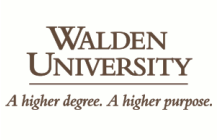

2015

The Effects of a Sickle Cell Disease Education Intervention Among College Students

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This is to certify that the doctoral dissertation by

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has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
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Walden University
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Abstract

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MSW, University of New York, Stony Brook, 2005

MA, University of New York, Stony Brook, 1981

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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November 2015

Abstract

Sickle cell disease (SCD) is a genetic disorder that affects millions of people worldwide. According to the Centers for Disease Control and Prevention, over 100,000 Americans have SCD, and more than 2 million Americans have a sickle cell trait (SCT). People with SCD are more likely than others to suffer premature mortality. Genetic screening is an important step in improving quality of life and increasing longevity for those with SCD. Early detection may lead to effective management of the disease and reduction of complicating factors. The purpose of this quasi-experimental study was to determine whether health education about SCD would impact college students' knowledge, attitudes, perceived risk, and intention to seek genetic screening and counseling in relation to the disease. The theoretical foundation for this study was the health belief model (HBM). This study involved 80 college students selected from a North Texas college. These students completed pre and post versions of an SCD questionnaire. Independent samples *t* tests were used to determine if there were significant differences in pre- and posttest scores of participants in both groups, and a MANOVA was used to determine differences among the scores of participants in the experimental group when grouped by age, gender, race, religiosity, and socioeconomic status. The results of this study showed that SCD health education improved the knowledge of and attitudes towards participants. Future research could explore barriers to seeking SCD screening and genetic counseling. Results of this study may further social change by encouraging the development of college-based health education efforts to increase awareness about SCD.

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Dedication

This study is dedicated to my brother, Collins Guobadia, who lived with sickle cell disease, and whose untimely death in 2008 at age 48 motivated me to commence this study of sickle cell disease.

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Chapter 1: Introduction to the Study

Introduction to the Study

Sickle cell disease (SCD) is a genetic disease that affects more than 100,000 Americans and millions of people in the rest of the world (Centers for Disease Control and Prevention [CDC], 2011a). There have been more than 100 years of research to find a cure for SCD, but so far there is no universally accepted cure without side effects. Current research supports the idea that SCD is preventable if individuals are aware of their sickle cell trait (SCT) status and undergo genetic counseling (Creary, Williamson, & Kulkarni, 2007). However, most individuals do not know whether or not they have SCT. If people are aware if they have the SCT, then there is a higher likelihood that they will seek genetic screening and genetic counseling prior to making reproductive decisions (Acharya, Lang & Ross, 2009; Boyd, Watkins, Price, Fleming, & Debaun, 2005; Treadwell, McClough & Vichinsky, 2006). This research study is premised on the belief that seeking screening and genetic counseling may ultimately lead to a reduction in the prevalence of SCD and SCT.

Background

People who carry the sickle cell trait (SCT) are more likely to have ancestors from regions where malaria is or was common, such as sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere, South America, the Caribbean, and Central America; Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Southern European countries such as Italy (National Heart, Lung, and Blood Institute [NHLBI], 2009). Researchers have noted that SCD is the most common genetic disease

internationally (Odesina et al., 2010). Millions of people suffer from SCD in the Middle East, Southern Europe, Asia, South America, the Caribbean, North America, and Africa (Pack-Mabien et al., 2009). According to the World Health Organization (WHO), more than 300,000 children born worldwide have SCD, and millions of people have the SCT (Toni-Uebari & Inusa, 2009; WHO, 2011). SCD is widespread in certain parts of Africa, especially in Nigeria, where approximately 20 out of 1,000 births are diagnosed with SCD, resulting in 150,000 children born with the disease every year (Abioye-Kuteyi, Oyegbade, Bello, & Osakwe, 2009).

In the United States, SCD is the most common genetic disease (Pack-Mabien et al., 2009). The CDC reported that SCD affects more than 100,000 people in the United States (CDCa, 2011; Creary et al., 2007). According to the CDC, 1 in 12 African Americans in the United States carries the SCT. This constitutes more than 3 million people, making African Americans the largest at-risk population for SCD (Creary et al., 2007). In the United States, more than 2,000 children are born annually with SCD (Buchanan, Vichinsky, Krishnamurti, & Shenoy, 2010). Individuals who have SCD in the United States have an average life span of approximately 42 years for men and 48 years for women, compared to 70 years for an American without the disease (Chakrabarti & Bareford, 2004; Lanzkron et al. 2008; Pack-Mabien & Haynes, 2009).

Sickle cell disease is characterized by anemia, pains and premature mortality. People diagnosed with SCD inherited one defective gene from each parent. These patients produce abnormal hemoglobin, which results in red blood cells assuming a sickle shape that tends to obstruct the flow of blood to parts of the body (Creary et al., 2007).

The body parts that do not receive adequate blood supply are the areas where patients experience severe pain, known as *crisis* (Cole, 2007; Creary et al., 2007; Lanzkron et al., 2008).

When a person has a SCD crisis, he or she typically goes to an emergency room for pain management and a blood transfusion. In addition to pain, SCD patients suffer from frequent infection, iron overload, stroke, acute chest syndrome (ACS), damage to their body's vital organs, and a lifetime of frequent hospitalizations (Creary et al., 2007; Mann-Jiles & Morris, 2009). SCD remains an important health issue because patients diagnosed with the disease have multiple medical problems leading to premature mortality. Most SCD patients will eventually succumb to one of the many medical problems that ultimately reduce their life expectancy by several years (Creary et al., 2007). The CDC reported that millions of dollars are spent annually to provide medical care for adult and pediatric SCD patients (CDC, 2011). In spite of 100 years of medical research investigating SCD, there is still no universally accepted cure or treatment approach that is without controversy or side effects.

Problem Statement

SCD is a serious public health problem for a number of reasons: First, those who have been diagnosed with SCD suffer multiple medical problems, such as strokes, frequent infections, organ damage, anemia, frequent pain, priapism, chronic renal insufficiency, and leg ulcers (Pack-Mabien & Haynes, 2009). Many SCD patients die in infancy, but those who survive past infancy may endure low quality of life (Mann-Jiles & Morris, 2009), and many may not achieve their full potential (Creary et al., 2007). At the

present time, more than 2,000 children born each year in the United States are diagnosed with SCD (Brawley, Cornelius, Edwards, Gamble, Green, Inturrisi et al., 2004; Buchanan, Vichinsky, Krishnamurti, & Shenoy, 2010). Also, there are more than 300 million people worldwide and 3 million people in the United States who have the SCT (Grant et al., 2011). With such a high number of individuals with SCT, SCD is a major health problem. According to a U.S. government-sponsored mortality data report presented by the Healthcare Cost and Utilization Project (HCUP, 2006), there were 758 deaths in 2004 that were directly attributable to SCD (Steiner & Miller, 2006). In addition, SCD patients made more than 122,000 physician visits annually, and more than 83,149 hospitalizations were recorded for SCD patients in 2004 (HCUP, 2006). The CDC reported that between 1989 and 1993, more than $475 million were spent on medical care for SCD patients in the United States (CDC, 2015c). However, more recent data revealed that in 2004, the average cost for SCD hospitalization was $6,223, resulting in a total annual expenditure of $488 million (Steiner & Miller, 2006). Based on the high morbidity, mortality and cost of medical care for SCD patients, more empirical study is needed to reduce the cost of medical care as well morbidity and mortality attributable to the disease.

The problem of reducing the prevalence of SCD is worthy of study because researchers have devoted almost 100 years to finding ways to reduce the morbidity and mortality of SCD yet there is still no cure or treatment for this disease that is without controversy. Research studies on SCD have established that SCD is transmitted if both parents each have the SCT and the unborn child inherited a SCT from each parent. In the

case where both parents have the SCT, there is a 25% chance that each pregnancy may result in a child with SCD and a 50% chance of the child having SCT (Treadwell et al., 2006). In spite of the fact that this pattern of disease transmission has been established over several decades, many newborns are still being diagnosed with SCD in the US, making the disease a major health problem (Brawley et al., 2004; Buchanan et al., 2010).

In a 2006 study by Treadwell et al., three focus groups were set up to evaluate effective sources of SCD/SCT information. One of the focus groups consisting of healthcare providers recommended SCD/SCT education for students "from grade school through college" (p. 706). The study concluded that it was vital for a healthcare provider to be "a source of accurate and current information about SCD/SCT in order to increase the awareness of the disease among young adults" (p. 709). This study focused on the importance of SCD health education as a way of creating awareness about the disease and how this may impact college students' SCD knowledge, attitudes, intentions to seek screening and genetic counseling if at risk.

Providing education about SCD may be an effective way to reduce the transmission rate and empower individuals most at risk to understand the medical conditions associated with SCD, such as frequent painful episodes known as *crisis*, stroke, renal failure and many other medical problems that ultimately result in premature mortality (Acharya, Lang, & Ross, 2009; Boyd et al., 2005; Acharya, Lang, Ross & Stark, 2009; Treadwell et al., 2006; Weatherall, 2005). Health education about the disease may also empower individuals to make educated decisions related to receiving

genetic screening, getting genetic counseling, and discussing SCD transmission with their partner.

The need for new strategies to reduce the incidence of SCD was highlighted in a 2005 cross-sectional study conducted by Boyd et al. Two hundred sixty-four African American women were recruited to participate in a study whose objective was to assess SCD knowledge among women of childbearing age (18 to 30 years). Prior to the commencement of the survey, 102 out of 264 women were dismissed from the study because they were not aware of SCD. The researchers surveyed the remaining 162 African American women and found that 91% of these participants were able to identify SCD as a blood disorder, but only 9.3% were familiar with how SCD is transmitted (Boyd et al., 2005). Another study by Rowley et al. (1991), as reported by Treadwell et al. in their 2006 study, found that pregnant women who had SCT were reluctant to ask their partners about their SCT status. These women were aware of their SCT status and clearly knew their risk. Their decision to have children without knowing the SCT status of their partners illustrates the challenges that plague efforts to prevent SCD (Rowley et al., 1991; Treadwell et al., 2006).

The absence of a universal cure, the lack of treatment devoid of severe side effects, and the fact that many people at risk have low awareness and knowledge about the disease all contribute to making SCD a very significant health issue for all who are at risk for the disease. Lack of education and awareness, coupled with the high rate of migration of people across regions, supports the likelihood that SCD will continue to be the most common chronic disease in the world affecting people in North and South

America, Asia, the Middle East, Europe and Africa (Boyd et al., 2005; Buchanan, Vichinsky, Krishnamurti & Shenoy, 2011). Though individuals with SCD are faced with numerous medical problems that result in them experiencing a lower quality of life, many are able to develop to their fullest potential (Mann-Jiles & Morris, 2009). Medical advances have contributed to a reduction in the morbidity and mortality of this disease, especially through symptom management and many individuals with SCD can and do achieve many of their goals (Niihara, 2012).

Many studies have recommended prevention by way of increased awareness about the disease and dissemination of carrier status, thereby enabling at-risk populations to make informed decisions regarding child bearing (Creary et al., 2007; Kenner, Gallo, Kellie, & Bryant, 2005; Lang, Stark, Acharya, & Ross, 2009; Parker, Quereshi, Ulph, & Kai, 2007; Uebari & Inusa, 2009; Treadwell, et al., 2006). The current literature on SCD indicates that treatment protocols range from medications to gene therapy, and all have one side effect or another (Creary et al., 2007; Frenette & Atweh, 2007; Lanzkron et al., 2008). Many research studies have recommended prevention strategies such as newborn screening and genetic counseling as effective approaches in reducing the prevalence of SCD (Abioye-Kuteyi et al., 2009; Creary et al., 2007). Evidence-based research supports the idea that SCD is preventable if individuals are aware of their SCT status and undergo genetic counseling (Creary et al., 2007). However, most individuals do not know whether or not they have SCT. In order for prevention to become a viable approach to reducing the prevalence of SCD, this study explored whether SCD/SCT education would increase

awareness about SCD/SCT and affect individuals' intentions to seek SCD screening and genetic counseling if at risk.

Purpose Statement

The purpose of this study was to determine whether a health education intervention about SCD would impact college students' SCD knowledge, perceived risk, attitudes about the disease and motivate them to (a) seek genetic testing to know their SCT status and (b) seek genetic counseling if at risk. This study assessed the impact of SCD education on a diverse population of college students attending a community college in northern Texas. This study was unlike many previous studies on SCD, which typically restricted the participants to African Americans.

Nature of the Study and Study Design

The research question for this study was post positivist in nature and employed a quantitative, quasi-experimental pretest/posttest design to test the effectiveness of a health education intervention about SCD among college students attending a state college in northern Texas. In a 2011 study, researchers Borglin et al. sought to investigate whether a theory-based education would significantly improve the practice of nursing, especially as related to the pain management of patients under nurses' care. The researchers declared that a quasi-experimental design provided a "systematic framework for answering questions" (Borglin, Gustafson & Krona, 2011, p. 2). I selected a quasi-experimental research design rooted in positivism and post positivism because of the need "to identify and assess the causes that influence outcomes" (Creswell, 2009, p. 7). In the case of this study, a quasi-experimental design was appropriate because the objective

of this study was to assess the effect of education on knowledge, attitudes, intent to seek screening and genetic counseling by those at risk. The use of a quasi-experimental design provided a clearer understanding and determination of cause and effect (Creswell, 2009).

Traditionally, when research does not include a random sample of participants, the research design is considered quasi experimental (Creswell, 2009). The study participants were recruited on the campus of a large community college in North Texas. The participants comprised a convenience sample of 80 students. A power analysis determined that 70 students would be appropriate. The power analysis is explained in more detail in Chapters 2 and 3. I recruited students in four different classes of first and second year college students. Students in two classrooms served as the experimental group, and students in two other classrooms served as the control group. I was assured by the school authorities that at least 35 students were registered in two courses that I selected to be the experimental group. I was also assured that at least 35 students were registered for the two courses that I selected to be the control group. The assignment into groups was not random, as these were intact groups. I obtained consent from participants prior to administering the sickle cell disease questionnaire. Additional details about this process are provided in the study methodology description in Chapter 3.

The data collected were compared numerically to determine the differences between the experimental and the control groups. Both the control and experimental group received pre/posttest surveys measuring (1) knowledge and awareness about SCD/SCT; (2) attitudes toward SCD screening and genetic counseling; (3) intentions to seek screening, pursue genetic counseling, or talk to prospective partners about SCD/SCT

before making reproductive decisions. The independent variable was SCD education, and the four dependent variables were knowledge about SCD; attitudes about SCD, screening, and genetic counseling; perceived risk; intent to seek screening, pursue genetic counseling, or talk to perspective partners about the disease.

In order to determine the impact of this educational intervention, a priori power analysis determined that the experimental and control groups should have at least 35 participants each for a moderate effect size. This was based on the following:

Statistical power .80

Alpha set at: a = .05

Effect size set at *d* =.70

The process of determining this sample size is explained in more detail in Chapter 3.

Theoretical Framework

The theoretical basis for this study was the health belief model (HBM). The HBM was developed in 1950 by three social psychologists, Hochbaum, Kegels and Rosenstock, who were employees of the United States Public Health Services (Denison, 1996). These public health employees were motivated to develop the HBM as a response to their failed attempt to implement a tuberculosis screening program in the 1950s when tuberculosis caused high morbidity and mortality. Despite the high morbidity associated with tuberculosis, those who were most at risk for the disease did not take advantage of a free screening program (Rosenstock, Stretcher, & Becker, 1988). The developers of the HBM

were motivated to explore the factors that influence individuals to take actions related to their health (Rosenstock, Stretcher, & Becker, 1988).

The HBM is based on six constructs:

1. The individual perceives that he or she is susceptible to a health condition.
2. The individual perceives the severity of the medical condition.
3. The individual perceives the health benefit that will accrue from adhering to the recommended action.
4. The individual perceives the potential barriers to taking the recommended action (Rosenstock, Stretcher, & Becker, 1988).
5. Cues to action, such as a knowing a family member or neighbor with SCD or as a result of media publicity (Denison, 1996).
6. Self-efficacy, which relates to the individual's ability to adopt a positive health behavior (Bandura, 1989, pp. 128-141).

The HBM has been shown to be successful when implemented in public health programs designed to encourage individuals who are susceptible to a particular health issue to adopt a positive health behavior (Meischke, Fahrenbruch, Ike, Hannon, & Harris, 2012; Rosenstock, 1985). Motivating individuals to participate in screening for a disease is more likely to be successful if the individuals can perceive their risk to the disease. Individuals' ability to perceive their susceptibility to the health issue can be triggered by one of the HBM core principles, "cue to action," based on bodily or environmental events that individuals observe, thereby causing the individuals to acknowledge the barriers to taking action and the benefits that will accrue from taking action (Rosenstock, 1985).

Health messages and programs that have used the HBM have demonstrated success in motivating at-risk individuals to reduce their risk by adopting certain health behaviors (Rosenstock, 1985).

In a 2007 study that used HBM, Gustafson, Gettig, Watt-Morse, and Krishnamurti sought to understand acceptance of screening among African Americans. The study involved surveying 101 participants to gauge their acceptance of SCD preventive strategies and then providing SCD education to participants (Gustafson et al., 2007). The study found that the participants had a high perception of the severity of SCD but that most had a low perception of their susceptibility to having a child with SCD. The researchers also found that the participants had a good perception of the benefits that accrue from screening and counseling but exhibited a low perception of the barriers to screening and counseling (Gustafson et al., 2007). Gustafson and colleagues concluded that although many African Americans had a high perception of the severity and the benefits of preventive strategies, they had very low perception of their risk of having a child with SCD (Gustafson et al., 2007). Additional literature that supports the use of the HBM in health education planning is further discussed in Chapter 2.

This research study used the constructs of HBM to determine whether a health education intervention on SCD would have a positive impact on the dependent measures under study. If an individual perceives that he or she is susceptible to SCD, he or she may take a recommended action (genetic screening/genetic counseling) in order to better understand the mode of disease transmission.

Research Questions

The research questions were the following:

1. Will health education about SCD positively impact college students' knowledge and attitudes about the disease?
2. Will health education about SCD influence college students' intentions to seek screening and genetic counseling if at risk?

Research Hypotheses

Hypothesis 1

Ho1: There will be no significant difference between SCD *knowledge* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Ha1: There will be a significant difference between SCD *knowledge* pretest scores and posttest scores between college students assigned to the experimental group and the control group.

Hypothesis 2

Ho2: There will be no significant difference ($p > .05$) between SCD *attitudes* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Ha2: There will be a significant difference ($p < .05$) between SCD *attitudes* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Hypothesis 3

Ho3: There will be no significant difference ($p > .05$) between SCD *perceived risk* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Ha3: There will be a significant difference ($p < .05$) between SCD *perceived risk* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Hypotheses 4

Ho4: There will be no significant difference ($p > .05$) between *intent to seek SCD screening* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Ha4: There will be a significant difference ($p < .05$) between *intent to seek SCD screening* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Hypothesis 5

Ho5: There will be no significant difference ($p > .05$) between *intent to seek genetic counseling* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Ha5: There will be a significant difference ($p < .05$) between *intent to seek genetic counseling* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Hypotheses 6

Ho6: There will be no significant difference ($p > .05$) in pretest SCD knowledge, attitudes, perceived risk, and intention to seek screening scores in experimental group participants when grouped by age, gender, race, religiosity, and socioeconomic status/income (MANOVA).

Ha6: There will be a significant difference in pretest scores ($p < .05$) for SCD knowledge, attitudes, perceived risk, and intention to seek screening and genetic counseling between the experimental group participants when grouped by age, gender, race, religiosity, and socioeconomic status/income (MANOVA).

Hypothesis 7

Ho7: There will be no significant difference ($p > .05$) in posttest scores for SCD knowledge, attitudes, perceived risk, and intention to seek screening scores between experimental group participants when grouped by age, gender, race, religiosity, and socioeconomic status/income (MANOVA).

Ha7: There will be a significant difference ($p < .05$) in posttest scores for SCD knowledge, attitudes, perceived risk, and intention to seek screening and genetic counseling between the experimental group participants when grouped by age, gender, race, religiosity, and socioeconomic status/income (MANOVA).

Study Variables

The variables that were measured in this study were as follows:

- Independent variables: Age, race, gender, religiosity, and socioeconomic status/income; pre/post.

- Dependent variables: SCD knowledge, SCD attitudes, perceived risk of SCD, intent to seek SCD screening; and intent to undergo genetic counseling.

Assumptions

The main assumption of this study was that all the participants would take the survey seriously and provide thoughtful answers. I was concerned about students not taking this seriously because as a student, I did not take many exercises seriously except those that impacted my course grade. The participants were informed in advance that completing the SCD questionnaire would not affect their course grade. Another assumption was that participants would provide accurate and honest answers to questions on the pre- and posttests. The racial groups represented among the participants were African American, Asian/Other, Caucasian, and Hispanic. Upon learning that the study was related to SCD, those who had always considered SCD an African American disease might have wanted to show that they were more knowledgeable about the disease than they really were in an attempt to impress their classmates. Another assumption was that the participants in the experimental group would offer their undivided attention when they viewed the DVD *Let's Talk About Sickle Cell*. Finally, it was my assumption that most if not all the participants would complete both the pretest and posttest. This was a concern because the pretest and posttest were held several days apart, and it was hard to know in advance if all participants would attend lecture on any given day.

Limitations

The study was limited by the use of convenience sampling. This sampling method was used because it was convenient and less time consuming. Since I did not use true

random sampling, the results of this study cannot be generalized to the greater population of U.S. college students (Creswell, 2009). Another limitation was that due to the lack of randomization, there was a possibility that existing differences between both the experimental and control groups such as prior knowledge about SCD or family history of SCD caused the statistical analysis to reveal validity issues such as a regression to the mean (Barnett, Van Der Pols, & Dobson, 2005). Another limitation was that this study did not include a follow-up posttest and only measured effects immediately following the intervention. Therefore, the long-term impact of the intervention on SCD knowledge, attitudes, and actual screening behavior was not assessed.

There was a possibility of recall bias because many participants did not remember whether they were screened at birth and what their results were. Another limitation to this study was that it used self-report data. Therefore, the participants may have provided inaccurate responses, or in some cases, participants may have underreported or over reported (Christensen Fan, Miller, Park, Tai, Winward, et al., 2006; Gorber, Tremblay, Moher, & Gorber, 2007).The lack of significance during the MANOVA analysis of the scores of participants in the experimental group could be attributable to this study's small sample size.

Delimitations

College students were chosen as targets for this quasi-experimental study mainly because the authors of several studies that I reviewed during the literature search recommended that future preventive programs target college students, as most of them would be approaching the age when many individuals make reproductive decisions

(Boyd et al., 2005; Treadwell et al., 2006). The decision to target college students can be considered delimitation, and as such the results of this study may not be generalizable to the general population for the following reasons: Many young individuals decide to start raising a family soon after they graduate from high school and do not attend college. Other young adults who drop out of school may also start families without ever going back to complete high school or attend college.

I set a requirement that only those individuals who could read and write in English could participate in the research because the SCD questionnaire is written in the English language. Happily, this requirement was met, because all students at the college where this study took place are required to read and speak the English language. The SCD survey was written in such a way as to be comprehensible to an individual with a sixth grade level education. In order to ensure that participants had a minimum level of maturity, only students who were 18 years of age or over were included as participants.

Definition of Terms

The following terms and phrases are defined as used in this study.

Cues to action: An event that motivates an individual to take action (Rosenstock, Strecher and Becker, 1994, pp. 5-24).

Genetic counseling: "A communication process that deals with the human problems associated with the occurrence or the risk of occurrence of a genetic disorder in a family" (Fraser, 1974, p. 637).

Genetic screening: The clinical process of examining individuals for the presence of, or risk for, a disease (Grosse et al, 2009, p.2).

Health belief model (HBM): A model used in providing health education and formulating health programs that is based on the perceptions of individuals about their susceptibility to disease, severity of disease, barriers to adopting new behaviors, and benefits of adopting new behaviors (Rosenstock et al., 1994, pp. 5-24).

Newborn Genetic Screening Act: Mandates the genetic screening of newborns nationwide ("Newborn Screening," n. d.).

Perceived barrier: A construct of the health belief model. An individual's perception of barriers that constitutes a barrier to adopting new health behavior (Rosenstock et al., 1994, pp. 5-24).

Perceived benefit: A construct of the health belief model. Individuals' perception of the benefits that accrue to them if they adopt a health behavior (Rosenstock et al., 1994, pp. 5-24).

Perceived susceptibility: A construct of the health belief model. Individuals' perception of their risk for contracting a disease (Rosenstock et al., 1994, pp. 5-24).

Religiosity: The extent of adherence to the beliefs and practices of an organized religion (Gupta, Avasthi, & Kumar, 2011, pp. 330-335). This variable is measured by a participant's response to one item allowing for self-rating on the demographic questionnaire. The level of religiosity was coded into three categories: 1 = barely religious, 2= moderately religious, and 3= very religious.

Self-efficacy: Relates to the individual's ability to adopt a positive health behavior (Bandura, 1977, pp. 191-215).

Sickle cell disease (SCD): SCD genetic is blood disorder that is transmitted when a newborn inherits a defective gene from each parent. (CDC, 2015g, *pp.* 1-4).

Sickle cell trait (SCT): SCT is the defective gene that causes sickle cell disease (CDC, 2015h, pp. 1-2).

Socioeconomic status: The commonly accepted measure of the educational and income status of an individual or group (www.apa.org).

Young adults: Individuals between the ages of 18 and 35 inclusive of college students in higher institutions as well as those working or seeking employment (Nazarene.org, 2012, para. 1).

The Significance of the Study

This study was unique because it used a quasi-experimental design to test whether education about SCD and SCT impacted college students' SCD knowledge, SCD attitudes, perceived risk of SCD, intentions to seek screening, and intention to seek genetic counseling relating to prevention of SCD. Prevention is important because research to find a cure for SCD has been going on for over 100 years, yet there is still no universally accepted cure for SCD without controversy. Most studies relating to SCD and behavior have employed a descriptive vs. quasi-experimental approach (Chudasama & Godara, 2009; Creary et al., 2007; Kenner et al., 2005; Raghupathy & Billett, 2009; Alemayehou, Aletra, Karakasidou, Plata, Prappas, Theodoridou et al., 2008; Treadwell et al., 2006). Finding a cure and identifying new treatment strategies for SCD were the overwhelming foci of most of the literature reviewed for this study. The few studies that focused on strategies to enhance preventative approaches were conducted in countries

outside the United States such as Bahrain, Cuba, India and Saudi Arabia (Al Arrayed, 2005; Memish & Saeedi, 2011). In addition, this study is significant because, unlike most of the published studies, it assessed knowledge and awareness about SCD among a variety of racial groups instead of just African Americans. Most of the literature reviewed presented SCD as if it only affects people in the African American community, leading to the perception that it is a "Black disease" (Bediako, 2009; Boyd et al., 2005; Gustafson et al., 2007; Long et al., 2011; Zimmerman et al., 2006). This study design acknowledges that there is a high incidence of SCD among other racial groups, including Americans of Hispanic descent from South America and the Caribbean, especially Jamaica and Cuba, as well as Americans from Asia, especially India and Thailand; the Middle East, especially Saudi Arabia; and the Southern European countries of Italy and Greece (Treadwell et al., 2006).

Furthermore, this study is significant because findings may lead to positive social change. Results may provide justification for increased SCD education among college students and lead to the development of increased health education interventions on college campuses. College campuses may serve as effective sites for health education relating to this disease. In many research studies developed to address SCD screening and counseling, 18 years and over has been the target age group because individuals are more likely to make reproductive decisions after age 18 (Gustafson et al., 2007; Lang et al., 2009; Long et al., 2010). Health education focusing on college students' beliefs, attitudes, and behavioral factors relating to SCD screening may empower individuals to know their risk of SCD and make informed decisions based on knowledge of their status,

which may improve their quality of life and reduce transmission of the disease. Such information may be of immense value to future public health program practitioners who wish to develop prevention programs for SCD or any other chronic disease.

Summary

The study addressed a gap in the literature by using a quasi-experimental approach to test the impact of SCD education on intent to undergo SCD screening and genetic counseling for those at risk. There has not been as much attention paid to increasing awareness about SCD and SCT by way of education for college students, who are often in their prime reproductive years and unaware of their SCD status. The main objective of this study was to determine whether health education about SCD increased participants' knowledge about the disease, impacted participants' attitudes about it, and motivated college students who may be at risk of transmitting the disease to undergo screening and genetic counseling. Health education may be a way to reduce the transmission of SCD.

Chapter 1 covered the introduction, problem statement, nature of the study, purpose of the study, theoretical framework, and significance of the study, as well as definitions of terms, limitations, and delimitations. In Chapter 2, I discussed the peer-reviewed studies relating to SCD and factors impacting disease transmission as well as prevention. Ch. 2 further presents how constructs of the *Health Belief Model* such as perceived susceptibility, perceived severity, perceived barriers and perceived benefits have been used to explain SCD transmission as well as prevention. In Chapter 3, I discussed the study methodology in detail. In chapter 4, the results of the data analysis

were presented, and in chapter 5, I discussed recommendations, implications for social change and conclusion.

Chapter 2: Literature Review

Introduction

This chapter presents findings from a review of current literature that focused on the factors that impact SCD screening and the intention of college students and young adults to seek screening or genetic counseling, as well as the motivation of those at risk to talk about SCD with their prospective partners. All the studies included in this review are peer-reviewed journal articles that were obtained from the following sites: Walden University Library, Medline, CINAHL, PubMed, Cochrane Library, CDC, and the National Institutes of Health (NIH). A deliberate effort was made to include the most recent studies, defined as studies published within the past few years from 2005, and to exclude studies published before 2005. However, it was necessary to include a few studies published before 2005 because such studies present groundbreaking research findings about prevention strategy or effective treatments for those who have SCD. A few studies before 2005 that were included represent major breakthroughs in the approximately 100-year effort to find a cure and treatment for those who have SCD. This review of literature examined various peer-reviewed articles on SCD and SCT.

Method, Overview and Results of Literature Search

Selection Criteria

This review focused on articles that (a) explored efforts to prevent SCD, (b) explored factors that influence SCD knowledge and attitudes of college students and

young adults toward screening and genetic counseling, (c) focused on the quality of life of SCD patients, (d) evaluated the national newborn screening program, and (e) reviewed numerous treatment strategies.

Search Terms for the Literature Review

The search terms that were used to locate articles included *sickle cell disease, sickle cell trait, treatments for sickle cell disease, sickle cell disease transmission, education about sickle cell disease, awareness about sickle cell disease, religion and sickle cell disease, attitudes about genetic screening for sickle cell disease, perceptions about sickle cell disease, socioeconomic status*, and *sickle cell disease transmission*.

Method of Review

The method used for this literature review was the thematic approach. This approach was necessary because there were many aspects of this disease, and I found it useful to sort the selected journal articles according to topic. In this case, the subthemes that emerged as important influences that impact screening, transmission, and treatment were age and SCD, education and SCD, gender and SCD, religion and SCD, and socioeconomic status and SCD. These variables are discussed further in this chapter.

Overview of SCD

SCD is a genetic blood disorder that affects more than 100,000 Americans at any given time (CDC, 2003a; Lanzkron et al., 2008). Other studies have given SCD incidence estimates as high as 104,000 to 138,900 in the United States (Hassell, 2010). According to the CDC, one in twelve African Americans has the SCT; this means that more than 3

million Americans have the sickle cell trait (CDC, 2015h; Creary et al., 2007; Gallo et al., 2010; Grant et al., 2011).

SCD is the most common genetic disease in the United States (Toni-Uebari & Inusa, 2009) as well as in the world (Andemariam, Bellini, Bona, Delaney, Odesina, Leger et al., 2010). SCD impacts many systems of the body, such as circulatory and respiratory, resulting in many chronic medical conditions. No cure for SCD is universally accepted, mainly because none are without side effects (Creary et al., 2007). The lack of a cure without side effects as well as the high cost of medical care and the high mortality associated with the disease were the primary reasons for the call for more SCD education to increase awareness among the general population, thereby encouraging screening and ultimately prevention.

In 1972, President Nixon signed an order that added SCD to the list of diseases for which children are screened at birth. Screening is credited with improving early detection. Early detection has made early intervention possible, and this has improved the chances of newborns surviving beyond infancy (Creary et al., 2007; Dyson, Atkin, Culley, Dyson, Evans, Rowley, 2010: Pack-Mabien & Hynes, 2008; Serjeant, Mason, Hambleton, Fisher & Higgs, 2008). Most individuals diagnosed with SCD who survive past infancy are more likely to have an abbreviated lifespan that is several years lower than that of Americans who do not have the disease (Dyson et al., 2010; Pack-Mabien & Hynes, 2008; Serjeant, 2008). The increase in the lifespan of SCD patients is attributable to medical research that has led to improvements in the medical care of SCD patients. In a study conducted by Yu et al. (2009), findings showed that in 1973, the typical patient

with SCD lived to the age of 14 years, with most succumbing to the numerous medical complications associated with SCD.

According to the CDC (2011), the prevalence of SCD among the major racial groups in the United States is as follows:

Table 1

Prevalence of Sickle Cell Disease by Race or Ethnic Group

Race or ethnic group	Average prevalence per 100,000 live births
Caucasian	1.72
African American	289.00
Hispanic—Eastern states	89.8
Hispanic—Western states	3.14
Asian	7.61
Native American	36.20

Note. From "Table 2. Prevalence of sickle cell disease by racial or ethnic group, per 100,000 live births, United States, 1990 and unspecified years," in "Newborn Screening for Sickle Cell Disease: Public Health Impact and Evaluation," by R. S. Olney, in ,*Genetics and Public Health in the 21st century*. Atlanta, GA: Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention.

In addition, the CDC reported that 1 in every 36,000 Hispanic American newborns and 1 in 500 African American newborns have SCD (CDC 2011). Data on the prevalence of children born with SCD among other races in the United States are limited. This omission has helped to perpetuate the belief among people that SCD only affects African Americans. Increased education about SCD and SCT could provide a major

boost for primary prevention strategies and approaches to reducing the prevalence of SCD (CDC, 2012).

The major manifestations of SCD are frequent severe pain episodes that are known as *SCD crises* (Cole, 2007; Creary et al., 2007; Lanzkron et al., 2008). Treatment for vaso-occlusive episodes typically includes hospitalization and blood transfusions. The other complications of this disease are anemia, iron overload, strokes, splenic infarction, pulmonary hypertensions, vision problems, leg ulcers, and sexual problems such as priapism (Creary et al., 2007; Raghupathy & Billett, 2009; Raghupathy, Manwani & Little, 2010). The severity of the disease is determined by the onset of treatment, the medical care available to SCD patients, and the disease variant.

There are as many as six variants of SCD (Kenner et al., 2005; Pack-Mabien & Haynes, 2007; Shenoy, 2007). The best known of these variants is the variant known as HbSS. This variant causes the most severe form of SCD (Kenner et al., 2005; Pack-Mabien & Haynes, 2007; Shenoy, 2007). The next variant is the HbSC. This variant causes a mild form of sickle cell disease (Kenner et al., 2005; Pack-Mabien & Haynes, 2007; Shenoy, 2007). The variant HbS beta thalassemia occurs in two forms (Kenner et al., 2005; Pack-Mabien & Haynes, 2007; Shenoy, 2007). The HbS beta 0 causes a severe form of SCD, and the HbS beta + causes a mild form of SCD (Kenner et al., 2005, Pack-Mabien & Haynes, 2007; Shenoy, 2007). The variants HbSD, HbSE and HbSO all cause SCD disease with varying degrees of severity (Kenner et al., 2005, Pack-Mabien & Haynes, 2007; Shenoy, 2007). The large number of variants makes the disease

unpredictable and a source of frustration for researchers who seek to manage it or find a cure (Shenoy, 2007).

SCT variants are unique to particular regions in Africa, Asia, Europe, North and South America. There is a high prevalence of SCD in Africa, South America, Europe, several countries in the Middle East and in some countries in Asia such as India, and Thailand (Townes, 2008; Weatherall, 2005). Though, this disease occurs at varying prevalence globally, its incidence is particularly high among people of African descent. In places such as Nigeria, more than 150, 000 newborns are diagnosed with SCD every year (Abioye-Kuteyi et al., 2009).

In the United States estimates of newborn diagnosed with the disease varies from 1000 to 8000 annually. There are no definitive morbidity data of deaths attributable directly to SCD in the US, but a 2004 report produced by the US Agency for Healthcare Research and Quality (AHRQ) showed that in 1997, there were 516 deaths, in 1998 there were 758 deaths and in 2004 there were 746 deaths that were directly attributable to SCD. The report explains the difficulty in obtaining data for mortality that occurs outside the hospitals. The report also acknowledged that many deaths that result from complications of SCD may not be attributed to SCD (Steiner & Miller, 2006).

Efforts to reduce SCD morbidity and mortality dates back to 1910. Almost 100 years, ago, a young student from Guyana was found to have a medical condition that puzzled his doctors in a Chicago Hospital (Frenette & Atweh, 2007). The medical research which started more than 100 years ago has led to evidence based findings on how the disease is transmitted. The ongoing medical research has also identified the

medical problems that afflict those who have the disease as well as continue efforts to, improve treatment strategies, find a cure and ultimately improve the quality of life and increase the life span of SCD patients. Progress has been made in many areas related to SCD, especially in pain management and the reduction in infant mortality (Frenette & Atweh, 2007).

In spite of the advances made in the medical management of SCD, victims are still likely to experience painful crisis that almost always require hospitalization, blood transfusions and side effects which are associated with frequent blood transfusions. One such side effect is iron overload which has been shown to accelerate the damage of the internal organs of those patients who have sickle cell disease (Raghupathy, Manwani & Little, 2010). In spite of more than 100 years of medical research to find a cure there is still no definitive treatment that is accepted universally as effective and without side effects (Frenette & Atweh, 2007). SCD patients continue to experience crisis and are susceptible to numerous medical problems and premature mortality leading to a wide array of medical strategies proposed, developed, tried and under trial as a remedy and or cure for SCD (Creary et al, 2007).

Efforts to reduce disease prevalence, mortality and morbidity appear to be hampered because of contradictions in institutional policies. For instance, the decision to screen newborns has been in place in the US since 1987, yet according to Parker et al (year?), the Federal Government policy 38 U.S.C 7332 (Federal Register) forbids disclosure of the results of genetic screening. There is no universal policy on how the carrier status result is to be disseminated to those who were screened. Many become

young adults and are unaware of their SCT status. The 2006 study by Treadwell et al. showed that young adults often do not know their SCT status (2006). Furthermore, there are those who are opposed to screening, who are opposed to disclosure of carrier status, and those who consider screening and genetic counseling as tantamount to birth control and possible discrimination in employment and insurance (Parker et al, 2007; Treadwell et al., 2006).

A major reason that hampers the efforts of those who wish to advocate for prevention is the lack of definitive data on mortality and morbidity. The various journal articles used for this review have given estimates of individuals with SCD as low as 75,000 to 90,000 (Pack-Mabien, 2009) and as high as 138,900 (Hassell, 2010). The lack of reliable data could be a barrier to efforts to develop a cohesive prevention strategy. Recently, the CDC inaugurated a registry and surveillance system for hemoglobinopathies (RUSH) to collect current data on incidence and prevalence of SCD (CDCd, 2011).

Results of Literature Search

The majority of articles I reviewed about SCD focused on ways to improve existing treatment for the disease and others focused on new treatment approaches. A few of the articles discussed the need for more awareness about the disease in their introductory paragraph, but ultimately the research studies focused on the effectiveness of a particular treatment method that the researchers favored without much discussion about the side effects. For instance many of the articles focused on treatments such as blood transfusion, and medications such as penicillin and hydroxyurea and their ability to

improve disease management and the quality of life of SCD patients (Brawley, et al., 2008, Creary et al., 2007, Lanzkron et al., 2008). Many of these articles advocated for surgical interventions such gene therapy, blood cord or bone marrow transplantations. These articles did not always put into account the historical experience and cultural appropriateness of their preferred approach. Many other articles barely acknowledged primary prevention strategies such genetic screening, genetic counseling and the role of causal factors such as the sickle cell trait. Many of the articles that mentioned sickle cell trait, newborn screening, and genetic counseling did so in the introduction to their study or as recommendations for future studies. Overall, many of the articles reviewed briefly discussed prevention and other factors that constitute barriers to widespread adoption of preventive strategies for the reduction of the prevalence of SCD.

Prevention

One of the more significant breakthroughs in the history of SCD research is the work of Linus Pauling who noted in 1945 that SCD is the result of a defect in the hemoglobin molecule (Frenette & Atweh, 2007). The hypothesis that made the causal connection between the disease and hemoglobin disorder is credited with the advances in understanding how SCD is transmitted (Frenette & Atweh, 2007). Pauling's research into SCD shaped his advocacy for primary prevention even though at that time his views that people with SCD and SCT should be branded on their forehead. This suggestion proposed by Pauling reinforced the concerns of African Americans and other minorities had about screening as a disease prevention strategy. The perception that screening can reveal an individual's SCT leaving them open to discrimination in employment, in the

issuance of life, and health insurance policies is common among African Americans who are familiar with the Tuskegee Syphilis Study (Zimmerman et al., 2006). Though many researchers support prevention efforts there are no records of any who openly supports the kind of action recommended by SCD researcher Linus Pauling whose research provided the breakthrough explanation of how SCD is transmitted (Zimmerman et al., 2006.)

Understanding the mode of transmission of SCD has motivated many researchers to recommend genetic screening and genetic counseling as a way of reducing the prevalence of SCD (Abioye-Kuteyi, 2009, Gallo et al., 2010; Pack-Mabien & Haynes, 2009). The mode of transmission of SCD is predictable (Gallo et al., 2010). The odds of being born with SCD are well documented. A couple with SCT will have 25% chance that every pregnancy will result in a newborn with SCD, 25% chance that every pregnancy will result in newborn having neither the disease nor the trait; and a 50% chance that the newborn will have SCT (Creary et al., 2007; Gallo, 2010; Treadwell. 2007). Many studies agree that screening is a good first step in identifying newborns with SCD and SCT which makes early intervention possible (Abioye-Kuteyi et al., 2009; Creary et al., 2007; Frenette & Atweh, 2007). The study by Abioye-Kuteyi et al., 2009 concluded that genetic testing and screening are "the only realistic approach to reduce the impact of the disease" (p. 1). Despite such strong recommendation for screening, not all segments of society embrace genetic screening as a strategy to reduce disease transmission.

Importance of prevention In spite of more than 100 years of medical research, there is still no universally accepted cure for SCD. The incidence of SCD has not decreased over the years (Ogamdi, 1976). In view of the fact that the prevalence of SCD has remained over the years, prevention programs such as increased awareness, screening and genetic counseling could become the primary approach to reducing the prevalence of SCD among all at risk populations. There are examples of countries that adopted prevention programs and after several years they recorded significant drops in incidence of newborns with SCD.

In 1992, the nation of Bahrain began a program that focused on screening and providing education about SCD to all its citizens of child bearing age. In 1993, the premarital counseling for individuals commenced and this became mandatory in 2001. In 1998 widespread screening of students began. Students who were screened received a card that identified the genetic disease that they were susceptible and they also received a booklet about the genetic disease. In 2002 between February and April, 2000 newborns were tested at birth. Five of the samples from the newborns could not be used because the blood had clotted. Out of the remaining 1995, only 18 had SCD while 335 had SCT. The researchers compared these results to a similar one carried out in 1984/1985 when screening and genetic had not commenced. In 1984/1985, 217 newborn were found to have SCD. The reduction of newborn with SCD from 217 in 1984/85 to 18 in 2002 represented a 60% decrease in the incidence of newborns diagnosed with SCD in Bahrain (Arrayed, 2005)

Saudi Arabia has also inaugurated a program that mandates premarital genetic screening for all couples planning to get married. Couples who were found to be at risk for SCD were informed that they were at risk to have children with SCD. Though the decision to cancel marriage plans were left to the couple, the 2011 study by Memish and Saeedi reported that 60% of at risk couple canceled their marriage plans. While mandating genetic screening and counseling as condition for getting a marriage license may be acceptable in Saudi Arabia, it certainly will trigger ethical concerns in the US (Memish & Saeedi, 2011).

In the US, the SCD National Control Act established newborn screening nationwide (Boyd et al., 2005), but I am not aware of any U.S. law that mandates that individuals with SCD and SCT should undergo genetic screening of genetic counseling prior to marriage. So far in the US, decisions to undergo screening or genetic counseling are voluntary. In a 2007, researchers Gustafson, Getting, Watt-Morse, and Krishnamurti found that African American college women in the study believed that screening was necessary and useful, even if they did not think that either they or members of their family could be affected by the disease (Gustafson et al., 2007). The study by Gustafson et al. suggests that SCD education may impact college students and young adults' attitudes about SCD screening. This finding that SCD education can impact the attitudes of college students and young adults is important because current data show that 1 in 12 African Americans have SCT (CDC, 2012, NIH #96-4057, 2005). Due to the fact that so many Americans have SCT, increased SCD education could increase awareness and

understanding about SCD disease prevalence and severity, and this ultimately can impact the screening behavior of college students and young adults (Creary et al., 2007).

Screening

Screening for SCD is a simple process that begins when a small blood sample is obtained from the patient (Vasava, Srivastava, Chudasama & Godara, 2009). The blood is subjected to a process known as electrophoresis and from the readings physicians are able to determine who has SCD and who have the trait (Vasava et al., 2009). In the case of newborns the blood samples are obtained shortly after birth and subjected to same process described earlier (Vasava et al., 2009). Usually, the parents of a SCD patient are informed about the diagnosis before the newborn is discharged to their care. Though newborn screening is mandated in the US, premarital screening is not, nor is genetic screening. In Saudi Arabia, premarital screening is mandatory, and if the test reveals that a couple intending on getting married have the trait and are at risk for having children with SCD, they are referred for genetic counseling (AL-Sharani, 2009). Whether or not they get married and have children is their choice. The health department does not attempt to prevent them from getting married or having children (AL-Sharani, 2009). In the US genetic screening and genetic counseling produced a 92% decline in the incidence of newborns diagnosed with Tay-Sacs disease (Kaback, 2000; Kaplan, 1998). Tay- Sacs is a genetic disorder that primarily affects people of Jewish descent. The Jewish community in the Northeastern part of the United States utilized screening and genetic counseling as cornerstone of their efforts to reduce Tay-Sacs disease (Kaback, 2000; Kaplan, 1998). The community's religious leaders were able to motivate their

congregation to agree to screening and genetic counseling. Over the years there was a steady decline in the incidence of Tay-Sacs disease which was attributed to preventative efforts (Kaback, 2000; Kaplan, 1998). While genetic testing and genetic counseling were successfully implemented in the Northeast US Jewish communities, there are barriers to screening for genetic diseases and other medical problems (Deeks, Lombard, Michelmore & Teele, 2009; Regan & Durvasula, 2008; Stamatiou, Skolarikos, Heretis, Papadimitriou, Alevizos, Ilias et al., (2008)

Barriers to Screening

Attitudes. Attitudes to screening are impacted by many factors besides awareness about SCD/SCT. Even among those who are aware about SCD/SCT, factors such as age, ethnicity, gender, religion and socioeconomic factors all contribute to impact the decision to screen, undergo genetic counseling and discuss SCD/SCT with other people in their lives.

Lack of awareness. The importance of increased awareness about SCD/SCT was highlighted in a 2005 study by Boyd et al., The researchers found that 30% of African American women in that study did not have any awareness of SCD neither did they know about their status. In a major study conducted in 2007, Stamatiou et al., were interested in finding out how increased awareness can make a difference in whether or not individuals agreed to undergo prostate cancer screening among men. There were 1,167 participants included in the study who were between 50 and 86 years old. The participants were divided into two groups with 580 in a group that received that received printed information prostate cancer and 587 participants made up the non-informed group which

did not receive any printed information. These participants were followed for 24 months and at the researchers reported that 93% of the informed group has undergone prostate cancer screening, only 31% of the non-informed group had undergone prostate cancer screening. This study confirms the fact that providing education about a health condition will increase awareness and increased awareness can ultimately lead to a disease prevention strategy such as seeking screening (Stamatiou, Skolarikos, Heretis, Papadimitriou, Alevizos and Ilias et al., 2008). Since research has established that SCD is preventable if individuals are aware of their SCT status and undergo genetic counseling (Creary et al., 2007), then it is important for programs to be developed on college campuses to increase awareness about SCD/SCT.

Several research studies such as those by Acharya et al., (2009); Boyd et al., (2005); Gallo et al., (2008) and Treadwell et al. (2006) have recommended that efforts to prevent SCD should target college students in order to impact their reproductive decision making. Though, having awareness about a health condition may not always mean that individuals will take a preventative approach. In a 1991 study by Rowley et al., the researchers conducted a prospective study on pregnant women in Rochester, New York. The researchers reported that 60% of all the participants who were pregnant were unaware of their SCT status (Rowley et al, 1991; Treadwell et al., 2006).

Increased awareness will also help college students and other young adults to understand that SCD/SCT is not a “Black People Only “problem but that people in all continents are affected. The current perception among many that SCD/SCT is a Black people problem could change with increased awareness about SCD/SCT. This change

could lead to a change in attitude among college students and young adults and lead to them embracing a screening behavior. In order for prevention to become a viable approach to reducing the prevalence of SCD, this study will explore if SCD/SCT education will motivate individuals to take certain actions such as screening that may ultimately impact the decision they make regarding reproduction.

In 2011, a study was conducted on 195 pregnant young adults between ages 13 and 18 in the state of Michigan. In that study, O'Brien et al. found that 59 out of the 195 participants had SCD. One of the ground breaking outcomes of this study is that the 59 SCD patients who were pregnant were not aware of the SCD status of their romantic partners (O'Brien, Klima, Reed, Chisholm, Schwarz & Kelleher, 2011). Since newborn screening is conducted in Michigan, it is very likely that these participants are aware of SCT because they themselves have SCD. But it appears that having the SCD or SCT did not seem to have motivated these young adults to consider their risk factor when they made the decision about reproduction. This study supports the view that there is low awareness about SCD among young adults (O'Brien, Klima, Reed, Chisholm, Schwarz & Kelleher, 2011). In 1994, a study conducted in Houston, Texas, Ogamdi found that among 20 to 25 year old university students, 60% of the participants did not know that SCD is a preventable disease. While the study by O'Brien et al. in Michigan highlights the lack of awareness among those 18 and younger, the one conducted by Ogamdi in Texas highlighted the lack of SCD awareness among college students and young adults over 18 years.

Ethnicity/racial discrimination. Some opponents of genetic screening have compared this practice to the racial purity policies advocated by the Nazi regime in Germany (Dyson, Atkin, Culley & Dyson, 2007). Many among individuals at risk for SCD and stakeholders who oppose screening and genetic counseling continue to view these prevention approaches negatively. They go as far as comparing prevention policies to genocide because of the misconception that when a fetus is suspected to be SCD then an abortion will be recommended (Konote-Ahulu, 1991). Comparing preventative actions to genocide may not find much support but many people are sensitive to any attempt that they perceive as encouraging the termination of a pregnancy or promoting birth control. In the African American communities, sensitivity is partly invoked by existing health disparity and events such as the Tuskegee Syphilis Study that deliberately denied medical care to African Americans and watched them die slowly to a disease for which treatment was available (Zimmerman et. al., 2006).

Whether or not there is an association between Tuskegee Syphilis study in particular or one's racial identity in general and an individual's mistrust of the healthcare is not the objective of this current study (Shelton, Winkel, Davis, Roberts, Valdimarsdottir, Simon et al., 2010). However, in a study whose objective was to "investigate the psychometric properties of the Group-Based Medical Mistrust Scale (GBMMS) in a Black Male sample" (p. 549). Shelton and colleagues recruited 201 men of African American descent. The GBMMS is a test that was developed to measure discriminatory experiences and reports of mistrust of the healthcare system by members of different racial groups (Shelton et al., 2010). This study focused on factors that impact

the attitudes of these participants to prostate screening. Study participants completed self-administered questionnaire at the end of which they received a small stipend. The researchers found that men without a regular health care provider had high scores on the GBMMS compared to men who had a regular medical provider (Shelton et al., 2010). The researchers also reported that the participants who had been seen by a physician in within the past year had lower scores on the GBMMS scale. In addition, the authors reported a negative correlation between GBMMS and attitude to prostate cancer screening as well as between GBMMS and suspicion of the health care system (Shelton et al., 2010). The authors concluded that the participants who had high GBMMS scores had higher mistrust of the healthcare system and those who had higher mistrust also were the ones who declared a strongest identification with their racial group (Shelton et al., 2010).

Whether or not to disclose the results of trait status is a source of contention among researchers, policy makers and healthcare providers. Many in communities at risk for certain genetic diseases are distrustful of attempts to disclose SCT status because of associated discrimination, real or imagined. Many individuals outside the African American communities continue to hold the erroneous view that SCD is a “black disease” (Miller, Paynter, Hayeems, Little, Carroll, Wilson et al., 2010, Parker & Quereshi, 2007). This is contrary to CDC data which shows that all races in the US are susceptible to SCD and SCT. Nonetheless, there are advocates who are still opposed to disclosure of trait status because of fears that the results could serve the purpose of those who advocate “coercive reproductive politics” (Treadwell et al., 2006 p.705).

There is an official US policy regarding how SCT status should be disseminated. This policy is addressed in the bill titled Confidentiality of certain medical records located in the United States Code as Section 38 U.S.C 7332 of. This law prohibits the disclosure of information about drug abuse, alcoholism, alcohol abuse, HIV infection and Sickle Cell Anemia (US Federal Register). The National Academy of Sciences recommends that "based on the principles of autonomy, privacy, confidentiality and equity, disclosure of genetic information and genetic testing should not be mandated" (Zimmerman, 2006, p. 375). Many who are opposed to disclosure of SCT status cite reasons such as discrimination in issuance of insurance policies, and as a factor in determining participation in organized sports (Dyson et al., 2010, Parker, 2007; Treadwell et al., 2006). Others have wondered if it was possible to screen for SCD at birth, without the test revealing whether or not the patient being screened also has SCT (Parker et al., 2007). This is particularly of significance to young adults because NCAA, a major college sports organizer now mandates that all would be college athletes must be screened before they are allowed to participate in organized sports. The implications of this mandatory screening are that those who are found to be SCD or SCT may be barred or allowed to participate in sports with restrictions. The requirement of mandatory screening did not factor in the fact that all SCT are not the same. A new NCAA policy which restricted college athletes with SCT from participating in sports did not appear to have factored in the variance in sickle cell traits. The recognition that variance in sickle cell trait was important emboldened critics who called for the repeal of the NCAA sickle cell law on the grounds that it unfairly penalized athletes just because they have the

disease trait, which except in exceptional situations such as high altitude or extreme weather does not cause carrier any medical problems (Treadwell et. al., 2006).

Religiosity. For many individuals their religious beliefs provide the compass for all decisions that they make from the food they eat to the way they dress. Whether or not individuals agree to undergo genetic screening or genetic counseling can be influenced by their religion worship day to day. How these individuals interpret the objectives of screening or genetic counseling can be influenced by their religious background. The connection of screening to genocide is relevant because many individuals especially African Americans and Hispanics who are prospective parents assume that when genetic screening or medical test reveal that a pregnancy will result in a child with SCD, there is the perception that an abortion was expected (Zimmerman et al., 2006). Zimmerman et al. also found that African Americans are less likely than other groups to consider abortion even when the unborn is suspected of having a genetic disease. In 2006, a study by Zimmerman et al. found that 83% of African Americans in that study stated that religion "influences their lives quite a lot" (Zimmerman et al., 2006, p. 376) and screenings and abortions were like "playing God" (Zimmerman et al., 2006, p. 376). Among Hispanics, their religious background impacts many decisions that they make. In the case of genetic screening, the majority of Hispanics will refuse to terminate a pregnancy because of suspicion of a genetic abnormality (Zimmerman et al., 2006)

In a recent study that was conducted in fulfillment of requirements for an MPH degree, researcher Lopez conducted a survey of the attitude of 6541 Latina female to breast cancer screening. The study sought to explore if an individual's religiosity impacts

their willingness or desire to undergo breast cancer screening. The researcher reported that participants who said religion was very important to them were more likely to undergo cancer screening (Lopez, 2010). In another study, Gullate and colleagues sought to investigate if an individual religiosity influences their attitude toward treatment of a cancer diagnosis. The researchers recruited 129 women between the ages of 30 to 84 and they completed a self-report questionnaire. The researchers reported that the participants who were more likely to delay seeking medical treatment of their medical condition were those who were highly religious because they were more likely to talk to God before seeking treatment thereby causing an average of 3 months delay in seeking treatment for their medical condition (Gullatte, Brawley, Kinney, & Mooney, 2010).

Amniocentesis is a procedure that can detect a genetic disorder in a fetus (Gallo et al., 2010). Amniocentesis is an option for those who are pregnant and are unsure whether their unborn child may have SCD or any other genetic abnormality. In their 2010 study, Gallo and colleagues offered participants who were pregnant an opportunity to undergo amniocentesis but most of them refused the test because they were afraid it may harm their unborn child. They were willing to have the child even if it had SCD. Some of the participants based their reluctance on the fact that they did not "believe in abortion" (Gallo et al., 2010, p.1085) or because of religious or personal opposition to abortions (Gallo et al., 2010). Again, as with genetic screening and counseling, the general perception is that abortion is the expected outcome when a fetus is suspected to be SCD or SCT (Gallo et al., 2010).

Allen et al. (2012) sought to measure the level of religiousness and how it influences screening behavior among church going Latina women in Boston, Massachusetts. The researchers recruited 78 Latina women who were selected based on religiousness determined by their church participation as well as their claim to being very religious. The minimum age for participants was 18 and above. The participants were to be judged on whether or not they been screened for mammography, Pap test or colonoscopy at the recommended age. The researchers reported that 46% of the study participants have not been screened for all the health conditions at the recommended age. Though role of religiousness was the primary focus, the study showed that other variables such as income and access to health care are also capable of impacting the decision to undergo screening (Allen, Perez. Pischke, Tom, Juarez, Ospino et al., 2012).

Age. In 2008, Regan and Durvasula conducted a study to investigate the predictors of breast cancer screening behavior among Asian and Latina university students (Regan & Durvasula, 2008). The researchers recruited 240 participants, all of whom were 18 years of age or older (M age=20.15 years SD=3.91 years). The participants completed a 38 item questionnaire on how they perceive their susceptibility to breast cancer and their desire to seek screening. The researchers found that sexual activity was the most consistent predictor of positive screening behavior. The researchers attributed this to the likelihood that participants who were sexually active were also more likely to seek medical attention during the process of seeking contraception or general gynecological health care. However, the researchers found that older women of Asian descent were more likely to seek screening for breast cancer (Regan & Durvasula, 2008).

Though the study did not claim to know why age influenced breast screening besides the fact that the older a woman is the more likely she is sexually active. However, these researchers did acknowledge that previous studies have identified perceived barriers such as embarrassment and discomfort with the procedure as perceived barriers that may become less of an impact as an individual grows older (Regan & Durvassula, 2008).

Another study conducted in 2009, Katapodi et al. sought to estimate the accuracy of women's perception of their cancer risk. This study recruited 184 participants who completed a questionnaire that was designed to measure their perception about getting breast cancer. The researchers reported that older women were more likely than younger women to have undergone screening. The researchers also reported that 80% to 96% of all the participants in the study underestimated their cancer risk which constitutes a barrier to seeking screening (Katapodi, Dodd, Lee & Facione, 2009).

In 2009, Deeks and colleagues conducted a cross sectional study to explore the effects of gender and age on the health behaviors of individuals (Deeks, Lombard, Michelmore & Teede, 2009). The researchers recruited 1456 participants but only 866 completed a self-administered survey. The researchers reported that 13% of participants were less than 30 years old; 18% were between 31 and 40 years old; 20% were 41 to 50 years old ; 22% were 51 to 60;17% were 61 to 70 and 10% were 70 years or older. The researchers found that younger people were less likely than older participants to undergo annual health checkup and were therefore less likely to seek screening. Specifically, the data showed that participants who were 51 years and older were more likely than younger individuals to seek screenings for the following health conditions: breast cancer, prostate

cancer, cholesterol, blood pressure and blood glucose. The researchers reported that the only exception was that younger participants who were female more likely than the older females to seek pap smear regularly (Deeks et al., 2009). The researchers also reported that the older participants were more likely than the younger ones to have made plans for their future health care (Deeks et al., 2009).

Gender. According to the findings of a 2010 study that sought to measure public awareness about SCD in Bahrain, Al Arrayed and Al Hajeri, found that women were more knowledgeable about SCD than men (Al Arrayed & Al Hajeri, 2010). This study recruited 2000 participants made up of professionals and members of the general public. The participants comprised of 1,106 females and 894 males. All participants were interviewed by a trained professional who assisted in completing a questionnaire. The researchers claimed 100% response rate (Al Arrayed & Al Hajeri, 2010).

The researchers reported that female participants answered more questions correctly and concluded that overall females had more knowledge about SCD/SCT than their male counterparts in the study (Al Arrayed & Al Hajeri, 2010). This finding was considered relevant to my study because even though the target group was college students, studies such as this further point to the fact that for the purposes of designing programs that can enhance prevention, the primary focus should not be females but instead it should be males.

However, a 1991 prospective study by Rowley et al. showed that pregnant females who are aware of their risk to have a child with SCD may or may not agree to have their partner tested for SCD/SCT. In this study conducted in the Rochester, New

York area, the researchers sought to find out how receptive pregnant women were to screening and for those at risk to be referred for genetic counseling. Over a 5 year period, the researchers obtained and tested blood samples of pregnant women provided by several area health care clinics. Among the samples tested 810 showed the presence of 21 different types of hemoglobinopathies, out of which 59% were SCT. Among the 453 pregnant women with SCT, 390 or 86% were willing to have their partners screened. The researchers reported that 254 or 55% were actually screened. The researchers reported that 209 or 45% were not screened due to many reasons including refusal by the patient or by the prospective father (Rowley et al., 1991). This could be a major setback for the advocates of screening and genetic counseling because in many communities women exercise more influence than men over decisions about reproduction. So it is difficult for advocates of prevention to understand why as many as 45% of pregnant women did not ensure that the prospective father of their child was screened (Rowley, 1991; Treadwell et al., 2006). This study also supported the fact that a fairly large percentage of men do not get involved in making reproductive decisions. For this study it will be important to ensure that there are an equal number of male participants so that one can have a better understanding of the variables that significantly affect the decision to seek screening or genetic counseling.

Socioeconomic status. In their 2000 study, Haque and Telfair found that individual's socioeconomic status were factors that impacted educational background and disease awareness. In that study Haque and Telfair (2000) found that an individual's socioeconomic status affected their ability to utilize medical care when such facilities are

few and far away. This problem is exacerbated in the case of individuals who live in rural areas far from clinics or hospitals. By extension, these same individuals will likely have limited education which means that he or she will have little or no awareness about SCD/SCT (Haque & Telfair, 2000).

In their 2009 study, Deeks and colleagues sought to investigate the effects of gender and age on the screening behaviors. The researcher surveyed 866 participants and the result of this survey showed that young people were less likely than older people to seek screening. These researchers made an important discovery relating to the socioeconomic variable. The researchers reported that participants in this study indicated that their health was a top priority and that they feared having health problems more than they feared having financial problems. The researchers reported that despite the concern about poor health most of the participants had made very careful plans for their financial "health" yet no such plans had been made for their health (Deeks, Lombard, Michelmore & Teede, 2009). The researchers did observe that many financial plans are associated with retirement benefits that are provided by employers (Deeks et al., 2009).

The role of socioeconomic status was discussed in an article by Lee et al. (2010) who explored the factors that influence the screening behavior of Asian and Latina women in California. This 2010 publication was a review of the merged data of 2001, 2003 and 2005 obtained from California health survey of Asian and Latina women. The study reported differences among the Asian and Latina women with regards to race, and education and incomes. With regards to socioeconomic status which was measured by family income, the researchers reported that the participants with higher income, which in

addition to family, was further evidenced by having health insurance, were more likely to undergo screening for cancer or other genetic disease (Lee, Ju, Vang & Lundquist, 2010).

In another study that highlighted the role of socioeconomic factors as an influence on screening behavior, Maxwell et al., (2011) analyzed screening and pregnancy outcome data for provided by the health department of Western Australia. The pregnancy outcome data that was analyzed was for 35,142 women out of whom 92.3% were reported to have undergone screening before or during the pregnancy (Maxwell, Brameld, Bower, Dickinson, Goldblatt, Hadlow et al., 2011). The researchers reported two findings related to the role of a participant's socio economic status. The first influence was that screening behavior was very low among participants considered to be in the category classified as low socio economic status. The researcher also reported that screening behavior was much higher among those classified as been in high socio economic status. In addition, the researchers also reported that another indication of a positive correlation between high socio economic status and a likelihood of undergoing screening was the fact that many of the women who gave birth in private hospitals had also been screened. This is based on the inference that giving birth in a private hospital is an indication that the patient has health insurance and is therefore likely to belong to a higher socio-economic status (Maxwell et al., 2011).

In an another study that sought to understand the influence of socio-economic status on screening behavior, Dunn and Tan (2011) analyzed data obtained from Malaysia Non Communicable Disease Surveillance-1 cross survey that was conducted for the period 2005 to 2006. The objective of these researchers was to understand the factors

that influence screening behavior in Malaysian households. The researchers analyzed 916 women and found that there were different attitudes to screening among the different ethnic groups in Malaysia. However, the researchers reported that though there are differences among ethnic groups in Malaysia, the differences could not be attributed to socioeconomic factors. The researchers did state that several surveys did not include household income leading to them being omitted yet they admitted that there were widespread differences in access to resources (Maxwell et al., 2011).

Educational background. Educational background of an individual may determine his or her awareness level about SCD as well their attitude towards genetic testing and genetic counseling. In a 2009 study that measured the SCD knowledge and attitude towards screening by government employees, Abioye-Kuteyi et al., (2009) found that the participants who had more education were more knowledgeable about SCD. The study also reported that those who had more education also had better attitudes towards genetic screening and counseling than those who had less education (Abioye-Kuteyi et al., 2009).

Further support for education level as having a positive influence on screening behavior was provided by a study conducted by Stamatiou el al., (2008). Stamatiou and colleagues evaluated the impact of increased education about prostate cancer on the screening behavior of 1, 135 men who were recruited as participants. The researchers conducted a quasi-experimental study with two groups. One group comprising of 548 men received increased education, the other group comprising of 587 men who did not receive any education about prostate cancer. The researchers found that there was a

statistical significance between the educational level of the participants in the informed group and their knowledge about prostate leading to higher screening behavior. The researcher stated that there was also a statistical significance between educational level of the participants in the non-informed group and higher screening behavior. This study provides supports for the inference that an individual's educational level can influence a positive screening behavior (Stamatiou et al., 2008).

The impact of an individual's level of education on their screening behavior was also highlighted in the 2010 study by Al Arrayed and Al Hajeri. In this study, the researchers found that undergraduate score higher than graduate students in a questionnaire that was designed to test knowledge and attitudes towards SCD screening in Bahrain. The researchers explained this exception by stating that the screening program was a recent inclusion in the curriculum which was first presented to the current undergraduate students after the current graduates had completed their bachelor's degree program (Al Arrayed & Al Hajeri, 2008). The role of level of education was further restated in a study conducted by Katapodi et al., 2009. In that study, the researchers found that women with higher education were more likely to perceive that they are at risk for breast cancer as opposed to women with lower literacy level (Katapodi et al., 2009). In another study, Dunn & Tann found that an individual's educational level was a strong predictor of that individual's likelihood of seeking screening behaviors as a preventive strategy for breast cancer. The researchers stated further that for every additional year of higher education will increase the chances that an individual will adopt a screening behavior (Dunn & Tann, 2011).

The Importance of Health Education to Address Barriers

SCD is transmitted to newborns when both parents have the sickle cell trait. However, there is only a 25% chance that a newborn will inherit a defective trait from each parent. It is for this reason that providing SCD education to the general population will be an important step in reducing the prevalence of SCD. There is no universally accepted cure for SCD hence prevention is an important approach to reducing the prevalence of the disease. Providing SCD education to general population will increase awareness about the mode of disease transmission, which ultimately will reduce prevalence. The objective of this study is to explore the role of SCD education on the knowledge, attitude, perceived risk, and intention to seek screening and genetic counseling by college students of all races. This study is unique because previous studies have focused on African Americans.

Another reason why SCD education is important is the fact that when individuals become aware of their Sickle cell status those who have the trait are at risk will likely undergo genetic counseling prior to making reproductive decisions. The goal of screening and genetic counseling is to educate at risk population about their risk factor/s to provide an opportunity for early diagnosis, and intervention but also to motivate at risk couples to make informed reproductive decisions (Kenner, Gallo, Kellie, & Bryant, 2005; Lang, Stark, Acharya & Ross, 2009). In 2005, Boyd et al., conducted a study designed to gauge the knowledge level of African Americans about SCD. The study revealed that 30% of study participants who were of reproductive age did not know about SCD (Boyd, Watkins, Price, Fleming & DeBaun, 2005). In a 2006 study designed to evaluate

knowledge and perceptions among 282 participants, Treadwell et al. reported a high level of mis-information about SCD. In that study 17% of 257 African Americans participants believed that an individual can be infected with SCD during blood transfusion. They were wrong because SCD cannot be transmitted during a blood transfusion (Treadwell et al., 2006).

Existing SCD Resources and Programs

Over the years the CDC, NIH and other agencies have collaborated to produce educational materials that were designed to provide health education about SCD and SCT to individuals, researchers and other stakeholders. Several years ago the CDC designated the month of September as Sickle cell awareness month. In the month of September, many activities are organized nationwide to increase awareness about SCD. Many of the activities and events are sponsored by government agencies as well as stakeholders. During these events SCD educational resources are distributed to members of the public. More recently, a day in the month of June was designated by World Health Organization (WHO) as World Sickle Cell Awareness Day. World Sickle Cell Awareness day is marked all over the world and the objective is to bring awareness about SCD/SCT to the general public (WHOb, 2011).

The CDC, NIH and other agencies has also collaborated in organizing and hosting the inaugural National Conference on Blood Disorders in Public Health in 2010. A follow up Conference on blood disorder was held in Atlanta, Georgia in 2012.Other conferences in which the CDC and other US based health agencies have collaborated include the Conference on the Global Sickle cell disease network and the Worldwide Initiative on

Social Studies on Hemoglobinopathies which have been organized to increase awareness and for researchers to share ideas and data about SCD/SCT (CDCc, 2011; WHOb, 2011).

The CDC in collaboration with NIH has recently inaugurated a Registry and Surveillance System for Hemoglobinopathies (RUSH) "to collect state specific, population based data on people with SCD and thalassemia" RUSH will gather data on incidence, prevalence, trends in medical care, information relating to SCD disease complications and the mortality rates in designated states. This initiative has only been tested in the following states, California, Florida, Georgia, Michigan, New York, North Carolina and Pennsylvania. With time, more states may be designated as sites for RUSH (CDCb, 2011).

For more than ten years the CDC has designated certain medical facilities located in several parts of the country to serve as Comprehensive Sickle Cell Centers (NIH, 2011). Comprehensive Sickle Cell Centers serve as regional research and treatment centers for SCD and SCT. The major comprehensive sickle cell centers that receive CDC support and funding are located in Pennsylvania, Georgia, Memphis, Alabama, Dallas, and North Carolina (NIH). The access to SCD patients and ongoing research has contributed to the availability of so many treatment strategies that are have been proposed as interventions for SCD (NIH, 2011).

The Health Belief Model and SCD Screening

In the 1950s, three social psychologists namely Hochbaum, Kegels and Rosenstock who were employees of the US Public Health Services developed HBM (Denison, 1996). These public health employees were motivated to develop HBM as a

way of increasing the public's willingness to adopt new health behaviors. These public health employees sought a new way to encourage members of the public to seek screening in order to determine their susceptibility to a disease. The public health employees had acknowledged that their previous effort to provide free tuberculosis screening had failed because of a lack of interest of the public to seek screening for tuberculosis in the 1950s when tuberculosis was responsible for high morbidity and mortality in the US population. Despite the high morbidity associated with tuberculosis, those were most at risk for the disease did not take advantage of a free screening program. The developers of HBM were motivated to explore the factors that influence an individual to take an action related to their health (Rosenstock, Stretcher & Becker, 1988).

HBM is based on the premise that individuals will be willing to change a particular health behavior if they believe they are at risk, the condition is severe, and it would benefit them to change. Hence the core concepts of HBM are the individual's perceptions of the following:

1. The individual perceives that they are susceptible to a health condition.
2. The individual perceives the severity of the medical condition
3. The individual perceives the potential barriers to taking the recommended action.
4. The individual perceives the health benefit that will accrue from adhering to the recommended action (Rosenstock, Stretcher & Becker, 1994).

5. Cues to action such as a knowing a family member or neighbor with SCD or as a result of media publicity (Rosenstock, Stretcher & Becker, 1994).
6. Self-efficacy relates to the individual's ability to adopt a positive health behavior (Bandura, 1977).

Health Belief Model

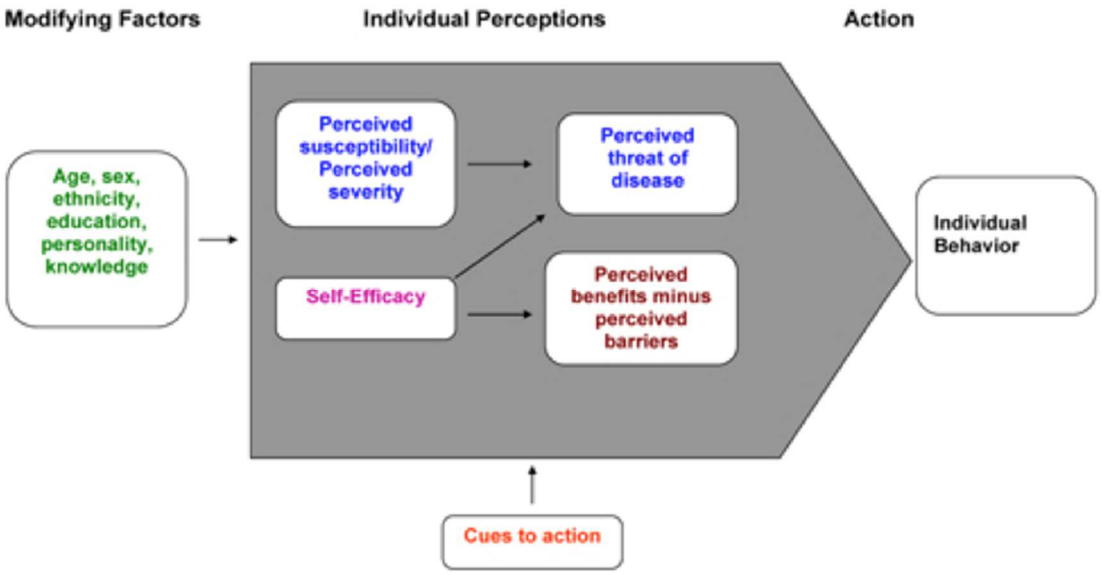

Figure 1. Core concepts of the HBM.

HBM was chosen as a theoretical framework for this study because the core concepts explore the factors that can motivate individual to change their health behaviors. HBM was considered appropriate for the primary objective of this study is to assess if SCD education can increase young adults' knowledge of SCD and impact their attitudes about the severity of the disease as well as their perceived risk. Furthermore, this sought to explore if an increase in awareness about SCD may serve as motivation for young adults to seek out genetic screening and for those who are at risk will the next step of

discussing SCD with their romantic partner; and hopefully both of them will seek genetic counseling prior to making decisions about reproduction. HBM's core perception of susceptibility to SCD will be an important strategy in trying to educate young adults and college students and young adults that SCD does affect other racial groups besides African Americans.

Several researchers have used the HBM as the theoretical foundation of studies designed to investigate health behavior of young adults represented by college students. One such study was conducted in 2010 by a group of researchers who sought to investigate the attitudes of college students to using a bicycle helmet (Ross, Ross, Rahman, and Cataldo, 2010). The researchers recruited 337 undergraduate students from a university located in the US. Most of the participants were female. The participants completed a survey that was designed based on the core concepts of HBM. The researchers reported that 53% of the participants rode a bicycle a few times a year but only 12% of them reported regular helmet. The researchers also reported that 75% of participants have been injured while riding a bicycle and 60% knew of somebody who had been in a bicycle accident. Sadly, about 6% of the participants knew of somebody who was killed in a bicycle accident (Ross, Ross, Rahman, and Cataldo, 2010).

This study was important because the results revealed that 72% of the participants have no intention of wearing a helmet and they stated why. The study showed the reasons participants provided for why they do not wear helmets but more importantly, it revealed under what circumstances they will wear a helmet. This study will be useful to towns and

municipalities hoping to encourage its citizens to protect themselves by wearing helmets when they ride bicycles (Ross, Ross, Rahman, and Cataldo, 2010).

Another study that used HBM as its guiding theory was conducted by Kim, Ahn and No in 2012. In that study, the researchers sought to investigate college student's health behavior, eating behavior and involvement in physical activities. The researchers choose to recruit college students because most college students leave home and have for the first become primarily responsible for planning their own meals (Kim, Ahn and No, 2012). The researchers recruited 251 students between ages 18 to 25 who completed an online survey testing their knowledge of nutrition. (Kim, Ahn and No, 2012). The researchers reported that participants who believed that eating healthy food had good benefits are more likely to overcome barriers and incorporate health beliefs which can translate into eating healthy food. This study should provide a good starting point for university administrators who are eager to positively impact the eating behavior of college students (Kim, Ahn and No, 2012).

In another study that utilized HBM, the research team of Coe, Gatewood, Moczygemba, Goode, and Beckner sought to explore the attitude and perceptions of college students and other members of society to receive the influenza vaccine. The major objective of this study was to apply the following core concepts of HBM susceptibility of participants to a severe disease (H1N1 virus), and assess participants perception of the severity of the disease, barriers to receiving the vaccine and the benefits of receiving the vaccine (Coe, Gatewood, Moczygemba, Goode, and Beckner, 2009). Perhaps more important was the fact that the study sought to assess participants'

intentions to take the vaccine. This study was a cross-sectional descriptive study that was conducted in the US and utilized a 36 item questionnaire to collect data from participants (Coe, Gatewood, Moczygemba, Goode, and Beckner, 2009).

The questionnaire was completed by 664 participants ages ranged from 25 to 64. The major significant finding in this study was the fact that those who intent to receive the H1N1 vaccine were mainly those who typically receive the annual flu vaccine. The researchers reported that this finding was consistent with other studies conducted in other parts of the world. However this study and others before it have that race or ethnicity were not found to be predictors of intention but found that non Caucasian ethnic population will more likely receive the H1N1 vaccine. The major benefit of this study is the recommendation that public health programs wishing to increase the utilization on the H1N1 vaccine should target members of the population who traditionally do not receive the annual flu vaccine (Coe, Gatewood, Moczygemba, Goode, and Beckner, 2009).

The research studies by Coe et al., (2009); Kim et al., (2012); and Ross et al., (2009) all used the HBM model as the theoretical foundation of their studies on the health behaviors of college students. The overall objective of the developers of the HBM theory was to improve the health literacy of individuals by providing education about a particular disease (Nutbeam, 2000). The first objective was to bring the attention of individual's to a disease that they are susceptible to. The second objective was to let individuals' know that the disease in question was severe. The third objective was to let people know that there are benefits if individuals take a certain action. The forth

objective was to let individuals know that there are barriers that can prevent them from show taking actions that can be beneficial to them.

In this current study, HBM was the most appropriate theory because the overall objective was to improve the health literacy of college students with the hope that they will be empowered to adopt new positive health behaviors such as screening and genetic counseling prior to making reproductive decisions. Besides, improving health literacy, HBM can also help identify what group to target for education. For instance, in the study by Coe et al. (2009) which used HBM as a theory in the study of students eating habits, the results showed that those participants who believed that there were benefits to eating healthy were the ones who indicated that they will adopt the recommendation to eat healthy. In the case of the study of helmet use among by students, the researchers Ross et al. (2009) found that only 12% of participants regularly wear a helmet when riding a bicycle even though 75% of them admitted that they have been injured while riding a bicycle. This study will be a motivation for policy makers to enact regulations that will make using helmet mandatory for the public good.

In the case of this study, the HBM as a theory was able to help me identify what changed as a result of providing SCD health education to the participants in the experimental group compared to those in the control group who did not receive the SCD education. Future studies will also be able to modify this current study so also to explore other independent variables that may impact participants' decisions to seek screening and genetic counseling prior to making reproductive decisions. HBM focuses on improving communication and education about a health condition. HBM also provides avenue for

advocacy such as identifying barriers and Cues to action which can improve overall health communication as well as enhance health promotion and ultimately improve disease prevention.

Gaps in Literature

The most significant gap in the literature is the absence of studies on SCD/SCT among other races besides African Americans. In spite of the broad search words used to locate studies, there were no recent studies on the prevalence, incidence and impact of SCD/SCT on members of other racial groups present in the US. The studies that were found on other races besides African Americans were studies on Middle Easterners, Greeks, Indians and Africans. These studies were conducted in locations outside of the United States.

Another gap in the literature is the lack of studies to explore why individuals who believe that they are susceptible to SCD and believe that seeking screening and undergoing genetic counseling are beneficial choose to not seek screening or may perceive they have a low risk of having a child with SCD. In a 2007 study by Gustafson et al., with 101 African American women participants revealed that most of them believed that SCD is severe and genetic counseling is beneficial. However, the researchers also found that these participants did not seem to believe that their future offspring could be susceptible to SCD (Gustafson et al., 2007 pp. 303-310). The tendency of those at risk to wish the disease away can help public health researchers to design more appropriate public health programs.

Summary

The proposed study evaluated existing literature and found several variables that researchers have identified as posing barriers to screening and efforts to prevent SCD. The major variables that impact screening were age, educational level, gender, socio economic status, ethnicity and religiosity. Age as factor was found to impact screening behavior among women. Some of the studies reviewed revealed that older women were more likely to screen for breast cancer, while younger women were more likely to screen for medical conditions that are recommended for individuals who are sexually active (Deeks et al., 2009; Katapodi, et al., 2009; Reagan et al., 2088).

The educational level of an individual was also shown to impact screening behavior among different groups. The findings support the conclusion that educational level is a strong predictor of screening behavior. In studies conducted in SCD, Prostate cancer and breast cancer, researchers found that in almost all cases, the educational level of an individual was inversely related to his or her knowledge about a medical condition. These studies also revealed that the more knowledgeable an individual is about health condition, the more likely he or she will seek screening (Abioye-Kuteyi et al., 2009; Al Arrayed et al., 2010; Dunn et al., 2011; Katapodi et al., 2009).

Gender was also found to impact screening behavior. Some studies found that women were more knowledgeable about certain health conditions than men (Al Arrayed et. al., 2010). However, with regards to SCD, a study by Boyd and associates showed that many women were not aware of SCD (Boyd et al., 2005). Another study revealed that many women who were pregnant did not know their own SCT. This study also showed

that many of these women refused to ask their romantic partners to seek SCD screening or their partners refused to cooperate with screening (Rowley, 1991; Treadwell et al., 2006).

The studies reviewed showed that the socioeconomic status of an individual plays an important role in whether or not they seek screening. Many studies identified factors such as lack of access, lack of insurance, lack of transportation, lack of awareness and lack of resources as the major reason that acts as barriers to the adoption of preventive health behavior (Deeks et al., 2009, Lee et al., 2010; Maxwell et al., 2010). The study by Deeks et al revealed that while many individuals were very concerned about their current and future health, they were more likely to make future financial plans than future health plans (Deeks et al., 2009).

The studies reviewed also showed that ethnic and racial factors also impede the adoption of screening behaviors. Some of the researchers reported there was distrust of the health care system due to events such as the Tuskegee Syphilis study (Zimmerman et al., 2006). Other researchers identified the fear of discrimination in employment or in obtaining health and life insurance as barriers to seeking screening (Dyson et al., 2007; Miller et al., 2010; Shelton et al., 2010; Zimmerman et al., 2006). Another factor that was identified was the fear that seeking screening will lead to a recommendation for a pregnant woman to have an abortion (Konote-Ahulu et al., 1991)

Concern about abortion was also a major concern expressed by those who were religious. Several studies revealed that individuals who were religious were hesitant to engage in screening because of concern that they maybe be faced with the choice of

having an abortion which is against their religious belief (Gallo et al. 2010; Zimmerman et al., 2006). Religions also played a role in whether or not individuals sought screening or commence treatment for a medical condition (Allen et al., 2012; Gulate et al., 2010).

This literature review revealed that these factors could affect screening behavior to varying degrees. This study will use the quasi-experimental approach to test the impact of SCD education intervention on college students and young adults' knowledge, attitude and motivation to seek screening, adopt preventive strategies such as genetic counseling, and adopt new health behaviors based on the core principles of HBM of perceiving susceptibility and benefits from adopting the new behavior. This chapter provided an overview of SCD and factors that may impact screening behavior, especially among college students, young adults and ethnic minority populations. The relevance of the Health Belief Model was also discussed and how the theoretical framework may provide a basis for educational and prevention efforts which impact SCD transmission. The positive social change that may result from this study is that there will be an increase in awareness about SCD among college students. The increased awareness will create a change in their attitude to perception of their risk to SCD and other preventable diseases. The change in attitude will be reflected in an increase in their motivation to undergo screening and genetic counseling. The overarching benefit in increased awareness, increased screening, and increased genetic counseling may be a reduction in the prevalence of SCD as well as reducing the amount of money budgeted for caring for newly diagnosed patients with SCD. The money saved can be diverted to other preventive programs that will enhance the general well-being of Americans in line with

the objectives of the Healthy People 2020. The results of this study will add to the knowledge base about SCD and the impact of health education on college students' knowledge, attitudes, perceived risk, and intention to seek screening. Results of this study may further social change by encouraging college-based health education efforts about SCD and other preventable diseases. Chapter 3 will address the study methodology, the sampling strategy, the sample size analysis, protection of human participants, data collection procedures, treatment of the data and data analysis.

Chapter 3: Research Method

Introduction

The objective of this quasi-experimental study was to explore whether health education about SCD had a significant impact on college students' knowledge of, attitudes about, and perceived risk of SCD and their intentions to seek screening and counseling if they felt they were at risk. This study used a cross-sectional, quasi-experimental pretest/posttest design to determine whether a health education intervention about SCD would have immediate impact on college students' knowledge, attitudes, perceived risk, and intention to participation in screening. Another purpose was to determine whether college students' knowledge, attitudes, perceived risk, and desire to seek screening and genetic counseling if at risk were associated with age, gender, religiosity, and socioeconomic status.

The research questions that were asked are:

1. Will health education about SCD positively impact college students' knowledge and attitudes about the disease?
2. Will health education about SCD have an effect on college students' intentions to seek screening and genetic counseling if at risk?

The research hypotheses were as follows:

Hypothesis 1

Ho1: There is no significant difference between SCD *knowledge* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Ha1: There is a significant difference between SCD *knowledge* pretest scores and posttest scores between college students assigned to the experimental group and the control group.

Hypothesis 2

Ho2: There is no significant difference ($p. > .05$) between SCD *attitudes* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Ha2: There is a significant difference ($p. < .05$) between SCD *attitudes* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Hypothesis 3

Ho3: There is no significant difference ($p. > .05$) between SCD *perceived risk* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

Ha3: There is a significant difference ($p. < .05$) between SCD *perceived risk* pretest scores and posttest scores in college students assigned to the experimental group and the control group.

The following hypotheses were associated with the second research question.

Hypothesis 4

Ho4: There is no significant difference *(p. > .05)* between *intent to seek SCD screening* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group .

Ha4: There is a significant difference ($p. < .05$) between *intent to seek SCD screening* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Hypothesis 5

Ho5: There is no significant difference ($p. > .05$) between *intent to seek genetic counseling* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Ha5: There is a significant difference ($p. < .05$) between *intent to undergo genetic counseling* pretest scores and posttest scores in college students perceived to be at risk for SCD who are assigned to the experimental group and the control group.

Hypothesis 6

Ho6: There is no significant difference ($p. > .05$) in pretest SCD knowledge, attitudes, perceived risk, and intention to seek screening scores in experimental group participants when grouped by gender, age, religiosity, and socioeconomic status (MANOVA).

Ha6: There is a significant difference in pretest scores ($p. < .05$) for SCD knowledge, attitudes, perceived risk, and intention to seek screening and genetic counseling between the experimental group participants when grouped by gender, age, religiosity, and socioeconomic status (MANOVA).

Hypothesis 7

Ho7: There is no significant difference ($p. > .05$) in posttest scores for SCD knowledge, attitudes, perceived risk, and intention to seek screening scores between

experimental group participants when grouped by gender, age, religiosity, and socioeconomic status (MANOVA).

Ha7: There is a significant difference ($p. < .05$) in posttest scores for SCD knowledge, attitudes, perceived risk, and intention to seek screening and genetic counseling between the experimental group participants when grouped by gender, age, religiosity, and socioeconomic status (MANOVA).

Research Approach

I chose a quantitative approach for this study because the research questions were post positivist in nature. Quantitative approaches typically provide a platform to explore the relationship between two or more variables. A quantitative approach provided the best opportunity to test an existing theory by examining the relationship between variables in the context of that theory (Creswell, 2009). According to Creswell (2009), a researcher who has assumptions and who wishes to test a theory and expects to replicate the findings is better served by using the quantitative approach (p. 4).

Research Design

I chose a quasi-experimental, pretest/posttest design for this study. A quasi-experimental approach is appropriate when the objective is to determine whether an intervention has the intended effect on the dependent variable (Creswell, 2009). This design provided an opportunity to compare the effectiveness of an intervention (SCD health education) on an experimental group compared to a control group. Additional details about the quasi-experimental design are provided below.

Quasi-Experimental Design

The quasi-experimental design approach is used to determine whether an intervention is responsible for an observed change. It is prefixed with the word *quasi*, meaning "sort of," to distinguish it from an experimental design approach because it lacks certain controls such as random assignment that are key components of experimental designs (Creswell, 2009, pp. 4 -7). There are several types of quasi-experimental designs, but the one selected for this study was control group with pretest and posttest. The experimental and control groups received pretests and posttests as represented by the following formula:

O_1 x O2

O_3 O_4

Line 1: O1 above represents the pretest for the experimental group, where x represents the intervention and O2 represents the posttest for the experimental group.
Line 2: O_3 represents the pretest for the control group and O_4 represents the posttest for the control group (Gribbons & Herman, 1997).

A quasi-experimental design is "a practical and feasible" design that provides a systematic framework for answering questions and testing hypotheses about causation in field settings (Borglin, Gustafson & Krona, 2011, p. 2). Furthermore, Borglin et al., (2011) stated that when compared to other approaches, quasi-experimental designs are less intrusive on conditions when conducted in natural setting.

Strengths of quasi-experimental design. A major strength of quasi experimental design is the fact that it can help a researcher determine if the intervention produced the

observed change. Quasi-experimental design is also appropriate where randomization is either not possible or is unethical. Quasi- experimental research design is appropriate when the study is conducted in a natural setting (Gribbons & Herman, 1997; Schoenfeld, 2006).

Limitations of quasi-experimental design. There are several limitations associated with quasi experimental research design. The first is the lack of random assignment of participants into groups based on criteria. Instead most quasi experimental research studies assign participants based on convenience and availability (Blumenthal & DiClemente, 2004). The second limitation is that a study using quasi experimental design may not be able to control other factors that can affect the observed change. The third limitation is the likelihood that when the study involves an experimental and a control group, participants in both groups are typically not equivalent in composition. The fourth limitation is that results of study are hard to interpret if the performance by the experimental and control group in the pre-test is unequal. Finally, all these limitations can reduce a researchers' ability to make a causality claim because of the difficulty in attributing the change to the intervention (Gribbons et al., 1997; Shuttleworth, 2008). However, it is difficult when working with human participants in education to use true experimental design because of the difficulty in avoiding bias during assignment of participants to groups (Creswell, 2009, p. 155).

Intervention: SCD Health Education

The intervention for this study was a 27 minute DVD titled "Let's talk about sickle cell". The DVD provided a detailed explanation about SCD, the mode of disease

transmission, the medical problems associated with SCD, and a review of available treatments for SCD. The DVD was commissioned by the Sickle Cell Thalassemia Patients Network of New York (SCTPN) with additional support from other organizations including the New York State Department of Health, and the New York State Black Psychologists Association. The DVD was released in 2013. The DVD was offered for use for this project by SCTPN. The contents of the DVD provide plenty of useful information about SCD that enabled participants that viewed it to answer questions about the mode of transmission, the medical problems associated with the disease and the daily physical, medical, mental, and social challenges of people with SCD.

Setting

The setting selected for this study was the Tarrant County College (TCC) located in North Texas. Tarrant County College System consists of five campuses located all over Tarrant County. According to data provided by College officials, there were approximately 49,108 students enrolled in the five campuses in 2010. The majority of the students at TCC are Caucasian, followed closely by Hispanic students and African American constitutes the third largest group of students. Table 2 shows the racial/ethnic background of the student body:

Table 2

Race/Ethnicity of TCC Student Body

Race or ethnic group	Percentage
African American	17.2%
Caucasian	52.2%
Hispanics	22.1%
Asian	6.0%
N. American	0.5%
Other	1.9%

Note. $N = 46{,}750$. From "Quick Facts," retrieved May 3, 2013, from http://www.tccd.edu/About_TCC/Quick_Facts

Table 2 above shows the racial distribution of students of Tarrant Community College Southeast campus located in Arlington, Texas. During the time of my study, the majority of the student body at TCC Southeast campus was comprised of Caucasian students, followed by those of Hispanic and African American background.

There are more female students than male students in attendance at Southeast campus of TCC. Table 3 shows the distribution of the gender of the student body at TCC.

Table 3

Gender of TCC Student Body

Gender	*n*	Percentage
Female	27,115	58.5%
Male	19,635	41.5%

Note. *n* = 46,750. From "Quick Facts," retrieved May 3, 2013, from http://www.tccd.edu/

Table 3 above shows the gender distribution of students of Tarrant County College South East Campus located in Arlington, Texas. Arlington is a major city in North Texas. According to the 2000 US census, Arlington has a population of 380,084. The 2000 US Census indicates that the racial compositions of Arlington are as follows:

Table 4 below shows the racial distribution of residents of Arlington, Texas where TCC Southeast campus is located. The largest racial group in Arlington during the time of this study was Caucasian, followed by the Hispanics, African Americans and Asians.

Table 4

Racial Composition of Arlington, Texas

Race	Total	Percentage
Caucasian	166,474	43.8%
Hispanics	110,795	29.2%
African American	66,967	17.6%
Asian	25,592	6.7%
Native American	2,232	0.6%
Hawaiian/Pacific Islander	110	0.03%
Other	874	0.2%
Two or more races	7,027	1.8%

Note. From "Racial Composition of Arlington, TX," retrieved May 3, 2013, from http://www.city-data.com/Arlington-Texas.html

The Tarrant County College South east campus was chosen as site of this study because of access to a college student population that is representative of the major racial groups identified in the U.S. 2010 census. The major racial groups identified by the U.S. Census can be found among the student population of Tarrant County College. As shown on Table 4 above, Caucasians, African Americans, Hispanics, Asians, Native Americans and others (which are those that do not clearly fit into any of the other groups) are represented in the student population at Tarrant County College. It was necessary to have a target group that is reflective of the racial composition of the county because SCD does not just impact African Americans as is widely believed by the public, but affects all

racial groups (Olney, 2004). For this reason it was important to have a sample that is diverse (See Table 1).

Promoting good health for all is the main foci of the Healthy People 2020 program (USDHHS, 2010). One of the stated overarching goals of the Healthy People 2020 is to improve quality of life, reduce premature death and increase life span and promote programs and health behaviors that have the potential of reducing deaths and medical problems that can be prevented (USDHHS, 2010). In order to meet these objectives, increased awareness about SCD will improve efforts to reduce transmission of SCD among all races.

This study was different from previous studies because it was a quasi-experimental design with a sample of college students that included a diverse representation of racial and ethnic groups as opposed to many previous studies that focused on SCD primarily among African Americans in the U.S. (Boyd et al., 2005; Long et al., 2011; Ogamdi 1976; Thompson et al., 2008; Treadwell et al., 2006; and Zimmerman et al., 2006). However, SCD affects members of other races as described in chapter 2 (see Table 1). The prevalence of SCD in among members of other races has been ignored over the years.

Sampling Strategy

I used a volunteer convenience sampling strategy to recruit 80 college students attending Tarrant County College (TCC). The findings during the literature review showed that there was a lack of awareness about SCD among the majority of women of child bearing age, as well a need to increase awareness about SCD among young adults.

These are the main reasons why college students are the target population for this study. Other studies that were reviewed included a 2010 article by Camelo and Slater. These researchers recruited college students as the target population in a study that examined the prototype of marijuana users among students. The goal of the study was to contribute to the ongoing efforts to develop a more effective marijuana use prevention programs (Camelo & Slater, 2010). In an another study that used students as the target population, Avci and Fendrich conducted a study in 2010 on drinking related problems and how understanding students drinking behavior can lead to improvements in efforts to reduce problems associated with drinking (Avci & Fendrich, 2010). Over the years and as shown by the above studies, researchers have used students as targets populations in many other studies including drug use, HIV, nutrition, drunk driving, seat belt use and obesity. In many of these studies students were recruited because they were accessible and it was convenient for the researcher(s).

Volunteer convenience sampling method was selected for this study because students will be available and willing to volunteer (Blumenthal & DiClemente, 2004). Volunteer convenience sampling was selected over a random sampling method because it was less expensive and less time consuming. A volunteer convenience sample enabled me to explore my objective of gauging the SCD knowledge and attitude of students who are likely to be sexually active and on the verge of making reproductive decisions. For example, in a study to determine the level of health knowledge about epilepsy, researchers Behrouzian and Meamatpour utilized convenience sampling to recruit parents who had children with epilepsy (2010). In another study conducted in 2011, Cerigo and

colleagues utilized convenience sampling to recruit participants to explore the awareness and knowledge of Inuit women about Human Papilloma virus (HPV). In that study, the researchers excluded other women because the target population was women of Inuit extraction.

A probability sample such as random sampling method provided the best chance that every element represented in the student population at TCC is included in the study sample. However, I determined that it will be costly and time consuming to include a representation of all the elements represented in TCC in the study sample. Therefore, a volunteer convenience sample was the method chosen to recruit participants for this study. According to Frankfort-Nachmias and Nachmias (2008), "the essential requirement of any sample is that it be as representative as possible of the population from which it is drawn" (p. 167).

Sample Size

The initial objective of this study was to explore whether education about SCD will motivate African Americans to undergo genetic screening. However, after reviewing the scholarly literature, it became apparent that there was is a prevalence of SCD and SCT among other racial groups in the United States. This necessitated the need for a diverse sample as represented in TCC, and the larger community of Tarrant County where the school is located. Prior studies that focused on African Americans were located in predominantly African American communities (Abioye-Kuteyi et al., 2009; Bediako et al., 2009; Boyd et al., 2005; Gustafson et al., 2007; Long et al., 2011; Treadwell et al., 2006; Zimmerman et al., 2006). As the ethnic/racial group table 3 shows, African

Americans do not constitute a majority in either Tarrant County or Tarrant County College. The decision to include non-African Americans as participants improved the scope of the study (since all groups can acquire SCD) in order to measure knowledge, attitudes, perceived risk, and intent among a representative sample of college students in North Texas.

The sample size for this quasi-experimental research design was determined based on an alpha of .05, effect size of .70, and a statistical power of .80. The Cohen's t test table for Two Independent Samples recommends that the sample size should be set at about 34 participants in each of the experimental and control groups (see Appendix A). The registrar at the college where this study was conducted informed me that several undergraduate classes typically have between 15 and 30 enrolled students. This improved the chances that the minimum number of participants was available during pre-test and posttests.

Effect size provided the best estimation for how strong the relationship was between the dependent and independent variables (Burkholder, 2009).The conventional guide for selecting an effect size was represented by Cohen's formula where effect size was the sum of the difference between the means of pre-test and post-test scores divided by the average standard deviation (Burkholder). Cohen has provided three levels of effect size as follow:

Small effect: $d<.50$

Medium effect: $d = .50$ to $.80$

Large effect: $d > .80$

This study selected the medium effect of .70. Many of the scholarly journal articles reviewed for this study recommended that determining the effect size should be based on effect sizes used in prior studies that are similar to current study. When no prior effect sizes are available as in this study, several researchers recommend estimating effect sizes (Brand, Bradley, Best & Stoica, 2011; Bukszar, Van den Oord, 2010; Richy, Ethgen, Bruyere, & Frederic, 2004; Thompson, 2007). These researches are cautious in their recommendations because of rampant tendency to over or under estimate effect sizes. During sample size analysis for this study, I relied on the recommendations of Dr. Gary Burkholder of Walden University. Dr. Burkholder recommended Alpha .05 and Statistical Power of .80.

For effect size calculation he provided this formula based on t statistic:

The difference between the means divided by standard deviation.

D=M1-M2 (difference between the means before and after intervention) divided by SD (standard deviation).

I chose a medium effect size at *d*=.70.

On the t test table for two independent samples power of .80 and effect size of .70 recommended 34 participants per group as an appropriate sample size.

Participant Eligibility Criteria

Students selected as participants in the study met the following criteria:

1. They were students of TCC.
2. They signed consent forms before the start of study.
3. They were all at least 18 years of age or older.

4. They all could read and write proficiently in English.

Exclusion Criteria

On the day of data collection all the students who agreed to participate and signed the consent forms indicated that they were 18 years or older. Any student under 18 years old was excluded because this study did not include minors. The participants that formed the core of the experimental group were an intact group of students registered in two courses: Social Psychology and Social Problems. The participants that formed the core of the control group were an intact group of students registered in two sections of an Introduction to Sociology courses: The students who did not wish to participate were offered an opportunity to return during post-test and view the SCD DVD. Those who agreed to participate were reminded that they could withdraw from participating in the study at any time.

Instrumentation

The principal instrument was a questionnaire I have named Sickle Cell Disease Questionnaire. This questionnaire was based on survey questions used in four research studies conducted by Acharya et al., 2009; Boyd et al., 2005; Gallo et al., 2010; Zimmerman et al., 2006. Several studies whose goals were to investigate if awareness and knowledge about a disease can impact positive health behaviors have used questionnaires to explore the connection between knowledge and its influence on attitude (Acharya et al., 2009; Boyd et al., 2005; Gallo et al., 2010; Zimmerman et al., 2006). Other questions were adapted from a knowledge quiz that is available on the CDC website named Sickle Cell Disease Quiz. In order to enhance face validity, all the

questions on the Sickle Cell disease questionnaire were reviewed by two focus groups made up of healthcare providers knowledgeable about SCD. The focus group consisted of hospital employees in Houston Texas and Brooklyn, New York. The comments and recommendations of the focus group formed the basis of the modifications that were made to ensure that the Sickle Cell disease Questionnaire had face validity.

The Sickle Cell disease Questionnaire consisted of 44 questions and 40 of the questions measured participant's SCD knowledge, attitudes, perception of risk, religiosity, intentions to seek screening and genetic counseling. An example of a knowledge question is as follow: "You can have a sickle cell trait when both parents do not have the trait?" An example of an attitude question is "Research on genetics and sickle cell disease is tampering with nature?" An example of a perception question is "Do you perceive your offspring would be at risk for sickle cell disease?" An example of an intention question is "Do you intend to seek screening for sickle cell disease?" An example of a religiosity question is "To what extent do religious beliefs influence your daily decisions?" The remaining four questions collected demographic information from the participants such as age, gender, race, and socio economic status of the participant's family.

The scoring was based on questions 1 through 40. Questions one through 23 measured SCD knowledge. The highest possible score a participant could receive in this category was 23. A high score in this category meant that a participant had more SCD knowledge than another participant with a lower score. The cumulative score was grouped into five categories: extremely familiar, moderately familiar, somewhat familiar,

slightly familiar and not at all familiar. The participants with the highest score were placed in the extremely familiar group while those with the lowest scores were classified as not at all familiar with SCD.

The 40 knowledge, intent and attitude questions were scored while the four demographic questions were not scored. The maximum points any participant could receive in the knowledge category was 23 points. Participants who scored 20 and above were considered to be very familiar with SCD. Participants who scored 15 and above were considered to be moderately familiar with SCD and participants who scored 10 and above were considered somewhat familiar. Those participants who scored six and above were considered to be slightly familiar with SCD and those who scored less than five were considered not to be too familiar with SCD.

Attitude about SCD were measured by questions 24 through 30. In this category the highest score a participant could receive were seven. A participant who received a high score was considered to have a more positive attitude towards seeking screening and genetic counseling.

Perceived risk was measured by questions 31 through 35. The highest score a participant could receive was five. A participant who received a high score was considered to be more perceptive about his or her own risk to SCD.

Intention for screening or counseling was measured by questions 36 through 38. In this category, the highest score a participant could receive was three. A participant who received a high score was considered to have a higher intention to seek genetic screening and genetic counseling. Religiosity was measured by questions 39 and 40. In

this category, the cumulative scores were grouped into the following categories: Not at all religious, somewhat religious, moderately religious and very religious, a higher score meant that the participant's decision making can be influenced by religion. In this category, the higher the score the more likely a participant's decisions are influenced by their religious beliefs. (Vagias, 2006). The demographic questions were not scored.

The SCD questionnaire was used to collect data from participants in the experimental and the control groups during pre-test and post-test. The SCD questionnaire was scored and analyzed using SPSS helped to compare the pre-test and post-test scores of the participants in the experimental group against those of the participants in the control group. The SCD questionnaire took about 15 minutes to complete. Two weeks before collecting data, I asked several students if they would complete a survey as a pilot to a larger study which involved efforts to educate students about the SCD. I asked students if they would agree to complete a questionnaire. Twenty students agreed to complete the SCD questionnaire. None of the 20 students who participated in this pilot exercise were enrolled in any of the four courses I had chosen to use for collecting data. The purpose of this pilot exercise was to ensure clarity in the language and moderate reliability of the questions.

Reliability

The key concern about the Sickle Cell Disease questionnaire was whether it could measure what I intended to measure. In order to ensure that the questionnaire had content validity, all the questions except the demographic questions were adapted and modified from questions used prior studies published in peer reviewed journals. One of the authors

of an article from where some of the questions were adapted stated that the questions were designed by a multidisciplinary team (Zimmerman et al., 2006). Modifications that were made to the Sickle Cell disease questionnaire were based on recommendations of the focus groups at the VA Hospital in Houston and at Tarrant County College in North Texas in order to enhance content validity. According to Frankfort-Nachmias and Nachmias (2008), content validity criteria is met when a "measurement instrument covers all the attributes of the concepts you are trying to measure" (2008, p. 149). In order to establish face-validity, the Sickle Cell Disease questionnaire (see Appendix A) was reviewed by two focus groups located in Houston, Texas and Brooklyn, New York. The focus group in Texas comprised of 30 healthcare professionals made up of physicians, social workers, nurses, sociologists and psychologists all of whom are employed in the Veterans Administration medical center located in Houston, Texas. These healthcare professionals are knowledgeable about SCD because of prior or current interactions with adult patients with sickle cell disease.

The focus group in New York comprised of several social workers, nurses, nurse practitioners, dieticians, physicians and psychologists all of whom are affiliated in one capacity or another with the Sickle Cell Thalassemia Patients Network (SCTPN) based in Brooklyn, New York. These healthcare providers affiliated with SCTPN work almost exclusively with SCD patients hence they are very knowledgeable about the disease and the medical problems associated with the disease. The reviewers answered all the questions on the questionnaire and most of them inserted comments expressing their opinions or concerns about one question or another. Some of the comments brought my

attention to questions that needed to be rephrased for clarity. Other comments brought my attention to the need for consistency such as referring to Blacks as African Americans or as Blacks. The original questionnaires with comments and opinions were summarized, saved, and can be made available on request. The input of members of the focus group formed the core of the modifications that were made to the Sickle Cell Disease Questionnaire (Attached as Appendix A).

Procedures

After this proposal was approved by my committee members, I submitted an application to Walden University for permission to gather data. After I received authorization from Walden IRB (02-05-14 00 88 400), I submitted a request to recruit participants and collect data at Tarrant County College by completing the following forms: Research Data Request Form, Education Research Request and Request to Perform Research. After I received authorization from TCC, I contacted Mr. Roderick Callaway, a lecturer in the department of Sociology whom TCC had designated as my contact/sponsor.

Participants were recruited from an in-tact group of students registered in three courses in four different sections. Students from two sections made up the experimental group and the other two sections made up the control group. The major reason why an introductory course in sociology was selected was because the school registrar's office informed me that the introductory sociology class and other courses in the department of sociology typically have high number of enrolled students. Recruiting from an intact group was necessary in order to ensure that a sample size of at least 40 was achieved for

both the experimental and control groups. In addition recruiting from an intact group necessary in order to reduce the likelihood of attrition and capture the same participants for the pre-test and the post test.

The first week of data collection was devoted to obtaining consent from all students who had indicated their willingness to participate. During this week the participants signed the consent form. Participants were advised that they could withdraw from the study at any time. During the second week participants in both groups completed the pretest questionnaire. During the third week, the participants in the experimental group were shown the DVD "Lets Talk about Sickle Cell" and provided brochures about SCD, then completed the posttest questionnaire. During this week the participants in the control group completed the posttest after which they viewed the DVD titled "Let's Talk about Sickle Cell Disease". They were also provided the SCD brochures. On the days of the pre-test and post-test, the participants assembled in their usual classroom before the start of their lecture to complete the Sickle Cell Disease Quiz. On the day of the intervention, the participants assigned to the experimental group viewed the DVD "Let's Talk about Sickle Cell" before the commencement of lectures. On the day of post-test, the participants in the control group completed the post-test before they viewed the DVD "Let's Talk about Sickle Cell" and received the SCD brochures.

The Intervention

The interventions that the experimental group received were two brochures produced by the CDC and SCTPN, and the 27 minute DVD named "Let's Talk about

Sickle Cell". On the day of posttest for the experimental group, I gave a short introduction of SCD and then I handed out brochures to them. The SCD brochures contained information about SCD and SCT and its role in the transmission of sickle cell disease. The brochures also provided information about treatment options and recommendations for lifestyle changes that can help people with SCD to manage the disease effectively. The brochures were handed to the participants in the control group after they completed their posttest. The DVD titled "Let's Talk about Sickle Cell Disease" provided information about sickle cell disease and the medical problems that people with the disease endure. The DVD showed individuals with SCD and physicians who provide care for people with SCD providing education about SCD including detailed discussions on the benefits of genetic screening and genetic counseling. The video also related the experiences of caregivers such as nurses and other medical care providers who specialize in caring for people with SCD. Perhaps, more important was the fact that the video showed that SCD does affect individuals of other races.

Data Analyses

Data were analyzed using IBM Statistical Package for Social Sciences (IBM-SPSS version 22) and Stata version 12.1. Data were screened for outliers and none were found. The independent variables were coded for the analyses as follows.

Age.

18 - 25 years old = 1

26 and above = 2

The decision to code participants into two groups was borne out of the fact that the location of this study was a two year community college which traditionally recruits students from all walks of life. One of the questions I asked my contact in TCC, Mr. Callaway, was the age distribution of students who attend TCC. Mr. Callaway informed me that many of the students who choose community colleges are either recent high school graduates or older individuals returning to school to begin their university education or obtain prerequisite to fulfill a requirement for entry into one program or another (R. Callaway, personal communication, March 13, 2013). Mr. Calloway also informed me that the students' ages can vary from 18 to 50 years of age (R. Callaway, personal communication, March 13, 2013). Though some of the studies I reviewed during literature search which had students as participants did not code by ages, I decided to do this because of the wide range of ages that can be found in a community college student population. I chose to have them respond by age range instead of reporting their actual age to further insure confidentiality.

Ethnicity.

African American = 1

Caucasian = 2

Hispanic = 3

Asian/Other = 4

The decision to code ethnicity into the four racial categories listed above was based partly on the fact that the website of Tarrant County College listed five racial categories. The

City of Arlington where TCC Southeast campus is located also listed five racial categories on its website. However, the racial categories Asian/Pacific/Other were merged and re-coded in order to meet one of the requirements for running a MANOVA analysis.

Gender.

Male = 1

Female = 2

SES/income.

$30,000 - $70,000 = 1

Above $71,000 = 2

The decision to code SES/Income into the four categories listed above was based on groupings listed within city demographic reports for Arlington, TX. These categories represent income possibilities that can be found in most US cities. However, this was re-coded for the MANOVA analysis in order to have sufficient participants in each cell.

Religiosity.

Barely religious = 1

Moderately religious = 2

Very religious = 3

Religiosity was initially coded into five categories. The decision to re-code religiosity into three categories was based on the requirement that there must be at least as four participants in each cell for all categories because there were four dependent variables.

Re-coding religiosity to three categories ensured that there were enough participants in each cell for the MANOVA analysis.

Descriptive and parametric statistics were used to test the seven hypotheses that were discussed in detail in chapters 1 and 4. A pre and posttest survey design can provide an explanation of the effect of an intervention when analyzed using paired *t* tests and two independent samples *t* tests. Before undertaking the two independent samples *t* test for experimental group versus control group as a whole, I performed a paired *t* test for pretest scores versus posttest scores of participants in the Control group as well as well as the pretest and posttest scores of the participants in the experimental group. This statistical analysis measured the effect of intervention in experimental group and in the control group it measured the placebo effect by comparing the responses of the posttest versus pre-test among the control group. Subsequently, a two independent samples *t* test were performed to determine the differences between the means in the scores of the experimental group compared to that of control group.

MANOVA analyses were run to determine whether there were significant associations or interactions among the independent variables of: age, ethnicity, gender, religiosity, and socioeconomic status. All tests were run with an alpha of .05 and a confidence interval of 95% which meant there was a 5% chance of rejecting the null hypothesis incorrectly or making a Type 1 error (Banerjee, Chitnis, Jadhav, Bhawalkar, & Chaudhury, 2009).

The consistency of the SCD Questionnaire was verified with a test retest analysis (Frankfort-Nachmias & Nachmias, 2008). Prior to launch of this study, the SCD

Questionnaire was piloted in two places: among the staff of the Veteran's Hospital in Houston and the staff of a Sickle Cell Agency in New York City. At a later date and shortly before data collection, I recruited a small group of TCC students in the Southeast campus who completed the SCD questionnaire as part of a pilot program. Modifications to the SCD questionnaire were made based on feedback from participants in the pilot study. The SCD questionnaire was designed to measure SCD knowledge, perceptions about SCD risk, and intention to seek screening and genetic counseling. These variables that were measured in this study were similar to the ones measured in the research studies from where the questions in the Sickle Cell Disease Questionnaire were adapted. The questions were arranged to begin with the assessment of knowledge and perception of risk about SCD and SCT and progressed to measuring attitude, perceptions and intention to seek genetic screening and genetic counseling.

Other threats to reliability that were addressed were as follows:

History: Any of many potential issues that may occur between the pretest and posttest that can affect the responses of participants. The likelihood that participants could discuss their participation with other students who may or may not be in the study was considered very high. This concern was addressed when participants were told prior to the start of the study to refrain from discussing the study with anybody. Participants signed consent forms prior to the start of this study and this form reminded them not to discuss their participation with other students (Shadish, Cook & Campbell, 2002).

Maturation: This threat occurs when due to elapsed time, a participant in a control group show improvement regardless. This threat is less likely in this study because pre-test and post-test were both conducted within days (Shadish, Cook & Campbell, 2002).

Testing: This threat occurs when taking the pretest can affect taking the same test a second time during posttest. During this study some of the participants seemed less interested during post-test when they found out that they were completing the same survey (Shadish, Cook & Campbell, 2002).

I was mindful of the potential effect on participants who may be motivated to seek SCT testing after the completion of this study. The medical office of the Tarrant County College South East Campus had protocols in place for students who may need counseling regarding their health. In addition to the medical office of TCC, brochures produced by CDC and SCTPN with information regarding screening and genetic counseling were distributed to the participants in the experimental group during the intervention. The same brochures were distributed to the participants in the control group after they completed the posttest.

Prior to the commencement of this study all the students who were recruited as participants signed a consent form. The consent form advised participants that their participation was voluntary and they can withdraw at any stage during the study. The consent form also advised participants that the principal researcher of this study received a Human Protection Certificate which attested to his competence in conducting studies with human participants. The Human Protection Certificate course was given by the

National Institute of Health (NIH). All participants were given a copy of the consent form that they signed.

Summary

Empirical studies which test educational interventions relating to SCD are lacking as well as studies focusing on interventions tailored for college students. A quantitative, quasi-experimental, pretest/posttest design was selected for this study because the objective was to measure the immediate impact of a health education intervention about SCD on college students' attitudes, knowledge, perceived risk, and intention to seek genetic screening and counseling if at risk for SCD. The strength of the quasi experimental design was that it provided the best approach to measure the observed changes between the experimental and control groups given the researcher's timeline and financial resources. However, major limitations of the quasi experimental design are lack of randomization as well as inability to control all variables that may influence outcomes relating to the SCD education intervention. Chapter 3 covered the research questions, hypotheses, research design, instrumentation, sample and sampling methods, treatment of the data, protection of human participants and data analyses. Chapter 4 presents the results of data analysis, and Chapter 5 discusses the results, implications of findings, and provided suggestions for future research.

Chapter 4: Results

Introduction

The objective of this study was to determine whether sickle cell education would have a significant effect on college students' knowledge about sickle cell disease, their attitudes toward screening for the disease, their perceived risk, and their intention to seek screening if it was determined that they were at risk. This study also explored whether pretest and posttest scores would vary significantly according to the independent variables of age, gender, ethnicity, religiosity, and socioeconomic status.

The research question was "What is the effect of sickle cell disease education on college students' knowledge, attitudes, perceived risk intention for screening?" The research questions and hypotheses outlined in Chapters 1 and 3 required a quantitative, quasi-experimental approach. A quasi-experimental pretest/posttest design was the most appropriate approach in order to determine if the SCD intervention had a positive impact on the dependent scores, and if dependent scores would significantly vary if grouped by factors such as gender, age, ethnicity, religiosity, and SES/income.

This chapter reports the findings of the study, which was conducted at Tarrant County College Southeast campus in Northeast, Texas. On the first day of data collection, the SCD Questionnaire was distributed to student participants in an introduction to sociology course and a social problems course. The total number of participants in the introduction to sociology course and the social problems course which made up the control group was 53. There were 41 students in the introduction to sociology course and

the social problems course which formed the experimental group. All sections of these classes were undergraduate-level courses.

In Week 2, the same SCD Questionnaire that was used to collect pretest data was used to collect posttest data. However, during this stage of data collection, the survey was administered differently for the experimental and control groups. The participants in the experimental group were given SCD brochures and then viewed a 30-minute DVD titled *Let's Talk About Sickle Cell*, after which they completed the SCD Questionnaire. The participants in the control group completed the SCD Questionnaire, after which they were given SCD brochures and then viewed the DVD *Let's Talk About Sickle Cell*.

Data Collection

Pretest data were collected in week 1 using the SCD Questionnaire. In the two classrooms that were designated as control group, there were 32 students and 20 students, respectively, for a total of 53 participants. During data analysis, only the scores of 40 students in the control group were included in the data, and the scores of 12 participants were excluded because they missed either the pretest or the posttest. In the two classrooms designated as the experimental group, there were seven students in one classroom and 34 students in the other classroom, respectively, for a total of 41 participants. During data analysis, only the scores of 40 students were included in the data, and the scores of one participant was excluded because the student did not participate in the pretest. The SCD Questionnaire was used to collect data from participants assigned to the control and experimental groups.

Posttest data were collected in week 2 using the SCD Questionnaire. In the two classrooms that were designated as control group, there were 32 students and 21 students, respectively, for a total of 53. During data analysis, only the scores of 40 students were included in the data, and the scores of 13 participants were excluded either because they were not present during the pretest or did not properly complete the questionnaire. During posttest data collection, the SCD Questionnaire was also used to collect posttest data from the participants designated as the experimental group. In the two classrooms designated as the experimental group, there were seven students and 34 students, respectively, for a total of 41 participants. During data analysis, the scores of one participant who did not participate in the pretest were excluded.

Treatment of the Data

There were a total of 94 students who signed consent forms and completed the SCD Questionnaire. Out of this number, 53 were in the two classes that were designated as the control group, and 41 were in the two classes designated as the experimental group. The recommended sample size for this study was 34 per group for a minimum of 68; however, after excluding the scores of 14 participants who were not present for both the pretest and posttest session, an even number of 40 participants each in the experimental and control groups was included in data analysis. By discarding the scores of these participants, I eliminated the problems of missing data in my dataset.

The Sickle Cell Disease Questionnaire was designed to measure the knowledge, attitude perceived risk of college students in relation to SCD. In order to clearly divide the students into groups consisting of those with knowledge and those without, it was

essential to collect dichotomous-type data with *yes* or *no* options as responses. In this study, for the knowledge questions, every correct answer received 1 point, and every wrong answer did not receive any point. The demographic questions were not assigned any points.

The questions on attitude, intention to seek screening, and ability to perceive risk to SCD were analyzed separately. For example, during data analysis, the Sickle Cell Disease Questionnaire was further grouped into the following subgroup categories: knowledge about SCD, attitude about SCD, intention to seek screening, and religiosity. After the overall analysis of the 40 questions, further analysis of the data by categories enabled me to determine what percentage of respondents were likely to seek screening or counseling. This analysis of the subcategories also allowed me to explore the role of independent variables in decision making.

Data Cleaning and Prepping

The participants recorded their scores on Scantrons, and I hoped to feed them through the grader at the local college. Unfortunately, I was not able to do this because not all the questions were of the same value. While Questions 1 through 39 were worth 1 point, Question 40 was worth between 1 and 4 points. It was for this reason that I had to grade all the scores of participants by hand one by one. While doing this, I was able to identify the participants who were not present during both the pretest and posttest sessions, and those scores were excluded from data analysis.

Before transferring data from Scantrons, I checked to ensure that all responses were complete and legible. Those that were incomplete or ineligible were set aside. I then

created several tables and spreadsheets to record participants' responses to the questions on knowledge, attitude perception and intention questions. Another set of tables was created to extricate participants' responses to the demographic questions on race, age, gender, income, and religiosity. After entering all the data into spreadsheets, I came back to it a few days later to recheck the entries in order to spot errors.

Prior to entering data into SPSS, I checked the entries in the tables and spreadsheet against the Scantrons that participant completed in an effort to identify errors. Data was logged in a way that would enable me to refer to them quickly when I need to verify an entry. I personally entered all the data for all participants into SPSS. After entering all the data, I was able to see clearly whether there were any missing data, and the data for participants who had not completed their surveys fully or were not present for one of both sessions were discarded.

Looking at the data in SPSS, I identified nine coding errors and duplications. The coding errors were corrected, and the duplications were deleted. There were four missing data, which I corrected by going back to TTC, meeting the students individually, and giving them an opportunity to complete the omitted questions. In the control group, the scores of 13 participants were not included in the data analysis because they were not present for both the pretest and posttest. In the experimental group, only the score of one participant was discarded because the individual was not present for both the pre- and posttests. A visual examination as well as an SPSS test of normality supported that data was normally distributed. Due to the small sample size, there were no obvious outliers.

Data Analysis

Data were analyzed using IBM Statistical Package for Social Sciences (IBM-SPSS version 22) and Stata version 12.1. Descriptive and parametric statistics were used to describe the study sample and to test the hypotheses. A paired *t* test was conducted to ascertain the within group differences in the pretest and posttest scores of the participants in the experimental group and those in the control group. The paired *t* test also showed the differences across the group of participants in the control group versus those in the experimental groups.

A two independent samples *t* test was also conducted to discern whether the differences between the control group and the experimental group were statistically significantly different with a p value of 0.05 or lower. Also a MANOVA analysis was conducted to determine if there were any associations between the independent variables (namely age, gender, race, SES/Income and religiosity) and the dependent variables (SCD knowledge, SCD attitude, perception and intention to seek screening and genetic counseling).

The following table provides a breakdown of the demographic characteristics of the five variables that make up the independent variables.

Table 5

Demographic Characteristics of Control and Experimental Groups

Independent variable	Description	Control group *N* & %	Experimental group *N* & %
Age	18-25	35 (87.5%)	31 (77.5)
	26 and above	5 (12.5%)	9 (22.5%)
Gender	Male	14 (35%)	12 (30%)
	Female	26 (65%)	28 (70%)
Race	African American	7 (17.5%)	16 (40%)
	Caucasian	12 (30%)	10 (25%)
	Hispanic	13 (32.5%)	7 (17.5%)
	Asian/Pacific	8 (20%)	7 (17.5%)
Income/SES	Less than $30,000	32 (80%)	31 (77.5%)
	Over $71,000	8 (8%)	9 (22.5%)
Religiosity	Very Religious	12 (30%)	19 (47.5%)
	Moderately Religious	20 (50%)	8 (20%)
	Barely Religious	8 (20%)	13(32.5%)

Overall, there was no statistical difference among experimental group and control group by Age (Fisher's exact P-value=0.401), Gender (Pearson Chi^2 P-value= 0.633) and Race (Fisher's exact P-value=0.181). Income and Religiosity scores of participants in the control and experimental groups were comparable with the exception of the "very religious and moderately religious" categories.

Age

Age was an independent variable. Question 43 in the SCD questionnaire asked participants for their ages. Age was grouped into four categories because two year colleges are entry points for high school graduates as well adults who are returning to school. As the results in Table 5 showed 88% of participants in the control group and 78% of those in the experimental group belonged in the first age category. The large percentage of participants in this age range of 18 to 25 confirmed what my contact at TCC had told me which was that there was many of the students are typically recent high school graduates as well as adults returning to school (R. Callaway, personal communication, March 13, 2013). The age distribution was not statistically different due to sample size.

Gender

Gender was an independent variable and question 44 asked participants to state their gender. As shown in Table 5 the composition of males in the control group was similar to that of the male participants in the experimental group. The percentage of females in the control group was also similar to that of participants in the experimental group.

Race

Race was another independent variable and question 41 asked participants select the race they identify with. As shown on Table 5, a side by side comparison of the race of participants showed that most of them belonged to four racial groups namely African Americans, Caucasians, and Hispanics. The experimental group was made up of 40%

African Americans versus 18% in the Control group while Caucasians constituted 30% of the experimental group versus 25% in the control group. The experimental group was made up of 33% Hispanics versus 18% in the control group. In the Asian/Pacific/Other group, 20% of the participants were in the experimental group and 18% were in the control group. The percentage of the race of the participants in the experimental and control groups was not statistically different which is likely attributable to the sample size.

Socioeconomic Status/Income

The SES/income of participants was an independent variable that was measured by question 42. Table 5 show a side by side comparison of the SES/Income background of the participants in the control versus those in the experimental group. The SES/Income status of both the control and experimental groups were comparable. This category was one of the limitations of this study because the participants were specifically asked for their family's income but some of them may have provided their own individual income. Even if this occurred it does not appear to have caused any difference between the groups and they were still comparable.

Religiosity

This variable was measured by questions 39 and 40. Though question 39 had two options of yes or no for a maximum score of 1, but question 40 had 5 choices (a) has a value of 0; (b) has a value of 1; (c) has a value of 2; (d) has a value of 3 and (e) has a value of 4 and the highest score a participant could receive for religiosity is 5. A participant with a higher score represents an individual whose decisions are likely to be

influenced by his or her religious beliefs. The percentages of the three different categories of religiosity are reported in Table 5.

Paired sample *t* test:

Table 6

Pre and Post Scores for Control and Experimental Groups

Study variables	Control group (n = 40)			Treatment group (n = 40)		
	Mean	(*SD*)	Median	Mean	(*SD*)	Median
Attitude Pre	2.95	1.41	3	2.60	1.15	3
Attitude Post	2.83	1.43	3	3.40	1.37	3
Intention Pre	1.70	.91	2	2.15	.77	2
Intention Post	1.78	1.05	2	1.95	.64	2
Knowledge Pre	16.25	3.08	17	16.53	2.01	17
Knowledge Post	15.30	2.48	16	19.10	1.01	19
Perception Pre	.40	.67	.40	.78	.86	1
Perception Post	.70	.99	.70	.75	1.03	0

A paired analysis of the pre and post test data was conducted to delineate the within group differences in the pre-test and post-test scores of participants in the control group as well as of those in the experimental group. The participants in the control group did not receive any intervention prior to completing the post-test whereas those in the experimental group were shown a 30 minute education DVD about SCD and also received educational brochures about SCD/SCT. Table 6 above show the within group scores of participants in the control group as well as of those in the experimental group. The table also shows the between group differences of participants in the control group as well as of those in the experimental group.

Within Group Analysis—Control Group—0

Table 7

Paired Samples Statistics

Dependent Variables		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	attitude_pre	2.95	40	1.413	.223
	attitude_post	2.83	40	1.430	.226
Pair 2	knowledge_pre	16.25	40	3.078	.487
	knowledge_post	15.30	40	2.483	.393
Pair 3	perception_pre	.40	40	.672	.106
	perception_post	.70	40	.992	.157
Pair 4	intention_pre	1.70	40	.911	.144
	intention_post	1.78	40	1.050	.166

The results of a Paired Samples test were conducted to compare the differences between the pre and post test scores of participants in the Control group. Table 7 above showed that at Pre-test, the scores of participants for the DV Attitude were (M=2.95, SD = 1.413) and at Post-test (M=2.83, SD=1.430). As shown on Table 13 the p value for the DV attitude was (P = .712). For the DV Knowledge, the scores at Pre-test were (M=16.25, SD=3.078) and at Post-test (M=15.30, SD-2.483). As shown on Table 13 the p value for the DV knowledge was (P = .146). For the DV Perception, the scores at Pre-test was (M=.40, SD=.672) and at Post-test (M=.70, SD=.992). As shown on Table 13 the p value for the DV perception was (P =.110). For the DV Intention, the scores at Pre-test were (M=1.70, SD=.911 and at Post-test (M=1.78, SD= 1.050). As shown on Table 13 the p value for the DV intention was (P =.730). The differences in the pre and post-test scores of the participants in the control group for the DV's Attitude, Knowledge, Perception and Intention will be discussed in the next section titled "Differences Within Group."

Attitudes About SCD

This variable was measured by questions 24 to 30. There were two answer options, "Agree" and "Do not agree." Agree was given a value of 1 and do not agree was given a value of 0. The highest possible score a participant can attain is 7 and the higher the score the more positive the participant's attitude was. As shown on Table 7 the scores of participants in the control group at pre-test were (M=2.95, SD = 1.413) and at Post-test (M=2.83, SD=1.430) and as shown on Table 13 the p value was (P =.712). This p value is

higher than 0.05. Based on a paired analysis of the pre and post test scores conducted to delineate the within group differences in the pre-test and post-test scores of participants in the control group for the DV attitude was not statistically different.

Table 8

Attitude Pretest/Posttest Scores for Control Group

Score	Pre-test n & %	Post-test n & %	Sig: p = .712
0	3 (7.5%)	2 (5%)	
1	4 (10%)	8 (20%)	
2	6 (15%)	5 (12.5%)	
3	9 (22.5%)	8 (20%)	
4	16 (40%)	14 (35%)	
5	1 (2.5%)	3 (7.5%)	
6	1 (2.5%)	0 (0%)	
7	0 (0%)	0 (0%)	

For example as shown on Table 8 above, at Pre-test 67.5% of participants scored 3 and above while at posttest 62.5% scored 3 and above. The differences in the pre and posttest scores of the participants in the control group will be discussed in the next section under the title differences within groups.

Knowledge

This variable was measured by question 1 through 23. There were two answer choices Yes or No. Yes was assigned a value of 1 and No was assigned 0. The most

points any participant could receive in this category was 23 points. As shown on Table 8, for the DV Knowledge, the scores at pre-test were (M=16.25, SD=3.078) and at posttest (M=15.30, SD-2.483). As shown on Table 13 the p value was (P =.146). This p value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pre-test and posttest scores of participants in the control group for the DV knowledge was not statistically different.

Table 9

Knowledge Pretest/Posttest Scores for Control Group

Score	Pretest N & %	Posttest N & %	Sig: p = .146
3	1 (2.5%)	1 (2.5%)	
11	1 (2.5 %)	1 (2.5%)	
12	0 (0 %)	0 (0%)	
13	3 (7.5%)	4 (10%)	
14	3 (7.5 %)	4 (10%)	
15	5 (12.5 %)	2 (5%)	
16	6 (15 %)	16 (40%)	
17	6 (15 %)	12 (30%)	
18	7 (17.5%)	0 (%)	
19	4 (10%)	0 (0%)	
20	4 (10%)	0 (0%)	
22	0 (0%)	0 (0%)	

Participants who scored 20 and above were considered to be very familiar with SCD. Participants who scored 15 and above were considered to be moderately familiar with SCD and participants who scored 10 and above were considered somewhat familiar. Those participants who scored six and above were considered to be slightly familiar with SCD and those who scored less than five were considered not to be not too familiar with SCD.

Perceived Risk of SCD

Perceived risk was measured by questions 31 through 35 on the SCD Questionnaire. There were two answer choices Yes or No. Yes was assigned a value of 1 and No was assigned 0. The highest score a participant could receive was 5. The higher the score the more perceptive a participant was of their risk factor.

Table 10

Perception Pretest/Posttest Scores for Control Group

Score	Description	Pre-test n & %	Post-test n & % Sig: p = .110
0	No Positive Perception	28 (70%)	23 (57.5%)
1	Very Low Positive Perception	8 (20%)	9 (22.5%)
2	Low Positive Perception	4 (10%)	6 (15%)
3	Med. Positive Perception	0 (0%)	1 (2.5%)
4	High Positive Perception	0 (0%)	0 (0%)
5	Very High Positive Perception	0 (%)	0 (%)

As shown in Table 6 the scores at pretest were (M=.40, SD=.672) and at posttest (M=.70, SD=.992). As shown on Table 13 the *p* value was (P =.110). This *p* value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pre-test and posttest scores of participants in the control group for the DV perception was not statistically different. The difference in scores for the DV perception, at pre and posttest scores for the participants in the control group will be discussed in the section titled "differences within groups".

Intention

This variable was measured by questions 36 to 38 on the SCD Questionnaire. There were two answer choices Yes or No. Yes was assigned a value of 1 and No was assigned 0. The highest score a participant could receive was 3 (high intention). A higher score represented a higher intention to screen or undergo genetic counseling.

Table 11

Intention to Screen for SCD: Pretest/Posttest Scores for Control Group

Score	Description	Pre-test n & %	Post-test n & %	Sig. p = .730
0	No Positive Intention	5 (12.5%)	7 (17.5%)	
1	Low Intention	9 (22.5%)	6 (15%)	
2	Med. Intention	19 (47.5%)	16 (40%)	
3	High Intention	7 (17.5%)	11 (27.5%)	

For the DV Intention, the scores at pre-test were (M=1.70, SD=.911) and at post-test (M=1.78, SD= 1.050). As shown on Table 13 the p value was (P =.730). This p value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pretest and posttest scores of participants in the control group for the DV intention was not statistically different. The difference in scores at pre and posttest for the participants in the control group will be discussed in the next section under the title "differences within groups".

Table 12

Paired Sample t Test for Control Group

		Paired Differences							
					95% Confidence Interval of				
			Std.	Std. Error	the Difference				Sig. (2-
Dependent Variables		Mean	Deviation	Mean	Lower	Upper	t	df	tailed)
Pair 1	attitude_pre attitude_post	-.125	2.127	.336	-.805	.555	-.372	39	.712
Pair 2	knowledge_pre-knowledge_post	-.950	4.051	.640	-2.245	.345	-1.483	39	.146
Pair 3	perception_pre perception_post	.300	1.159	.183	-.071	.671	1.637	39	.110
Pair 4	intention_pre intention_post	.075	1.366	.216	-.362	.512	.347	39	.730

a. group = 0.

Table 12 showed that among the participants in the control group, there were no statistically significant differences between pre and post scores for DV Attitude (M=-.125, SD= 2.127, DF=39, P-value=0.73); Knowledge (M=-.950, SD= 4.051, DF=39, P-value=.146); Perception (M=.300, SD= 1.159, DF = 39, P-value=.110) and Intention

(M=.075, SD= 1.366, DF=39, P-value= .730) With *p*-values ranging from 0.11 up to 0.73 which is greater than type-*I* error (alpha) value of 0.05, the scores the participants in the control group at pre and posttest for the DV's Attitude, Knowledge, Perception and Intention were not statistically significant.

Within Group Analysis—Experimental Group = 1

Paired Sample *t* Test:

Table 13

Pre and Post Scores for Control and Experimental Groups

Study Variables	Control Group (n=40)			Treatment Group (n=40)		
	Mean	(Sd)	Median	Mean	(Sd)	Median
Attitude Pre	2.95	1.41	3	2.60	1.15	3
Attitude Post	2.83	1.43	3	3.40	1.37	3
Intention Pre	1.70	.91	2	2.15	.77	2
Intention Post	1.78	1.05	2	1.95	.64	2
Knowledge Pre	16.25	3.08	17	16.53	2.01	17
Knowledge Post	15.30	2.48	16	19.10	1.01	19
Perception Pre	.40	.67	.40	.78	.86	1
Perception Post	.70	.99	.70	.75	1.03	0

This table show the result of a paired analysis of the pre and posttest data which was conducted to delineate the within group differences in the pre-test and posttest scores of participants in the control group as well as of those in the experimental group.

Table 14

Paired Samples Statistics

Dependent Variables		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	attitude_pre	2.60	40	1.150	.182
	attitude_post	3.40	40	1.374	.217
Pair 2	knowledge_pre	16.53	40	2.013	.318
	knowledge_post	19.10	40	1.008	.159
Pair 3	perception_pre	.78	40	.826	.136
	perception_post	.75	40	1.032	.163
Pair 4	intention_pre	2.15	40	.770	.122
	intention_post	1.95	40	.639	.101

Table 14 shows the results of within-group differences for participants in the experimental group.

Above are the results of a Paired Samples t test conducted to compare the differences between the pre and post-test scores of participants in the experimental group. For the DV Attitude, the scores for participants at pretest was (M = 2.60, SD = 1.150) and at posttest (M = 3.40, SD =1.374). As shown on Table 19 the *p* value was (P =.013). This *p* value is lower than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pretest and posttest scores of participants in the experimental group was statistically significant. For the DV Knowledge, the scores for participants at Pretest was (M= 16.53, SD= 2.01) and at Posttest (M= 19.10, SD =1.01). As shown on Table 13 the *p* value was (P =.001). This *p* value is lower than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pretest and posttest scores of

participants in the experimental group was statistically significant. For the DV Perception the scores at pretest was (M= .78, SD = .826) and at posttest (M=.75, SD = 1.032). As shown on Table 13 the p value was (P =.910). This p value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pretest and posttest scores of participants in the experimental group not statistically significant. The scores for participants for the DV Intention at pretest was (M=2.15, SD .770) and at posttest the scores were (M=1.95, SD =.639). As shown on Table 19 the *p* value was (P =.160). This *p* value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pre-test and post-test scores of participants in the experimental group was not statistically significant.

Attitudes About SCD: Experimental Group

This variable was measured by questions 24 to 30. There were two answer options, "Agree" and "Do not agree." Agree was given a value of 1 and do not agree was given a value of 0. The highest possible score a participant can attain is 7 and the higher the score the more positive the participant's attitude was. As shown on Table 7 the scores of participants in the experimental group for the DV Attitude at Pretest were (M = 2.60, SD = 1.150) and at Posttest (M = 3.40, SD =1.374) and as shown on Table 19 the *p* value was (P =.013). This p value is lower than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pretest and posttest scores of participants in the experimental group for the DV attitude was statistically significant.

Table 15

Attitudes About SCD Pretest/Posttest Scores for Experimental Group

Score	Pre-test n & %	Post-test n & %	Sig: p = .013
0	0 (0%)	0 (0%)	
1	10 (25%)	3 (7.5%)	
2	7 (17.5%)	7 (17.5%)	
3	12 (30%)	11 (27.5%)	
4	11 (27.5%)	13 (32.5%)	
5	0 (0%)	4 (10%)	
6	0 (0%)	0 (0%)	
7	0 (0%)	2 (5%)	

As shown on Table 15 above, during pretest 58% of the participants in the experimental group recorded a score of 3 and above. During posttest 76% of the participants in the experimental group scored 3 and above. The differences in the pre and posttest scores of the participants in the experimental group for the DV attitude will be discussed in the next section under the title differences within groups.

Knowledge: Experimental Group

This variable was measured by question 1 through 23. There were two answer choices Yes or No. Yes was assigned a value of 1 and No was assigned 0. The most points any participant could receive in the knowledge category was 23 points. Participants who scored 20 and above were considered to be very familiar with SCD.

Participants who scored 15 and above were considered to be moderately familiar with SCD and participants who scored 10 and above were considered somewhat familiar. Those participants who scored six and above were considered to be slightly familiar with SCD and those who scored less than five were considered not to be too familiar with SCD. As shown in Table 7, the scores for participants in the experimental group for the DV knowledge at pretest was (M= 16.53, SD= 2.01) and at posttest (M= 19.10, SD =1.01) and as shown on Table 19 the *p* value was (P =.001). This *p* value is lower than 0.05. Based on a paired analysis of the pre and pos*tt*est scores conducted to delineate the within group differences in the pre-test and post-test scores of participants in the experimental group for the DV knowledge was statistically significant.

Table 16

Knowledge Pretest/Posttest Scores for Experimental Group

Score	Pre-test n & %	Post-test n & %	Sig: p = .001
3	0 (0%)	0 (0%)	
11	0 (0%)	0 (0%)	
12	2 (5%)	0 (0%)	
13	0 (0%)	0 (0%)	
14	5 (12.5%)	0 (0%)	
15	4 (10%)	0 (0%)	
16	5 (12.5%)	0 (0%)	
17	14 (35%)	0 (0%)	
18	5 (12.5%)	15 (37.5%)	
19	3 (7.5%)	9 (22.5%)	
20	1 (2.5%)	13 (32.5%)	
21	0 (0%)	3 (7.5%)	
22	1 (2.5%)	0 (0%)	

As shown on Table 16 above, 5% of the participant in the experimental group scored 20 and above out of possible 23 and fall in the category of very familiar with SCD. During posttest 40% scored 20 and above out of possible and belong in the category of very familiar with SCD. The differences in the pre and posttest scores of the participants in the experimental group for the DV knowledge will be discussed in the next section under the title differences within groups

Perceived Risk of SCD of Experimental Group

Perceived risk of the experimental group was measured by questions 31 through 35 on the SCD Questionnaire. There were two answer choices Yes or No. Yes was assigned a value of 1 and No was assigned 0. The highest score a participant could receive was 5. The higher the score the more perceptive a participant was of their risk factor. As shown in Table 7, a paired samples *t* test showed that the scores for the DV Perception at Pretest was (M= .78, SD = .826) and at Posttest (M=.75, SD = 1.032) and shown on Table 19 the *p* value was (P =.910). This *p* value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pre-test and posttest scores of participants in the experimental group for the DV perception was not statistically significant.

Table 17

Perception Pretest/Posttest Scores for Experimental Group

Score	Description	Pre-test n& %	Post-test n & %	Sig: p = .910
0	No Positive Perception	19 (47.5%)	21 (52.5%)	
1	Very Low Positive Perception	12 (30%)	11 (27.5%)	
2	Low Positive Perception	8(20%)	7 (17.5%)	
3	Med. Positive Perception	1 (2.50%)	0 (0%)	
4	High Positive Perception	0 (0%)	0 (0%)	
5	Very High Positive Perception	0 (%)	1 (2.5%)	

As shown on Table 17, at pretest 47.5% (n=19) recorded zero points and at posttest 52% (n=21) of participants recorded zero representing no positive perception of their risk to SCD. The differences in the pre and posttest scores of the participants in the experimental group for the DV perception will be discussed in the next section under the title differences within groups.

Intention to Seek SCD Screening: Experimental Group

This variable was measured by questions 36 to 38 on the SCD Questionnaire. There were two answer choices Yes or No. Yes was assigned a value of 1 and No was

assigned 0. The highest score a participant could receive was 3 (high intention). A higher score represented a higher intention to screen or undergo genetic counseling. As shown in Table 7, a paired samples t test showed that the scores for the DV intention at pretest was (M= 2.15, SD = .770) and at Post-test (M=1975, SD = .639) as shown on Table 19 the p value was (P = .160). This *p* value is higher than 0.05. Based on a paired analysis of the pre and posttest scores conducted to delineate the within group differences in the pretest and posttest scores of participants in the experimental group for the DV intention was not statistically significant.

Table 18

Intention to Screen: Pretest/Posttest Scores for Experimental Group

Score	Description	Pretest N & %	Posttest N & %	Sig: P = .160
0	No positive intention	2 (5%)	1 (2.5%)	
1	Low intention	3 (7.5%)	6 (15%)	
2	Medium intention	22 (55%)	27 (67.5%)	
3	High intention	13 (32.5%)	6 (15%)	

Table 18 above showed that 55% of participants in the experimental group recorded a score of 2 and 67% recorded a score of 2 at posttest. The differences in the pre and posttest scores of the participants in the experimental group for the DV intention will be discussed in the next section under the title differences within groups.

Table 19

Paired Sample t Test for Experimental Group

		Paired Differences							
					95% Confidence Interval of the Difference				
Dependent Variables		Mean	Std. Deviation	Std. Error Mean	Lower	Upper	t	df	Sig. (2-tailed)
Pair 1	attitude_pre - attitude_post	.800	1.951	.308	.176	1.424	2.594	39	.013
Pair 2	Knowledge-pre knowledge-post	2.575	2.581	.408	1.750	3.400	6.310	39	.000
Pair 3	Perception-pre perception-post	-.025	1.387	.219	-.468	.418	-.114	39	.910
Pair 4	intention_pre intention_post	-.200	.883	.140	-.482	.082	-1.433	39	.160

a. group = 1.

Table 19 showed that among the experimental group, there was a statistically significant differences between pre and post scores for DV Attitude (M=.800, SD= 1.951, DF=39, P-value=.013); Knowledge (M=2.575, SD= 2.581, DF=39, P-value=.001); Perception (M=-.025, SD= 1.387, DF = 39, P-value=.910) and Intention (M=.200, SD= .883, DF=39, P-value= .160) With p-values ranging from 0.13 up to 0.910 which is greater than type-I error (alpha) value of 0.05, the scores of the participants in the experimental group at pre and posttest for the DV's Attitude and Knowledge were statistically significant. The differences between the pre and posttest scores for the

participants in the experimental group for the DV's perception and intention were not statistically significant.

Between Group Analysis

Table 20

Paired Samples t Test: Experimental Versus Control Group

Dependent Variables	group	N	Mean	Std. Deviation	Std. Error Mean
knowledge_Diff	0	40	-.95	4.051	.640
	1	40	2.58	2.581	.408
attitude_Diff	0	40	-.13	2.127	.336
	1	40	.80	1.951	.308
perception_Diff	0	40	.30	1.159	.183
	1	40	-.03	1.387	.219
intention_Diff	0	40	.08	1.366	.216
	1	40	-.20	.883	.140

Table 20 show "within group" and "between group" differences between participants in the control group and those in the experimental group. For the DV Knowledge the differences in mean scores for participants in the control group were (M= -.95, SD=4.051) and for those in the experimental group it was (M=2.58, SD=2.581). For the DV Attitude, the differences in mean scores for participants in the control group were (M= -.13, SD= 2.127) and for those in the experimental group the difference in mean scores were (M= .80, SD = 1.951). For the DV Perception the difference in mean score for participants in the control group was (M=.30, SD=1.159) and for the experimental group the scores were (M= -.03, SD = 1.387). For the DV Intention, the difference in

mean score for participants in the control group was (M= .08, SD= 1.366) and for those in the experimental group the difference in mean was (M= .20, SD= .883).

Table 21

Two Independent Samples t Test for Control Versus Experimental Group

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Intervals	
		F	Sig.	t	DF	Significance (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Knowledge	Equal variances assumed	.467	.496	4.642	78	.000	3.525	.759	2.013	5.037
	No Equal variances			4.642	66.185	.000	3.525	.759	2.009	5.041
Attitude	Equal variances assumed	.021	.885	2.027	78	.046	0.925	.456	0.017	1.833
	Equal variances			2.027	77.426	.046	0.925	.456	0.017	1.833
Perception	Equal variances assumed	.183	.670	1.137	78	.259	.325	.286	-.244	.894
	No Equal variances			1.137	75.625	.259	.325	.286	-.244	.894
Intention	Equal variances assumed	9.027	.004	1.069	78	.288	.275	.257	-.237	.787
	No Equal variances			1.069	66.742	.289	.275	.257	-.238	.788

The two independent samples *t* test reported above in Table 21 are based on the following assumptions:

Random sampling without selection bias.

Normally distributed populations.

Unknown population variances.

Based on the two independent samples *t* test, the mean difference in scores for Knowledge was 3.5 {95% CI: 2.0, 5.0; P-Value :< 0.001}. The mean difference in the scores of the control group and the experimental group participants for the dependent variable SCD knowledge was significant. Therefore null hypotheses will be rejected.

For the dependent variable Attitude, the mean difference in the scores of the participants in the control group and the experimental group for the dependent variable Attitude was 0.925 {95% CI: 0.01, 1.8, P-Value :< 0.046}. The mean difference in the scores of the participants in the control group and the experimental group for the dependent variable Attitude was significant. Therefore the null hypotheses will be rejected.

For the dependent variable Perception, the mean difference in the scores between the participants in both groups was .325 {95% CI: .24, .89; P-Value :> 0.05}. The mean difference in the scores for control group and experimental group was a very small change that was not statistically significant. I failed to reject the null hypotheses.

For the dependent variable Intention, the mean difference is .275 {95% CI: .23, .78; P-Value :> 0.05}. The mean difference in scores for participants in the control group and the experimental group was small and not statistically significant. I failed to reject the null hypotheses.

Table 22

Summary of Findings for Two Independent Samples t Tests

Dependent Variable	Significance	Findings
SCD Knowledge	P = .001 (Significant)	Reject Null Hypotheses
SCD Attitude	P = .046 (Significant)	Reject Null Hypotheses
Risk Perception	P = .259 (Not Significant)	Failed to reject Null Hypotheses
Intention to screen/genetic counseling	P = .289 (Not Significant)	Failed to reject Null Hypotheses

Table 22 shows that of the four dependent variables only the means of SCD knowledge and SCD attitude were significantly different for the participants in the control group compared to the participants in the experimental group when analyzed using the Two Independent Samples t test.

MANOVA Results

The dependent variables are *Knowledge*, *Attitudes*, *Perceived Risk*, and *Intention to seek screening/genetic counseling*, and the independent variables *Age*, *Gender*, *Race*, *Religiosity*, and SES/*Income*. This analysis was based on the following assumptions: (i) The corresponding dependent variables were considered to be measured at the interval level for the purpose of the analysis, (ii) Observations were independently sampled from the population, (iii) Observations were from random sampling (iv) The dependent variables were normally distributed. Hypotheses 6 and 7 stated that there would be no significant differences in pre-test score and post-test scores of the participants in the experimental group when the dependent variables of knowledge, attitude, perception and intention are grouped with the independent variables of age, gender, race, religiosity and SES/Income.

Demographic Variables (MANOVA Results)

Multiple Analysis of Variance tests were run to determine if pre and post-tests scores of the experimental group participants differed significantly when grouped by the independent variables of age, gender, race, religiosity, and socioeconomic status. The results of these tests are described below. The MANOVA analysis was based on the following assumptions: that data being analyzed were independently obtained from the

population; that the dependent variables were measured at the interval level, and equal variances were assumed. These assumptions were not violated.

Ho6: There is no significant difference ($p. > .05$) in pre-test SCD knowledge, attitudes, perceived risk, and intention to seek screening scores in experimental group participants when grouped by age, gender, race, religiosity, and SES/Income. (MANOVA).

Ha6: There is a significant difference in pre-test scores ($p. < .05$) for SCD Knowledge, attitudes, perceived risk, and intention to seek screening and genetic counseling between the experimental group participants when grouped by age, gender, race, religiosity, and SES/Income. (MANOVA).

Table 23

New Coding for MANOVA

Independent Variable	Old description	Old code	New Description	New code
Age	18-25	1	18-25	1
	26-36	2	26 and above	2
	37-40	3		
	Over 40	4		
Gender	Male	1	Male	1
	Female	2	Female	2
Race	African American	1	African American	1
	Caucasian	2	Caucasian	2
	Hispanic	3	Hispanic	3
	Asian	4	Asian/Other	4
	Other	5		
Income/SES	Less $30,000	1	$30,000-71,000	1
	Over $31,000	2		
	Over $71,000	3	Over $71,000	2
	Over $100,000	4		
Religiosity	Very religious	5	Very Religious	
	Highly religious	4		3
	Moderately religious	3	Moderately religious	2
	Somewhat religious	2		
	Little religious	1	Barely religious	1
	Not religious	0		

General Linear Model for Pretest

Table 24

Between-Subject Factors—Experimental Group—Pretest

Variable	Code	Value label	*N* & %
Age	1	18-25	31 (77.5%)
	2	26 and above	9 (22.5%)
Gender	1	Male	12 (30%)
	2	Female	28 (70%)
Race	1	African American	16 (40%)
	2	Caucasian	10 (25%)
	3	Hispanic	7 (17.5%)
	4	Asian/Other	7 (17.5%)
SES/Income	1	$30,000-$71,000	31 (77.5%)
	2	Over $71,001	9 (22.5%)
Religiosity	1	Barely religious	13 (32.5%)
	2	Moderately religious	8 (20%)
	3	Very religious	19 (47.5%)

Table 24 shows the number and percentage of participants in each category.

Table 25

Multivariate Test Results—Pretest

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.961	170.483[b]	4.000	28.000	.000
	Wilks' Lambda	.039	170.483[b]	4.000	28.000	.000
	Hotelling's Trace	24.355	170.483[b]	4.000	28.000	.000
	Roy's Largest Root	24.355	170.483[b]	4.000	28.000	.000
gender	Pillai's Trace	.137	1.110[b]	4.000	28.000	.372
	Wilks' Lambda	.863	1.110[b]	4.000	28.000	.372
	Hotelling's Trace	.159	1.110[b]	4.000	28.000	.372
	Roy's Largest Root	.159	1.110[b]	4.000	28.000	.372
newAge	Pillai's Trace	.045	.329[b]	4.000	28.000	.856
	Wilks' Lambda	.955	.329[b]	4.000	28.000	.856
	Hotelling's Trace	.047	.329[b]	4.000	28.000	.856
	Roy's Largest Root	.047	.329[b]	4.000	28.000	.856
NewRace	Pillai's Trace	.138	.361	12.000	90.000	.974
	Wilks' Lambda	.867	.344	12.000	74.373	.978
	Hotelling's Trace	.148	.329	12.000	80.000	.982
	Roy's Largest Root	.094	.707[c]	4.000	30.000	.593
NewIncome	Pillai's Trace	.028	.204[b]	4.000	28.000	.934
	Wilks' Lambda	.972	.204[b]	4.000	28.000	.934
	Hotelling's Trace	.029	.204[b]	4.000	28.000	.934
	Roy's Largest Root	.029	.204[b]	4.000	28.000	.934
NewReligiosity	Pillai's Trace	.199	.800	8.000	58.000	.605
	Wilks' Lambda	.807	.792[b]	8.000	56.000	.612
	Hotelling's Trace	.232	.782	8.000	54.000	.620
	Roy's Largest Root	.194	1.406[c]	4.000	29.000	.257

Based on the MANOVA results in the Pre-test multivariate table 25 above, it is my conclusion that when knowledge, attitude, perception and intention are considered together as a vector dependent variable and when controlling for the independent variables age, gender, race, SES/Income and religiosity, none of the interactions were found to be significant and all the p values were greater than 0.05.

Estimated Marginal Means

Table 26

Pretest: Gender

DV	IV	Category	Means
Knowledge	Gender	Male	16.424
		Female	16.767
Attitude	Gender	Male	2.784
		Female	2.637
Perception	Gender	Male	.388
		Female	1.045
Intention	Gender	Male	2.229
		Female	2.306

The table above shows the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Gender: (F (4, 28) = 1.110, P=.372 > .05.

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = 1.10	P= 0.372	Not Significant

Estimated Marginal Means

Table 27

Pretest: Race

DV	IV	Category	Means
Knowledge	Race	African American	16.477
		Caucasian	16.467
		Hispanic	16.883
		Asian/Other	16.556
Attitude	Race	African American	2.376
		Caucasian	2.560
		Hispanic	2.615
		Asian/Other	3.291
Perception	Race	African American	.805
		Caucasian	.734
		Hispanic	.394
		Asian/Other	.934
Intention	Race	African American	2.148
		Caucasian	2.347
		Hispanic	2.055
		Asian/Other	2.521

The table above show the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Race: (F (12, 90) = .361, P=.974 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = .361	P= 0.974	Not Significant

Estimated Marginal Means

Table 28

Pretest: Age

DV	IV	Category	Means
Knowledge	Age	18-25	16.328
		26 and above	16.863
Attitude		18-25	2.816
		26 and above	2.605
Perception		18-25	.543
		26 and above	.890
Intention		18-25	2.234
		26 and above	2.301

The table above shows the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Age: (F (4, 28) = .329, P=.856 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = .329	P= 0.856	Not Significant

Estimated marginal means

Table 29

Pretest: SES/Income

DV	IV	Category	Means
Knowledge	SES/Income	$30,000-$71,000	16.797
		Over $71,000	16.394
Attitude	SES/Income	$30,000-$70,000	2.664
		Over $70,000	2.757
Perception	SES/Income	$30,000-$70,000	.640
		Over $71,000	.793
Intention	SES/Income	$30,000-$70,000	2.150
		Over $71,000	2.386

The table above show the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV SES/Income: (F (4, 28) = .204, P=.934 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = .204	P= 0.934	Not Significant

Estimated marginal means

Table 30

Pretest: Religiosity

DV	IV	Category	Means
Knowledge	Religiosity	Barely religious	16.176
		Moderately religious	17.067
		Very religious	16.544
Attitude	Religiosity	Barely religious	2.681
		Moderately religious	2.826
		Very religious	2.624
Perception	Religiosity	Barely religious	.640
		Moderately religious	.602
		Very religious	.908
Intention	Religiosity	Barely religious	1.815
		Moderately religious	2.621
		Very religious	2.368

The table above show the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Religiosity (F (8, 58) = .800, P=.605 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = .800	P= 0.605	Not Significant

Table 31

Summary of Pretest MANOVA Analysis—DVs Knowledge, Attitude, Perception, and Intention While Controlling for IVs Age, Gender, Race, Religiosity, and SES/Income

IV	Pillai's trace test	Sig:
Age	(F (4, 28) = .329, P=.856 > .05	Not Significant
Gender	(F (4, 28) = 1.110, P=.372 > .05.	Not Significant
Race	(F (12, 90) = .361, P=.974 > .05	Not Significant
Religiosity	(F (8, 58) = .800, P=.605 > .05	Not Significant
SES/Income	(F (4, 28) = .204, P=.934 > .05	Not Significant

Based on the multivariate Table 25 for pretest scores, I can report that none of the factors (independent variables) have a significant effect on any of the dependent variables, when the dependent variables are considered as a vector dependent variable.

Hypothesis 7

Ho7: There is no significant difference (*p*.> .05) in posttest scores for SCD Knowledge, attitudes, perceived risk, and intention to seek screening scores between experimental group participants when grouped by age, gender, race, religiosity, and SES/Income. (MANOVA).

Ha7: There is a significant difference (p. < .05) in posttest scores for SCD Knowledge, attitudes, perceived risk, and intention to seek screening and genetic counseling between the experimental group participants when grouped by age, gender, race, religiosity, and SES/Income. (MANOVA).

Table 32

General Linear Model for Posttest

Variable	Code	Value label	N & %
Age	1	18-25	31 (77.5%)
	2	26 and above	9 (22.5%)
Gender	1	Male	12 (30%)
	2	Female	28 (70%)
Race	1	African American	16 (40%)
	2	Caucasian	10 (25%)
	3	Hispanic	7 (17.5%)
	4	Asian/Other	7 (17.5%)
SES/Income	1	$30,000-$71,000	31 (77.5%)
	2	Over $71,001	9 (22.5%)
Religiosity	1	Barely religious	13 (32.5%)
	2	Moderately religious	8 (20%)
	3	Very religious	19 (47.5%)

Table 33

Multivariate Test Results—Posttest

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.994	1184.042[b]	4.000	28.000	.000
	Wilks' Lambda	.006	1184.042[b]	4.000	28.000	.000
	Hotelling's Trace	169.149	1184.042[b]	4.000	28.000	.000
	Roy's Largest Root	169.149	1184.042[b]	4.000	28.000	.000
gender	Pillai's Trace	.259	2.446[b]	4.000	28.000	.070
	Wilks' Lambda	.741	2.446[b]	4.000	28.000	.070
	Hotelling's Trace	.349	2.446[b]	4.000	28.000	.070
	Roy's Largest Root	.349	2.446[b]	4.000	28.000	.070
newAge	Pillai's Trace	.159	1.319[b]	4.000	28.000	.287
	Wilks' Lambda	.841	1.319[b]	4.000	28.000	.287
	Hotelling's Trace	.188	1.319[b]	4.000	28.000	.287
	Roy's Largest Root	.188	1.319[b]	4.000	28.000	.287
NewRace	Pillai's Trace	.203	.545	12.000	90.000	.879
	Wilks' Lambda	.804	.532	12.000	74.373	.887
	Hotelling's Trace	.234	.521	12.000	80.000	.895
	Roy's Largest Root	.185	1.390[c]	4.000	30.000	.261
NewIncome	Pillai's Trace	.021	.147[b]	4.000	28.000	.963
	Wilks' Lambda	.979	.147[b]	4.000	28.000	.963
	Hotelling's Trace	.021	.147[b]	4.000	28.000	.963
	Roy's Largest Root	.021	.147[b]	4.000	28.000	.963
NewReligiosity	Pillai's Trace	.275	1.154	8.000	58.000	.343
	Wilks' Lambda	.734	1.171[b]	8.000	56.000	.333
	Hotelling's Trace	.351	1.185	8.000	54.000	.325
	Roy's Largest Root	.315	2.280[c]	4.000	29.000	.085

Based on the MANOVA results in the posttest multivariate table 33 above, it is my conclusion that when knowledge, attitude, perception and intention are considered together as a vector dependent variable and when controlling for the independent variables age, gender, race, SES/Income and religiosity, none of the interactions were found to be significant and all the *p* values were greater than 0.05.

Estimated Marginal Means

Table 34

Posttest: Gender

DV	IV	Category	Means
Knowledge	Gender	Male	18.358
		Female	18.861
Attitude	Gender	Male	3.618
		Female	3.295
Perception	Gender	Male	1.369
		Female	.427
Intention	Gender	Male	2.154
		Female	1.671

The table above shows the estimated marginal means of the DVs knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Gender : (F (4, 28) = 2.446, P=.070 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = 2.446	P= 0.070	Not Significant

Estimated marginal means

Table 35

Posttest: Race

DV	IV	Category	Means
Knowledge	Race	African American	18.839
		Caucasian	18.768
		Hispanic	18.925
		Asian/Other	18.953
Attitude	Race	African American	3.408
		Caucasian	3.798
		Hispanic	2.907
		Asian/Other	3.713
Perception	Race	African American	.944
		Caucasian	1.190
		Hispanic	1.039
		Asian/Other	.418
Intention	Race	African American	1.881
		Caucasian	2.104
		Hispanic	1.923
		Asian/Other	1.743

The table above shows the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Race (F (12, 90) = .545, P=.879 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = .545	P= 0.879	Not Significant

Estimated marginal means

Table 36

Posttest: Age

DV	IV	Category	Means
Knowledge	Age	18-25	19.084
		26 and above	18.659
Attitude	Age	18-25	3.310
		26 and above	3.603
Perception	Age	18-25	.838
		26 and above	.958
Intention	Age	18-25	2.142
		26 and above	1.683

The table above shows the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Age : (F (4, 28) = 1.319, P=.287 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = 1.319	P= 0.287	Not Significant

Estimated marginal means

Table 37

Posttest: SES/Income

DV	IV	Category	Means
Knowledge	SES/Income	$30,000-$71,000	18.977
		Over $71,000	18.766
Attitude	SES/Income	$30,000-$71,000	3.611
		Over $70,000	3.303
Perception	SES/Income	$30,000-$71,000	.998
		Over $71,000	.797
Intention	SES/Income	$30,000-$71,000	1.923
		Over $71,000	1.902

The table above show the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV SES/Income: (F (4, 28) = .147, P=.963 > .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = .147	P= 0.963	Not Significant

Estimated marginal means

Table 38

Posttest: Religiosity

DV	IV	Category	Means
Knowledge	Religiosity	Barely religious	19.425
		Moderately religious	18.305
		Very religious	18.885
Attitude	Religiosity	Barely religious	3.932
		Moderately religious	3.236
		Very religious	3.201
Perception	Religiosity	Barely religious	1.177
		Moderately religious	.797
		Very religious	.720
Intention	Religiosity	Barely religious	1.804
		Moderately religious	1.991
		Very religious	1.943

The table above shows the estimated marginal means of the DV's knowledge, attitude, perception and intention when considered as a vector dependent variable while controlling for IV Religiosity (F (8, 58) = 1.110, P=.343> .05

TYPE OF TEST	**F value**	**P value**	**Significance**
Pillai's Trace	F = 1.154	P= 0.343	Not Significant

Table 39

Summary of Posttest MANOVA Analysis—DVs Knowledge, Attitude, Perception, and Intention While Controlling for IVs Age, Gender, Race, Religiosity, and SES/Income

IV	Pillai's trace test	Sig:
Age	(F (4, 28) = 1.319, P=.287 > .05	Not Significant
Gender	(F (4, 28) = 2.446, P=.070 > .05	Not Significant
Race	(F (12, 90) = .545, P=.879 > .05	Not Significant
Religiosity	(F (8, 58) = 1.110, P=.343> .05	Not Significant
SES/Income	(F (4, 28) = .147, P=.963 > .05	Not Significant

Based on the multivariate Table 33 for posttest scores, I can report that none of the factors (independent variables) have a significant effect on any of the dependent variables, when the dependent variables are considered as a vector dependent variable.

Summary and Transition

This chapter reported the results of the data analyses performed using SPSS version 22. The first four hypotheses were tested and the results are shown in Table 22. The results indicated that there was a significant difference between SCD knowledge pre-test scores and post-test scores of participants in the experimental group and those in the control group. The results also show that there was significant difference between the SCD attitude pretest and posttest scores of participants in the experimental and control groups. The other hypotheses tested including whether there would be any differences between the pretest and posttest scores of participants perceived risk of SCD; Intention to seek screening; and undergo genetic counseling did not show any significant differences. Though there were differences between the participants in the experimental

and the control group among the variables perception and intention, the differences were not significant. Failure to find significant differences between the pretest and posttest scores of participants in the control group and experimental groups supports what I found during literature review that there are generally low awareness about SCD; that among those who have perception about SCD, they may not necessarily be influenced to seek screening because of ethnic or religious or other factors (Boyd et al., 2005; Miller et al., 2010; Parker and Quereshi, 2007;Treadwell et al., 2006 and Zimmerman et al., 2006).

The independent variables for this study were age, gender, race, religiosity and SES/Income did not show any significant difference between the pretest and posttest scores between the experimental and control groups. A MANOVA analysis was undertaken to look at the differences in the mean scores when the dependent variables knowledge, attitude, intention and perception are grouped by the independent variables age, race, gender, religiosity and income. The result showed that there were no significant differences in pre and posttests scores within the experimental group when controlling by age, gender, race, religiosity, and SES/Income.

Chapter 5: Discussions, Conclusions and Recommendations

Introduction

The purpose of this study was to determine whether a health education intervention about SCD would impact college students' SCD knowledge, perceived risk, and attitudes about the disease and motivate them to seek screening in order to know their SCT status and to seek genetic counseling if at risk for SCD. This study targeted college students on a college campus who completed the SCD questionnaire during pretest and posttest sessions to assess the impact of SCD education, which served as an intervention that was presented to the experimental group. This study was unlike many previous studies on SCD, which have typically been limited to African Americans (Boyd et al., 2005; Treadwell et al., 2006). This chapter presents the interpretations of the findings, recommendations pertaining to health education, recommendations for further research, implications for social change and conclusions.

During the literature search, most of the articles I reviewed focused on existing treatments for SCD, as well as new, promising treatments under trial or under development (Creary et al., 2007; Raghupathy & Billett, 2009; Raghupathy, Manwani, & Little, 2010). Most of the articles and studies only briefly addressed primary prevention strategies such genetic screening and genetic counseling, and the authors only briefly discussed the role of causal factors such as the sickle cell trait (Boyd et al., 2005; Miller et al., 2010; Parker & Quereshi, 2007; Treadwell et al., 2006; Zimmerman et al., 2006). Many of the articles that mentioned sickle cell trait, newborn screening, and genetic counseling did so in the introduction to the study or as recommendations for future

studies (Brawley et al., 2008, Creary et al., 2007, Lanzkron et al., 2008). Overall, many of the articles reviewed only provided brief discussions about prevention and factors that constitute barriers to widespread adoption of preventive strategies for the reduction of the prevalence of SCD (Brawley et al., 2008, Creary et al., 2007, Lanzkron et al., 2008).

The findings during the literature search led me to adopt a different approach from most of the previous studies, which focused on finding cures or new treatments for SCD. I decided to explore ways to reduce the prevalence of SCD using the Health Belief Model (HBM) as a framework to promote primary prevention. Primary prevention would focus on educating the public about SCD/SCT and encouraging young adults to know their SCT status before they make decisions about reproduction.

The HBM, as previously discussed in Chapter 1, was developed in 1950 as a strategy to encourage members of the public to adopt new health behaviors such as seeking screening in order to determine their susceptibility to a disease. HBM is based on the premise that individuals will be willing to adopt a health behavior in the following situations: (a) if they believe they are at risk for a disease, (b) if the disease is severe, and (c) if it would benefit them if they adopt the new behavior.

The data was gathered using a SCD questionnaire that was designed to capture the participants' responses to questions that sought to gauge their individual perceptions based on the core concepts of the HBM such as (a) individual's susceptibility to a disease, (b) individual's perception of disease severity, (c) individual's perceptions of barriers, (d) individual's perception of the health benefits of new health behavior, (e) factors that provide cues for action, and (f) individual's ability to adopt new behavior.

Perceived Susceptibility and Intent

HBM was chosen as a theoretical framework in order to explore the impact of health education about SCD on young adults' knowledge of the disease, attitudes about the severity of the disease, and perceived risk. The objective was to find out if SCD health education may have a significant impact on young adults' knowledge, attitudes, perceived susceptibility, and intention to seek screening so that those who are at risk can seek genetic counseling prior to making decisions about reproduction. HBM would be an important strategy in trying to educate young adults and college students that SCD does affect racial groups other than African Americans.

I hypothesized that participants who received SCD health education would have more knowledge about SCD than participants who did not receive any health education. I also hypothesized that participants who received SCD health education would have a more positive attitude about the disease than those participants who did not receive the health education. Another hypothesis was that those participants who received the SCD health education would be more likely to have a better perception of their susceptibility to the disease than those who did not receive the SCD health education. I also hypothesized that those participants who received SCD health education would be more likely to seek screening and genetic counseling than those who did not receive SCD health education. Another hypothesis was that demographic characteristics of the participants such as age, gender, religiosity, socioeconomic/income status would be significantly associated with dependent variables such as SCD knowledge, SCD attitude, perceived risk of SCD, and intention to seek screening and/or genetic counseling if at risk.

Interpretation of Findings

Knowledge

Numerous prior studies have shown deficits in the knowledge base of the general population about SCD (Acharya et al., 2009; Boyd et al., 2005; Treadwell et al., 2006). In a study to explore knowledge and attitudes about SCD, Acharya and colleagues found that individuals who had better knowledge about SCD were likely to have children with the disease (Acharya et al., 2009). In an another study, Treadwell and colleagues found that individuals who had received SCD education through contacts with relatives or friends were 3 times more likely to know their SCT than members of the general population (Treadwell et al., 2006). The first null hypotheses stated that there would be no significant difference between SCD knowledge in the pretest and posttest scores of participants in the experimental group compared to those in the control group. However, as shown in Table 7, though the scores in the knowledge category for the participants in the experimental group and control group were similar during pretest, there was a significant difference during posttest. When these differences were analyzed using the two independent sample *t* tests, the differences was significant at $p < .05$. Based on this finding, I am able to reject the null hypotheses.

This finding that SCD education can increase awareness and knowledge about SCD is similar to what I found in the literature (Acharya et al., 2009; Treadwell et al., 2006). This finding that SCD education can increase awareness about a disease is important because one of the purposes of this study was to determine whether health

education about SCD would increase awareness and knowledge about the disease among young adults before they made reproductive decisions.

Attitude

The second null hypothesis stated that there would be no significant differences between SCD attitudes pretest and posttest scores of participants in the experimental group and the control group. The data in Table 7 showed that although the control group and the experimental groups had similar pretest scores, there was a significant difference between both groups at posttest when their scores were analyzed using the two independent sample *t* test ($p < .05$). Based on this finding, I am able to reject the null hypothesis.

This is an important finding because attitudes are harder to impact than knowledge (Gustafson et al., 2007; Miller et al., 2010), and attitudes may influence feeling of perceived susceptibility or intent (Parker & Quereshi, 2007; Zimmerman et al., 2006). There was a slight anomaly in the pretest mean score of the control group, which was 2.95 but surprisingly went down to 2.83 during the posttest. The only explanation I can come up with was that there was a pretesting effect because the participants were using the same questionnaire that they had used for the pretest a few days earlier. In addition, because the control group did not receive the intervention, it is possible that many of the members of this group were somewhat disinterested while completing the posttest. The participants in the control group did receive the intervention after they had completed the posttest.

Perception

The third hypothesis stated that there will be no significant difference between SCD perceived risk scores at pre-test and post-test between the experimental and control groups. The data in Table 7 shows that at pre-test the scores of the control group and the experimental group were similar. However the difference in scores between both groups at post-test was small and a two independent sample t-test analysis showed that the change was a non-significant difference ($p \geq .05$). Based on this data I am not able to reject the null hypotheses. The fact that there was no statistical significance between the means of the control and experimental groups was also unexpected. In order to have a better understanding of low perception, I looked at the Table 7 and found that the 79.9% of participants in the control group scored between 0 and 1 out of a possible score of 5 while 80% of the participants in the experimental group scored 0 and 1 out of a possible score of 5. Thus, most of the participants in both groups did not feel that they were at risk.

The low perception was a surprise for two reasons. The first reason is the fact that the SCD patients who were featured in the DVD that was used for the intervention had numerous medical problems. For this reason I would have expected that all participants who saw the DVD would be interested in finding out if they are at risk for SCD. The second reason why the low perception recorded by the participants was a surprise was because some of the SCD patients who were featured in the DVD were Caucasians. For this reason I would have expected that all participants would be eager to know their risk factor. This finding supports existing studies that have shown that there is a tendency in

the general population that SCD is a Black people's disease (Miller et al., 2010, Parker & Quereshi, 2007). But even among African Americans, many who are aware of SCD tend to act as if they are immune and may "wish it away" as if to say that will not happen to me thereby ignoring established inheritance patterns (Acharya et. al, 2009; Boyd et al., 2005; Gallo et al., 2010). This was understandable because African Americans made up 40% of the participants in the experimental group while the three other racial groups Caucasians, Hispanics and Asians constituted 60% of participants in the same group. The large number of other racial groups besides African Americans may have impacted the low perception because members of these racial groups tend to think that SCD is a Black disease (Miller et al., 2010. These findings are in line with previous studies cited above that show that many in the general population still have the assumption that SCD affects only African Americans and members of the other races do not feel that they are at risk for SCD and this any influences their intent to seek screening (Miller et al., 2010). One of the core concepts of the theory HBM held true in this situation because the participants in this study showed a low perception of their susceptibility in spite of the fact that those assigned to the experimental group viewed a DVD which showed many SCD patients who were of Caucasian and Hispanic descent.

Intention to Seek Genetic Screening/Genetic Counseling

The fourth and fifth hypotheses were combined during data analysis because they both measured intent to seek genetic screening and genetic counseling. These hypotheses stated that there would be no significant differences between intent to seek screening and intent to seek genetic counseling during pre-test and post-test among participants in the

experimental group and the control group. The pre-test scores were similar at 1.70 and 2.15 for control group and experimental groups. During post-test, the scores were similar at 1.78 and 1.95 for the control and experimental groups respectively. The mean difference was .275. This was not significant as shown in Table 22 when analyzed using a two independent sample t test ($p. \geq .05$). Based on this finding, I am not able to reject the null hypotheses. The lack of statistical significance in the intention variable may be due to the majority of participants not thinking that they are at risk. There are numerous reasons why individuals may not think that they are susceptible to a disease and among these reasons could be a strong feeling that their religious faith can protect them from harm (Zimmerman et al., 2006). It is important to note here that in both groups more than half of participants indicated that they were moderately to highly religious. With regards to intention to seek screening, there was no big difference in the responses to the intention questions between participants who stated that they were highly religious or moderately religious.

As discussed under the sub title Perception, religiosity and ethnicity are two independent variables that can also impact the decision to seek screening. The study by Miller et al., (2010) and Zimmerman et al., (2006) suggested that ethnicity and religious beliefs can influence the decision whether or not individuals seek screening. Most of the participants in this study were not African American and more than half identified themselves as moderately, or very religious which may be the main reason for the lack of intention to seek screening despite being exposed to an educational intervention. In terms of the Health Belief Model, until there is a "cue to action" for individuals to feel at risk,

the decision to not feel at risk will continue to be the case. However, other follow-up quantitative or qualitative research would be needed to further explore this finding.

Demographic Factors

Hypotheses 6 and 7 tested whether there were significant differences in pre and post test scores within the experimental group when the dependent variables knowledge, attitude, perception, and intention are grouped as a vector dependent variable when controlling for the independent variables age, gender, race, religiosity, and SES/Income. The results of the MANOVA revealed that there were no significant differences in pre and post-tests scores of participants in the experimental group at pre and posttest. Based on the MANOVA the differences in the estimated marginal means at pretest and posttest scores of participants in the experimental group when the DV's knowledge, attitude, perception and intention are considered together as a vector dependent variable and when controlling for the independent variables age, gender, race, SES/Income and religiosity, there was no statistical significance found and all the p values were greater than >0.05.

As for the variable religiosity, Table 6 shows that only 30% of participants in the control group and 47% of participants in the experimental group indicated that they belonged in two categories of moderately religious and very religious. This is consistent with my finding during literature review that decision making by many individuals may be influenced by their religious beliefs (Zimmerman et al., 2006). However this quantitative study alone cannot explain the impact of individual's religiosity on intent to screen or seek genetic counseling.

Recommendations Pertaining to Health Education

In light of the findings that only two of the dependent variables knowledge and attitude were impacted, a new study using a different approach may improve this current study so that perceived risk and intention to seek screening will be impacted. The HBM model could be incorporated into school curriculum in any plans designed to motivate college students to seek screening and genetic counseling. The main reason why HBM was selected as the theory for this study was because the constructs were intended to motivate individuals by targeting certain messages about a particular disease. In this case, HBM's first construct susceptibility brings the message to the target population that they are vulnerable to the disease that is the target of the campaign (Rosenstock, Stretcher & Becker, 1994). This is particularly relevant in the effort to reduce the incidence of SCD because there is widespread misconception that SCD is an African American disease and other races need not worry. As the DVD Let's talk about sickle cell showed there are many non- African American who are diagnosed with SCD.

HBM's second construct focuses on disease severity. This is also very important in any campaign that is designed to reduce the incidence of SCD (Rosenstock, Stretcher & Becker, 1994). It is a natural reaction that individuals would like to avoid a disease especially when they know that it is severe. As was shown in the DVD Let's talk about sickle cell, many of the patients that were featured in the DVD recounted how they frequent the Emergency Rooms just to get relief from excruciating pains they experience during crisis. The next HBM construct that will be relevant in a campaign that targets college students is third construct which touts the health benefits that will accrue to those

who adhere to a particular health campaign (Rosenstock, Stretcher & Becker, 1994). For instance in the case of SCD prevention campaign geared to college students, an emphasis on the fact that the disease is preventable if neither parent have the trait may bring forth the benefits of genetic screening and genetic counseling.

The next HBM construct that will an important part of any SCD prevention campaign directed at college students is the recognition that there are barriers that prevent individuals from changing their behaviors (Rosenstock, Stretcher & Becker, 1994). Providing SCD education to college freshmen by showing them educational DVD such as Let's talk about sickle cell that was used for this study will enhance health education efforts and create "cues to action," such that college students will understand their risk regardless of ethnicity, and frame tailored interventions for college students that work within religious values. The last HBM construct self- efficacy describes the fact individuals may not always have faith in their ability to adopt a new health behavior (Rosenstock, Stretcher & Becker, 1994).

Overall, the fact that the changes that were observed in SCD education and SCD attitude among the participants in the Experimental group did not lead to a significant difference in risk perception and the desire to seek screening, only helps to emphasize the need for a different strategy beyond awareness in order to increase the desire for college students to seek genetic screening prior to making reproductive decisions. It is for this reason that I have made the recommendation that the Federal Government provide SCT test results to all those who were screened. However the one time intervention provided during this study did not show a significant change attributable specifically to any of the

independent variables age, gender, race SES/Income, and religiosity. A Qualitative study will more likely provide a better explanation for how these independent variables can impact a decision to seek screening or genetic counseling.

Recommendations for Action

The most urgent changes that I wish to recommend are that SCD education should be made available to all young adults as a way of increasing awareness about SCD and SCT. Improvement in awareness will improve college student's knowledge about their susceptibility to SCD, the severity of SCD and the health benefits that accrue to those who understand the mode of disease transmission thereby improving future reproductive decision in particular and overall health in general. An improved knowledge of SCD among college students will likely be their cues to action to seek genetic screening and genetic counseling.

Another recommendation will be for the US government to continue to screen all newborns for SCD disease. The US government should also continue to provide the results of SCD screening results to parents of the newborn. A potential cues to action could be for the US government to provide SCD newborn screening results to all 18 year olds who were screened as newborns. There are several reasons why providing test results may decrease the incidence of children born with SCD. One such reason is that many- at risk individuals do not know that they have the SCT (Boyd et al., 2005; Treadwell et al., 2006). Many people who were screened at birth must depend on their parents or guardian to provide them with their SCD test result. There are no records

available to show how many parents pass on the valuable SCD test results to their offspring.

Another reason why it would be a good idea for the Federal Government to authorize that SCD newborn screening results be released to all 18 year olds who were screened at birth is the fact that many young people do not plan to become pregnant and as such may not necessarily pay much attention to their SCD risk factor. If the US government were to make the SCD screening result available to all 18 years old that were screened at birth, then there would be a higher likelihood that most young people who are approaching reproductive age will be aware of SCD and their risk factor. Releasing the SCD screening results to young people who were screened at birth could be the singular event that is capable of motivating that individual to change their behavior or adopt a particular behavior as espoused by HBM core concept cues to action.

Recommendations for Further Research

Prior research into the reasons why certain segments of the American society do not fully embrace genetic screening and genetic counseling have identified cultural and religious beliefs as some of the factors that influence individuals' decisions regarding genetic screening and genetic counseling (Rowley et al., 1991; Treadwell et al., 2006). Findings in studies by Treadwell et al., (2006) and Rowley et al., (1991) showed that even when some study participants were aware of their risk factors they were reluctant to undergo genetic screening and genetic counseling and many erroneously believed that they underwent screening and their unborn child has genetic disease they will be forced

to have an abortion. In order to have a better understanding of this phenomenon, a qualitative study might be appropriate.

Research into why SCD continues to be viewed as a Black disease will go a long way to prepare college students to have the understanding that SCD has been found in all segments of society regardless of race or nationality. A qualitative research approach may provide answers to why college students who recorded high positive perception of SCD did not feel they were susceptible even after watching the DVD, and be motivated enough to seek genetic screening and genetic counseling for those at risk.

Implications for Social Change

The findings of this study may provide justification for increased SCD education among college students other young adults and lead to the development of increased health education interventions on college campuses. College campuses could serve as an effective outlet for health education relating to this disease and many research studies have selected participants age 18 and over as the target age group to address SCD screening and counseling because individuals are more likely to make reproductive decisions after age 18. Health education focusing on college students' beliefs, attitudes, and behavioral factors relating to SCD screening can empower individuals to know if they have the sickle cell trait and understand their risk factor for SCD. Those who have increased SCD knowledge may make informed decisions and ultimately this will lead to a reduction in the transmission of the disease. Such information will be of immense value for future public health programs practitioners who wish to develop prevention programs for SCD or any other chronic disease.

Conclusion

The findings of this quasi-experimental study suggest that a SCD health education can improve college students' knowledge and attitudes about SCD, but it did not have any significant effect on perceived risk or intention to seek screening. Prior studies such as the 2007 study by Gustafson et al. showed that the African American participants in that study acknowledged that they had a high perception of their risk factor, but most of them rated themselves low on susceptibility. The low susceptibility to SCD is not realistic since 1 in 12 African American has the sickle cell trait (CDCh, 2011). What is unique about this study is that participants of all races were included in the study as opposed to previous studies on SCD that only recruited African Americans. According to Bediako (2009); Boyd (2005; Gustafson et al (2007) and Long (2011), SCD is considered a Black disease. The DVD that was shown to the experimental group during post- test showed that SCD occurs among other races besides African Americans. Overall, the lack of a significant increase in perception and intention points to the fact that more needs to be done to address SCD.

The challenge is for future programs to tackle two problems which are to find a way to incorporate a theory such as HBM into programs to address the issue of susceptibility and perception. As I found in this study, individuals who should know their Sickle cell trait do not know and those who know do not necessarily take steps to avoid having offspring with SCD. The finding of a statistical significance between SCD education and increased knowledge and improved attitude about SCD is an important first step in developing a preventive strategy towards SCD. Though it is important for

ongoing research to continue the search for improved treatment and ultimately a cure, there is need for a continuous ongoing dissemination of SCD health education so as to increase awareness and motivate more people to seek screening.

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Appendix A: Sickle Cell Disease Questionnaire

Knowledge Questions: Respond to the following statements according to your knowledge of sickle cell disease.

(1) Have you ever heard of sickle cell disease?
- (a) Yes
- (b) No

(2) Sickle cell disease is a blood disorder.
- (a) Yes
- (b) No

(3) Sickle cell disease is hereditary.
- (a) Yes
- (b) No

(4) You cannot get sickle cell disease from a blood transfusion.
- (a) Yes
- (b) No

(5) You cannot get sickle cell disease through physical contact with an affected person.
- (a) Yes
- (b) No

(6) Sickle cell disease is caused by a sickle cell genetic trait.
- (a) Yes
- (b) No

(7) Sickle cell disease and sickle cell trait can be identified by a blood test.
- (a) Yes
- (b) No

(8) Is it important to know if you have sickle cell trait?
- (a) Yes
- (b) No

(9) It is possible to have a mild form of sickle cell disease.
- (a) Yes
- (b) No

(10) You can have a sickle cell genetic trait even when both parents do not have the trait.
- (a) Yes
- (b) No

(11) People who inherit a sickle cell genetic trait from one of their parents will not develop sickle cell disease and may live normal lives.
- (a) Yes
- (b) No

(12) People from all ethnic backgrounds can acquire sickle cell disease.
- (a) Yes
- (b) No

(13) Sickle cell disease affects different people in different ways, but almost always includes pain.

(a) Yes
(b) No

(14) There are things a person with sickle cell disease can do to avoid some of the complications.
(a) Yes
(b) No
(15) People with sickle cell disease need to have their vision checked more often than people who do not have sickle cell disease.
(a) Yes
(b) No
(16) People with sickle cell disease are less likely to get malaria.
(a) Yes
(b) No
(17) People with sickle cell disease should still get routine vaccinations.
(a) Yes
(b) No
(18) A woman with sickle cell disease can have a healthy pregnancy.
(a) Yes
(b) No
(19) People with sickle cell disease are more likely to suffer from life-threatening infections than people who do not have the disease.
(a) Yes
(b) No
(20) Sickle cell disease can impact a child's school performance.
(a) Yes
(b) No
(21)Stem cell or bone marrow transplant is an important approach for treating Sickle cell disease.
(a) Yes
(b) No
(22) Sickle cell disease sometimes skips generations.
(a) Yes
(b) No
(23) There is no universally accepted cure for sickle cell disease.
(a) Yes
(b) No
Attitude Questions:
Respond to the following statements by indicating whether you agree or do not agree to the statement.
24) It is important that I know about sickle cell disease?
(a) Agree
(b) Do not agree
(25) Research on genetics and sickle cell disease is tampering with nature.

(a) Agree
(b) Do not agree

(26) Research on genetics is unethical.
(a) Agree
(b) Do not agree

(27) Genetic testing will lead to racial discrimination.
(a) Agree
(b) Do not agree

(28) Pregnant women should be required to undergo tests to determine if the unborn child has sickle cell disease.
(a) Agree
(b) Do not agree

(29) Religious people should seek genetic screening.
(a) Agree
(b) Do not agree

(30) Religious people should seek genetic counseling.
(a) Agree
(b) Do not agree

Perceived Risk Questions:
Respond to the following statements by indicating whether you perceive you are at risk.

(31) Do you have a genetic trait for sickle cell?
(a) Yes
(b) No

(32) Do you perceive you are at risk for sickle cell disease?
(a) Yes
(b) No

(33) Do you perceive your offspring would be at risk for sickle cell disease?
(a) Yes
(b) No

(34) Do you perceive that you should undergo genetic screening for sickle cell disease?
(a) Yes
(b) No

(35) Do you perceive that you should undergo genetic counseling for sickle cell disease?
(a) Yes
(b) No

Intention Questions:
Respond to the following statements by indicating your intention: yes or no.

(36) Do you intend to seek genetic screening for sickle cell disease?
(a) Yes
(b) No

(37) If you knew you were at risk, would you seek genetic counseling?
(a) Yes

(b) No

(38) Will you talk to your partner about sickle cell trait?

(a) Yes

(b) No

Religiosity Questions:

Respond to the following statements by indicating to what extent religion plays a role in your life.

(39) Do you consider yourself a religious person?

(a) Yes

(b) No

(40) To what extent do religious beliefs influence your daily decisions?

(a) Not at all/not religious (0)

(b) A little (1)

(c) Somewhat (2)

d) Moderately (3)

(e) Very Much (4)

Demographic Questions

Choose one.

(41) What is your racial classification?

(a) African American

(b) Caucasian

(c) Hispanic

(d) Asian/Pacific Islander

(e) Other

(42) What is your family Income?

(a) Below $31,000 per year

(b) Between $31,001 and $71,000 per year

(c) Between $71,001 and $100,000

(d) Over $100,000

(43) How old are you? (Write in)

(a) 18 to 25

(b) 26 to 35

© 36 to 40

(d) Over 41

(44) What is your gender?

(a) Male

(b) Female

Key

There will be a cumulative scoring based on questions 1 through 44.

There will also be a subscale of the following variables:

Knowledge will be measured by questions 1 through 23 (higher score = more knowledge)

Attitude will be measured by questions 24 through 30; (higher score = more negative attitudes)

Perceived Risk will be measured by questions 31 through 35;

Intention for screening or counseling will be measured by questions 36 through 38;

Religiosity will be measured by questions 39 through 40

Demographic questions are questions 41 through 44.