood cell

Sickled red blood cell

More about Sickle Cell Trait

While SCT may be without symptoms there is a possibility for serious complications. Knowing ones SCT status can help with quick recognition of these complications .

In their extreme form, and in rare cases, the following conditions could be harmful for people with SCT:

- Increased pressure in the atmosphere (which can be experienced, for example, while scuba diving).
- Low oxygen levels in the air (which can be experienced, for example, when mountain climbing, exercising extremely hard in military boot camp, or training for an athletic competition).
- Dehydration (for example, when one has too little water in the body).

High altitudes (which can be experienced, for example, when flying, mountain climbing, or visiting a city at a high altitude). (CDC, 2016).

References

CDC (2016). Sickle cell trait toolkit. Retrieved from http://www.cdc.gov/ncbddd/sicklecell/toolkit.html

Appendix D: Permission for Pretest Tool

On Thu, Dec 1, 2016 at 6:00 PM, Housten,Ashley Jayne <AJHousten@mdanderson.org> wrote:

Hi Tricia,

You are welcome to use our measure. We would appreciate it if you referenced our paper in your work. Also, I'm sure you know, it is not a validated measure.

Thanks and good luck with your work! Let us know if you have questions!

Ashley

On Nov 30, 2016, at 4:17 PM, tricia salmon <salmontricia@gmail.com> wrote:

> Good day Dr. Housten,
> My name is Tricia Salmon Anderson, I am a Family Nurse Practitioner in the State of Georgia, and a Doctor of Nursing Practice (DNP) student at Walden University. I am currently conducting a DNP project initiative under the direction of my dissertation committee chaired by Dr. Mary Verklan. The title of the project is Sickle Cell Trait and Genetic Counseling in the Primary care setting. I would like to request permission to use the pretest and posttest measure and evaluation tool featured in the following study: Housten, A. J., Abel, R. A., Lindsey, T., & King, A. A. (2016). Feasibility of a Community-Based Sickle Cell Trait Testing and Counseling Program. Journal of Health Disparities Research and Practice, 9(3), 1.
> The pretest, posttest, and evaluation will only be used for the purposes of the project. I will include copyright statement on all the copies of the instrument. Please feel free to email me at salmontricia@gmail.com or call at 678-777-7165. Thank you for your

Housten,Ashley Jayne <AJHousten@mdanderson.org> 12/1/16

to me

Hi Tricia,

You are welcome to use our measure. We would appreciate it if you referenced our paper in your work. Also, I'm sure you know, it is not a validated measure.

Thanks and good luck with your work! Let us know if you have questions!

Ashley

<Letter Requesting Pretest H.docx>