FACTORS THAT CONTRIBUTE TO THE KNOWLEDGE, HEALTH BELIEFS, ATTITUDES, AND BEHAVIORS REGARDING SICKLE CELL DISEASE AMONG COLLEGE STUDENTS

by

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Abstract

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SCD and Thalassemia are considered the two major Hemoglobin Disorders, and have recently been declared a global health problem by the World Health Organization (WHO). Despite SCD being a global health issue, the United States (US) still focuses on treatment and management of the disease rather than prevention. The overall purpose of this study was to assess the factors that contribute to knowledge, health beliefs, and attitudes about SCD, and screening behaviors among college students to provide pertinent information for SCD prevention. A non-experimental, cross-sectional research design using a convenience sample of college students was used for this study. Descriptive statistics, such as frequency distributions and percentages were used to describe the sample. MANOVA was used to determine if there were any group differences in the knowledge, health beliefs, attitudes, and behaviors about SCD. Finally, linear and multiple regression analyses were conducted to determine the predictive value of gender, race/ethnicity, family history, and familiarity with SCD as it relates to the knowledge, health beliefs, attitudes, and behaviors about SCD. Regression analyses were also used to determine the strength of the relationship between knowledge, health

beliefs, attitudes, and behaviors about SCD. An important finding from this study is that there was a significant relationship between knowledge, health beliefs, and attitudes regarding SCD even after controlling for demographic factors. Race/Ethnicity was the best predictor of knowledge about SCD. This finding highlights the importance of Universal SCD education and should be an important factor to consider in the development of prevention programs. Implications for SCD prevention using the Universal, Selective, and Indicative Prevention Framework are presented.

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Chapter 1

Introduction

Sickle Cell Disease (SCD) is a hereditary blood disorder affecting the shape of the red blood cells that block blood vessels leading to organ damage and frequent erratic painful episodes (Meir & Miller, 2012). SCD occurs from the change in the hemoglobin-Beta gene. Hemoglobin carries oxygen from the lungs to the rest of the body. Normal red blood cells (hemoglobin A) are round and move smoothly and continuously through the blood vessels. In individuals with SCD, the abnormal hemoglobin (hemoglobin S) stick to each other causing the red blood cells to stiffen, forming a sickle shape. The sickle shape results in the accumulation of the red blood cells blocking the vessels and harming the organs. The sickle cells are destroyed very quickly resulting in anemia (National Human Genome Research Institute [NHGRI], 2010). Effects of anemia include “shortness of breath, dizziness, headache, coldness in your hands and feet, pale skin, chest pain, weakness, and fatigue” (NIH, 2014, p.10).

Statement of The Problem

SCD and Thalassemia are considered the two major Hemoglobin Disorders, and have recently been declared a global health problem by the World Health Organization (WHO) (Odame, Kulkarni & Ohene-Frempong, 2011). Despite SCD being a global health issue, the United States (US) still focuses on treatment and management of the disease rather than prevention. This focus on treatment and management is mostly on the physical effects; the psychosocial impact of the disease on the person affected and his/her family and support system is all but forgotten. We have come so far since the first report of SCD, but in order to solve this problem, social workers must take a holistic approach. There have been many medical advances to manage complications and increase life expectancy. Meanwhile, not much has been done to reduce future cases.

Key to prevention is an understanding of how SCD and are inherited from parents in the same way as blood type or any physical traits. Since it is inherited genetically, a major approach to prevention should be education about the reproductive implications of the disease. The literature on informed reproductive decisions among people with SCD is limited. The current literature suggests that there is a lack of knowledge about SCD, carrier status (includes both Sickle Cell Trait (SCT) and Beta-Thalassemia trait) and reproductive implications of the disease among high-risk populations. The gaps in knowledge indicate the need for adequate education of at risk individuals; particularly, prevention needs to be aimed at young people who are starting to plan their long-term relationships and reproductive decisions. Prevention and intervention programming should be geared towards increasing knowledge, beliefs, and attitudes about the disease as well as its reproductive implications. Alao, Araoye, and Ojabo (2009) suggest that university level students are involved in dating relationships, therefore SCD carrier screening and increased education, especially among college and university students is essential to reduce the spreading of SCD.

Prevalence of the Problem

SCD is a global public health issue affecting millions of people throughout the world (Abedian, Howard, Rawle & Thomas, 2010; Rees, Williams & Gladwin, 2010). In the U.S., people are often shocked to learn that someone who is not African American has SCD (SCDAA, 2012). SCD is particularly prevalent among people whose ancestors come from Africa, South and Central America, the Caribbean, Saudi Arabia, India, Sri Lanka, and Mediterranean countries including Turkey, Greece, and Italy (National Heart Lung and Blood Institute [NHLBI], 2012; SCDAA, 2012). SCD can also be found in Southern Europe (Portuguese, Spaniards, French Corsicans, Sardinians, Sicilians, and Cypriots) and in the Near and Middle East countries (Lebanon, Israel, Saudi Arabia,

Kuwait and Yemen) (SCDAA, 2012). In the U.S., an estimated 70,000 to 100,000 people have SCD and 3 million have SCT (SCDAA, 2012). In the U.S., 1 in 400 African Americans and 1 in 19,000 Latinos have SCD (Smith, Oyeku, Homer, & Zuckerman, 2006). Additionally, approximately 1 in 12 African Americans, 1 in 100 Latinos (National Human Genome Research Institute (NHGRI), 2010) and 1 in 660 Caucasians (Rogers, 2008) have SCT. Furthermore, hemoglobin gene variants can be present in people of all ethnic groups, especially with increasing ethnic diversity in relationships (Locock & Kai, 2008); see table 1-1.

Table 1-1.SCD Carrier Frequency (Hb S)

Race Ethnicity	Carrier Ratio
African Americans	1 in 14
Native Americans	1 in 176
Hispanics	1 in 183
Middle Eastern Groups	1 in 360
Caucasians not of Middle Eastern origin	1 in 625
Asians	1 in 1336

Purpose of the Study

The purpose of this study was to assess the knowledge, beliefs, and attitudes about SCD, and screening behaviors among college students. After reviewing the sparse amount of literature available regarding the knowledge, health beliefs, and attitudes about SCD and carrier screening, significant gaps in the literature were found. First, the literature on knowledge, health beliefs, and attitudes about SCD is limited. In addition, most of these studies were conducted with African Americans. Although African

Americans are the largest group affected by SCD, other racial/ethnic groups are also at-risk (See table 1-1); yet, there are hardly any studies assessing the knowledge, beliefs, attitudes, and screening behaviors among other groups at risk (Burnes et al., 2008; Gustafon, 2006; Stewart, 2007). Given the misconception that SCD is an 'African American' disease (Gallo et al., 2010), other racial/ethnic groups may be carriers of the disease and not be aware (Treadwell et al., 2006). Furthermore, with the increasing rates of interracial relationships, this may be a problem for other racial/ethnic groups as well. For instance, in the Unites States, 1 in 12 marriages are interracial. Furthermore, a study conducted by Pew Research Center, found that in 2010, 15% of all new marriages were interracial. (Hayes, 2012; "Interracial Marriages", 2012; Jayson, 2012). Moreover, unmarried households had a higher percentage of interracial partners (Lofquist, Lugalia, O'Connell, & Feliz, 2012). Therefore, with the growing interracial relationships, research on the knowledge, beliefs, attitudes, and screening behaviors of all racial/ethnic groups is necessary. Such knowledge is needed in order to plan for and develop effective prevention programs. Thus, the current study will assess the knowledge, beliefs, attitudes, and behaviors regarding SCD and carrier screening among a diverse group of college students.

Specifically, the aims of the study was to:

1. Assess the knowledge, health beliefs, attitudes, and behaviors regarding SCD and carrier screening among college students
2. Explore what factors contribute to the knowledge, health beliefs, attitudes, and behaviors about SCD among college students.
3. Explore the relationship among knowledge, health beliefs, attitudes, and behaviors about SCD among college students.

Research Questions

The study was designed to answer the following questions:

1. What is college students' level of knowledge about SCD, health beliefs about SCD and carrier screening, attitudes regarding carrier-screening, attitudes towards those with disease or carriers, and screening behaviors?
2. What differences do factors such as race/ethnicity, gender, age, family history, and familiarity with SCD have on knowledge, health beliefs, attitudes, and screening behaviors about SCD among college students?
3. What is the relationship between knowledge about SCD, health beliefs about SCD, attitudes towards carrier screening, attitudes towards those with the disease or who are carriers, and screening behaviors among college students?

Importance to the Field of Social Work

Most studies focus on patient education and disease management (King, Tang, Ferguson, & DeBaun, 2005; Manhat et al., 2007; Valente et al., 2010). However, there was a gap in the literature regarding education efforts to increase knowledge, health beliefs, attitudes, and screening behaviors among individuals (non-patients) at risk. Social workers have an important role to play in the development, implementation, and evaluation of educational programs to improve knowledge and attitudes about SCD and carrier status with the goal of preventing or reducing future cases of SCD. Prevention is a significant element of social work practice and it is critical that researchers devote time and resources to address the effectiveness of prevention programs to better address societal issues, including those associated with SCD given the psychosocial impacts of SCD.

Social attitudes about chronic conditions are important factors influencing preventive behaviors such as seeking screening. Furthermore, attitudes about the

disease, form preventive behaviors among individuals not yet affected by the disease and among those who are at different levels of risk. If most individuals who perceive SCD as a “Black” disease are also more inclined to support unfavorable perspectives about the disease, then those racial views are harmful and may cause individuals from other race/ethnicity to misjudge their predisposition of being a SCD carrier. These views form a significant problem requiring greater research focus (Bediako & Moffitt, 2011). Given the racial undertones about the disease and the responsibility of women for genetic consideration, this study will address the issue of cultural and gender relevance, and ethnic sensitivity in terms of future prevention programming for SCD.

One of the core values of social work is social justice. The National Association for Social Workers (NASW) Code of Ethics states:

> Social workers promote social justice and social change with and on behalf of clients. Social workers are sensitive to cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people. These activities may be in the form of direct practice, community organizing, supervision, consultation administration, advocacy, social and political action, policy development and implementation, education, and research and evaluation. (NASW, 2008, p. 22-26)

Finally, in terms of social justice, “differences in race/ethnicity, socioeconomic status, and inherited family background should not skew how the benefits of genomic research are distributed” (Critin & Modell, 2003, p. 53). Yet, there are considerable gaps in both the public and private support for SCD research while more publicized conditions such as cystic fibrosis and muscular dystrophy receive three times more grants as

compared to those for SCD. In 2004 the National Institutes of Health (NIH) spent $128 million on cystic fibrosis which affects 30,000 people (mostly Caucasian); however, it only spent $90 million on SCD which affects more than 80,000 (mostly African American) (Johnson, 2011; Smith et al., 2006).

Chapter 2

Literature Review

This chapter begins by providing the reader with an overview of SCD in terms of background and impact of the disease. The chapter provides an overview of the literature related to SCD knowledge, health beliefs, attitudes, and screening behaviors. The gaps in the literature are addressed.

Background

The first formal description of SCD took place over 100 years ago. November 2010 made it 100 years since a Chicago cardiologist Dr. James Herrick provided the first conventional report of SCD. This first reported case involved a 20 year-old male dental student from the island of Grenada in the Caribbean who was attending the Chicago College of Dental Surgery. After becoming a dentist, he returned to Grenada where he was a successful dentist until he died of SCD complications at the age of 32 (Sergeant, 2010). Three months later, the second formal case was reported regarding a 25- year-old female who was being treated at the Medical College of Virginia for several years. The third case involved another female at the age of 21 as well as a report on her father. The father's fresh blood came back normal but then when tested again on blood that was stored and observed several days later, came back as abnormal red cells. This initial illustration of the 'sickle test' led to confusion between the disease and carrier status. This case also indicated that SCD might be hereditary (Sergeant, 2010). The fourth case involving a 21-year old male patient at John Hopkins Hospital was the first time that the term 'sickle cell anemia' was used. Given the African origin in all four patients, the misconception that SCD only affected this group evolved. However, SCD was found in areas without an African origin, including the Arabian Gulf, India, Greece, Turkey, Italy

and Sicily (Sergeant; 2001; Sergeant, 2010). Thirty years following the fourth case of SCD, yielded increasing number of cases. It was later found that there was a connection between individuals with SCT and protection from malaria (Desai, 2004; Sergeant, 2010). People with SCT were immune to malaria and this contributed to the high number of SCT cases found in areas with high prevalence of malaria (Sergeant, 2010).

Hemoglobin electrophoresis which became available around 1954 led to identification of other types of SCD including Sickle Cell-Hemoglobin C (SC) Disease, the Sickle Cell-Beta Thalassemia's and the rarer types, HbS/D Punjab and HbS/O Arab (Sergeant, 2010). There are various forms of SCD. Sickle Cell Anemia (SS), generally the most severe type, occurs when a sickle gene (S) is inherited from each parent. Sickle-Hemoglobin C Disease (SC), a generally less serious type, occurs when a sickle gene (S) is inherited from one parent and an abnormal hemoglobin gene (C) from the other parent. Sickle Beta Thalassemia (ST) occurs when a sickle cell gene (S) is inherited from one parent and a beta thalassemia gene from the other parent (T). There are two forms: Beta-Plus Thalassemia (ST+), generally more severe, and Sickle Beta-Zero Thalassemia (ST0), less severe (Center for Disease Control (CDC), 2011; Sickle Cell Disease Association of America Inc. (SCDAA), 2012). Sickle Cell Trait (SCT) occurs when normal hemoglobin (A) is inherited from one parent and abnormal hemoglobin (S) from the other. Individuals with SCT are usually healthy with no symptoms; however, they can transmit the SCT to their offspring (CDC, 2011). A hemoglobin gene is inherited from each parent. Thus, if one parent has SCD and the other has normal hemoglobin, their children will only inherit SCT. However, if one parent has SCD and the other has SCT, with each pregnancy there is a 50% possibility (1 in 2) of passing on SCD or SCT. If both parents have SCT, there is a 25% chance (1 in 4) to pass on SCD with each pregnancy (SCDAA, 2005) and 50% chance of SCT (Treadwell, McClough, & Vichinsky,

2006).

Impact of the Problem

Medical Issues

SCD is a serious condition with life-threatening effects resulting in an average lifespan of around mid to late 40's (Jenerette & Murdaugh, 2008). For instance, SCD affects multiple parts of the body resulting in anemia that includes symptoms of fatigue, jaundice, and shortness of breath; continuous tissue and organ damage; pulmonary disease; and stroke (Creary, Williamson & Kulkarni, 2007; Gold, Treadwell, Weissman & Vichinsky, 2011; Reese et al., 2010).

Pain crises

Pain crises, caused by vasoocclusion, are the trademark of SCD and affect most people with the disease (Creary et al., 2007; Gustafon et al., 2006; Meier & Miller, 2012). Vasoocclusion occurs when the sickled red blood cells (RBC) obstruct the other blood cells resulting in an inadequate supply of blood to the organs (Creary et al., 2007). The initial pain episode generally occurs as swelling in the hands and feet (hand-foot syndrome or dactylitis) resulting from decreased oxygen caused by blocked blood vessels. Moreover, almost 50% of children with SCD get dactylitis by the age of two. For children with SCD, approximately 50 to 60% of all emergency room visits and 60 to 80% of hospitalizations are due to pain crises (Gustafon, 2006; Meier & Miller, 2012). Additionally, studies indicate that acute pain is the main cause of hospitalization for people with SCD of all ages; however, it occurs more often in teens and young adults (Dorsey & Murdaugh, 2003; Elander, 2006; Jenerette, Funk, & Murdaugh, 2005; NHLBI, 2010). Furthermore, frequent reoccurrences of acute pain are related to premature death in SCD patients over 20 years old (Rees et al., 2010). Several factors including

dehydration, extreme temperatures, infection, and low oxygen levels (high altitudes) can trigger SCD crises (Creary et al., 2007).

Acute chest syndrome

Another severe complication of SCD is Acute chest syndrome (ACS). ACS results from infiltrates in the lungs or can also result from infections. Besides, ACS may also result in fever, chest pain, wheezing and cough symptoms following or accompanied by other acute symptoms (Gustafon, 2006; Meier & Miller, 2012). There are numerous causes for ACS including infection, sickling, fluid overload and atelectasis caused by hypoventilation from over sedation or inadequate pain control (Meier & Miller, 2012). ACS is the second most common reason for hospital admissions among people with SCD (Rees et al., 2010) with admissions lasting an average of 10 days (Laurie, 2010). There are several factors related to longer length of admission including, older age, fever, pain, transfusion, and respiratory failure. ACS results in about 25% of deaths in people with SCD (Paul, Castro, Aggarwal & Oneal, 2011). The effects of ACS are worst on adults with SCD in comparison to children with SCD. For example, patients older than 20 years old with SCD (9%) have a higher fatality rate than patients younger than 20 years old with SCD (2%) (Laurie, 2010; Paul et al., 2011). Therefore, immediate treatment of ACS is necessary to prevent progression of the condition resulting in respiratory failure and death (Gustafon, 2006).

Strokes

SCD is also considered to be one of the most widespread reasons for strokes in children (Rees et al., 2010). About 10 % of individuals with SCD experience a stroke during some point in their lives with the highest prevalence found in children between 4 and 6 years old. Strokes develop following a vasoocclusion in the blood vessels within

the brain, restricting oxygen resulting in headache, partial paralysis, cranial nerve palsy, and difficulty or inability to swallow (Gustafon, 2006).

Splenic sequestration

Splenic sequestration refers to the enlargement of the spleen resulting in a reduction in hemoglobin creation and higher risk of infection. If left untreated, splenic sequestration can result in death (Gustafon, 2006). Splenic sequestration develops in about 30% of SCD patients younger than six years old. [1]. The manifestations of splenic sequestration increases the risk of infection for children with SCD compared to their healthy counterparts. Children with SS and ST0 generally experience auto-infarction of the spleen by the time they are 5 years old; however, those with SC and ST+ are at risk for splenic sequestration throughout their lifetime. For instance, the oldest patient with SC found to have splenic sequestration was 44 years old (Meier & Miller, 2012).

Psychosocial Consequences

Psychosocial problems affecting individuals with SCD and their families generally develop from the effect of pain and other SCD symptoms on individuals' daily lives. Moreover, people's attitudes about SCD and towards those with the disease can also lead to psychosocial problems (Anie, Dasgupta, Ezenduka, Anardo & Emodi, 2007). Due to lengthy school absences from pain crises and frequent hospitalizations, children and adolescents with SCD have a greater risk of unsuccessful school performance than their healthy peers (Adegoke & Kuteyi, 2012; Brown et al., 2010; Jisieke, 2007).

Mental health

SCD pain crises also lead to depression, anxiety, and other mental disorders. Such mental disorders are also associated with the decreased capacity to cope with pain

[1] More than 80% of children with SS and ST0 have their spleen removed before they are a year old.

and may increase the pain experienced (Edwards et al., 2005). Additionally, depression, anxiety, challenges with social functioning, and low academic achievement associated with pain crises was found in more than 25% of children with SCD. As children reach adolescence, the difficulties of living with SCD become increasingly noticeable. For instance, adolescents with SCD get tired more easily when participating in sports and this may result in feelings of despair, hopelessness or social isolation (Jisieke, 2007). Many children with SCD experience inadequate growth and delayed sexual development resulting in low self-esteem and depressive symptoms, particularly discontent with their body's appearance. Similarly, the psychological complications of SCD in adults include many such as anxiety regarding one's appearance, treatments, and death, depression, self-pity, and poor self-esteem (Jisieke, 2007). Depression in adults with SCD may manifest as guilt, sleeplessness, weight loss or gain, and suicidal thoughts (Jisieke, 2007).

Frequent pain crisis and hospitalizations from SCD complications may contribute to dissatisfaction, resentment, depression, and emotional strain in the health and wellbeing of caregivers and 30 to 40% of caregivers experience mental health problems (Brown et al., 2010). In a recent study, Adegoke & Kuteyi (2012) found that approximately 40% of the caregivers of children with SCD often paid little or no attention to other family members due to demands resulting from the child's disease. Healthy siblings may not understand why increased attention, special treatment or extra privileges are given to the sick child. Decreased attention given to healthy siblings may also lead to mental health problems (Jisieke, 2007). Furthermore, the number of emergency room visits by SCD children was an indicator of poor psychosocial adaptation among their siblings. Emergency room visits are not only traumatic for the child with SCD, but is also disturbing for the other family members as well. This event may require sudden changes to the

family's plans or daily activities, involve prolonged time away from home or family, and generate feelings of distress, fury, or guilt as the family face the sick child's mortality (Gold et al., 2011).

Social interactions

Due to the many years of social isolation associated with their disease and constant hospitalizations, adolescents with SCD generally develop slower interpersonally compared to their peers and may lack problem solving abilities required for adequate interactions (Edwards et al., 2005). What's more is that the effects of the disease are not confined to the affected child but also significantly affect other family members (Gold et al., 2011; Jisieke, 2007). The main caregivers, generally mothers, report considerably less opportunities to socialize with people other than family and frequently feel hopeless, powerless, discouraged, and not supported by family and friends during an SCD pain crisis. Mothers of children with SCD have fewer social relationships and inadequate social networks in comparison to mothers of children without the disease (Edwards et al., 2005).

Family relationships

SCD also affects family relationships. The difficulty in caring for a child with SCD may result in little or no attention to other family members and challenges for family members to participate in desirable activities (Brown et al., 2010). Caring for a child with SCD created a tense and hostile environment, arguments or altercations among family members, and marital problems (Brown et al., 2010; Gold et al., 2011). Parents, for instance, must assume the responsibility of caring for the child with SCD, but also need to balance other responsibilities associated with the rest of the family, work, and their own emotional welfare. Healthy siblings of children with SCD are also affected by the distress and interruptions to daily activities that the disease puts on a family (Gold et al.,

2011). SCD can also affect family functioning and the interactions between parents, siblings, and children may disintegrate (Jisieke, 2007).

Financial issues

SCD was also found to have detrimental effects on family finances. Frequent pain crisis in adults with SCD may disrupt their social and economic status (Jisieke, 2007). Financial stress may be associated with frequent hospitalizations and along with other stressors associated with disease can interfere with the coping capability among people caring for someone with SCD (Brown et al., 2010). Additionally, the diminished health condition of a child with SCD has been connected to the parents' decreased capability of holding a job (Brown et al., 2010). Adults are frequently unemployed, without health insurance and are unable to attain public assistance or disability insurance. Moreover, when employed, it is usually unpredictable and without health insurance benefits (Jisieke, 2007). Adegoke and Kuteyi (2012) found a high level of financial burden of SCD on the caregivers and family members. More than half of the caregivers indicated that the costs of the child's disease had detrimental effects on the family's essential needs such as food and rent. In addition, approximately 70% of the caregivers in the study lost income or financial benefits because of time spent caring for their children with SCD (Adegoke & Kuteyi, 2012). The time spent in caring for a child with SCD resulted in financial problems leading families to get loans, which were sometimes difficult to repay. (Brown et al., 2010).

Knowledge about SCD among the At-Risk Populations

Identifying individuals with SCT and educating them to make informed decisions in selecting life partners seems to be the most practical method in preventing further transmission of SCD before other interventions become easily attainable and accessible to the general public. In order for this approach to work, the general public must have

sufficient knowledge about SCD and of how to further decrease its transmission within the community (Owolabi et al., 2011). Thus, assessing college student's knowledge about SCD would aid in planning the most effective educational approaches to improve knowledge regarding SCD. An important finding from the literature review was that several studies indicate that some high-risk populations have never even heard about SCD. Burnes, Antle, Williams and Cook (2008) conducted a qualitative study in Toronto, Canada with African and African Caribbean descent mothers of children with SCD and found that there is a pressing need for improved SCD education for populations at risk as well as the general public. The majority of the mothers had never heard of SCD. All the mothers in this study clearly indicated their irritation with the low level of SCD knowledge and awareness among the general public. The mothers in the study also described a lack of awareness about SCD among populations at risk (Burnes et al., 2008). Boyd, Watkins, Price, Fleming and DeBaun (2005) conducted a cross-sectional telephone survey evaluating the knowledge about SCD among African American women in St. Louis, Missouri. The study found that 30% of the women could not complete the study because they had never heard of SCD (Boyd et al., 2005). Similarly, in a pre-post study of high school adolescents in India, only 46% had heard about SCD at pretest (Vasava, Chudasama, Godara & Srivastava, 2009) despite the high prevalence of SCD in India (Tewari & Rees, 2013). In a mixed methods study assessing the knowledge and perceptions about SCD and SCT in Northern California, Treadwell, McClough and Vichinsky (2006) found that 40% of participants were unable to provide a definition of SCD; 13.1% provided completely correct; and 16.7% partially correct responses. Moreover, participants in the three focus groups concurred that there was a lack of awareness about SCD and SCT among the general public. Focus groups included medical professionals (40% (n=4) African American and 60% (n=6) Caucasian; 80% (n=

8) females), SCD patients (All African American; 80% (n=8) females), patients' family members with SCT (66.6% (n =3) African American; 33.3% (n=1) Latino), and members of the community (All African Americans; 60% (n=6) female (40% (n= 4) males) (Treadwell et al., 2006).

Knowledge about Prevalence and Inheritance of SCD

Although the previously mentioned studies indicate that some at-risk individuals have little or no knowledge about SCD, other studies indicate that at-risk individuals with some knowledge lack a clear understanding of specific aspects of the disease (Boyd et al., 2005, Burnes et al., 2008; Owlabi, 2011). For instance, in samples of African Americans, participants had basic knowledge of SCD but did not know the prevalence of SCD within their population (Boyd et al., 2005; Stewart, 2007). Boyd et al. (2005) found that only 27.2% were aware of the prevalence of SCD among African Americans. Owlabi, Alabi, Daniel, Ajayi, Otu, and Ogundiran (2011) conducted a study exploring the knowledge of SCD among secondary school students in Abuja, Nigeria. Most (81.8%) of the students indicated that they had heard about SCD. However, few (38.0%) students were knowledgeable about how the disease is transmitted (Owlabi et al., 2011). In another study, although the African American women were aware that SCD is inherited, they did not fully understand that the prevalence was the same for each pregnancy; instead, they believed it skipped generations. Less than 10% understood the inheritance pattern (Boyd et al., 2005). Similarly, in Burnes et al. (2008) study, the majority of African and African Caribbean mothers did not know how SCD was transmitted. Treadwell et al. (2006) found that though most (86.2%) African American participants were aware of the transmission of SCD and most (81.6%) were aware of the reproductive implications of SCT, 17% of the participants still thought SCD was transmitted through blood transfusions. Gender and age differences were found in knowledge about the inheritance

of SCD. For instance, more men believed that SCD could be transmitted through a blood transfusion. Also, participants over 33 were more knowledgeable about the inheritance of SCD compared to participants younger than 33. Younger participants believed SCD was transmitted through blood transfusions rather than inherited (Treadwell et al., 2006). Finally, in a study of African American parent carriers, Acharya, Lang and Ross (2009) also found that there was a lack of knowledge about the inheritance of SCD. Parents who had a child with SCD (78%) were more knowledgeable about SCD compared to parents whose child did not have SCD (58%) (Acharya et al., 2009).

Knowledge about SCD Carrier Status

Another distressing finding from the review was the lack of awareness about carrier status among high-risk populations (Alao et al., 2009; Boyd et al., 2005; Owlabi et al., 2011; Treadwell et al., 2006). Some individuals were not aware of the reproductive implications even though they were carriers of the disease. Treadwell et al. (2006) found that only 15.9% of African American participants knew their carrier status. More women were aware of the reproductive implications of being a carrier of SCD than men. However, no relationship was found between gender, age and knowledge of carrier status (Treadwell et al., 2006). In the Burnes et al. 2008 study of participants from African and African Caribbean descent, only 20% of the mothers knew that they were SCD carriers prior to learning their children had SCD. As one mother said, "My community doesn't know much about [SCD]. I was very ignorant before my daughter was diagnosed... I didn't even know I had the trait. Even me. Being from the Caribbean where [SCD] is prevalent, was very ignorant" (Burnes et al., 2008, p. 214). Similarly, the Abioye-Kuteyi, Oyegbade, Bello and Osakwe (2009) study of government workers in Nigeria, showed that most (69%) of the participants had limited knowledge about SCD; approximately 13.3% of individuals knew their carrier status. Furthermore, 25.1% of the

married participants did not know their spouse's carrier status, and 26.1% of participants who were engaged were unaware of their prospective partner's carrier status. Among participants who knew their own carrier status and that of their partners, a high number (34.4 to 64.5%) of participants with SCD disorders indicated that they will stay in those marital relationships; and, in relationships where both partners have an SCD disorder, 50% of the participants stay in the relationships. Individuals with tertiary education had a higher level of knowledge about SCD (Abioye-Kuteyi et al., 2009). In a study examining the level of the general public awareness of SCD in Bahrian where SCD is quite prevalent, Arrayed and Hajeri (2010) found that there was a good level of knowledge about SCD among the general population; however, some participants failed to distinguish between disease and carrier status. Females had a higher level of knowledge about SCD, including how it is inherited, individual disease or trait status, distinction between SCD and SCT, diagnosis, symptoms, and management. Participants who were age 60 and older had better knowledge of SCD following with 30 to 39 years, 40 to 49, 10 to 29, and 50-59 respectively. The study also found a positive relationship between job status and knowledge about SCD. University students had a higher level of knowledge about SCD compared to individuals with lower (illiterate and school) and higher levels of education (postgraduates). Married couples had better knowledge compared to single people (Arrayed & Hajeri, 2010). A comparison study conducted with Dominicans and African Americans in their childbearing age, showed that African Americans (76%) were more knowledgeable about SCD and SCT compared to Dominicans (27%). Despite the lack of knowledge about SCD among Dominicans, those with a family member with SCT seemed to have the same level of knowledge as their African American counterparts. On the contrary, African American parents without affected family members have a higher level of knowledge compared to Dominicans. More than 43% of Dominican participants

did not know their SCD carrier status compared to (7%) of African Americans. Similarly, (37%) of Dominicans compared to (21%) of African Americans did not know their family members' SCD carrier status (Siddiqui et al., 2011).

Knowledge about SCD among Secondary School Students

In Owlabi et al.'s (2011) study of secondary students in Nigeria, less than half (48.7%) knew their carrier status. The study found a relationship between students' knowledge of their carrier status and age 15 and older (Owlabi et al., 2011). On the contrary, Alao et al. (2009) found no relationship between age and students level of knowledge about SCD. Owlabi et al. (2011) also found a relationship between students' knowledge of their carrier status, being in a senior class, mother's educational level, knowledge of SCD transmission, being taught about SCD in school, ever heard about SCD, watching someone suffering from SCD, and loosing family to SCD. In a recent study conducted with secondary students in Nigeria, most of the participants knew about SCD and its inheritance; half of the participants even knew someone with the disease. However, participants were less knowledgeable about the symptoms, diagnosis, and preventive measures (Olarewaju, Enwerem, Adebimpe & Olugbenga-Bello, 2013). Even though most of the participants (89.6%) agreed that everyone should know their carrier status, only 59.2% knew their carrier status (Olarewaju, Enwerem, Adebimpe & Olugbenga-Bello, 2013).

Knowledge about SCD among College Students

Several studies assessing knowledge about SCD have been conducted among college students in Nigeria. In a cross-sectional survey design, Moronkola's and Fadairo's (2006) study of University students in Nigeria found that although more than half (76.6%) of the students knew their carrier status and 23.4% of the students did not know their carrier status (Moronkola & Fadairo, 2006). In another cross-sectional study of

university students in Makurdi, Nigeria, Alao, Araoye, and Ojabo (2009) found that although all the students indicated that they had heard of SCD at some point, most (82%) knew that SCD was a hereditary disease and most (89.1%) of the students knew how the disease was transmitted, only 47% had good knowledge about the disease. The study showed that family history was associated with knowledge about SCD. For instance, students who had a relative with SCD had better knowledge compared to those without an affected relative. However, the study found no relationship between students' knowledge of their own carrier status and having a relative affected by the disease. Only 47% of the students knew their carrier status and only 48.7% of students with an affected relative, were aware of their carrier status (Alao et al., 2009). A recent study of trainee teachers, who were students at the University of Rivers State University of Education in Nigeria, showed that although only (1.8%) reported that they had never heard of SCD, some students believed SCD was caused by evil spirits (19%) or bad food (27%) and could be cured by spiritual healers (27%). Females had better knowledge about SCD compared to males (Ani, Oranda, Kinanee, Ola & Kramer, 2012). In another more recent study conducted with undergraduate Ekiti State University in Nigeria, the majority of students (97.8%) had heard about SCD. However, only (34.4%) understood the nature of SCD and a little over 50% of the participants knew their carrier status (Olubiyi, S., Umar, Ajiboye, Olubiyi, V. & Abioye, 2013).

In the US, studies assessing the knowledge about SCD among college students are limited. In a mixed method study of African American college students', Stewart (2007) found that the students seemed to have a good knowledge about the transmission of the disease. However, 40% of the students incorrectly indicated that SCD was contracted through blood transfusions. Approximately 58.2% of the students provided correct responses to at least six out of ten questions. Participants had basic knowledge

about SCD. For example, participants were aware that SCD was a blood disorder but they could not provide specific characteristics about the disease. Participants knew that SCD was inherited; however, they did not have a good understanding of the SCD inheritance pattern. Carriers were not clear about the reproductive implications of having children with another carrier and non-carriers were unclear about the reproductive implications of having children with a carrier (Stewart, 2007). Stewart (2007) also found significant gender differences in knowledge about SCD. Females had a higher level of knowledge about SCD compared to males. The study also found that younger participants had slightly better knowledge about SCD than the older participants (Stewart, 2007). This study along with most of the literature on SCD is conducted with people of African decent. Therefore, there is a huge need for more research on SCD involving a more diverse sample.

Health Beliefs about SCD and Screening

Health beliefs are important factors to consider in addressing the issue of SCD. According to the health belief model, individuals must perceive SCD to be a serious condition for which they are at high risk and must perceive high benefits and low barriers to carrier screening (Rosenstock, 1974). Therefore, assessing college students' health beliefs about SCD and screening will provide important information for prevention and intervention programs addressing SCD particularly, the severity, risk and benefits of knowing one's own and partner's carrier status as well as addressing barriers.

Severity of SCD

Overall in the literature, participants who were familiar with SCD seemed to agree that SCD is a serious disease. Most African American participants (86.2%) reported that SCD results in serious health issues (Treadwell et al., 2006). In a study of African American women, Gustafon (2007) found that participants believed that SCD was

a serious disease. The study also found a positive correlation between the average level of knowledge and perceived severity of SCD. Perceived severity was positively correlated with knowledge of SCD inheritance, severity of symptoms, and carrier status. Perceived severity was significantly related to knowledge about SCD. Participants with greater knowledge about SCD believed SCD to be more serious than those with less knowledge (Gustafon et al., 2007). Similarly, another study showed that perceived severity of SCD increased by (18.2%) after a health education intervention (Olatona et al., 2012). In a qualitative study including SCD patients, parents of children with SCD and individuals from the community with SCT, Gallo et al. (2010) found that participants had a high-perceived severity of SCD. Many participants indicated that SCD involved serious complications for them and their children, or anyone with the disease. Participants described SCD as “suffering” and “struggle” when referring to pain crisis and frequent hospital admissions. Study participants were “grateful” their children did not have SCD and did not want their children or grandchildren to ever experience SCD. One of the participant with SCT indicated, “Most people don’t know how horrible [sickle cell disease] is, or can be” (Gallo, 2010, p. 1080). Participants also reported that they had family members who died from SCD at a young age (Gallo et al., 2010). Contrary, to the previous studies, Stewart (2007) found that African American participants had a low perceived severity or seriousness of SCD. However, males were more likely to believe that SCD was not as serious compared to females (Stewart, 2007). This finding is concerning given the high risk of SCD among this population, and shows the need for improved SCD education.

Susceptibility to SCD

In Gustafon et al. (2007) study, African American women had a low perceived susceptibility of passing on SCD to their children. This is concerning considering the high

prevalence of SCD among the African American population. Perceived susceptibility to SCD was positively correlated with knowledge of SCD inheritance and age (Gustafon et al., 2007). Contrary to the previous study, Stewart (2007) study of African American college students had a high-perceived susceptibility for having SCT. Marital status had an effect on perceived susceptibility. Single participants had a higher perceived susceptibility compared to married participants. The study also found a significant difference between participants with a family history of SCD and participants without a family history of the disease. Participants with a family history of SCD had a slightly lower perceived susceptibility of SCD compared to participants without a history or unknown history of the disease (Stewart, 2007). This is concerning, since it is possible that the participants may not understand the inheritance pattern of SCD. In Gallo et al. (2010) study, some participants expressed that overall, people believe SCD and SCT to be "just minority" disease. One participant also indicated "sickle cell is a major concern for America, not just minorities" (Gallo et al., 2010, p. 1081). A Hispanic participant with SCT believed that it was important for other racial/ethnic groups to know about their risk of being a carrier, since she did not know her carrier status and had a child with SCD. This same participant indicated that her medical provider told her that SCD was only an "African American Disease." She said, "Education needs to be spread not only to African Americans but to Latinos, Hispanics, and Indians . . . because they are susceptible to get the trait or the disease [too]." (Gallo et al., 2010, p. 1081). Given the recent status of the study, it is concerning that there is still a lack of knowledge about SCD among at-risk populations as well as among medical providers, highlighting the need for improved SCD education (Smith & Aguirre, 2012). Knowledge about SCD may influence susceptibility. For instance, perceived susceptibility to SCD increased by (11%) after a health education intervention (Olatona et al., 2012).

Barriers and Benefits to Screening

Gustafon et al. (2007) found a positive correlation between knowledge and perceived benefits to screening. Participants had a high perceived benefits and low perceived barriers to screening for SCD. Perceived benefits of testing were positively correlated with knowledge of SCD inheritance and carrier status. Participants with greater knowledge about SCD perceived screening to be more beneficial compared to those with less knowledge (Gustafon et al., 2007). Similarly, Gallo et al. (2010) found that the majority of participants believed that carrier screening for SCD prior to pregnancy could provide pertinent information regarding reproductive options instead of taking the risk of having a child with SCD. Some of the barriers to carrier screening reported by participants included lack of knowledge about the complications and inheritance pattern of SCD/SCT among family members and fear of needles (Gallo et al., 2010). Sweeny and Legg (2011) found that females had higher perceived barriers to genetic testing compared to males. The study also found a relationship between race/ethnicity and perceived benefits and barriers to genetic testing. Native Americans had lower perceived benefits and higher perceived barriers to genetic testing compared to Pacific Islanders and participants who indicated “other” or multiple racial/ethnic groups. The majority of the sample was female (80%) and Caucasian (71%), Hispanic/Latino (8%), Asian (6%), African-American (4%), American Indian/Alaska Native (3%), Native Hawaiian/Pacific Islander (2%), Middle Eastern (2%) and Other (3%) (Sweeny & Legg, 2011).

Attitudes Towards Carrier Screening

Genetic testing is an unbiased approach for providing important information that may be useful in order to prepare for a genetic condition and/or to make informed reproductive choices (Ross et al., 2011). Given the limited research and the importance of carrier screening and knowing ones carrier status, it is important to understand the

attitudes towards carrier screening for SCD in order to plan for SCD prevention programming.

Positive Attitudes Towards Screening

Several studies indicate that overall, people have positive attitudes about carrier screening (Al-Farsi et al., 2014; Al Kindi, Al Rujaibi and Al Kendi; 2012; Ross et al., 2011; Stewart, 2007; Wong, George, and Tan, 2011; Zimmerman et al., 2006). In a study including 50% African Americans and 50% Caucasians, Zimmerman et al. (2006) found that the majority (> 90%) of the participants believed that genetic screening was a good thing with the most significant benefit of prevention of or preparation for the disease. African Americans were more likely to believe that genetic screening would lead to racial discrimination compared to Caucasians. However, African Americans were more likely to think that all pregnant women should have genetic screening compared to Caucasians (Zimmerman et al., 2006). Most of the African American participants (85.3%) in Stewart (2007) study had positive attitudes regarding carrier screening for SCD. The study also found a significant difference between age and attitudes toward carrier testing for SCD. Younger participants had a less favorable attitude towards screening compared to older participants (Stewart, 2007). There was a significant difference between age and attitudes about SCD and SCT. Younger participants felt less comfortable talking about carrier status with others compared to older participants. The study also found a relationship between family history of SCD. Students with a family history of SCD or SCT were more likely to have positive attitudes about talking about SCD carrier status compared to those without a family history. Students with a family history were also more likely to have positive attitudes regarding the possibility of testing positive for SCD or SCT. Participants with no family history had neither positive nor negative attitudes (Stewart, 2007). Ross et al. (2011) conducted a study assessing the attitudes of

Ghanaian women toward genetic screening. The sample included both SCD carriers and non-carriers. Women who had undergone screening (88.6%) were more likely than women who had not been screened (69.4%) to agree that knowledge of their SCT status would aid them in making important life decisions. A greater number of women in the screening group believed that knowledge of SCT status was important. The study also found that a greater number of women (70.8%) who had not undergone screening reported that they would feel less healthy if they were aware that they were SCD carriers. Moreover, women who had not been screened also had greater concern that they may feel singled out if their screening was positive (Ross et al., 2011).

Studies also found favorable attitudes towards carrier screening before marriage. For instance, Abioye-Kuteyi et al. (2009) found that (95%) of the Nigerian government workers had positive attitudes about premarital screening with more positive attitudes in individuals with tertiary education. Similarly, in a study of multi-racial Malaysians, Wong et al. (2011) found that most of the participants (90.6%) believed that premarital screening for thalassemia was needed for everyone. Almost 35% of the participants believed that couples should not get married if they were both carriers of thalassemia. Some participants had never been screened because they felt they were not at risk (Wong et al., 2011). In a recent study of Omani adults aged 20–35 who attended primary healthcare institutions at the South Batinah Governorate in Oman, Al-Farsi et al. (2014) found that most of the participants (84.5%) agreed that premarital carrier screening was essential. Most of the participants also indicated that they would advise their partners to do premarital carrier screening. Furthermore, more than 60% indicated that they would think about the premarital carrier screening results carefully before marrying their partners. However, 30.5% of the participants indicated that they did not agree with premarital carrier screening regardless of marital status. Lack of knowledge (36%) was

the most common reason reported by married participants who did not get screening. Other participants reported a lack of screening locations (13%), no interest (10%), lack of family history (9%), not important (7%), no partner (6%) as reasons for not seeking screening (Al-Farsi et al., 2014).

Positive attitudes about premarital screening were also found among college students. For instance, in a study of unmarried, Omani, undergraduate students, Al Kindi, et al. (2012) found that students had favorable attitudes towards premarital screening. Most of the students (92%) believed premarital screening was important and said they would get screened in the future. Students that agreed with premarital screening believed it would prevent transmission of the disease to future children, ensuring their partners were healthy, and ensuring fitness for marriage. Students who refused to do screening, had a fear of unfavorable test results, perceived the test results as an insult, felt it interfered with God's will, and that it would prevent marriage (Al Kindi et al., 2012, p. 293). Similarly, in another study of university students in Nigeria, (94.2%) of the students had positive attitudes regarding premarital screening for SCD (Omuemu, Obarisiagbone & Ogboghodo, 2013).

Negative Attitudes Towards Screening

Although carrier screening is an important element in preventing future cases of SCD, there are numerous challenges associated with this particular method. For instance, insurance companies increased their rates and declined to grant or reinstate policies to people with SCT, although SCT does not indicate any risks (Mitchell, 2007). The long history of genetic discrimination started in the 1970's when several states performed mandatory screening for SCD specifically targeting African Americans. In fact, individuals felt that they were denied health insurance due to genetic screening. Mandatory screenings also led to anxiety among African Americans and many did not bill

their insurance for screening services due to fear of genetic discrimination, impact on future insurability, and discrimination against their children (Fulda & Lykens, 2006; Long, Thomas, Grubs, Gettig, & Krishnamurti, 2011; Treadwell et al., 2006). Moreover, there have been numerous cases of health, life, and disability insurers using genetic information to deny coverage, limit coverage, and raise rates. This can be concerning to anyone, especially people with SCT and SCD given the unpredictability of the disease and continuous need for medical care (Stewart, 2007). Furthermore, research also shows that African Americans exhibit more negative attitudes about the medical system than Caucasians and Latinos (Stewart, 2007). Studies indicate that participants' distrust of the medical system was due to past exploitation against African Americans including the Tuskegee Syphilis Study (Long et al., 2011; Treadwell et al., 2006; Zimmerman et al., 2006). African American men were more likely to report mistrust of the medical system, however, African American women were more anxious about confidentiality (Stewart, 2007).

Attitudes Towards People With SCD

The literature on attitudes toward people affected by SCD is limited. Moreover, the few available studies show varied attitudes toward people with SCD. A study conducted with trainee teachers who were university students in Southern Nigeria, showed that participants had negative attitudes towards their classmates with SCD. For instance only (24%) of the students believed their peers would invite a fellow classmates with SCD to their birthday party and (31.9%) believed most of their peers would engage in study sessions with a fellow classmate with SCD. Fifteen to fifty three percent of the students believed that other students would not associate with their peers with SCD. The study found that gender and perceived negative family attitudes significantly influenced stigmatizing attitudes towards SCD. Males had more negative attitudes towards their

peers with SCD compared to females and stigmatizing attitudes increased with the person's perceive family negative attitude. A significant proportion of participants believed that their family members perceived SCD as something to be ashamed of (43.6%) kept secret (32%), and would oppose friendships with anyone with SCD (32%) (Ani, et al., 2012).

Other studies show that participants had mixed feelings regarding marrying someone with SCD. Olarewaju, et al. (2013) study of Nigerian secondary students showed that although a greater number of participants (66.9%) indicated that carrier status would not affect their decision to marry, (43.1%) said it was a significant factor to consider. Moreover, 22.3% of the participants reported that they would not marry someone who had SCD. In terms of what couples should do if they find out that they are both carriers of SCD, most participants (51.9%) indicated that couples should seek genetic counseling and make an informed decision, (24.1%) did not know, (23.4%) end the relationship, and (0.7%), stay in the relationship and deal with the consequences (Olarewaju, et al., 2013). In another recent study of premarital couples attending an outpatient clinic for premarital SCD screening in Nigeria, Nnaji, G., Ezeagwuna, Nnaji, I., Osakwe, Nwigwe and Onwurah (2013) found a relationship between decision to end the marriage and the denomination of each couple. A greater number of participants from Catholic churches (78.6% females; 77.3% males), followed by Anglicans (69.2% females; 66.7% males) and Pentecostals (55.6% females; 55.9% males) reported that they would end the relationship and not marry their partners if both turned out to be SCD carriers (Nnaji et al., 2013). Contrary to the previous studies, Abioye-Kuteyi et al. (2009) found that participants would continue a relationship even after finding out that both partners are SCD carriers As many as (50%) of the participants decided not to end their

relationships even when both partners were carriers. These findings demonstrate the importance of knowing carrier status before starting a relationship.

SCD Carrier Screening Behaviors

In Mediterranean countries, prevention approaches like carrier screening for couples prior to marriage, has led to significant decline in occurrences of hemoglobin disorders including SCD. However, positive screening results could lead to feelings of low self-esteem, stigmatization, discrimination, and denial of health and life insurance, and employment opportunities (Van-Elderen, Mutlu, Karstanje, Passchier, Tibben, & Duivenvoorden, 2010, p. 416). Additionally misinformation, mistrust, and disillusion from past SCD screening programs may influence present perceptions of SCD/SCT and SCD carrier screening utilization, especially among the African American population (Stewart, 2007). There was a significant relationship between attitude towards SCD carrier screening and screening participation (Abioye-Kuteyi et al., 2009). Therefore, exploring screening behaviors along with factors that may influence screening among a diverse population would yield pertinent information in improving screening behaviors.

In the U.S., minority groups, the less educated, and males are underrepresented in genetic research (Alford, McBride, Reid, Larson, Baxevanis & Brody, 2011). Minority populations are less likely to utilize healthcare services due to greater mistrust and dissatisfaction with the medical system. Studies show that African Americans report far less trust in medical providers compared to Caucasians (Weiner, Silk, & Parrott, 2005; Zimmerman et al., 2006). Furthermore, minorities suspect substantial risks in relation to genetic screening, including the misuse of genetic information with the aim of racial discrimination in employment (Singer, Antonucci and Hoewyk, 2004; Zimmerman et al., 2006). In a study involving healthy insured adults enrolled with the Henry Ford Health System in Detroit, Alford et al. (2011) found that even with health care access, African

Americans were less likely to participate in genetic testing. When asked about interest in screening, the majority of the participants (52.4%) indicated that they wanted to be screened, (28%) refused screening, and (19.7%) were unsure about screening. Race was significantly related to their decision status. Caucasians were 2.5 times more likely than African Americans to provide a definite response to genetic screening. Most of the participants (71%) who were unsure about screening, agreed to be screened after being contacted by a research educator; African Americans (32%) were still less likely than Caucasians (61%) to undergo screening. Race was significantly related to participation in genetic screening. Caucasians were more likely to agree to undergo screening compared to African Americans (Alford et al., 2011).

Singer et al. (2004) suggest that the fact that participants are less likely to use screening may be due more to barriers to access rather than their lack of trust of the healthcare system. Several barriers to screening surfaced including lack of information about genetic testing, lack of knowledge and interest, insurance coverage, concerns about the possible misuse of genetic testing, and concerns about privacy and confidentiality (Long et al., 2011; Singer et al., 2004; Treadwell et al., 2006). In Wong et al. (2011) study, only 13.6% of unmarried participants indicated that they had been screened for thalassemia including (30.8%) Chinese, (17.4%) Indians, (8.6%) Malay and (8.2%) non-Malay. Most of the unmarried participants (86.9%) who had not undergone screening reported that they would be willing to be screened. Participants who refused to participate in screening reported reasons such fear of screening results, fear of discrimination, lack of knowledge about screening, and not knowing where to get screened (Wong et al., 2011). In another study conducted with Turkish female immigrants in the Netherlands, Van-Elderen et al. (2010) found that feelings of uncertainty, risk-estimation, and worrying about carrier status for hemoglobin disorders were significant

predictors of participants' intentions regarding preconception carrier screening for haemoglobin disorders.

Studies found that gender had a significant influence on screening behaviors. Alford et al. (2011) found that males were less likely to consider screening compared to females. Similarly, in a qualitative study including participants and non-participants in a colorectal cancer-screening program in Valencia, Molina-Barcelo, Salas, Peiro-Perez, and Malaga Lopez (2011), found that gender influenced screening participation for colorectal cancer. Women were more likely to participate in screening because they valued self-care and for early detection in order to avoid personal and family suffering while men had to be encouraged by their partners. Reasons for not participating in screening were also different between genders. Women perceived the test to be unpleasant and were afraid of what the results may say, while men had no care or concern (Molina-Barcelo et al., 2011). Molina-Barcelo et al. (2011), suggests that women take on the responsibility of caregivers and are interested in their health as well as their families, which increases screening participation. However, men are less likely to take on that responsibility and pay less attention to their health resulting in lower participation in screening (Molina-Barcelo et al., 2011). Contrary, Sweeny and Legg (2011) found no racial/ethnic or gender differences in intention to undergo genetic testing.

Gaps

The literature on knowledge, health beliefs, attitudes, and behaviors about SCD is limited. Furthermore, the literature on SCD is based on people of African decent. Although this is the largest group at risk, there is still a need to explore the issue among other populations at risk. Literature on other racial/ethnic groups is limited or non-existent. Gustafon et al. (2007) suggest that more studies should be conducted with other populations including at-risk Hispanics since health beliefs may differ among cultures.

The majority of studies assessing knowledge or attitudes include African Americans and women. It was difficult to explore racial/ethnic differences in SCD knowledge, beliefs, attitudes and screening behaviors. An understanding of how these factors influence individuals SCD knowledge, beliefs, attitudes and screening behaviors, is important in order to develop culturally effective prevention programming. Another gap in the literature is the limited number of studies conducted in the US assessing the knowledge; beliefs, attitudes and behaviors about SCD even though an estimated 2.5 million people in the US have SCT (Vichinsky, 2014). An additional gap in the literature is research on the factors that influence knowledge, health beliefs, attitudes, and behaviors about SCD and carrier screening. Such information is also important for the development and implementation of effective prevention programing.

Conclusion

In order to address the gaps mentioned above, this study will attempt to include a diverse sample of college students. The study will contribute to the existing literature by exploring factors that have received less attention such as SCD knowledge, beliefs, attitudes, and screening behaviors especially among a more diverse sample. In addition, this study will investigate factors that influence knowledge, beliefs, attitudes, and screening behaviors. The researcher hopes to provide important information for program and policy development in the area of SCD prevention.

Chapter 3

Theoretical Framework

This chapter discusses how Ecological Systems Theory (EST) and the Health Belief Model (HBM) were used to provide a better understanding of the factors that contribute to the knowledge, health beliefs, attitudes, and behaviors regarding SCD. These theoretical frameworks can be used as a guide in the development of SCD prevention programs. This chapter discusses each perspective in general and then also how these perspectives apply to this study and influence survey content.

Ecological Systems Theory

Historical Foundations

Ecological Systems Theory (EST) originated in development psychology research for understanding human behavior and the relationship between the person and their environment. Through developmental research and public policy, Brofenbrenner (1979) made an effort to create public policies that could influence people's lives and were vital for advancing the scientific study of human development (Garza-Higgens, 2011, p. 3).

Key Assumptions

According to Bronfenbrenner (1979), individuals are not only shaped by personal attributes, but also by their environments. Therefore, EST provides a framework to understand how multiple influences within a person's environment shapes the individual. According to Bronfenbrenner (1979), these influences occur through five levels including the micro-system, meso-system, exo-system, macro-system, and chrono-system (Figure 3-1). Changes in one system constantly generate changes in other systems through a process of reciprocal adaptation (Pinker-Amaker & Bell, 2012; Shen-Miller et al., 2013, Tacón, 2008). There are three major assumptions associated with EST:

> 1) Human development takes place through reciprocal interaction between a person and its environment; 2) To be effective, the interaction must occur on a regular basis over an extended period of time; and 3) The ecological environment is conceived as a set of interrelated structures moving from the innermost level to the outermost level. (Garza-Higgens, 2011, p.3)

Application to Study

In terms of the current study, the relationship between person and environment plays a significant part on how college students view their environment and how this influences their SCD knowledge, health beliefs, attitudes, and screening behaviors. An individual's environment has significant influence on their overall development and subsequent experiences. The rationale for using the EST rests in the complexity of the goal to change college students' SCD knowledge, health beliefs, attitudes, and screening behaviors. Therefore, to address this goal, it is important to consider how multiple systems can influence one's SCD knowledge, health beliefs, attitudes, and screening behaviors. "Bronfenbrenner (1979, 1989) emphasized how perceptions of relations within and among an individual's varied systems influence attitudes, behaviors, and expression of social roles" (Shen-Miller et al., 2013, p. 500). The Ecological Systems Theory is suitable for the current study in identifying the factors influencing college students' SCD knowledge, health beliefs, attitudes, and screening behaviors in order to develop culturally effective prevention programs. In this study, ecological factors such as gender, age, race/ethnicity, and familiarity with SCD, will be examined to determine how these factors may influence college students' SCD knowledge, health beliefs, attitudes, and screening behaviors.

Micro-system

The microsystem is the system closest to the individual in which they have a direct interaction (Smith, 2013). For instance family members, romantic partners, friends, school and work are all located within the microsystem. The micro-system also includes biological characteristics such as gender, race/ethnicity, age, and family history of SCD; each of which have an influence on the individual's SCD knowledge, health beliefs, attitudes, and screening behaviors. Microsystems directly influences the individual's knowledge, health beliefs and attitudes about SCD, carrier status, and carrier screening. In this level, an individual's knowledge and familiarity with SCD depends on the information they get from individuals in this system.

Meso-system

The mesosystem includes the interaction between microsystems in which the individual actively participates (Algood et al., 2013; Pinker-Amaker & Bell, 2012; Shen-Miller et al., 2013; Tacón, 2008). This system can significantly affect attitudes about SCD based on family members, friends, or romantic partners experience with other systems such as work and school. For instance, if a parent experienced discrimination in employment or insurance, it may have affected the level of care provided to the college student. Likewise, if a family member had a positive experience with screening, the college student may have a more positive attitude about screening. Therefore, interactions between the microsystems can have either a positive or negative effect on college students' SCD knowledge, health beliefs, attitudes, and screening behaviors.

Exo-system

The exo-system refers to interactions between the larger community and social systems in which the individual may not be actively involved but the interactions affect the individual's immediate environment (Algood et al., 2013; Pinker-Amaker & Bell, 2012;

Shen-Miller et al., 2013; Tacón, 2008). Popular media statements may influence attitudes about chronic diseases such as SCD. Therefore, in addition to personal experience such as knowing someone with SCD or learning about the disease in school, a person's perception about SCD may be influenced by what they learn from the media. For instance, educational materials about SCD usually portray dark-skinned individuals associated with SCD. This is significant because, in spite of the global prevalence and the racial/ethnic diversity of SCD, the restrictive coupling of the disease with 'darker-skinned' people may add to the misconception that 'people of color' (specifically, African Americans) represent all individuals with SCD. This misconception leaves other racial/ethnic groups with a false understanding about their risk for SCD (Bediako & Moffitt, 2011). Therefore, the media may have a significant influence on college students' SCD knowledge, beliefs, attitudes, and screening behaviors.

Macro-system

The macro-system consists of society's cultural beliefs that affect the other systems (Algood et al., 2013; Pinker-Amaker & Bell, 2012; Shen-Miller et al., 2013; Tacón, 2008). The macrosystem also includes subcultures and group memberships (Shen-Miller, et al., 2013) that influence SCD knowledge, health beliefs and attitudes, and screening behaviors such as gender and race/ethnicity. Cultural factors including societal beliefs about SCD and carrier screening are found within the macrosystem and may be viewed as society's cultural values and customs (Pinker-Amaker & Bell, 2012). Cultural beliefs may affect certain race/ethnic groups' health beliefs and carrier screening behaviors. SCD within the broader system generally focuses on disease management and less emphasis is placed on improving knowledge and attitudes about SCD and carrier screening. In addition to the many challenges that exist within each system, challenges that arise between systems can result in lack of knowledge and

misinformation resulting in negative health beliefs and attitudes about SCD and lower screening participation.

Chrono-system

Chrono-system refers to the series of events over the life course including personal or socio-historical (Garza-Higgens, 2011; Tacón, 2008). Chrono-system includes internal and external factors in the person's development. While internal factors including age, gender, race/ethnicity, and culture may influence an individual's SCD knowledge, health beliefs, attitudes, and screening behaviors; external factors over the period of time may also have an effect (Pang, 2012). When assessing SCD knowledge, health beliefs, attitudes and screening behaviors,, it is important that we examine the socio-historical context such as the long history of stigma and discrimination associated with the disease (Shen-Miller et al., 2013). Family history of SCD can also affect an individual's SCD knowledge, beliefs, attitudes, and screening behavior.

Strengths and Limitations

The ecological perspective has achieved extensive recognition in the social sciences including social work and is currently one of the main frameworks in the field (Smith, 2013). The rapid increase of existing ecological models is grounded in the theoretical customs within the behavioral and social sciences (Salis, Owen & Fisher, 2008). Ecological models have been key to health promotion for more than twenty years. An important strength of ecological models is their attention to multileveled approach that expands opportunities for intervention programs (Salis et al., 2008). Ecological models are considered to provide a complete model for understanding the multiple and interconnecting influences of health behaviors. Ecological models can be utilized to develop intervention techniques that consistently aim at changing systems at each level (Salis et al., 2008).

Figure 3-1 Ecological Systems Theory Applied to SCD

Health Belief Model

Historical Foundations

Rosenstock, Hochbaum, Leventhal and Kegles (Rosenstock, 1974) first introduced the HBM in the 1950s, in an effort to explain the lack of participation in preventive health behaviors (Guvenc, Akyuz & Acikel, 2011; Stewart, 2007). The original model included four general constructs: susceptibility, seriousness, benefits and barriers. Common health motivation and confidence were later included (Guvenc, Akyuz & Acikel, 2011). The HBM has been widely used to examine health-related views associated with protective behaviors (Mahmoodi, Kohan, Azar, Solhi, & Rahimi, 2011). The HBM is generally used to demonstrate why people change or continue a particular health behavior (James, Pobee, Oxidine, Brown, & Joshi, 2012). The HBM is a ”value expectancy” model (Wong, Wong et al., 2013, p. 2) meaning that behavior depends on “the individuals expectancies or subjective probabilities concerning the outcomes of a given action and the perceived values or utilities attached to those outcomes” (Sutton, 1987, p. 355). The HBM uses a cognitive approach with the goal to recognize patterns of health behaviors (Mahmoodi et al., 2011). The HBM is one of the oldest and most extensively used models where theory has been modified from the behavioral sciences to address health problems (Guvenc et al., 2011).

Key Assumptions

The basic assumption of the HBM is that people with “better information make better health decisions, with each step in the decision making process dependent on the previous decision or belief” (Hollister & Anema, 2004, p. 2). According to the HBM, a person “must believe that s/he is susceptible to a condition; the condition is serious; there is a successful intervention for the condition; and can overcome all barriers to using the

intervention. Each step is dependent on the previous belief" (Hollister & Anema, 2004, p. 2). The HBM proposes that there are six general contributors to one's health beliefs: 1) perceived susceptibility or the risk of developing the disease, 2) perceived threats or severity of the disease, 3) perceived benefits from the health behavior outcome, 4) perceived barriers preventing the health behavior, 5) health motivation or cues to action, and 6) self-efficacy or belief in one's ability to carryout the health behavior affect an individual's 'acting on a health belief' (Davis, Buchanan, & Green, 2013; Guvenc et al., 2011; James et al., 2012; Mahmoodi et al., 2011; Wong, Wong, Chan, Feng, Wai, & Yeoh, 2013). Perceived susceptibility refers to a person's own perception of the probability of encountering a situation that would be detrimental to their health. Perceived seriousness is an individual's understanding of the extent of severity of the disease. Perceived benefits are things done to prevent the disease or cope with the illness. Perceived barriers refer to features of the prevention or intervention approaches that may be viewed as "inconvenient, expensive, unpleasant, painful or upsetting" (Guvenc, Akyuz & Acikel, 2011, p. 429). Health motivation is a general intention leading to the behavior intended to continue or enhance health. Confidence presents the idea that an increase in perceived confidence in carrying out a behavior will lead to an increase in that behavior (Guvenc et al., 2011).

Application to Study

Applying the HBM to the current study (Figure 3-2), perceived susceptibility refers to the belief that the individual is likely to have SCT as well as the belief that the person will likely pass on SCD to their future children. Factors such as current SCD knowledge and awareness or family history can influence the person's belief of being susceptible to being a carrier or passing on the disease to their children. Perceived severity refers to the person's belief of how serious it would be to have SCT and how

serious the consequences would be to have a child with the disease. Factors that influence perceived severity include the life threatening state of the disease and the social stigma and discrimination attached to SCD. According to the HBM if the person believes that they are likely to have SCT and understand the severity of having a child with the disease, the person perceives this as a threat. The likelihood that a person will make an effort to seek education, SCT screening or genetic counseling, or prenatal testing, depends on their belief that these interventions will result in improved knowledge and awareness and preventing SCD on future children. The likelihood that people will make an effort to seek these services also depends on their belief that they can overcome the barriers associated with these interventions. Finally the person has to feel confident that they have the ability to carryout the behavior.

Cues to Action refer to awareness about SCD through education, media, or a family member's direct experience with SCD influences the person perception of the threat. Due to the media's implicit message that SCD is an "African American" disease, other racial groups may have the misconception that they are not susceptible to the disease. Furthermore, when negative attitudes and stereotypes about African Americans (such as them having defective genes) are combined with the misconception that SCD only affects the African American population this results in a false understanding of the risk (Bedaiko & Moffitt, 2011).

Due to limited funding and public support, there is a lack of information about the knowledge, perceptions, and attitudes about SCD and SCT among populations at-risk who are usually unaware of their own carrier status (Boyd et al., 2005; Treadwell et al., 2006). An understanding of how sociocultural attitudes and health beliefs affect SCD screening, and counseling behaviors will be useful to create effective programs that are culturally appropriate (Guvenc et al., 2011). African Americans have different health

beliefs than Caucasians (Gustafon, 2006). Education can influence the constructs of HBM. Mahmoodi et al. (2011) found that education improved awareness, attitudes, and perceptions about family planning participation in a group of male teachers. Education programs can eradicate inaccurate beliefs and encourage positive attitude and awareness (Mahmoodi et al., 2011). Mahmoodi et al. (2011) found that individuals with greater awareness had more positive perceptions about their participation in the family planning programs. Therefore, this study will assess college students' SCD knowledge health beliefs, attitudes, and screening behaviors to inform the development of effective SCD prevention programs.

Strengths and Limitations

A major weakness of the HBM is that it does not consider cultural factors, which may also have a significant effect on a person's health belief (Davis et al., 2013). Despite its weakness, the HBM has several strengths. The model has been extensively used to explain many health-related beliefs and screening behaviors (Guvenc et al., 2011, Mahmoodi et al., 2011) including SCT screening (Gustafon, 2006; Stewart, 2007). Furthermore, the model continues to be one of the most widely accepted theories explaining health behaviors (Guvenc et al., 2011). The HBM has also been used with diverse racial/ethnic populations (Davis et al., 2013, Wong et al., 2013). According to Mahmoodi et al. (2011), education "eliminates" inaccurate views and encourages favorable attitudes and awareness among participants. The HBM is instrumental because not only does it enhance health behavior but it also influences intervention programs by recognizing possible preliminary factors of health behavior that can be changed (Zhi-Juan, Zhi-Juan, Yue, & Shu-Mei, 2014).

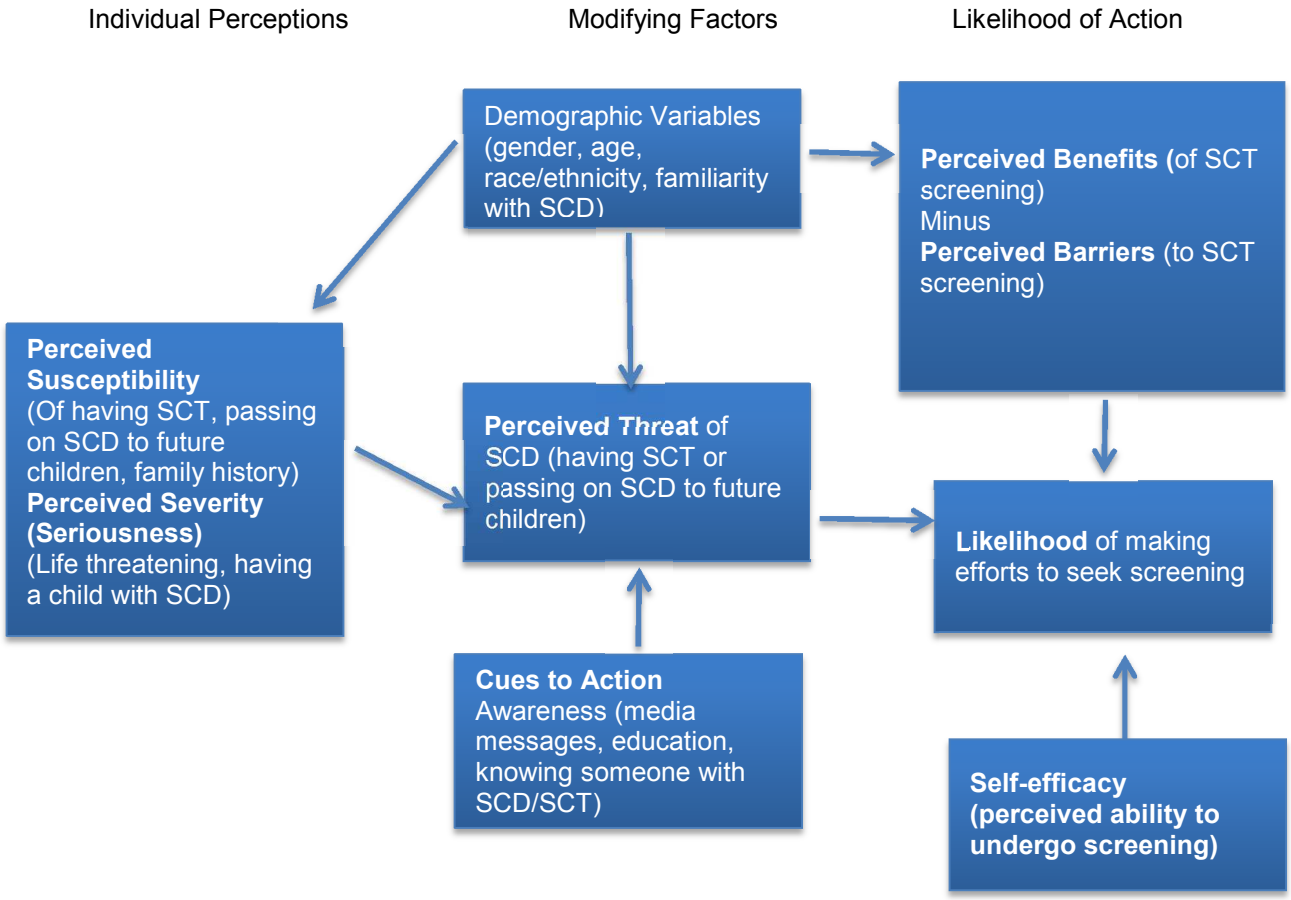

Figure 3-2 Health Belief Model Applied to SCD

Summary of Conceptual Framework

The EST and HBM are suitable for understanding SCD knowledge, health beliefs, attitudes, and screening behaviors. The EST provides a comprehensive framework to provide a better understanding of how multiple factors within the individual's environment may influence the person's SCD knowledge, health beliefs, attitudes, and screening behaviors. The HBM provides a framework to explain how this knowledge, health beliefs, and attitudes influence health behavior. When used together, these two theories complement each other and provide a useful tool to understand the different factors that influence SCD knowledge, health beliefs, attitudes, and screening behaviors to inform prevention efforts.

Chapter 4

Method

The purpose of this study was to assess the factors that contribute to the knowledge, health beliefs, attitudes about SCD, and screening behaviors among college students. The driving force for this study was a result of the identification of gaps in the literature regarding the limited research on SCD knowledge health beliefs, attitudes, and screening behaviors among high-risk individuals. This study aims to provide social work researchers and practitioners with useful information regarding effective prevention strategies for SCD education and prevention among college students. This chapter presents the research questions and hypotheses that were tested. An overview of the research design is also provided. Study participants are presented. The instrumentation and data collection procedures are explained and the validity threats are discussed. Finally, data analysis procedures will be presented.

Purpose of the Study

The purpose of this study was to assess the SCD knowledge, health beliefs, attitudes, and screening behaviors among college students. After reviewing the sparse literature available regarding the knowledge, health beliefs, and attitudes about SCD and carrier screening, significant gaps in the literature were found. Such knowledge is needed to guide the development of SCD educational prevention programs. Thus, the current study explored the factors that contribute to the knowledge, health beliefs, and attitudes about SCD and carrier status among college students.

Specifically, the aims of the study were to:

1. Assess college students' knowledge, health beliefs, attitudes, and behaviors regarding SCD and carrier screening;
2. Explore what factors contribute to college students' knowledge, health beliefs,

attitudes, and behaviors regarding SCD and carrier screening; and

3. Explore the relationship among college students' knowledge, health beliefs, attitudes, and behaviors regarding SCD and carrier screening.

Research Question

The guiding research question for this study was: What factors contribute to the knowledge, health beliefs, attitudes, and behaviors about SCD among college students? More specifically, the study was designed to answer the following sub questions:

1. What are college students' levels of knowledge about SCD; health beliefs about SCD and carrier screening; attitudes regarding carrier screening, those with the disease, carriers, and screening behaviors?
2. What differences do factors such as race/ethnicity, gender, age, family history, and familiarity with SCD have on knowledge, health beliefs, attitudes, and screening behaviors regarding SCD among college students?
3. What are the relationships among knowledge about SCD, health beliefs about SCD, attitudes towards carrier screening, those with the disease, carriers, and screening behaviors among college students?

Research Hypotheses and Data Analyses

Hypothesis 1

Research Hypothesis 1: There will be significant group differences in knowledge, health beliefs, attitudes, and screening behaviors regarding SCD among college students.

Null Hypothesis 1: There will be no significant group differences in knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students.

Multiple Analysis of Variance (MANOVA) was used to test the outcome of this hypothesis. Three assumptions must be met in order for MANOVA to be valid including:

independent observations, homoscedasticity (equal variances) among the groups, and normality. In addition, to these assumptions, other issues such as linearity and multicollinearity among the dependent variables, and outliers should be examined for possible effects.

Hypothesis 2

Research Hypothesis 2: Gender, age, and race/ethnicity, family history, and familiarity with SCD will be predictive factors of knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students.

Null Hypothesis 2: Gender, age, race/ethnicity, family history of SCD, and familiarity with SCD will not be predictive factors of knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students.

To determine the outcome for this hypothesis, a multiple regression analysis was performed to determine if the independent variables (gender, age, race/ethnicity, family history and familiarity with SCD) predict each dependent variable (knowledge, health beliefs, attitudes, screening behaviors).

Hypothesis 3

Research Hypothesis 3: Knowledge will be a predictive factor of health beliefs, attitudes, and behaviors regarding SCD among college students.

Null Hypothesis 3: Knowledge will not be a predictive factor of health beliefs, attitudes, and behaviors regarding SCD among college students.

A two-step regression was performed on this hypothesis. The second step in this hypothesis depended on the outcome of hypothesis 2; that is, a second regression was performed based on the statistical significance of gender, race/ethnicity ethnicity, family history, and familiarity with SCD, which were used as control variables.

Hypothesis 4

Research Hypothesis 4: Health Beliefs will be a predictive factor of SCD screening behaviors among college students.

Null Hypothesis 4: Health beliefs will not be a predictive factor of SCD screening behaviors among college students.

A two-step regression was conducted on this hypothesis. The second step in this hypothesis depended on the outcome of hypothesis 2; that is, a second regression was performed based on the statistical significance of gender, age, race/ethnicity ethnicity, family history, and familiarity with SCD, which were used as control variables.

Hypothesis 5

Research Hypothesis 5: Attitudes about carrier screening will be a predictive factor of SCD screening behaviors among college students.

Null Hypothesis 5: Attitudes about carrier screening will not be a predictive factor of SCD screening behaviors among college students.

A two-step regression was conducted on this hypothesis. The second step in this hypothesis depended on the outcome of hypothesis 2; that is, a second regression was performed based on the statistical significance of gender, age, race/ethnicity ethnicity, family history, and familiarity with SCD, which was used as control variables.

Hypothesis 6

Research Hypothesis 6: Of all the predictive factors race will be the best predictor of knowledge about SCD among college students.

Null Hypothesis 6: Of all the predictive factors, there will be no difference in the predictive effects of the different factors.

A multiple regression analysis was conducted for this hypothesis.

Hypothesis 7

Research Hypothesis 7: Of all the predictive factors knowledge about SCD will be the best predictor of health beliefs, attitudes, and behaviors regarding SCD among college students.

Null Hypothesis 7: Of all the predictive factors, there will be no difference in the predictive effects of the different factors.

A multiple regression analysis was conducted for this hypothesis. There are several assumptions that must be met and the procedures proposed for testing these assumptions are presented in Table 4-1.

Table 4-1 Multiple Regression Assumptions

Assumptions	Test for Assumptions
Linearity	• Plot of observed vs. predicted values Or • Plot of residuals vs. predicted values
Mean independence	• Auto correlation plot of residuals • Durbin Watson statistic
Normality	• Normal probability plot of the residuals
Homoscedasticity	• Plots of residuals vs. time and • Residuals vs. predicted value
Multicollinearity	• Variance inflated factor (VIF) • Condition index • Variance proportions

Design

A non-experimental, cross-sectional research design was used for this study to investigate predictors and relationships among factors that contribute to college students' knowledge, health beliefs, attitudes, and behaviors regarding SCD. Survey design is a suitable approach for assessing behavioral intentions, past experiences, social background, and attitudes (Guillory, 2007). Cross-sectional research includes measuring variables of interest to determine their relationship (Rubin & Babbie, 2011). Data were

collected at one point in time assessing SCD knowledge, health beliefs, attitudes, and behaviors among college students.

Sample

A power analysis was computed following Cohen's (1977,1992) standards to determine the sample size required for this study. According to Cohen, a minimal power of .80 and a medium effect size is an acceptable level of power (Cohen, 1992). Since this study had eight predictor variables for multiple regression analyses, *a priori* sample size calculations indicated that a minimum sample size of 108 would be necessary to obtain sufficient statistical power (Soper, 2014).

A non-probability sampling approach using a convenience sample of college students was used for this study. The study was conducted at the University of Texas at Arlington (UTA), which is located in the Dallas-Fort Worth metroplex. UTA serves a diverse student population of approximately 33,000 students including Caucasians (43%), Hispanics (22%), African Americans (14%), Asians (10%), and International students (9%) (Find the Best, 2014; UTA, 2013). The participants were recruited from the UTA student population by working with the different student organizations and professors. Students were offered the option of participating in a survey regarding SCD for extra credit (i.e., class recruitment), service hours (i.e., student organization recruitment) or a $25 visa gift card drawing.

Procedures

A cross-sectional design was used to assess college students' knowledge, health beliefs, attitudes, and behaviors regarding SCD. Participants were recruited through UTA professors who agreed to offer the study as an extra credit assignment. Participants were also be recruited through UTA student organizations that agreed to offer the study as service hours. Additionally, there were drawings for five $25 Visa gift cards for students

who take the survey that were not part of classes or organizations providing extra credit or service hours. IRB approved emails and flyers were used to recruit participants for the study (Appendix A). Recruitment strategies to ensure gender and race/ethnicity variability included targeting all student organizations with a special emphasis on reaching out to organizations that target a specific gender or race/ethnicity. Although, these organizations may not be all inclusive of that specific gender or race/ethnicity, it is highly likely that the majority of members belong to that specific gender or race/ethnicity, thus increasing variability within the sample. Finally, in an effort to strive toward a diverse sample of genders and races/ethnicities, the researcher monitored demographics periodically during data collection. The researcher sent additional invites through the aforementioned channels to increase participation and sample variability.

Participants were provided with the link to access the online survey that included informed consent and all study measures (Appendix B). After completion of the survey, students received a certificate of completion and were asked to print or email to their instructors or student organization officers for appropriate credit (Appendix C). For students who were recruited through means other than classes with extra credit and organizations with service hours, their information was collected at the end of the survey (kept separately from their responses to ensure anonymity) for entrance in the aforementioned gift card drawings (Appendix C).

Measures

Independent Variables

Familiarity with SCD

Familiarity with SCD was measured using a 34-item survey but only 16 was scored; the other questions were qualitative such as why or why not and received 0 points no matter what the response. Scores ranged from 0-16 with higher scores

meaning more familiarity with SCD. Question format included “Have you ever heard of Sickle Cell Disease” with response of “Yes; No; I don’t know; Not Sure” A response of “Yes” was given a score of 1 and a response of “No/Don’t know/Not Sure” was given a score of 0. The survey was self developed and included two questions from DeBaun (2012) Knowledge Assessment Survey: “Have you ever heard of C-trait? If yes, do you know if you personally have C-trait” and “ Have you ever heard of b-thalassemia trait? If yes, do you know if you personally have b-thalassemia trait?”(Appendix D). In order to identify poorly related items, items were deleted if the total scale reliability increased by more than 10 after deleting that item or if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). The final scale consisted of 10 items. Six items were deleted due to low correlations. Deletions were made after the survey was administered. Cronbach’s alpha for the current study was .78. The corrected-item total correlations ranged from .23 to .57 (Appendix H).

Family History

Family history of SCD was measured by the question “Does anyone in your family have SCD” Responses included “yes”, “no”, and “not sure” (Appendix D).

Demographic Variables

Demographic variables that were used in this study included college students’: age, gender, and race/ethnicity. These variables were measured by participants’ self-report on the demographic questionnaire. See (Appendix D) for further description on how each variable will be measured.

Dependent Variable

Screening Behaviors

Screening behaviors were measured using a questionnaire developed by this researcher. The screening behaviors questionnaire included 8 items, but only 4 were scored. The other 4 items were qualitative questions such as "why or why not" and received 0 points no matter what the response. For each question, a response of "yes" was given a score of one, and a response of "no" or "don't know" was given a score of zero, for a total possible score of 0-4, with higher scores indicating more favorable screening behaviors (Appendix D). The internal consistency reliability of the subscale was assessed using the Cronbach alpha coefficient. In order to identify poorly related items, items were deleted if the total scale reliability increased by more than 10 after deleting that item or if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). The alpha coefficient was .61. Two items were deleted. Deletions were made after the survey was administered. The final Screening Behaviors scale consisted of 2 items with a Cronbach's alpha of .85. The corrected item-total correlations were .74 for both items (Appenix H).

Health Belief Survey

Health beliefs about SCD and carrier testing were measured by a modified version of the Health Belief Survey (Bhatt, Reid, Lewis & Asnani, 2011). The researcher received permission to use and modify the instrument (M. Asnani, personal communication, June 7, 2014). The original survey included twelve questions in the domains of perceived severity, perceived susceptibility, perceived benefits, and perceived barriers. A five-point Likert-scale was used to assess the individuals' perceptions with 5 indicating a high perception and 1 indicating a low perception. The instrument was modified to a 24-item survey for this study to include Beta-Thalassemia in four subscales:

severity (3 items), susceptibility (6 items), benefits (6 items), and barriers (9 items). Perceptions measured were perceived severity “SCD is a serious disease”, susceptibility, “SCD can happen in my family”, benefits “It is useful to know if I have SCT”, and barriers ‘Testing for SCT is painful and difficult”. The survey was modified to include perceptions about carrier screening for Beta-Thalassemia (Appendix A). The Health Belief Survey (Bhatt, Reid, Lewis & Asnani, 2011) was used to assess knowledge and health beliefs among Jamaican adolescents as well as in Gustafon (2006) to determine health beliefs among African American women in childbearing age. The studies did not report content validity or reliability of the instrument. The Health Belief survey (Bhatt et al., 2011) was modeled after other studies examining the motivations for cancer screening participation (Barroso, McMillan, Casey, Gibson, Kaminski & Meyer, 2000; Foxall, Barron, & Houfek, 1998). Barroso et al. (2000) reported test-retest reliability between 0.36 and 0.71 and internal consistency using cronbach’s alpha between 0.40 and 0.77. Internal consistency was calculated by Cronbach’s alpha reliability analysis for the current study. In order to identify poorly related items, items were deleted if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). All items met the criteria for inclusion except for Benefits subscale. Two items were deleted due to correlations less than .30. Deletions were made after the survey was administered. The final scale consisted of Severity (3 items), Susceptibility (6 items), Benefits (4 items), and Barriers (9 items) items. Cronbach’s alpha coefficient for the current study ranged from 0.84 to 0.96 for the subscales. Corrected Item-total correlation ranged from .41 to .91 for the subscales (Appendix H).

Attitudes Towards Carrier Testing

Attitudes towards (SCD and Thalassemia) carrier testing were measured using a modified version of the Attitudes To Participation in Carrier Testing scale (Weinreich, Lange-de Klerk, Rijmen, Cornel, Kinderen & Plass, 2011) (Appendix D). Permission was received to use and modify instrument (S. Weinreich, personal communication, May 6, 2014). The original scale measured participation in carrier testing for SCD and/or Thalassemia combined. For this research, the statement was modified to measure participation in carrier testing for SCD separately from participation in carrier testing for Beta-thalassemia. Additionally, the original scale also used the terms “carriership” and “carriership testing” and were changed to “carrier status” and “carrier screening.” The scale included eight word pairs; each word pair was measured using a 5-point likert-scale. A score of 5 indicated a positive attitude and a score of 1 indicated a negative attitude towards carrier testing. The Cronbach’s alpha for the original scale was 0.8 (Weinreich, et al., 2011). Reliability for the modified scale was conducted as part of the dissertation. Crombach’s alpha for the current study was .92 and .93 for SCD and Beta-Thalassemia respectively. In order to identify poorly related items, items were deleted if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). All items met the criteria for inclusion. The corrected-item total correlations ranged from .57 to .83 (Appendix H).

Attitudes Towards People with SCD

Attitudes towards people who are carriers of SCD or Thalassemia were measured using the Behavior Towards SCD scale (Olarewaju, Enwerem, Adebimpe & Olugbenga-Bello, 2013). The original scale included 6 items assessing behaviors toward SCD. The questionnaire was pilot tested among senior secondary school students in Abuja and revised accordingly (Olarewaju et al., 2013). Questions asked whether

participants would marry someone with SCD. The instrument also used "genotype" referring to SCD status. Therefore, for this study, the scale was modified with permission (O. Olarewaju, personal communication, June 16, 2014) to a 12-item version to include items on Beta-Thalassemia and friendships and dating someone with SCD. "Genotype" was also changed to "carrier status" for simplification to the study population. For questions 3 to 8, a response of "yes" was given a score of zero, a response of "I don't know" was given a score of one, and a response of "no" was given a score of two. For questions 1, and 9 to 11, a response of "yes" was given a score of two, a response of "don't know" was given a score of one, and a response of "no" was given a score of two. Finally for question 12, a correct response was given a score of one for a total possible score of 0-21, with higher scores indicating more positive attitudes towards people with SCD (See Appendix D). Reliability for the modified scale was conducted as part of the dissertation. In order to identify poorly related items, items were deleted if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). Two items were deleted due to correlations less than .30. Deletions were made after the survey was administered. The final scale consisted of 10 items. Crombach's alpha for the current study was .89. The corrected-item total correlations ranged from .32 to .80 (Appendix H).

SCD and SCT Knowledge Assessment Tool

Knowledge about SCD was measured by a modified version of the SCD Knowledge Assessment Tool (M. DeBaun, personal communications, October 25, 2012) (Appendix D). See "Content Validity" below for further explanation of the modifications to this instrument. There were 40 questions; each correct answer will be given a score of 1, with a possible total maximum score of 39 (1 qualitative question) with higher scores indicating more knowledge about SCD/SCT (Appendix D).

Content validity

Content validity for the current study was assessed in an attempt to determine if the proposed instruments were relevant and appropriate for a college student population and research goals. An expert panel was developed and included eight multinational participants including five professors and three social workers that facilitate SCD support groups. The protocol received an exemption to the human subject regulations from the University of Texas at Arlington IRB. The IRB approval for the expert panel survey can be found in Appendix E. An email invitation was sent out to potential academic researchers and SCD support group facilitators inviting them to participate in an expert panel survey (Appendix F). The expert panel was provided with the intended study instrument (DeBaun, 2012) and asked to provide feedback on the appropriateness of the content to improve knowledge and attitudes about SCD/SCT among college students. The original measure included 32 items including multiple choice and true/false responses. "Assuming a total of 100 individuals, a 10-item SCD Knowledge Assessment Tool with a Cronbach's alpha of 0.75 will have a 95% confidence interval of 0.68 to 0.81" (DeBaun, 2012, p. 16). Revisions were made based on the panel's feedback regarding the structure and wording of questions. The panel provided feedback on whether or not to include each question as well as provided suggestions on wording. Questions were modified and redundant questions were deleted according to expert panel feedback. In order to identify poorly related items, items were deleted if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). Eighteen items were deleted due to correlations less than .30. Deletions were made after the survey was administered. The final scale consisted of 18 items. Cronbach's alpha for the current study was .86. The corrected-item total correlations ranged from .32 to .59 (Appendix H).

Table 4-2 Study Variables and Corresponding Measures

Variables	Measures
Familiarity with SCD	Familiarity with SCD Questionnaire
Family History	Familiarity with SCD Questionnaire
Gender, Age, Race/Ethnicity	Demographic Questionnaire
Knowledge about SCD	SCD & SCT Knowledge Assessment Tool
Health Beliefs	Health Beliefs Survey
Attitudes Toward Carrier Screening	Attitudes to participation in Carrier Testing
Attitudes Toward People with SCD	Behavior Towards SCD
Screening Behaviors	Screening Behaviors Questionnaire

Data Collection

Informed Consent Protection of Human Subjects and Threats to Research Credibility

An informed consent was provided to all participants. Participants were informed that participation in the study was completely voluntary and that it would not affect their university standing if they choose not to participate. Participants were made aware that they were participating in a study, were informed of the possible consequences of the study, and had to provide consent in order to participate. There were no privacy concerns since the survey was anonymous and no identifying information was collected. All information collected was kept confidential. All study data will be electronically stored for at least 3 years after the study is completed using encrypted USB thumb drives. Only the researcher and supervising committee chair have passwords to access the data for

research purposes. The study received an exemption from the University of Texas at Arlington IRB. The IRB approval for the SCD survey can be found in Appendix G.

In terms of threats to research validity, selection and unrepresentative sample were threats to internal and external validity. The study design used a convenience sample of college students who agreed to participate. Since the sample was not randomly selected, it is possible that instructors and group leaders accepted to offer the study to the students if they were passionate about SCD or decided not to participate if they were not familiar with the disease.

Data Analysis

Prior to data analyses, Cronbach's alpha was calculated for each modified instrument to verify sufficient levels of reliability. Generally, for Social Sciences, a cronbach's alpha of .70 or higher is considered acceptable (Tabachnick & Fidell, 2007). In order to identify poorly related items, items were deleted if the total scale reliability increased by more than 10 after deleting that item or if there was a correlation of < .30 between an item and the total subscale score (Guvenc, 2011; Morisky, Ang, Krousel-Wood & Ward, 2008). See Appendix H for deletions and final scales used for data analysis. The Statistical Package for Social Sciences (SPSS) version 22 was used to conduct all data analyses. Descriptive statistics, such as frequency distributions and percentages were used to describe the sample. MANOVA was used to determine if there were any demographic differences in the knowledge, health beliefs, attitudes, and behaviors about SCD. Correlations were performed to determine if the variables were related. Finally, simple linear and multiple regression analyses were used to test the hypotheses. Regression analyses were conducted to determine the predictive value of gender, race/ethnicity, family history, and familiarity with SCD as it relates to the knowledge, health beliefs, attitudes, and behaviors about SCD. Regression analyses

were also used to determine the strength of the relationship between knowledge, health beliefs, attitudes, and behaviors about SCD.

Chapter 5

Results

This chapter presents the descriptive findings with regard to individual variables in the study such as sociodemographic characteristics. Next, relationships between key variables, such as health beliefs, attitudes and behaviors regarding SCD are presented. The section concludes with the findings from the hypotheses testing based on bivariate and multivariate analyses.

Description of Sample

A total of 604 individuals responded to the invitation to participate in the study. Of the 604 respondents, 441 (73%) completed the study; 163 (27%) dropped out of the study before completion (42 Caucasians; 32 Hispanics; 31 “Other”; 26 Asians; 21 African Americans; 11 Unknown). Response rate was difficult to calculate since the researcher could only account for the number of invitations sent out to faculty and organizations. Thus, the researcher could not account for how many faculty and student organizations actually sent out the survey to their student members. Of the 441 who completed the study, 26 were identified as outliers; detailed discussion of outliers is presented later. For the purpose of this study, data belonging to attritional participants were not included in the data analyses. Thus, the final sample consisted of 415 college students who were recruited from UT Arlington’s student organizations. The majority of the sample was females (73.7%). More than a third (37.5%) of the participants were Caucasians. The majority of participants were single with no children. About one third (31%) of the participants were seniors. The mean age of the participants was 25 years old (SD = 7.21). The final sample was not representative of the University. UT Arlington serves a diverse student population of approximately 33,000 students including Caucasians

(43%), Hispanics (22%), African Americans (14%), Asians (10%), and International students (9%) (Find the Best, 2014; UT Arlington, 2013). See Table 5-1 for further demographic details of the sample of all college students who completed the survey.

Table 5-1 Participants' Individual Demographics

Characteristics	N	%
Gender		
Female	306	73.7
Male	109	26.3
Ethnicity		
African American	65	15.7
Hispanic	70	16.9
Caucasians	156	37.9
Asian	82	19.8
Other	42	10.1
Age		
18-35	371	89.4
36-64	44	10.6
Education		
Undergraduate freshman	35	8.4
Undergraduate sophomore	62	14.9
Undergraduate junior	92	22.2
Undergraduate senior	130	31.3
Graduate (Master's program)	68	16.4
Graduate (PhD program)	24	5.8
Non-seeking degree	4	.9
Degree Programs		
College of Business	38	9.2
College of Engineering	54	13.0
College of Science	25	6.0
College of Liberal Arts	46	11.1
College of Nursing	143	34.5
College of Education & Health Professions	21	5.1
School of Social Work	30	7.2
Other	58	14.0
Marital Status		
Single	291	70.1
Married	94	22.7
Divorced	13	3.1
Separated	5	1.2
Co-habiting	12	2.9

Table 5.1- *Continued*

Number of Children		
0	334	78.2
1	29	7.0
2	30	7.2
3	18	4.3
4	7	1.7
More than 4	3	.6
Expecting	3	.6
Living Arrangements		
Parents	119	28.7
Spouse	85	20.5
Partner	32	7.7
Other	179	43.1
Familiarity with SCD		
Less familiarity	229	55.2
More familiarity	186	44.8
Family History of SCD		
Yes	16	3.9
No	332	80.0
Don't Know	67	16.1

Description of Variables

Knowledge

The first research question assessed the level of college students' knowledge about SCD. Although the majority of participants (79%) reported that they have heard of SCD before, 21% of the participants reported that they have never heard of SCD. A little more than half of the participants (54.6%) reported having some type of SCD education in the past through presentations (15%), online (6%), videos (5%), brochures (4%), workshops (1%), and other sources (31%). Knowledge about SCD scores ranged from 0 to 18 with higher scores indicating better knowledge about SCD. The average score obtained by the participants on the SCD & SCT Knowledge Assessment Tool was 11.39

(*SD* = 4.38). Although most participants correctly indicated that SCD (81.9%) and Beta-Thalassemia (73%) are passed on by heredity, some participants believed SCD (14%) and Beta-Thalassemia (20%) could be passed on through blood transfusion. More participants correctly indicated that a baby could be affected by SCD (48%) than Beta-Thalassemia (18%) if both parents were carriers of either SCD or Beta-Thalassemia. Only 38% correctly indicated that there is a 25% chance with each pregnancy of having a baby with SCD when both parents have SCT. In terms of distinguishing SCT from SCD, 26.5% of participants incorrectly believed that people with SCT have a mild form of SCD and 40% did not know. Similarly, 31% incorrectly believed that SCT could change to SCD and 36% did not know. The majority of participants (83%) correctly knew that the only way to figure out if a person has SCT is through a special blood test. However, when it came to testing results, only 37% correctly knew that a negative sickle carrier test meant that the person definitely does not have SCT. While 70% of the participants correctly knew that if test results show that they are carriers of SCD, it was possible that their baby would have SCD, only 43% correctly knew that if they were carriers of Beta-Thalassemia, it was possible for their baby to have SCD. When asked who gets SCD in the United States, 64% correctly said mostly African Americans. In another question asking who is affected by SCD, 67% correctly indicated that SCD can be found in people from many nationalities, however 16% incorrectly believed that SCD only affects African Americans. Only 20.5% correctly knew the prevalence of SCD among African Americans. A little over half (55%) of the participants correctly knew the major complications of SCD however, 26% did not know what the complications were. Only 11% correctly knew that SCD could be cured by bone marrow transplant; 46% incorrectly believed that there was no cure and 31% did not know how SCD could be cured. In terms of prevention, 53% correctly believed that SCD could be prevented through premarital

trait testing. Fewer (43%) participants correctly believed that the best way to prevent SCD is by everyone knowing their trait status. However, 27% incorrectly believed that there is no way to prevent SCD and 26.3% indicated that they did not know how to prevent SCD.

Health Beliefs

Severity Of SCD

Severity scores ranged from 5 to 15 with higher scores indicating higher perception of severity of SCD. Overall, participants had a high perception of the severity of SCD (*M* = 12.23, *SD* = 2.30). Participants either believed or strongly believed that SCD was a serious disease (83.4%); having a child with SCD would be scary (76%); and that their life would change if their child had SCD (75%).

Susceptibility To SCD

Susceptibility scores ranged from 6 to 28 with higher scores indicating higher perceived susceptibility to SCD. Overall, participants had moderate perceptions of susceptibility to SCD (*M*= 14.35, *SD*= 4.84). Most of the participants either disagreed or strongly disagreed that they were susceptible to SCD. Only 7% believed that their children were at risk for SCD; 21% believed SCD could happen in their family. Only a few participants believed that they might be a carrier of SCD (10%) or Beta-Thalassemia (8%). A low percentage of participants believed that their partners might be carriers of SCD (11%) or Beta-Thalassemia (8%).

Benefits To SCD Carrier Screening

Benefits scores ranged from 6 to 20 with higher scores indicating higher perceived benefits to SCD carrier screening. Overall, participants had high perceptions of benefits to screening (*M*= 16.53, *SD*= 3.15). The majority of participants believed that it would be useful to know if they (80.3%) or their partners (79%) had SCT. Similarly, most

participants believed that it would be useful to know if they (77.8%) or their partners (78%) had Beta-Thalassemia trait. Only 39% believed that knowing the risk of having a child with SCD would change how they chose their partner. However, more than half of the participants (64%) believed that knowing the risk would change how they planned their pregnancy.

Barriers To SCD Carrier Screening

Barriers scores ranged from 9 to 40 with higher scores indicating higher perceived barriers to carrier screening. Overall, participants had moderate perceptions of barriers to carrier screening (*M* = 21.81, *SD* = 5.99). Only a few participants indicated that they would rather not know if they had SCT (9%) or Beta-Thalassemia trait (9%). A slightly higher percentage indicated that they were afraid of finding out if they had SCT (13%) or Beta-Thalassemia (13%). A low percentage of the participants believed that testing for SCT (5%) and Beta-Thalassemia (5%) would be painful and difficult. However, most participants neither agreed nor disagreed that testing for SCT (48%) or Beta-Thalassemia (53%) would be painful and difficult. Only 12% believed that it would be hard to convince their partners to have testing. However, 40% neither agreed nor disagreed that it would be hard to convince their partner to have testing. Participants had similar feelings that they would not want to pay for SCT testing (37%) or Beta-Thalassemia trait testing (35%) if not covered by insurance.

Attitudes Toward SCD Carrier Screening

Attitudes toward SCD carrier screening scores ranged from 19 to 40 with higher scores indicating more positive attitudes toward SCD carrier screening. Overall, participants had positive attitudes toward SCD carrier screening (*M* = 33.32, *SD* = 5.70). Participants considered carrier screening for SCD to be important (82%), good (83%), beneficial (79%), a privilege (58%), pleasant (50%), desirable (69%), sensible (80%), and

reassuring (72%). Although the majority of participants had positive attitudes toward SCD Carrier Screening, more than 18% of the participants had neutral feelings about carrier screening for SCD.

Attitudes Toward Beta-Thalassemia Carrier Screening

Attitudes toward Beta-Thalassemia carrier screening scores ranged from 20 to 40 with higher scores indicating more positive attitudes toward Beta-Thalassemia carrier screening. Overall, participants had positive attitudes toward Beta-Thalassemia carrier screening (*M*= 32.69, *SD*= 5.87). Participants considered carrier screening for Beta-Thalassemia to be important (77%), good (77%), beneficial (76%), a privilege (56%), pleasant (50%), desirable (63%), sensible (74%), and reassuring (68%).

Attitudes Toward People With SCD

Attitudes toward people with SCD scores ranged from 4 to 19. Overall, participants had positive attitudes toward people with SCD (M= 14.99, SD= 4.23). The majority (78%) of the participants believed that everyone should know their carrier status however; only 26% indicated that they knew their carrier status. Responses were similar for SCD and Beta-Thalassemia carrier status. Most participants indicated that a person's SCD (87%) or Beta-Thalassemia (83%) carrier status would not influence their decision to be friends with someone. Similarly, most participants indicated that a person's SCD (64%) or Beta-Thalassemia (60%) carrier status would not influence their decision to date them. However, more than (25%) were unsure and almost (10%) indicated it would influence their decision to date him or her. When asked if SCD carrier status would influence their decisions to marry their partners, 13% indicated that it would influence their decision to marry their partners 54% indicated it would not influence their decision to marry, and 34% said they did not know if it would influence their decision to marry. Similarly, when asked if Beta-Thalassemia carrier status would influence their decisions

to marry their partners, 12% indicated that it would influence their decision to marry their partners, 51% indicated it would not influence their decision to marry, and 38% said they did not know if it would influence their decision to marry. The majority of participants indicated that they would be friends (86%), date (62%), or marry (49%) someone if they had SCD. When asked about what a couple should do if they found out they are at risk of passing on SCD to their children, the majority (80%) agreed that they should seek genetic counseling and make an informed decision.

Screening Behaviors

The majority (87%) of participants indicated that they have never had SCD carrier screening. A little over half (55%) of the participants who never had screening indicated that they would be interested in participating in SCD carrier screening. However, 22% indicated that they would not be interested and 20% were unsure if they would want to undergo screening. The majority (95%) of the participants also indicated that they never had Beta-Thalassemia carrier screening. Similarly, 55% of the participants who never had Beta-Thalassemia carrier screening, indicated that they would be interested in carrier screening. However, 21% indicated that they would not be interested and 24% indicated that they were unsure if they would participate in Beta-Thalassemia carrier screening. Screening Behaviors scores ranged from 0 to 4 with higher scores indicating more favorable screening behaviors. Overall, participants had favorable screening behaviors. However, as stated earlier, a little over 20% of participants indicated that they would not be interested in carrier screening for either SCD or Beta-Thalassemia.

Hypotheses Testing

This section presents the specific steps implemented and the results for hypotheses testing. First, MANOVA and ANOVA were conducted to identify group differences. Next, multiple regression was conducted to determine the relationship between knowledge and Health Beliefs and Attitudes. A two-step linear regression process was implemented to assess if the selected variables were predictors of knowledge, health beliefs, attitudes, and behaviors regarding SCD. Finally, multiple regressions were implemented to assess the best predictors of knowledge, health beliefs, attitudes, and behaviors regarding SCD.

Hypothesis 1

Research Hypothesis 1: There will be significant group differences in knowledge, health beliefs, attitudes, and screening behaviors regarding SCD among college students.

Null Hypothesis 1: There will be no significant group differences in knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students.

Testing MANOVA Assumptions

Prior to conducting MANOVA, it was necessary to assess whether the data met the specific assumptions for this multivariate analysis. MANOVA was an appropriate statistical technique because there were multiple dependent variables. The first assumption of MANOVA is independence of observations. There was no reason to believe that this assumption was violated. According to Hair et al. (2010), this violation is mostly common in time-ordered effects and group settings. The second assumption is homogeneity of variance-covariance among the groups. Levene's test for equal variances (Table 5-2) and Box's M test (Hair et al., 2010) were used to assess this assumption and indicated that the assumption of the equality of variances was met for some of the

dependent variables and the assumption of the equality of covariance was not met for two (familiarity; family history) of the five independent variables. According to Lu (2007) the homogeneity of variance assumption in highly unlikely to be met in practice. However, there are adjustments that can be made to address the homogeneity assumption violation such as Brown-Forsythe F or Welch's F statistics (Mayers, 2013). Therefore, an independent one-way ANOVA with Brown-Forsythe F and Welch's F adjustments was examined for each dependent variable that violated the homogeneity assumption in the MANOVA analysis to determine if the violation had any impact on the outcome (Table 5-2). Additionally, if violations to homogeneity occurred, the robust statistic Pilai's trace was used to interpret results (Hair et al., 2010; Mertler & Vannatta 2005; Tabachnick & Fidell, 2013). Furthermore, according to Hair et al. (2010) F tests are usually robust if violations to the assumptions are modest.

Table 5-2 Adjusted Outcomes for Homogeneity of Variances

IV	DV	Levene Statistic		Welch & Brown-Forsythe	
		F	P	Adj. *F*	P
Gender	Knowledge about SCD				.06
	Severity				.15
	Susceptibility				.35
	Benefits	.529	.00	.453	.50
	Barriers				.31
	Attitudes toward SCD carrier screening	5.81	.03	5.11	.03
	Attitudes toward People with SCD				.70
	Screening behaviors				.79

Table 5.2- *Continued*

Race/Ethnicity	Knowledge about SCD	14.37	.00	13.45	.00
	Severity				.18
	Susceptibility	7.11	.03	7.87	.00
	Benefits				.95
	Barriers				.78
	Attitudes Toward SCD carrier screening	4.78	.01	4.91	.00
	Attitudes Toward People with SCD	5.25	.01	4.90	.00
	Screening Behaviors	3.78	.00	5.10	.00
Age	Knowledge about SCD	9.28	.00	15.10	.00
	Severity				.21
	Susceptibility				.55
	Benefits				.61
	Barriers				.42
	Attitudes toward SCD carrier screening				.06
	Attitudes toward People with SCD	1.91	.01	2.04	.13
	Screening Behaviors	17.90	.03	13.98	.00
Familiarity	Knowledge about SCD	159.56	.00	175.41	.00
	Severity				.14
	Susceptibility				.44
	Benefits				.76
	Barriers				.15
	Attitudes Toward SCD Carrier Screening	25.55	.00	27.05	.00
	Attitudes toward People with SCD	26.94	.00	28.18	.00
	Screening behaviors				.60
Family History	Knowledge about SCD				.15
	Severity				.18
	Susceptibility	22.21	.00	27.41	.00
	Benefits				.13
	Barriers				.06
	Attitudes toward SCD carrier screening				.09
	Attitudes Toward People with SCD	3.90	.00	9.96	.00
	Screening Behaviors	6.11	.00	9.00	.00

IV=Independent Variable; DV= Dependent Variable

The third assumption is multivariate normal distribution of the dependent variables. Assessing normality, each of the distributions was negatively skewed (Table 5-3). The distributions all appear platykurtic except for Severity of SCD, which appears to be leptokurtic. Taking the standard error of the kurtosis statistic (.24) and multiplying by 2 to construct the range of normality (-.48 to .48), four distributions approach normality because the values for the kurtosis fell within the range of -.48 to .48 (Knowledge = -.46; Severity = .02; Benefits = -.28; and Barriers = -.14) and five distributions did not approach normality because the values for the kurtosis fell outside the range of -.48 to .48 (Susceptibility = -.74; Attitudes Toward SCD Carrier Screening = -.91; Attitudes Toward Beta-Thalassemia Carrier Screening = -1.27; Attitudes Toward People with SCD = -.79; and Screening Behaviors = -1.05). Histograms for each dependent measure are presented in Figures 5-1 through 5-9. While the current sample does appear to deviate from normality, research has shown that MANOVA is fairly robust to violations of normality, especially when the overall sample is greater than 40, as it was in this study (Hair et al., 2010; Tabachnick & Fidel, 2007). In addition, transformations of the non-normal variables did not influence the MANOVA results, therefore the researcher decided to use the original variables.

Table 5-3 Skewness and Standard Error for Dependent Measures

	Skewnes	SE
Knowledge	-.64	.12
Severity	-.65	.12
Susceptibility	-.12	.12
Benefits	-.56	.12
Barriers	-.01	.12
Attitudes Toward SCD Carrier Screening	-.47	.12
Attitudes Toward Beta-Thalassemia Carrier Screening	-.23	.12
Attitudes Toward People with SCD	-.70	.12
Screening Behaviors	-.67	.12

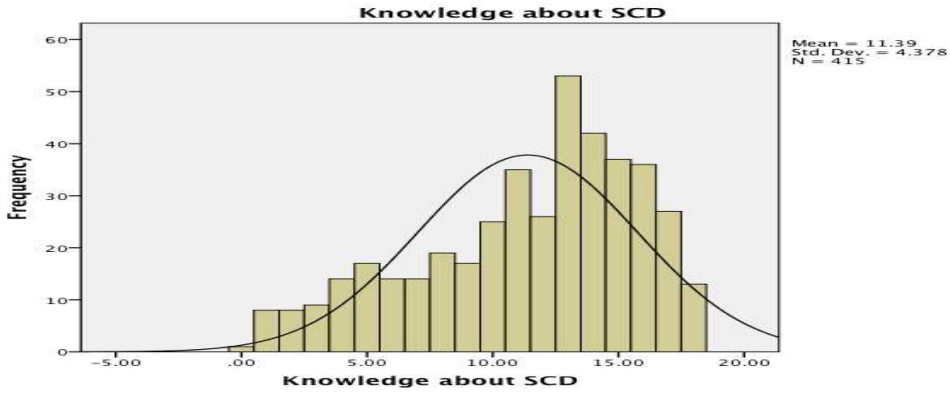

Figure 5-1 Histogram of Knowledge about SCD

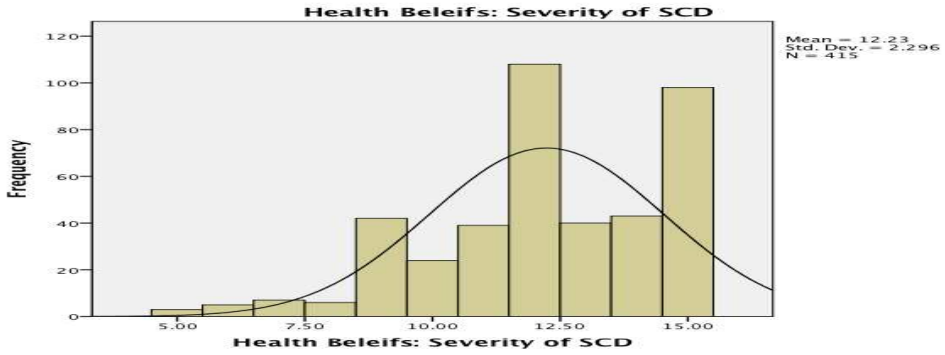

Figure 5-2 Histogram of Perceptions of Severity of SCD

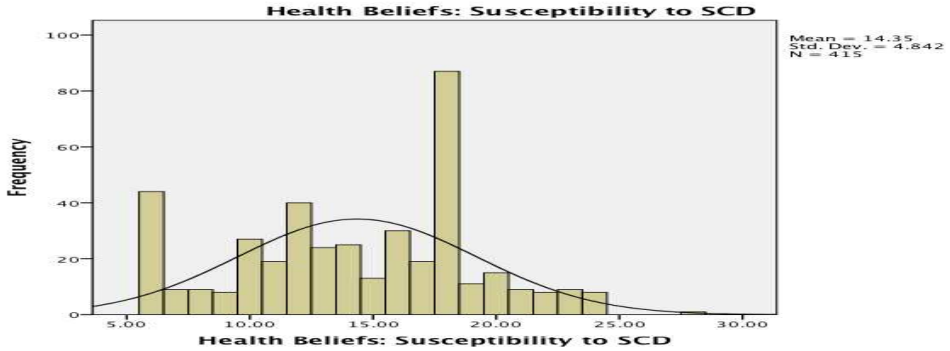

Figure 5-3 Histogram of Perceptions of Susceptibility of SCD

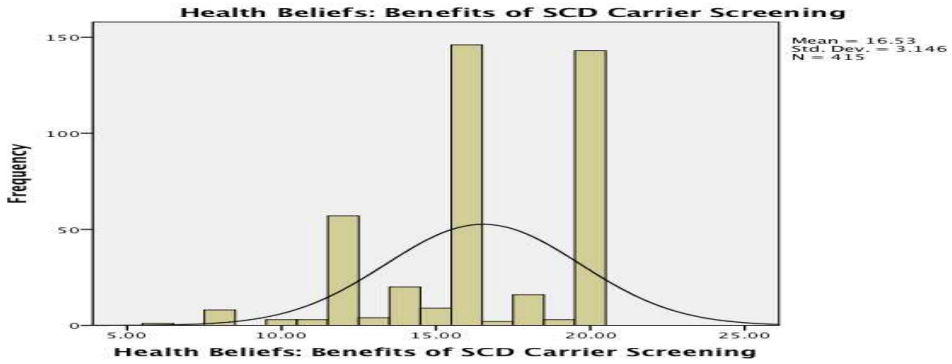

Figure 5-4 Histogram of Perceptions of Benefits of Carrier Screening

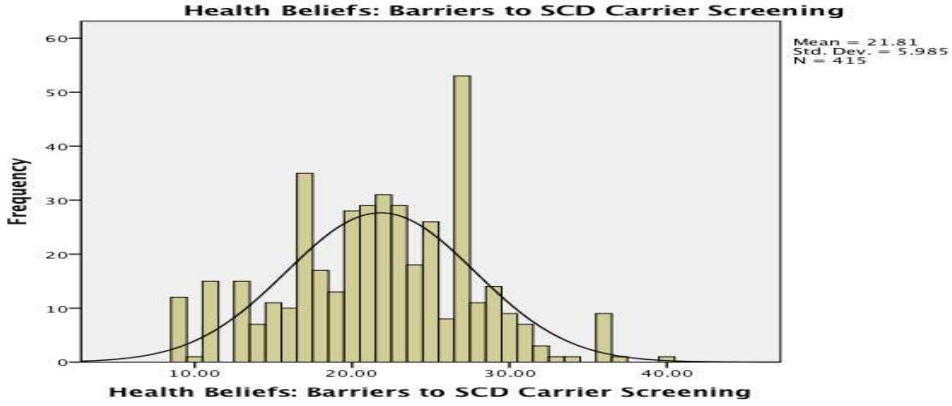

Figure 5-5 Histogram of Perceptions of Barriers to Carrier Screening

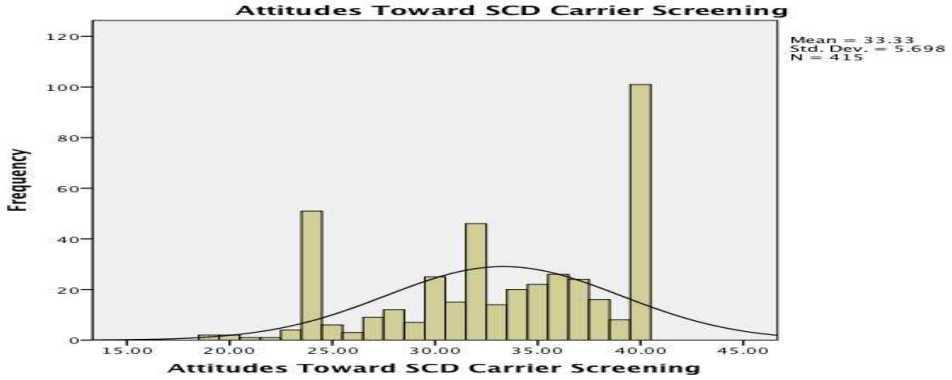

Figure 5-6 Histogram of Attitudes Toward SCD Carrier Screening

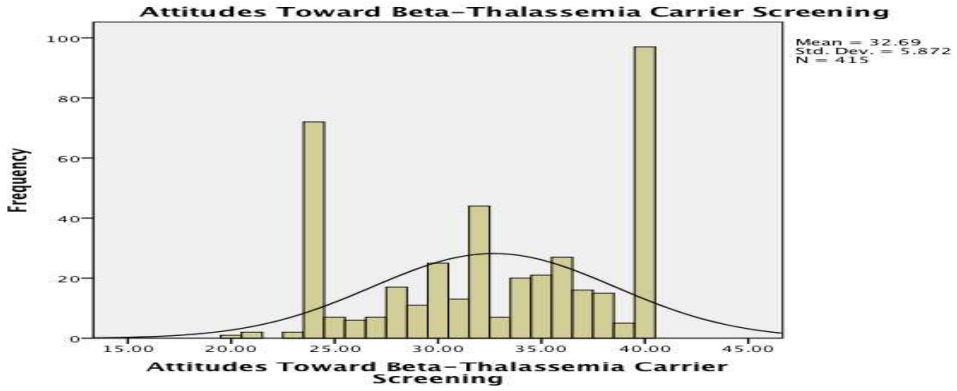

Figure 5-7 Histogram of Attitudes Toward Beta-Thalassemia Carrier Screening

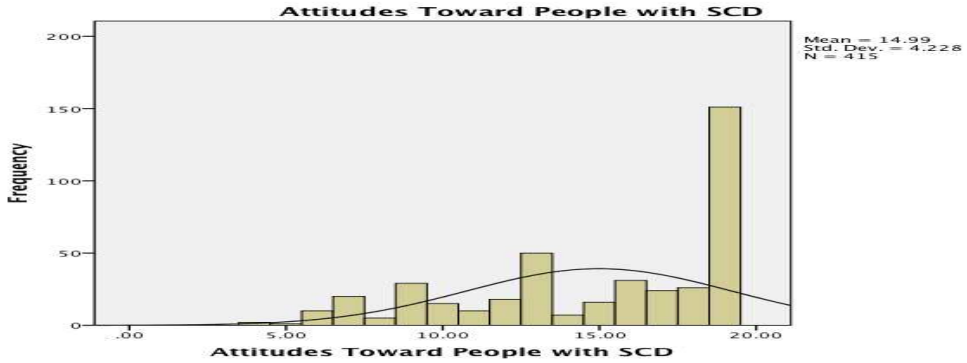

Figure 5-8 Histogram of Attitudes Toward People with SCD

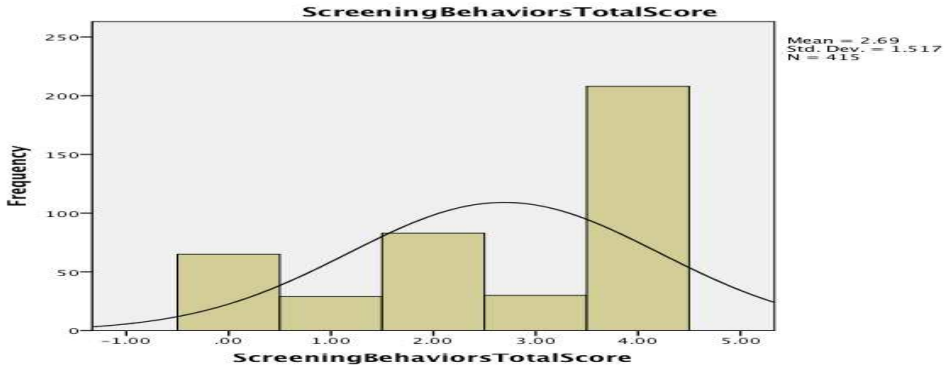

Figure 5-9 Histogram of Screening Behaviors

In addition to these assumptions, other issues such as linearity and multicollinearity among the dependent variables, and outliers were examined for possible effects. Scatterplots and correlation coefficients were used to determine the linear relationships between the variables. Examination of bivariate scatterplots and correlation coefficients revealed adequate linearity between the dependent variables. Another assumption of MANOVA is no multicollinearity among the dependent variables. A correlation matrix showed that there was multicolinearity between two dependent measures (Table 5-4) therefore Attitudes Toward Beta-Thalassemia Carrier Screening was removed from the analysis. The correlation matrix showed that this assumption was met ($r < .80$) for all pairs of variables since Attitudes Toward Beta-Thalassemia Carrier Screening was not included in the MANOVA analysis. In terms of outliers, the analysis identified 16 cases of univariate outliers because their extreme z-scores were greater than plus or minus 3.3 standard deviations from the mean (Hair et al., 2010; V. Pillai, personal communication, February, 21, 2011). Mahalanobis Distance with $p < .001$ was used to identify another nine cases as multivariate outliers (Hair et al., 2010). Outliers were deleted. There were no missing data since only completed surveys were included in the data analysis. Although there are unequal sample sizes in the groups, MANOVA is known to be a robust procedure. At a minimum, the sample in each group must exceed the number of dependent variables. However, the recommended minimum sample size per group is 20 (Hair et.al, 2010) and this study meets these requirements. For MANOVA analyses, the α level of significance was set to .05, which is generally acceptable in social sciences to avoid Type 1 errors (Gelo, Braakmann & Benetka, 2008; Vogt, 2007)

Table 5-4 Correlations Among Dependent Measures

Variables	1	2	3	4	5	6	7	8	9
1. Knowledge		.459**	-.300**	-.331**	-.477**	.315**	.245**	.370**	-.017
2. HB-Severity			-.221**	.396**	-.287**	.325**	.247*	.132**	.040
3. HB-Susceptibility				-.047	.376**	-.146**	-.082	.018	.313**
4. HB-Benefits					-.315**	.382**	.365**	.181**	.316**
5. HB-Barriers						-.351**	-.295**	-253**	-.026
6. Attitudes Toward SCD Carrier Screening							900**	.203**	.224**
7. Attitudes Toward Beta-Thalassemia Carrier Screening								.179**	.206**
8. Attitudes Toward People with SCD									.084
9. Screening Behaviors									

*p < .05. ** p <. 01

MANOVA Analyses

Gender differences

A one-way MANOVA was conducted to determine the effect of gender on Knowledge about SCD, Health Beliefs (Severity, Susceptibility, Benefits, & Barriers), Attitudes about SCD Carrier Screening, Attitudes Toward People with SCD, and Screening Behaviors. The results of the Box's M test was not significant, indicating no significant difference between the two groups on the eight dependent variables collectively ($F_{(36, 147877)}$ = 1.23 p = .17); thus, the assumption of homogeneity of covariance matrices was met. The results of the Levene's tests for equality of error variances (Table 5.2) revealed that six of the dependent measures (Knowledge, HB (Severity, Susceptibility, Barriers); Attitudes Toward People with SCD, Screening Behaviors) were not significantly different, and therefore, the assumption of homogeneity of variances was met. Two variables (Benefits; Attitudes Toward SCD Carrier Screening) indicated possible heteroscedasticity. However, if the assumption of homogeneity of variance-covariance is violated, the robust test statistic Pillai's Trace can be used to interpret the results (Hair et al., 2010; Mertler & Vannatta, 2005; Tabachnick & Fidell, 2013). Therefore, Pillai's Trace was used to interpret the results.

There was a statistically significant difference between genders on the combined dependent variables, Pillai's Λ = .07; ($F_{(8, 406)}$ = 4.06, p < .001, partial η^2 = .07). Observed power to detect the effect was .99, thus the null hypothesis was rejected. Follow-up univariate ANOVAS (Table 5-5 to 5-6) showed that there was a statistically significant difference between genders for three of the dependent measures. Females scored significantly higher than males on the SCD and SCT Knowledge Assessment Tool, Severity of SCD, and Attitudes Toward SCD Carrier Screening. Although there was

violation in homogeneity between group variance for attitudes toward SCD carrier screening, Brown-Forsythe F and Welch's F adjustments showed that this violation had no effect on the outcome. There was still a highly significant difference in attitudes toward SCD carrier screening scores between genders (Table 5-2). The violation to homogeneity of variance presented no threat to the validity of the results (Mayers, 2013). However, there was no statistically significant difference between genders in Susceptibility to SCD, Benefits to SCD Carrier Screening, Barriers to SCD Carrier Screening, Attitude Toward People with SCD, and Screening Behaviors.

Table 5-5 Descriptive Statistics for the Dependent Measures by Gender

	Gender	M	SD	N
Knowledge	Male	9.61	4.55	109
	Female	12.02	4.14	306
Severity	Male	11.64	2.48	109
	Female	12.44	2.19	306
Susceptibility	Male	15.02	4.69	109
	Female	14.12	4.88	306
Benefits	Male	16.34	3.63	109
	Female	16.59	2.96	306
Barriers	Male	22.41	6.11	109
	Female	21.60	5.94	306
Attitudes Toward SCD Carrier Screening	Male	32.20	6.24	109
	Female	33.73	5.45	306
Attitudes Toward People with SCD	Male	14.42	4.19	109
	Female	15.19	4.23	306
Screening Behaviors	Male	2.66	1.52	109
	Female	2.70	1.52	306

Table 5-6 MANOVA Main Effects Summary for Gender

	SS	*df*	MS	*F*	*p*	
Knowledge	466.11	1	466.11	25.78	.00	
Error	7468.66	413	(18.08)			
Total	61777.00	415				
Severity	51.73	1	51.73	10.03	.00	
Error	2130.61	413	(5.16)			
Total	64293.00	415				
Susceptibility	65.20	1	65.20	2.79	.10	
Error	9639.73	413	(23.34)			
Total	95213.00	415				
Benefits	5.24	1	5.24	.53	.47	
Error	4092.19	413	(9.91)			
Total	117461.00	415				
Barriers	52.93	1	52.93	1.48	.23	
Error	14777.78	413	(35.78)			
Total	212317.00	415				
Attitudes Toward SCD Carrier Screening	186.58	1	186.58	5.81	.02	
Error	13256.50	413	(32.10)			
Total	474332.00	415				
Attitudes Toward People with SCD	46.94	1	46.94	2.64	.11	
Error	17.81	413	(17.81)			
Total	100597.00	415				
Screening Behaviors	.14	1	.14	.06	.80	
Error	952.38	413	(2.31)			
Total	3959.00	415				

SS = sum of squares; *df* = degrees of freedom; MS = mean square

Racial differences

A one-way MANOVA was conducted to determine the effect of race on Knowledge about SCD, HB (Severity, Susceptibility, Benefits, & Barriers), Attitudes about SCD Carrier Screening, and Screening Behaviors. The results of the Box's M test was not significant, indicating no significant difference between the five groups on the eight

dependent variables collectively ($F_{(144, 126507)} = 1.31$, $p = .01$); thus the assumption of homogeneity of covariance matrices was met. The results of the Levene's tests for equality of error variances (Table 5.2) revealed that three of the dependent measures (HB: Severity; Benefits; Barriers) were not significantly different, and therefore, the assumption of homogeneity of variances was met. The significance level of the other five variables (Knowledge; Susceptibility to SCD; Attitudes Toward SCD Carrier Screening; Attitudes Toward People with SCD; Screening Behaviors) indicated possible heteroscedasticity for these variables. However, when the assumptions of homogeneity of variance-covariance is violated the robust test statistic Pillai's Trace can be used to interpret the results (Hair et al., 2010; Mertler & Vannatta, (2005); Tabachnick & Fidell, 2013). Therefore, Pillai's Trace was used to interpret the results. There was a statistically significant difference between race on the combined dependent variables, Pillai's $\Lambda = .30$; ($F_{(32, 1624)} = 4.06$, $p < .001$; partial $\eta^2 = .07$). Observed power to detect the effect was 1.00, thus the null hypothesis was rejected.

Follow-up univariate ANOVA's (Table 5-8) showed that there was a statistically significant difference between race/ethnicity in seven of the eight dependent measures. Although there were violations in homogeneity between group variances for some variables, (knowledge; Susceptibility to SCD; Attitudes toward SCD Carrier Screening; Attitudes toward people with SCD; Screening Behaviors), Brown-Forsythe F and Welch's F adjustments (Table 5-2) showed that these violations had no impact on the outcomes. There were still highly significant differences in knowledge, Susceptibility to SCD, attitudes toward SCD carrier screening, attitudes toward people with SCD, and screening behaviors scores across race/ethnicity. The violations to homogeneity of variance posed no threat to the validity of the results (Mayers, 2013).

Post hoc comparisons revealed that differences on the SCD and SCT Knowledge Assessment Tool were due to African Americans and Caucasians scoring significantly higher than Asians and Hispanic or Latinos (Table 5-7). On the Severity subscale, Asians scored significantly lower than African Americans, Caucasians, and Hispanic or Latinos. On the Susceptibility subscale, Caucasians scored significantly lower than African Americans and Asians. On the Barriers subscale, Asians scored significantly higher than African Americans, Caucasians, and "Other". Hispanic or Latinos scored significantly higher than African Americans and Caucasians. For the Attitudes Toward SCD Carrier Screening scores, Asians scored significantly lower than African Americans and Caucasians. Asians also scored significantly lower on Attitudes Toward People with SCD than African Americans, Caucasians, and "Other". For Screening Behaviors, African Americans scored significantly higher than Caucasians and Asians.

Table 5-7 Descriptive Statistics for the Dependent Measures For Each Level of Race/Ethnicity

	Race/Ethnicity	M	SD	N
Knowledge	African American	12.37	3.20	65
	Caucasian	12.94	3.76	156
	Asian	9.24	4.69	82
	Hispanic	9.96	4.50	70
	Other	10.71	4.79	42
Severity	African American	12.74	2.08	65
	Caucasian	12.77	2.01	156
	Asian	11.05	2.50	82
	Hispanic	12.15	2.20	70
	Other	11.88	2.51	42
Susceptibility	African American	15.43	4.77	65
	Caucasian	12.94	4.83	156
	Asian	16.05	3.91	82
	Hispanic	14.33	5.21	70
	Other	14.69	4.68	42

Table 5-7 –*Continued*

Benefits	African American	17.29	3.09	65
	Caucasian	16.54	3.14	156
	Asian	15.89	3.13	82
	Hispanic	16.74	2.98	70
	Other	16.19	3.41	42
Barriers	African American	19.89	5.57	65
	Caucasian	20.24	5.70	156
	Asian	24.76	5.45	82
	Hispanic	23.79	6.28	70
	Other	21.60	5.14	42
Attitudes Toward SCD Carrier Screening	African American	35.15	4.84	65
	Caucasian	33.64	5.22	156
	Asian	31.46	5.83	82
	Hispanic	33.84	6.17	70
	Other	32.10	6.53	42
Attitudes Toward People with SCD	African American	15.86	3.79	65
	Caucasian	15.49	4.05	156
	Asian	13.51	4.55	82
	Hispanic	14.15	4.40	70
	Other	16.02	3.73	42
Screening Behaviors	African American	3.25	1.06	65
	Caucasian	2.42	1.68	156
	Asian	2.65	1.44	82
	Hispanic	2.86	1.47	70
	Other	2.67	1.48	42

Table 5-8 MANOVA Main Effects Summary for Race/Ethnicity

	SS	*df*	MS	*F*	*p*
Knowledge	975.70	4	243.93	14.37	.00
Error	6959.06	410	(16.97)		
Total	61777.00	415			
Severity	183.15	4	45.79	9.39	.00
Error	1999.18	410	(4.88)		
Total	64293.00	415			
Susceptibility	629.41	4	157.35	7.11	.00
Error	9075.52	410	(22.14)		
Total	95213.00	415			
Benefits	79.36	4	19.84	2.02	.09
Error	4018.08	410	(9.80)		
Total	117461.00	415			
Barriers	1608.70	4	402.17	12.47	.00
Error	13222.02	410	(32.25)		
Total	212317.00	415			
Attitudes Toward SCD Carrier Screening	599.45	4	149.86	4.78	.00
Error	12843.64	410	(31.33)		
Total	474332.00	415			
Attitudes Toward People with SCD	360.45	4	90.11	5.25	.00
Error	7041.46	410	(17.17)		
Total	100597.00	415			
Screening Behaviors	33.89	4	8.47	3.78	.01
Error	918.63	410	(2.24)		
Total	3959.00	415			

SS = sum of squares; *df* = degrees of freedom; MS = mean square

Age differences

Age was recoded into two groups, 18 to 35 years and 36 to 64 years following Erikson's stages of development. According to Hutchinson (2011), there is no set agreed upon ages for either of these stages. While young adulthood is generally referred to as (22-34 or 18-34) some scholars have used a much broader range (17-40). Similarly, (40-

64) is often used, other scholars have included as low as 30 and as high as 70 in the middle adulthood stage. Participants who were between the ages of 18 and 35 were labeled young adults, and participants who were between the ages of 36 and 64 were labeled middle adults. A one-way MANOVA was conducted to determine the effect of age on Knowledge about SCD, Health Beliefs (Severity, Susceptibility, Benefits, & Barriers), Attitudes about SCD Carrier Screening, Attitude Toward People with SCD, and Screening Behaviors. The results of the Box's M test was not significant, indicating no significant differences between the three groups on the eight dependent variables collectively (F(36, 19050) = 1.570, p = .016); thus the assumption of homogeneity of covariance was met. The results of the Levene's tests for equality of error variances revealed that five of the dependent measures (Health Beliefs: Severity, Susceptibility, Benefits, Barriers; Attitudes Toward SCD Carrier Screening) were not significantly different, and therefore, the assumption of homogeneity of variances was met. In the case of the other three variables (Knowledge; Attitudes Toward People with SCD; Screening Behaviors), the significance level indicated possible heteroscedasticity for these variables (Hair et al., 2010). However, according to Hair et al. (2010) and Mertler and Vannatta (2005), Tabachnick and Fidell (2013), if the assumption of homogeneity of variance-covariance is violated the robust test statistic Pillai's Trace can be used to interpret the results. Therefore, Pillai's Trace was used to interpret the results.

There was a statistically significant difference between age on the combined dependent variables, Pillai's $\Lambda = .11$, ($F_{(8, 406)} = 6.01$, $p < .001$; partial $\eta^2 = .11$). Observed power to detect the effect was 1.00, thus the null hypothesis was rejected. Follow-up univariate ANOVA's showed that there was a statistically significant difference between age and four of the dependent measures (Tables 5-9 to 5-10). Although there were violations in homogeneity between group variances for Knowledge about SCD and

Screening Behaviors, Brown-Forsythe F and Welch's F adjustments showed that these violations had no impact on the outcomes. There were still highly significant differences in knowledge and screening behaviors scores across age. The violations to homogeneity of variance posed no threat to the validity of the results (Mayers, 2013). The older group scored significantly higher on the Knowledge and Severity scales than the younger group. However, the younger group scored significantly higher on the Susceptibility and Screening Behaviors scales than the older group.

Table 5-9 Descriptive Statistics for the Dependent Measures by Age

	Age	M	SD	N
Knowledge	18-35	11.17	4.44	371
	36-64	13.27	3.25	44
Severity	18-35	12.09	2.31	371
	36-64	13.48	1.75	44
Susceptibility	18-35	14.59	4.78	371
	36-64	12.39	4.97	44
Benefits	18-35	16.60	3.06	371
	36-64	15.91	3.76	44
Barriers	18-35	22.00	5.85	371
	36-64	20.23	6.89	44
Attitudes Toward SCD Carrier Screening	18-35	33.14	5.77	371
	36-64	34.89	4.88	44
Attitudes Toward People with SCD	18-35	14.89	4.29	371
	36-64	15.82	3.55	44
Screening Behaviors	18-35	2.80	1.46	371
	36-64	2.69	1.71	44

Table 5-10 MANOVA Main Effects Summary for Age

	SS	*df*	MS	*F*	*p*
Knowledge	174.40	1	174.40	9.28	.00
Error	7760.37	413	(18.79)		
Total	61777.00	415			
Severity	76.11	1	76.11	14.92	.00
Error	2106.22	413	(5.10)		
Total	64293.00	415			
Susceptibility	190.60	1	190.60	8.27	.00
Error	9514.34	413	(23.04)		
Total	95213.00	415			
Benefits	18.84	1	18.84	1.91	.17
Error	4078.60	413	(9.88)		
Total	117461.00	415			
Barriers	123.99	1	123.99	3.48	.06
Error	14706.73	413	(35.61)		
Total	212317.00	415			
Attitudes Toward SCD Carrier Screening	119.94	1	119.94	3.72	.06
Error	13323.14	413	(32.26)		
Total	474332.00	415			
Attitudes Toward People with SCD	34.12	1	34.12	1.91	.17
Error	7367.79	413	(17.84)		
Total	100597.00	415			
Screening Behaviors	39.52	1	39.52	17.88	.00
Error	913.00	413	(2.21)		
Total	3959.00	415			

SS = sum of squares; *df* = degrees of freedom; MS = mean square

Familiarity with SCD differences

A one-way MANOVA was conducted to determine the effect of familiarity with SCD on Knowledge about SCD, Health Beliefs (Severity, Susceptibility, Benefits, & Barriers), Attitudes about SCD Carrier Screening, Attitudes Toward People with SCD, and Screening Behaviors. The results of the Box's M test was significant, indicating

significant differences between the two groups on the eight dependent variables collectively ($F_{(36, 526424)} = 2.87$, $p < .001$); thus violating the assumption of homogeneity of covariance. The results of the Levene's tests for equality of error variances revealed that five of the dependent measures (Health Beliefs: Severity, Susceptibility, Benefits, Barriers; Screening Behaviors) were not significantly different, and therefore, the assumption of homogeneity of variances was met. In the case of Knowledge about SCD, attitudes toward SCD carrier screening, and attitudes toward people with SCD the significance level indicated possible heteroscedasticity for these variables. However, according to Hair et al. (2010), Mertler and Vannatta (2005), and Tabachnick and Fidell (2013), if the assumption of homogeneity of variance-covariance is violated the robust test statistic Pillai's Trace can be used to interpret the results. Therefore, Pillai's Trace was used to interpret the results. Additionally, when the number of participants in each group of the MANOVA is approximately equal, as was in the case in the current study, the MANOVA is considered to be robust to this violation (Hair et al., 2010; Tabachnick & Fidell, 2007). There was a statistically significant difference in familiarity with SCD on the combined dependent variables, Pillai's $\Lambda = .299$; ($F_{(8, 406)} = 21.68$ $p < .01$; partial $\eta^2 = .30$). Observed power to detect the effect was 1.00, thus the null hypothesis was rejected. Significant univariate effects were found for seven of the eight dependent measures (Table 5-11 to 5-12). Participants with more familiarity with SCD scored significantly lower on the Susceptibility and Barriers to SCD Carrier Screening and higher on all other scales than participants with less familiarity with SCD. Although there were violations in homogeneity between group variances for some variables, Brown-Forsythe F and Welch's F adjustments showed that these violations had no impact on the outcomes. There were still highly significant differences in knowledge, attitudes toward SCD carrier screening, and attitudes toward people with SCD scores across familiarity with SCD

(Table 5-2). The violations to homogeneity of variance posed no threat to the validity of the results (Mayers, 2013).

Table 5-11 Descriptive Statistics for the Dependent Measures For Each Level of Familiarity with SCD

	Familiarity with SCD	M	SD	N
Knowledge	Less familiarity	9.31	4.39	229
	More Familiarity	13.95	4.51	186
Severity	Less familiarity	11.66	2.32	229
	More Familiarity	12.94	2.06	186
Susceptibility	Less familiarity	14.97	4.71	229
	More Familiarity	13.60	4.91	186
Benefits	Less familiarity	15.89	3.20	229
	More Familiarity	17.32	2.90	186
Barriers	Less familiarity	23.64	5.32	229
	More Familiarity	19.56	6.00	186
Attitudes Toward SCD Carrier Screening	Less familiarity	32.09	6.16	229
	More Familiarity	34.85	4.65	186
Attitudes Toward People with SCD	Less familiarity	14.04	4.47	229
	More familiarity	16.15	4.65	186
Screening Behaviors	Less familiarity	2.59	1.48	229
	More familiarity	2.82	1.55	186

Table 5-12 MANOVA Main Effects Summary for Familiarity with SCD

	SS	*df*	MS	*F*	*p*
Knowledge	2211.21	1	2211.21	159.56	.00
Error	5723.55	413	(13.86)		
Total	61777.00	415			
Severity	168.55	1	168.55	34.57	.00
Error	2013.78	413	(4.88)		
Total	64293.00	415			
Susceptibility	190.65	1	190.65	8.28	.00
Error	9514.28	413	(23.04)		
Total	95213.00	415			
Benefits	210.10	1	210.10	22.32	.00
Error	3887.33	413	(9.41)		
Total	117461.00	415			
Barriers	1706.35	1	1706.35	53.70	.00
Error	13124.36	413	(31.78)		
Total	212317.00	415			
Attitudes Toward SCD Carrier Screening	783.05	1	783.05	25.55	.00
Error	12660.04	413	(30.65)		
Total	474332.00	415			
Attitudes Toward People with SCD	453.27	1	453.27	26.94	.00
Error	6948.64	413	(16.83)		
Total	100597.00	415			
Screening Behaviors	5.79	1	5.79	2.52	.11
Error	946.74	413	(2.29)		
Total	3959.00	415			

SS = sum of squares; *df* = degrees of freedom; MS = mean square

Family history differences

A one-way MANOVA was conducted to determine the effect of family history of SCD on Knowledge about SCD, Health Beliefs (Severity, Susceptibility, Benefits, & Barriers), Attitudes about SCD Carrier Screening, Attitude Toward People with SCD, and Screening Behaviors. The Box's M test result ($p < .001$) indicated a violation to the equality of variance-covariance matrices. The results of the Levene's tests for equality of error variances revealed that five of the dependent measures (Knowledge; Health Beliefs:

Severity, Benefits, Barriers; attitudes Toward SCD Carrier Screening) were not significantly different, and therefore, the assumption of homogeneity of variances was met. In the case of Susceptibility to SCD, Attitudes Toward People with SCD, and Screening Behaviors, the significance level indicated possible heteroscedasticity for these variables. However, according to Hair et al. (2010), Mertler and Vannatta (2005), and Tabachnick and Fidell (2013), if the assumptions of homogeneity of variance-covariance are violated the robust test statistic Pillai's Trace can be used to interpret the results. Therefore, Pillai's Trace was used to interpret the results.

There was a statistically significant difference between family history of SCD on the combined dependent variables, Pillai's $\Lambda = .22$, ($F_{(16, 812)} = 6.21$, $p < .001$; partial $\eta^2 = .11$). Observed power to detect the effect was 1.00, thus the null hypothesis was rejected. Follow-up univariate ANOVA's showed that there was a statistically significant difference between family history and six of the dependent measures (Tables 5-13 to 5-14). Although there were violations in homogeneity between group variances for some variables, Brown-Forsythe F and Welch's F adjustments showed that these violations had no impact on the outcomes (Table 5-2). There were still highly significant differences in Susceptibility to SCD, attitudes toward people with SCD, and screening behaviors scores across family history of SCD. The violations to homogeneity of variance posed no threat to the validity of the results (Mayers, 2013). Post hoc comparisons (Tukey for equal variances; Games-Howell for unequal variances) was conducted for the dependent variables with equal variances. Participants who were unsure of their family history of SCD scored significantly lower than both other groups on Knowledge about SCD and Severity to SCD. For Barriers to SCD Carrier Screening, participants with a family history of SCD scored significant lower than both other groups. For Susceptibility to SCD, participants who were unsure of their family history of SCD, scored significantly higher

than participants who had no family history of SCD. For attitudes toward people with SCD, participants with a family history of SCD scored significantly higher than both other groups. For Screening Behaviors, participants with no family history scored significantly lower than participants who were unsure of family history.

Table 5-13 Descriptive Statistics for the Dependent Measures by Family History

	Family History	M	SD	N
Knowledge	No	11.92	4.16	332
	Unsure	8.40	4.50	67
	Yes	13.00	3.10	16
Severity	No	12.42	2.26	332
	Unsure	11.00	2.20	67
	Yes	13.56	1.36	16
Susceptibility	No	13.62	4.73	332
	Unsure	17.67	3.94	67
	Yes	15.69	4.76	16
Benefits	No	16.46	3.17	332
	Unsure	16.43	3.15	67
	Yes	18.38	1.82	16
Barriers	No	21.61	6.10	332
	Unsure	23.93	4.79	67
	Yes	17.19	4.90	16
Attitudes Toward SCD Carrier Screening	No	33.40	5.61	332
	Unsure	32.40	6.18	67
	Yes	35.69	4.74	16
Attitudes Toward People with SCD	No	15.06	4.19	332
	Unsure	14.09	4.59	67
	Yes	17.25	2.05	16
Screening Behaviors	No	2.56	1.58	332
	Unsure	3.22	1.09	67
	Yes	3.13	1.52	16

Table 5-14 MANOVA Main Effects Summary for Family History of SCD

	SS	*df*	MS	*F*	*p*
Knowledge	731.00	2	365.50	20.90	.00
Error	7203.76	412	(17.49)		
Total	61777.00	415			
Severity	141.59	2	70.79	14.29	.00
Error	2040.74	412	(4.95)		
Total	64293.00	415			
Susceptibility	944.54	2	472.27	22.21	.00
Error	8760.39	412	(21.26)		
Total	95213.00	415			
Benefits	56.82	2	28.41	2.90	.06
Error	4040.94	412	(9.81)		
Total	117461.00	415			
Barriers	654.77	2	327.39	9.52	.00
Error	14175.94	412	(34.41)		
Total	212317.00	415			
Attitudes Toward SCD Carrier Screening	148.01	2	74.01	2.29	.10
Error	13295.08	412	(32.27)		
Total	474332.00	415			
Attitudes Toward People with SCD	137.54	2	68.77	3.90	.02
Error	7264.38	412	(17.63)		
Total	100597.00	415			
Screening Behaviors	27.46	2	13.73	6.11	.00
Error	925.06	412	(2.25)		
Total	3959.00	415			

SS = sum of squares; *df* = degrees of freedom; MS = mean square

Hypothesis 2

Research Hypothesis 2: Gender, age, and race/ethnicity, family history, and familiarity with SCD will be predictive factors of knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students.

Null Hypothesis 2: Gender, age, race/ethnicity, family history of SCD, and familiarity with SCD will not be predictive factors of knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students.

To determine the outcome for this hypothesis, multiple regression analysis was performed to determine if the independent variables (gender, age, race/ethnicity, family history and familiarity with SCD) predict each dependent variable (knowledge, health beliefs, attitudes, screening behaviors).

Three of the independent variables were categorical, so dummy variables were created. Table 5-15 presents the recoded categories for each of the variables. Caucasian, No family history, and female were used as the reference categories so no dummy variables were needed for those categories

Table 5-15 Dummy Coded Variables

Variable	If Yes	Otherwise
Race/Ethnicity		
African American	1	0
Asian	1	0
Hispanic or Latino	1	0
Other	1	0
Family History		
Yes	1	0
Unsure	1	0
Gender		
Male	1	0
Female	1	0

For each model the probability of F to enter the equation was set at .05 and the probability to be removed from the model was set at .10. Variables with the highest probability were removed from the regression analysis one at a time until it decreased the R^2. The data were examined for normality, linearity, and homoscedasticity. In addition, collinearity diagnostics and multiple regression diagnostics to detect the presence of influential outliers were analyzed.

Knowledge About SCD

A series of regression analyses were created in search of a model useful in predicting knowledge about SCD. All variables for this hypothesis were selected based on gaps identified in the literature (Alao et al., 2009; Boyd et al., 2005; Owlabi et al., 2011; Stewart, 2007; Treadwell et al., 2006). The entry method used for the Multiple Regression method in SPSS was “Enter” as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.97. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Knowledge about SCD (Figure 5-10) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot also revealed no violation to the assumption of homoscedasticity as there were no pattern of increasing or decreasing residuals.

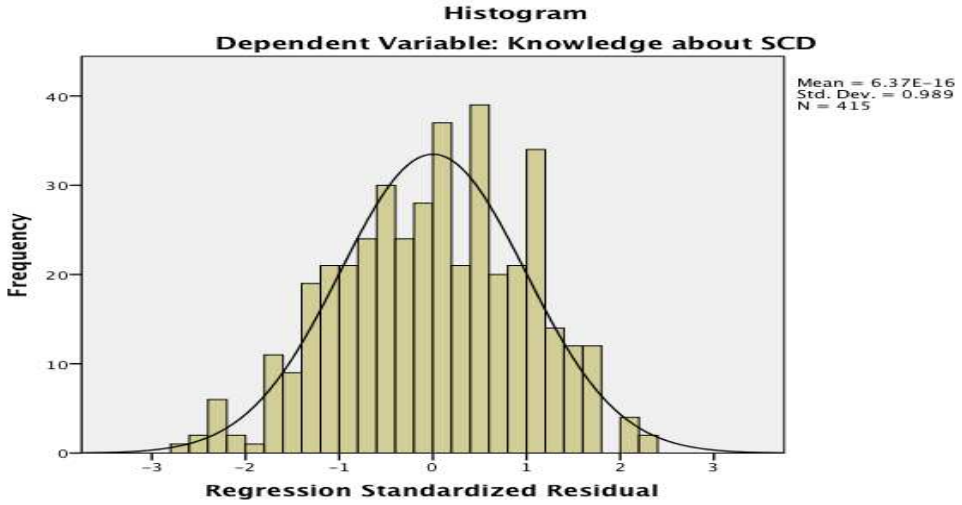

Figure 5-10 Standardized Residuals for Knowledge about SCD

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. “A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10” (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the knowledge about SCD distribution, 17 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the knowledge about SCD distribution, further diagnostics were completed. Influence (Cook’s D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For Knowledge about SCD there were no values of Cook’s D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (9) and n representing the sample size (415). Based on these criteria, case 41 was noted as a potential outlier. Case 41 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook’s D (Leverage = .07 Cook’s D = .00) Computations were performed to determine the degree of influence case 41 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the dependent variable Knowledge about SCD and each predictor variable for case 41. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 41 was determined to be an influential outlier and was deleted from the analysis.

There were four models tested before a statistically significant regression was found. The first model contained all nine predictors identified above and the ANOVA was

statistically significant $F_{(9, 404)} = 41.08$, $p < .001$, $R^2 = .48$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was family history of SCD (p = .99), which was then excluded. The second model was statistically significant $F_{(8, 405)} = 46.33$, $p < .001$, $R^2 = .48$ and age was the predictor identified with the highest significance level (p = .84), which was excluded. The third model was statistically significant $F_{(7, 406)} = 53.06$, $p < .001$, $R^2 = .48$ and Black or African American was the predictor identified with the highest significance level (p =.04), which was excluded. The fourth model was statistically significant $F_{(6, 407)} = 60.64$, $p < .001$, $R^2 = .47$, therefore model 3 was selected as the model that best predicts knowledge about SCD. In summary, age and family history of SCD were removed before a useful model was discovered.

Table 5-16 displays the statistics for the first regression analysis. The seven independent variables regressed on the dependent variable showed a significant overall model $F_{(7, 406)} = 53.06$, $p < .001$, $R^2 = .48$. The predictor variables collectively accounted for 48% of the variance in Knowledge about SCD and all seven were significant. Knowledge about SCD had a positive relationship with familiarity with SCD and a negative relationship with unsure of family history of SCD, Black or African American, Asian, Hispanic or Latino, and Other. In other words, for each unit of increase in familiarity with SCD, Knowledge about SCD increased by 1.00. Additionally participants who were unsure of their family history of SCD scored 1.83 points lower compared to those who had no family history of SCD. Asians had 2.34 points lower compared to Caucasians, Black or African American scored 1.05 points less compared to Caucasians, Hispanic or Latinos scored 1.42 points lower compared to Caucasians, and “Other” scored 1.35 points less compared to Caucasians. Additionally, males scored 1.25 points lower compared to females. These results partially support the hypothesis.

Severity To SCD

A series of regression analyses were created in search of a model useful in predicting Severity to SCD based on selected demographics (gender, Black or African American, Asian, Hispanic or Latino, Other, age, family history, unsure of family history, and familiarity with SCD). All variables for this hypothesis were selected based on gaps identified in the literature (Bhatt et al., 2011; Gallo, 2010; Stewart, 2007; Treadwell et al., 2006). The entry method used for the Multiple Regression method in SPSS was “Enter” as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.33. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Severity to SCD (Figure 5-11) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; scatterplots also showed no pattern of increasing or decreasing residuals indicating homoscedasticity.

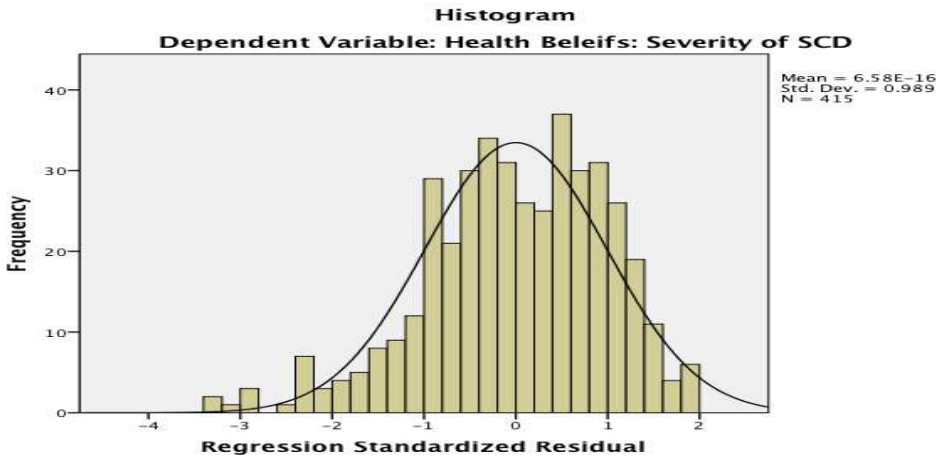

Figure 5-11 Standardized Residuals for Severity of SCD

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. “ A common cut-off threshold is a tolerance value of .10 which corresponds to a

VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the Severity distribution, 17 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Standardized residuals for the Severity distributions was plotted and presented in Figure 2. Before removal of these potential outliers from the Severity distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for the Severity distribution to inform the researcher as to whether the possible outliers should be removed. For Severity there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (9) and n representing the sample size (415). There were no cases with a leverage that was greater than .05. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Severity of SCD.

There were five models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 405)} = 12.70$, $p < .001$, $R^2 = .22$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was Hispanic or Latino (p = .88), which was then excluded. The second model was statistically significant $F_{(8, 406)} = 14.32$, $p < .001$, $R^2 = .22$ and Black or African American was the predictor identified with the highest significance level (p = .52), which was excluded. The third model was statistically significant $F_{(7, 407)} =$

16.33, $p < .001$, $R^2 = .22$, and family history of SCD was the predictor identified with the highest probability (p = .37) and was excluded. The fourth model was statistically significant $F_{(6, 408)} = 18.93$, $p < .001$, $R^2 = .22$, and "Other" was the predictor identified with the highest probability (p = .17) which was excluded. The fifth model was statistically significant $F_{(5, 409)} = 22.28$, $p < .001$, $R^2 = .21$, therefore model four was the model that best predicted Severity of SCD. In summary, Black or African American, Hispanic or Latino, and family history, were removed before a useful model was discovered.

Table (5-16) displays the statistics for the Severity regression analysis. The six independent variables regressed on the dependent variable showed a significant overall model $F_{(6, 408)} = 18.93$, $p < .001$, $R^2 = .22$. The predictor variables collectively accounted for 22 % of the variance in Severity of SCD, however only three were significant. The variables with the most predictive value according to their significance and beta weights were Asian, familiarity with SCD, and unsure of family history of SCD. Severity of SCD had a positive relationship with familiarity with SCD and a negative relationship with Asian and unsure of family history of SCD. In other words, for each unit of increase in familiarity with SCD, Severity scores increased by .27. Additionally participants who were Asians scored 1.14 lower compared to Caucasians, males and participants who were unsure of their family history of SCD scored .96 points lower compared to those who had no family history of SCD. These results partially supported the hypothesis.

Susceptibility To SCD

A series of regression analysis were created in search of a model useful in predicting Susceptibility to SCD. All variables for this hypothesis were selected based on gaps identified in the literature (Bhatt et al., 2011; Stewart, 2007; Gallo et al., 2010). The entry method used for the Multiple Regression method in SPSS was "Enter" as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There was independence of

residuals, as assessed by a Durbin-Watson statistic of 1.96. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Susceptibility (Figure 5-12) was approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot revealed that no violation to the assumption of homoscedasticity as there were no pattern of increasing or decreasing residuals.

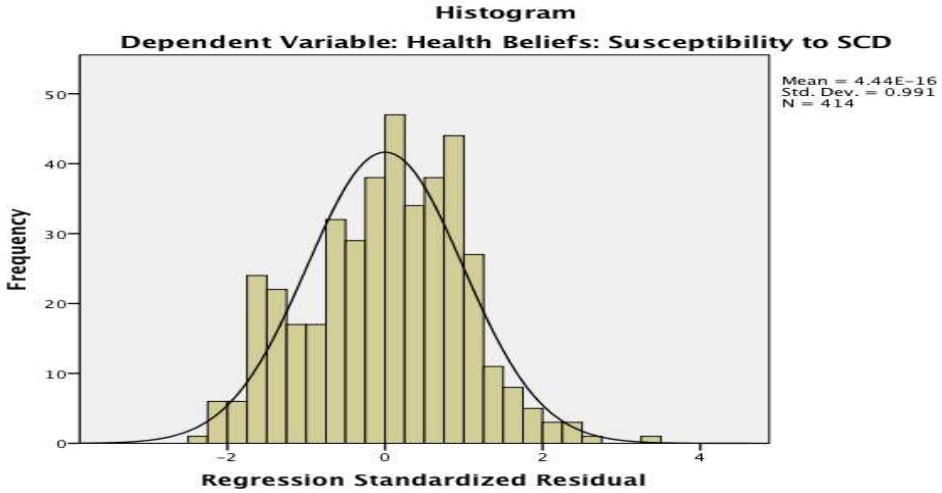

Figure 5-12 Standardized Residuals for Susceptibility to SCD

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the Susceptibility distribution, 16 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Susceptibility distribution, further diagnostics were completed. Influence (Cook's D) and

leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For Susceptibility there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula h > 2(k+1)/n with k representing the number of independent variables (9) and n representing the sample size (415). Based on these criteria, case 199 was noted as a potential outlier. Case 199 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .07 Cook's D = .04) Computations were performed to determine the degree of influence case 46 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the dependent variable Susceptibility and each predictor variable for case 199. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 199 was determined to be an influential outlier and was deleted from the analysis.

Table (5-16) displays the statistics for the Susceptibility regression analysis. There were five models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 404)} = 9.36$, $p < .001$, $R^2 = .17$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was Hispanic or Latino (p = .56), which was then excluded. The second model was statistically significant $F_{(8, 405)} = 10.51$, $p < .001$, $R^2 = .17$, and "Other" was the predictor identified with the highest probability value (p = .28) which was excluded. The third model was statistically significant $F_{(7, 406)} = 11.84$, $p < .001$, $R^2 = .17$ and gender was the predictor identified with the highest probability value (p = .18) which was excluded.

The fourth model was statistically significant $F_{(6, 407)} = 13.48$ $p < .001$, $R^2 = .17$ and family history was the predictor identified with the highest probability value (p = .05). The fifth model was statistically significant $F_{(5, 408)} = 15.31$, $p < .001$, $R^2 = .16$ therefore model four was the model that best predicted Susceptibility to SCD. In summary Hispanic or Latino, "Other", and gender were removed before a useful model was discovered.

The six independent variables regressed on the dependent variable showed a significant overall model $F_{(6, 407)} = 13.48$, $p < .001$, $R^2 = .17$. The predictor variables collectively accounted for 17% of the variance in Susceptibility to SCD and all six were significant. The variables with the most predictive value according to their significance and beta weights were Asian, Black or African American, family history, unsure of family history of SCD, familiarity with SCD, and age. Susceptibility to SCD had a positive relationship with Asian, Black or African American, family history, and unsure of family history of SCD and a negative relationship with familiarity with SCD and age. In other words, participants who were Asians scored 1.90 points higher compared to Caucasians, Black or African American scored 1.75 points higher compared to Caucasians, participants with a family history of SCD scored 2.43 points higher compared to participants with no family history and participants who unsure of their family history of SCD scored 3.38 points higher compared to those who had no family history of SCD. Additionally, for each unit increase in familiarity with SCD, Susceptibility scores decreased by .24 and for each unit of increase in age, Susceptibility scores decreased by .07. These results partially supported the hypothesis.

Benefits To SCD Carrier Screening

A series of regression analyses were created in search of a model useful in predicting Benefits to SCD Carrier Screening. All variables for this hypothesis were selected based on gaps identified in the literature (Bhatt et al., 2011; Sweeny and Legg, 2011). The entry method used for the Multiple Regression method in SPSS was “Enter” as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.83. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Benefits to SCD Carrier Screening (Figure 5-13) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot showed no violation to the assumption of homoscedasticity.

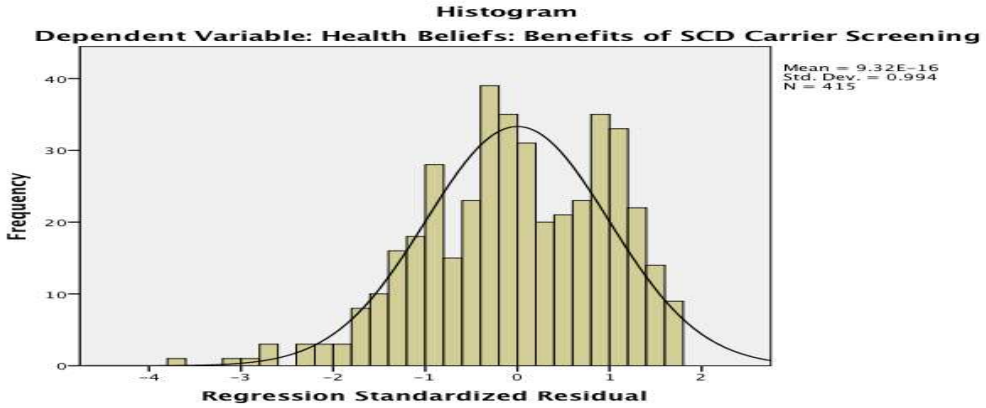

Figure 5-13 Standardized Residuals for Benefits

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. “A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10” (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the Benefits distribution, 13 of the observations

were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Benefits distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed to inform the researcher as to whether the possible outliers should be removed. There were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula h > 2(k+1)/n with k representing the number of independent variables (9) and n representing the sample size (415). There were no cases with a leverage that was greater than .05. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Benefits to SCD Carrier Screening.

There were six models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 405)} = 5.67$, $p < .001$, $R^2 = .11$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was Black or African American (p = .81), which was then excluded. The second model was statistically significant $F_{(8, 406)} = 6.38$, $p < .001$, $R^2 = .11$ and gender was the predictor identified with the highest significance level (p = .50), which was excluded. The third model was statistically significant $F_{(7, 407)} = 7.24$, $p < .001$, $R^2 = .11$ and Hispanic or Latino was the predictor identified with the highest probability value (p = .37), which was excluded. The fourth model was statistically significant $F_{(6, 408)} = 8.31$, $p < .001$, $R^2 = .11$ and unsure of family history of SCD was the predictor with the highest probability value (p = .29) which was then excluded. The fifth model was

statistically significant $F_{(5, 409)} = 9.75$, $p < .001$, $R^2 = .11$ and "Other" was the variable with the highest probability value (p = .24), which was excluded. The sixth model was statistically significant $F_{(4, 410)} = 11.83$, $p < .001$, $R^2 = .10$, therefore model 5 was the model that best predicted Benefits to SCD Carrier Screening. In summary, Black or African American, Hispanic or Latino, gender, and unsure of family history of SCD were removed before a useful model was discovered.

Table (5-16) displays the statistics for the Benefits regression analysis. The five independent variables regressed on the dependent variable showed a significant overall model $F_{(5, 409)} = 9.75$, $p < .001$, $R^2 = .11$. The predictor variables collectively accounted for 11 % of the variance in Benefits to SCD Carrier Screening, however only two were significant. The variables with the most predictive value according to their significance and beta weights were familiarity with SCD and age. Benefits to SCD Carrier Screening had a positive relationship with familiarity with SCD and a negative relationship with age. In other words, for each unit of increase in familiarity with SCD, Benefits scores increased by .38. Additionally, for each unit increase in age, there was a .06 decrease in Benefits scores. These results partially supported the hypothesis.

Barriers To SCD Carrier Screening

A series of regression analysis were created in search of a model useful in predicting Barriers to SCD Carrier Screening. All variables for this hypothesis were selected based on gaps identified in the literature (Bhatt et al., 2011; Sweeny & Legg, 2011). The entry method used for the Multiple Regression method in SPSS was "Enter" as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There were four models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 404)} = 16.31$, $p < .001$, $R^2 = .27$. The variable with the highest probability value was excluded and this

process was repeated until R^2 was reduced. The highest probability value identified was age (p = .55), which was then excluded. The second model was statistically significant $F_{(8, 405)} = 18.33$, $p < .001$, $R^2 = .27$ and unsure of family history of SCD was the predictor identified with the highest significance level (p = .50), which was excluded. The third model was statistically significant $F_{(7, 406)} = 20.91$, $p < .001$, $R^2 = .27$ and gender was the predictor identified with the highest significance level (p = .39), which was excluded. The fourth model was statistically significant $F_{(6, 407)} = 24.29$, $p < .001$, $R^2 = .26$, therefore model three was the model that best predicted Barriers to SCD Carrier Screening. In summary, the following variables were removed: age and unsure of family history of SCD were removed before a useful model was discovered.

There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.04. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Knowledge about SCD (Figure 5-14) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot revealed no violation to the assumption of homoscedasticity.

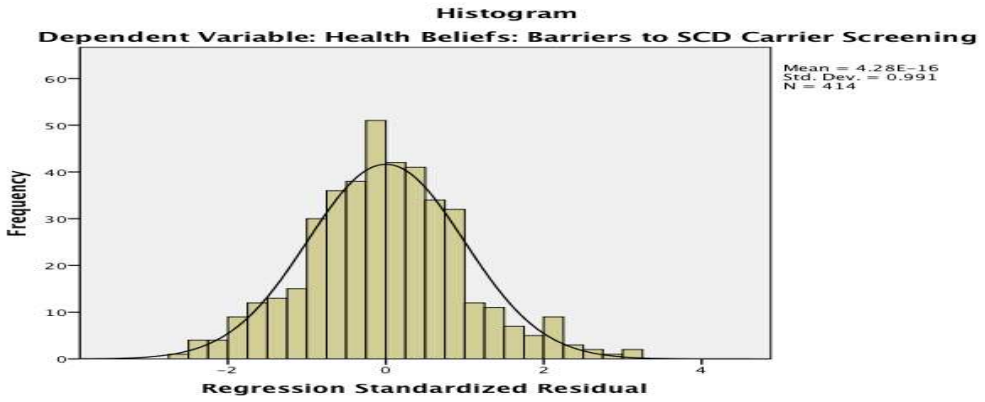

Figure 5-14 Histogram of Standardized Residuals of Barriers

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the Barriers distribution, 25 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Barriers distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for the Barriers distribution to inform the researcher as to whether the possible outliers should be removed. There were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (9) and n representing the sample size (415). . Leverage (h) was determined to have a maximum cutoff of .05 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (9) and n representing the sample size (415). Based on these criteria, case 66 was noted as a potential outlier. Case 66 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .09 Cook's D = .05) Computations were performed to determine the degree of influence case 66 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Barriers and predictor variables for case 66. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 66 was determined to be an influential outlier and was deleted from the analysis.

Table 5-16 displays the statistics for the Barriers regression analysis. The seven independent variables regressed on the dependent variable showed a significant overall model $F_{(7, 406)} = 20.91$ $p < .001$, $R^2 = .27$. The predictor variables collectively accounted for 26% of the variance in Barriers to SCD Carrier Screening, however, only four were significant. The variables with the most predictive value according to their significance and beta weights were family history of SCD, familiarity with SCD, Asian, and Hispanic or Latino. Barriers to SCD Carrier Screening had a positive relationship with Asian and Hispanic or Latino and a negative relationship with family history and familiarity with SCD. In other words, Asians scored about 3.42 points and Hispanic or Latino scored 2.29 points higher compared to Caucasian. Additionally, participants with a family history of SCD scored 3.44 points lower compared to participants with no family history. Also, for each unit increase in familiarity with SCD, Barriers scores decreased by 1.03. These results partially supported the hypothesis.

Attitudes Toward SCD Carrier Screening

A series of regression analysis were created in search of a model useful in predicting Attitudes Toward SCD Carrier Screening. All variables for this hypothesis were selected based on gaps identified in the literature (Al-Farsi et al., 2014; Stewart, 2007; Wong et al., 2011; Zimmerman et al., 2006). The entry method used for the Multiple Regression method in SPSS was “Enter” as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There were five models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 405)} = 7.18$, $p < .001$, $R^2 = .14$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was unsure of family history of SCD ($p = .98$), which was then excluded. The second model was statistically significant $F_{(8, 406)} = 8.10$, $p <$

.001, R^2 = .14 and family history of SCD was the predictor identified with the highest significance level (p = .77), which was excluded. The third model was statistically significant $F_{(7, 407)}$ = 9.27, p < .001, R^2 = .14, and “Other” was the variable with the highest probability (p = .39), which was excluded. The fourth model was statistically significant $F_{(6, 408)}$ = 10.70, p < .001, R^2 = .14 and gender was identified as the predictor with the highest probability value (p = .27), which was excluded. The fifth model was statistically significant $F_{(5, 409)}$ = 12.59, p < .001, R^2 = .13 therefore model four was the model that best predicted Attitudes Toward SCD Carrier Screening. In summary, “Other”, family history and unsure of family history of SCD, were removed before a useful model was discovered.

There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.84. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Knowledge about SCD (Figure 5-15) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot revealed no violation to the assumption of homoscedasticity.

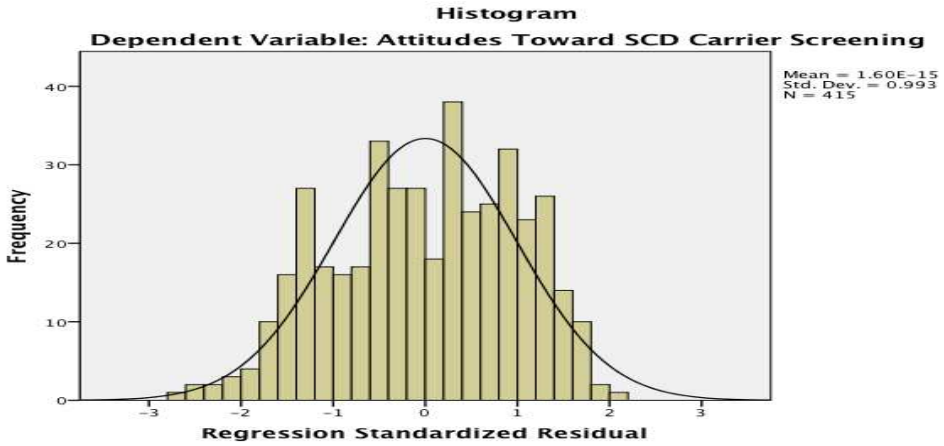

Figure 5-15 Standardized Residuals for Attitudes Toward SCD Carrier Screening

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each the Attitudes Toward SCD Carrier Screening distribution. In Attitudes Toward SCD Carrier Screening distribution, 8 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Severity distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For Attitudes Toward SCD Carrier Screening there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (9) and n representing the sample size (415). There were no cases with a leverage that was greater than .05. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Attitudes Toward SCD Carrier Screening.

Table 5-16 displays the statistics for the Attitudes Toward SCD Carrier Screening regression analysis. The six independent variables regressed on the dependent variable showed a significant overall model $F_{(6, 408)} = 10.70$, $p < .001$, $R^2 = .14$. The predictor variables collectively accounted for 14% of the variance in Attitudes Toward SCD Carrier Screening, however only two were significant. The variables with the most predictive

value according to their significance and beta weights were Hispanic or Latino and familiarity with SCD. Attitudes Toward SCD had a positive relationship with both variables. In other words, Hispanic or Latino scored 1.27 points higher compared to Caucasians and for each unit increase in familiarity with SCD, Barriers scores increased by .72. These results partially supported the hypothesis.

Attitudes Toward Beta-Thalassemia Carrier Screening

A series of regression analysis were created in search of a model useful in predicting Attitudes Toward Beta-Thalassemia Carrier Screening. The entry method used for the Multiple Regression method in SPSS was "Enter" as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There were four models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 403)} = 5.85$, $p < .001$, $R^2 = .12$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was gender (p = .85), which was then excluded. The second model was statistically significant $F_{(8, 404)} = 6.60$, $p < .001$, $R^2 = .12$ and Asian was the predicted value with the highest probability (p = .66), which was excluded. The third model was statistically significant $F_{(7, 405)} = 7.52$ $p < .001$, $R^2 = .12$, and "Other" was the predictor identified with the highest significance level (p= .39), which was excluded. The fourth model was statistically significant $F_{(6, 406)} = 8.66$ $p < .001$, $R^2 = .11$, therefore model three was selected as the model that best predicted Attitudes Toward Beta-Thalassemia Carrier Screening. In summary, gender and Asian were removed before a useful model was identified. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.93. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Attitudes Toward Beta-Thalassemia Carrier Screening (Figure 5-16) were approximately

normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot revealed no violation to the assumption of homoscedasticity.

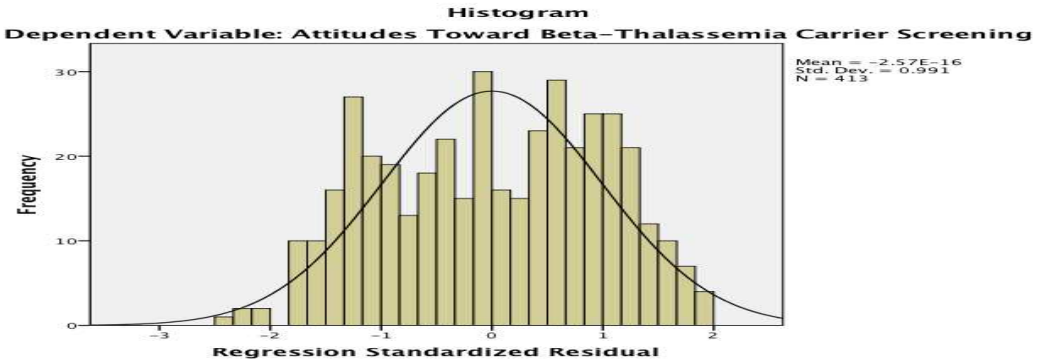

Figure 5-16 Standardized Residuals for Attitudes Toward Beta-Thalassemia Carrier Screening

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each the Attitudes Toward Beta-Thalassemia Carrier Screening distribution. In Attitudes Toward Beta-Thalassemia Carrier Screening distribution, 7 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Attitudes Toward Beta-Thalassemia Carrier Screening distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For Attitudes Toward Beta-Thalassemia Carrier Screening there were no values of Cook's D greater than the absolute value of one, indicating that none of the

potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula h > 2(k+1)/n with k representing the number of independent variables (9) and n representing the sample size (415). Based on these criteria, cases 155 and 352 were noted as potential outliers. Both cases 155 (Leverage = .06; Cook's D = .03) and 352 (Leverage = .08; Cook's D = .06) exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .07; Cook's D = .03). Computations were performed to determine the degree of influence cases 155 and 352 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Attitudes Toward Beta-Thalassemia Carrier Screening and each predictor variables for cases 155 and 352. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, cases 155 and 352 were determined to be influential outliers and were deleted from the analysis.

Table 5-15 displays the statistics for the Attitudes Toward Beta-Thalassemia Carrier Screening regression analysis. The seven independent variables regressed on the dependent variable showed a significant overall model $F_{(7, 405)} = 7.52$, $p < .001$, $R^2 = .12$. The predictor variables collectively accounted for 12% of the variance in Attitudes Toward Beta-Thalassemia Carrier Screening, however only three were significant. The variables with the most predictive value according to their significance and beta weights were familiarity with SCD, Hispanic or Latino, and age. Attitudes Toward Beta-Thalassemia Carrier Screening had a positive relationship with all three variables. In other words, for each unit increase in familiarity with SCD, Attitudes Toward Beta-Thalassemia Carrier Screening scores increased by .66, Hispanic or Latino participants scored 2.38 points higher compared to Caucasians, and for each increase in age,

Attitudes Toward Beta-Thalassemia increased by .08. These results partially supported the hypothesis.

Attitudes Toward People with SCD

A series of regression analysis were created in search of a model useful in predicting Attitudes Toward People with SCD. All variables for this hypothesis were selected based on gaps identified in the literature (Al-Farsi et al., 2014; Stewart, 2007; Wong et al., 2011; Zimmerman et al., 2006). The entry method used for the Multiple Regression method in SPSS was "Enter" as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There were six models tested before a useful model was discovered. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 405)} = 5.63$, $p < .001$, $R^2 = .11$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was Black or African American (p = .86), which was then excluded. The second model was statistically significant $F_{(8, 406)} = 6.35$, $p < .001$, $R^2 = .11$ and age was the predictor identified with the highest significance level (p = .72), which was excluded. The third model was statistically significant $F_{(7, 407)} = 7.25$ $p < .001$, $R^2 = .11$, and unsure of family history was the predictor identified as the highest significance level (p= .66), which was excluded. The fourth model was statistically significant $F_{(6, 408)} = 8.44$ $p < .001$, $R^2 = .11$ and gender was the predictor identified with the highest probability value (p = .57), which was excluded. The fifth model was statistically significant $F_{(5, 409)} = 10.08$ $p < .001$, $R^2 = .11$ and "Other" and family history were the predictor variables identified with the highest probability value (p = .25), which were excluded. The sixth model was statistically significant $F_{(3, 411)} = 15.89$ $p < .001$, $R^2 = .10$, therefore model five best predicts Attitudes Toward People with SCD. In summary,

the following variables were removed: Black or African American, age, unsure of family history, and gender were removed before a useful model was discovered.

There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.69. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Knowledge about SCD (Figure 5-17) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot showed violation to the assumption of homoscedasticity.

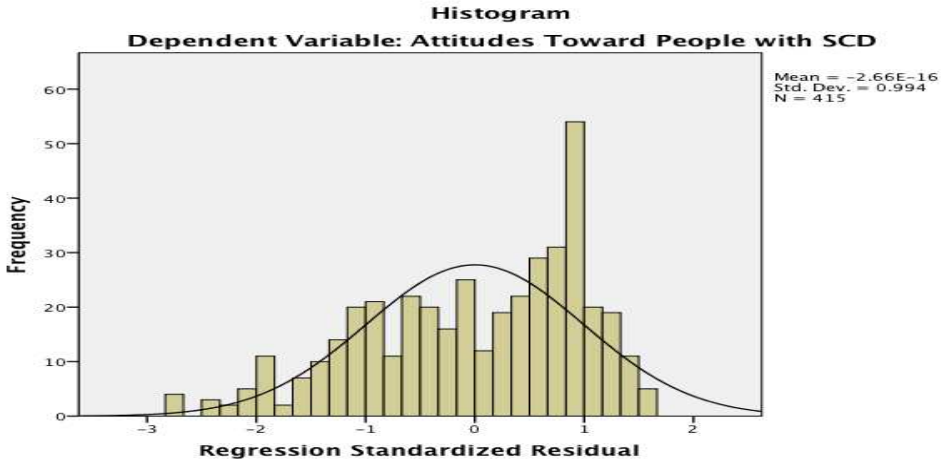

Figure 5-17 Standardized Residuals for Attitudes Toward People with SCD

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for the Attitudes Toward People with SCD distribution. Fifteen of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the

Attitudes Toward People with SCD distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For Attitudes Toward People with SCD, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula h > 2(k+1)/n with k representing the number of independent variables (9) and n representing the sample size (415). There were no cases with a leverage that was greater than .05. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Attitudes Toward People with SCD.

Table 5-15 displays the statistics for the Attitudes Toward People with SCD regression analysis. The five independent variables regressed on the dependent variable showed a significant overall model $F_{(5, 409)} = 10.08$ $p < .001$, $R^2 = .11$. The predictor variables collectively accounted for 11% of the variance in Attitudes Toward People with SCD, however only two were significant. The variables with the most predictive value according to their significance and beta weights were familiarity with SCD and Asian. Attitudes Toward People with SCD had a positive relationship with familiarity with SCD and a negative relationship with Asian. In other words, for each unit increase in familiarity with SCD, Attitudes Toward People with SCD scores increased by .45. Additionally, Asians scored 1.44 points lower compared to Caucasians. These results partially supported the hypothesis.

Screening Behaviors

A series of regression analysis were created in search of a model useful in predicting Screening Behaviors. All variables for this hypothesis were selected based on gaps identified in the literature (Alford et al., 2011; Singer et al., 2004; Stewart, 2007; Weiner et al., 2005; Molina-Barcelo et al., 2011; Zimmerman et al., 2006). The entry method used for the Multiple Regression method in SPSS was "Enter" as this is the most conservative (Brace, Kemp, & Snelgar, 2006). There were five models tested before a statistically significant regression was found. The first model contained all nine predictors identified above and the ANOVA was statistically significant $F_{(9, 404)} = 5.15$, $p < .001$, $R^2 = .10$. The variable with the highest probability value was excluded and this process was repeated until R^2 was reduced. The highest probability value identified was Asian (p = .98), which was then excluded. The second model was statistically significant $F_{(8, 405)} = 5.80$ $p < .001$, $R^2 = .10$ and gender was the predictor identified with the highest significance level (p = .91), which was excluded. The third model was statistically significant $F_{(7, 406)} = 6.65$ $p < .001$, $R^2 = .10$, and "Other" was the predictor identified as the highest significance level (p= .86), which was excluded. The fourth model was statistically significant $F_{(6, 407)} = 7.77$ $p < .001$, $R^2 = .10$, the predictor with the highest significance level was family history of SCD (p = .56), which was then excluded. The fifth model was statistically significant $F_{(5, 408)} = 9.27$ $p < .001$, $R^2 = .10$ and the predictor with the highest significance level was Hispanic or Latino (p = .19), which was excluded. The sixth model was statistically significant $F_{(4, 409)} = 11.14$ $p < .001$, $R^2 = .10$ and the predictor with the highest significance level was familiarity with SCD (p = .05), which was excluded. The seventh model was statistically significant $F_{(3, 410)} = 13.50$ $p < .001$, $R^2 = .09$, therefore model six was selected as the model that best predicts Screening Behaviors. In

summary, the following variables were removed: Asian, Hispanic or Latino, Other, and gender, and family history of SCD were removed before a useful model was discovered.

There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.98. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Screening Behaviors (Figure 5-18) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship; visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals indicating homoscedasticity.

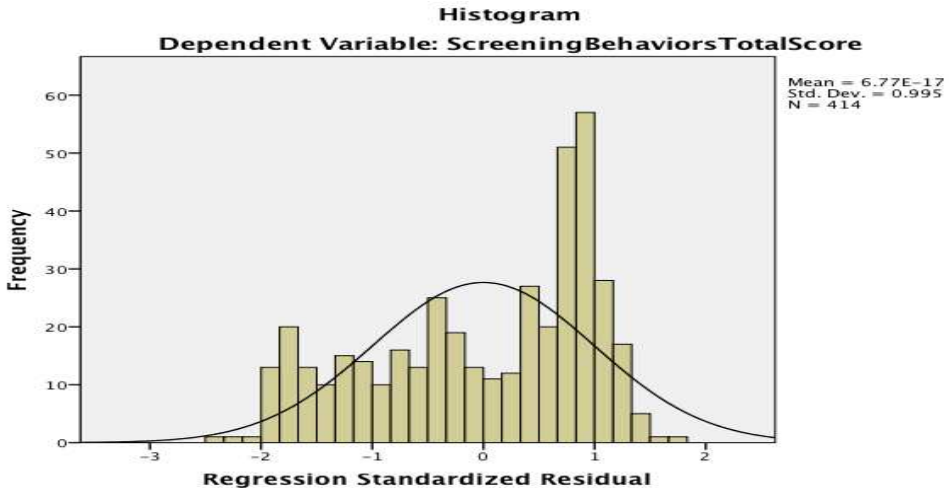

Figure 5-18 Standardized Residuals for Screening Behaviors

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for the Screening Behaviors distribution. Four of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Screening Behaviors

distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed to inform the researcher as to whether the possible outliers should be removed. For Screening Behaviors, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .05 using the formula h > 2(k+1)/n with k representing the number of independent variables (9) and n representing the sample size (415). Based on these criteria, case 250 was noted as a potential outlier. Case 250 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .07; Cook's D = .04). Computations were performed to determine the degree of influence case 250 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Screening Behaviors and each predictor variables for case 250. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 250 was determined to be an influential outlier and was deleted from the analysis.

Table 5-16 displays the statistics for the Screening Behaviors regression analysis. The four independent variables regressed on the dependent variable showed a significant overall model $F_{(4, 409)} = 11.14$ $p < .001$, $R^2 = .10$. The predictor variables collectively accounted for 10% of the variance in Screening Behaviors, however only four were significant. The variables with the most predictive value according to their significance and beta weights were familiarity with SCD, unsure of family history of SCD, Black or African American, and age. Screening Behaviors had a positive relationship with familiarity with SCD, unsure of family history of SCD, and Black or African American and a negative relationship with age. In other words, for each unit increase in familiarity with

SCD, Screening Behavior scores increased by .06. Additionally, participants who were unsure of family history of SCD scored .61 higher compared to participants who had no family history of SCD and Black or African Americans scored .64 higher compared to Caucasians. Additionally, for each unit increase in age, Screening Behaviors scores decreased by .05. These results partially supported the hypothesis.

Table 5-16 Predictors of SCD Knowledge, Health Beliefs, Attitudes, and Behaviors

	B	SE	β
Knowledge			
Model 1			
[a]Family History of SCD (Unsure)	-1.83	.44	-.15***
[b]Race (Black or African American)	-1.02	.48	-.08*
[c]Race/Ethnicity (Asian or Asian American)	-2.34	.44	-.21***
[d]Race/Ethnicity (Hispanic or Latino)	-1.42	.47	-.12**
[e]Race/Ethnicity (Other)	-1.35	.56	-.09*
Familiarity with SCD	1.00	.07	.53***
[f]Gender	-1.25	.37	-.13**
Severity			
Model 1			
Family History of SCD (Unsure)	-.96	.28	-.15**
Race/Ethnicity (Asian)	-1.14	.27	-.20***
Race/Ethnicity (Other)	-.48	.34	-.06
Familiarity with SCD	.27	.05	.27***
Gender	-.48	.23	-.08
Age	.03	.02	.08
Susceptibility			
Model 1			
Family History of SCD (Unsure)	3.38	.52	.26***
[g]Family History of SCD (Yes)	2.43	1.24	.09*
Race/Ethnicity (Black or African American)	1.75	.66	.13**
Race/Ethnicity (Asian)	1.90	.58	.16**
Familiarity with SCD	-.24	.10	-.11*
Age	-.07	.03	-.11*
Benefits			
Model 1			
Family History of SCD (Yes)	1.21	.77	.07
Race/Ethnicity (Asian)	-.72	.39	-.09
Race/Ethnicity (Other)	-.59	.50	-.06
Familiarity with SCD	.38	.07	.28***
Age	-.06	.02	-.14**

Table 5-16 –*Continued*

Barriers			
Model 1			
Family History of SCD (Yes)	-3.44	1.44	-.11*
Race/Ethnicity (Black or African American)	.80	.81	.05
Race/Ethnicity (Asian)	3.42	.72	.23***
Race/Ethnicity (Hispanic or Latino)	2.29	.76	.14**
Race/Ethnicity (Other)	1.00	.91	.05
Familiarity with SCD	-1.03	.12	-.40***
Gender	-.51	.59	-.04
Attitudes Toward SCD Carrier Screening			
Model 1			
Race/Ethnicity (Black or African American)	1.27	.77	.08
Race/Ethnicity (Asian)	-.84	.73	-.06
Race/Ethnicity (Hispanic or Latino)	1.56	.76	.10*
Familiarity with SCD	.72	.12	.29***
Gender	-.67	.61	-.05
Age	.06	.04	.08
Attitudes Toward Beta-Thalassemia Carrier Screening			
Model 1			
Family history of SCD (Unsure)	.82	.77	.05
Family history of SCD (Yes)	1.94	1.59	.06
Race/Ethnicity (Black or African American)	1.37	.84	.08
Race/Ethnicity (Hispanic or Latino)	2.37	.77	.15**
Race/Ethnicity (Other)	-.82	.94	-.04
Familiarity with SCD	.66	.13	.25***
Age	.08	.04	.06*
Attitudes Toward People with SCD			
Model 1			
Family history of SCD (Yes)	1.20	1.04	.06
Race/Ethnicity (Asian or Asian American)	-1.44	.53	-.14**
Race/Ethnicity (Hispanic or Latino)	-.73	.57	-.06
Race/Ethnicity (Other)	.78	.68	.06
Familiarity with SCD	.45	.09	.25***
Screening Behaviors			
Model 1			
Family history of SCD (Unsure)	.61	.20	.15**
Race/Ethnicity (Black or African American)	.64	.20	.15**
Familiarity with SCD	.06	.03	.10*
Age	-.05	.01	-.21***

*p < .05, **p < .01, ***p < .001

[a]Whether respondents were “unsure of family history of SCD” (coded 1) or not (coded 0)
[b]Whether respondents were “Black or African American” (coded 1) or not (coded 0).

Table 5-16 –*Continued*

[c]Whether respondents were “Asian” (coded 1) or not (coded 0).
[d]Whether respondents were “Hispanic or Latino” (coded 1) or not (coded 0).
[e]Whether respondents were “Other” (coded 1) or not (coded 0).
[f]Males (coded 1) females (coded 0)
[g]Whether respondents had a “family history of SCD” (coded 1) or not (coded 0)

Hypothesis 3

Research Hypothesis 3: Knowledge will be a predictive factor of health beliefs, attitudes, and behaviors regarding SCD among college students.

Null Hypothesis 3: Knowledge will not be a predictive factor of health beliefs, attitudes, and behaviors regarding SCD among college students.

A two-step regression was performed on this hypothesis. The second step in this hypothesis depended on the outcome of hypothesis 2; that is, a second regression was performed based on the statistical significance of gender, race/ethnicity, age, family history, and familiarity with SCD, which were used as control variables. The variable Race/Ethnicity (African American, Caucasians, Asians, Hispanic or Latino, Other) was recoded African American = 1 if yes, otherwise = 0, Asians= 1 if Yes, otherwise = 0, Hispanic or Latinos= 1 if yes, otherwise = 0, and Other = 1 if yes, otherwise = 0. The category Caucasian was used as the reference category. Gender was coded Male = 1 and female = 0; the category females was used as the reference group. The variable Family history of SCD (no family history, unsure of family history, family history of SCD) was recoded Unsure = 1 if yes, otherwise = 0 and family history of SCD = 1 if yes, otherwise = 0. The category No family history of SCD was used as the reference group.

Health Beliefs

Perceptions of severity of SCD

Linear regression analysis was conducted to evaluate this hypothesis (Table 5-17). There was independence of residuals, as assessed by a Durbin-Watson statistic of .851 for distribution and .927 for distribution. Normality, linearity, and homoscedasticity

were examined using Histograms and scatterplots. The data for dependent variable Severity of SCD (Figure 5-19 to 5-20) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

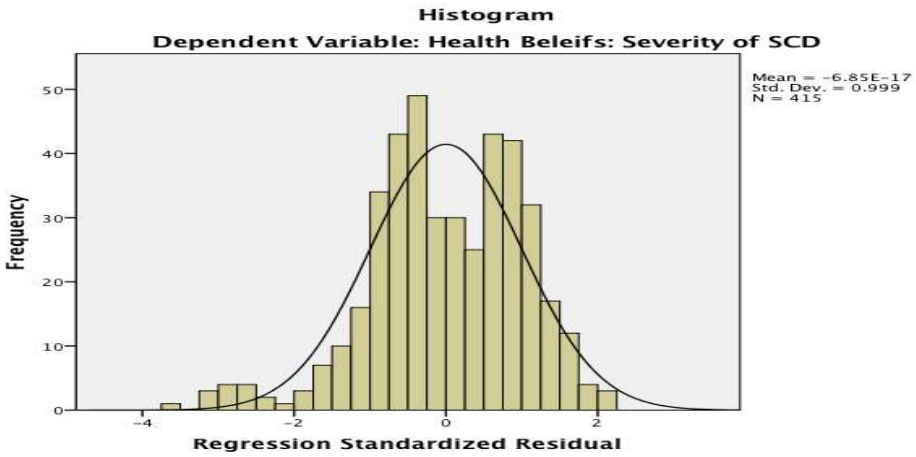

Figure 5-19 Standardized Residuals for Knowledge as a Predictor of Severity

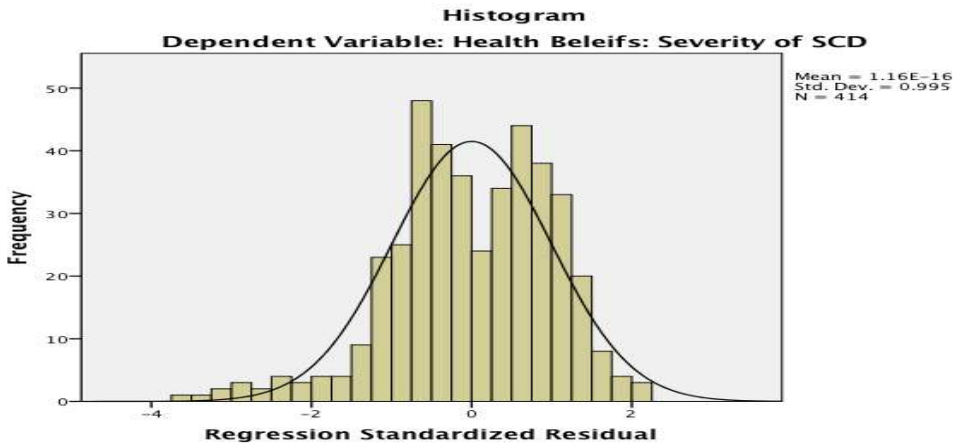

Figure 5-20 Standardized Residuals Severity Distribution with Controls

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Severity distributions. In the first Severity distribution (Figure 5-20), 18 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the second Severity distribution (Figure 5-21), 19 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Severity distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both the Severity distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .01 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (1) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Severity of SCD. However, for Severity of SCD distribution 2, Leverage (h) was determined to have a maximum cutoff of .02 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (4) and n representing the sample size (415). Based on these criteria, case 381 was noted as a potential outlier. Case 381 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for

Cook's D (Leverage = .04; Cook's D = .04). Computations were performed to determine the degree of influence case 381 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Severity of SCD, predictor variable, and each control variables for case 331. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 381 was determined to be an influential outlier and was deleted from the analysis.

Two separate regression models were examined for Severity of SCD. The first model examined the influence of knowledge about SCD on perceptions of Severity. The model was statistically significant $F_{(1, 413)} = 110.40$ $p < .001$, $R^2 = .21$. Knowledge about SCD accounted for 21% of the variance. Knowledge about SCD had a significant, positive relationship with perceptions of Severity of SCD. A unit increase in knowledge about SCD resulted in .24-point increase in Severity scores. In the second step, a second model was examined and the control variables unsure of family history of SCD, Asian, and familiarity with SCD were entered with knowledge about SCD. The model was statistically significant $F_{(4, 409)} = 34.77$ $p < .001$, $R^2 = .25$. Knowledge about SCD, race, family history, and familiarity of SCD accounted for 25% of the variance in perceptions of Severity of SCD. Knowledge about SCD remained significant after controlling for family history, race, and familiarity with SCD.

Perceptions of susceptibility to SCD

Linear regression analysis was conducted to evaluate this hypothesis (Table 5-17). There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.01 for distribution one and 1.95 for distribution two. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Susceptibility to SCD (Figure 5-21 to 5-22) were approximately

normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

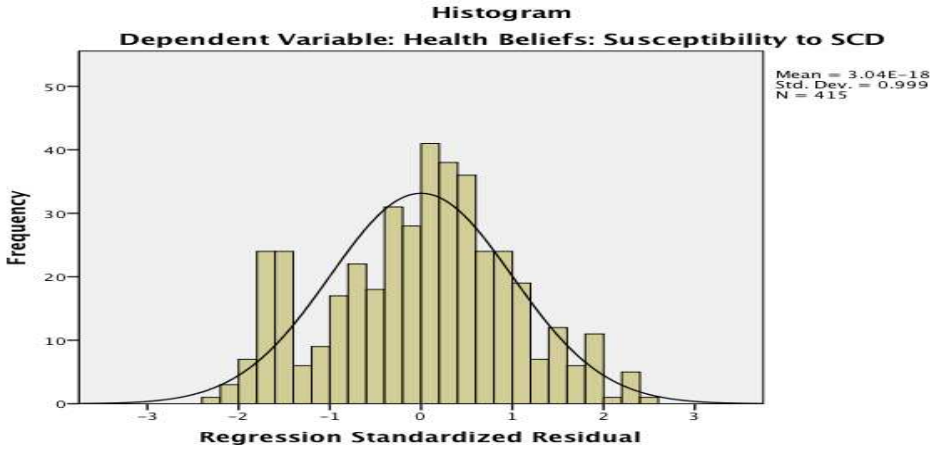

Figure 5-21 Knowledge Predicting Susceptibility

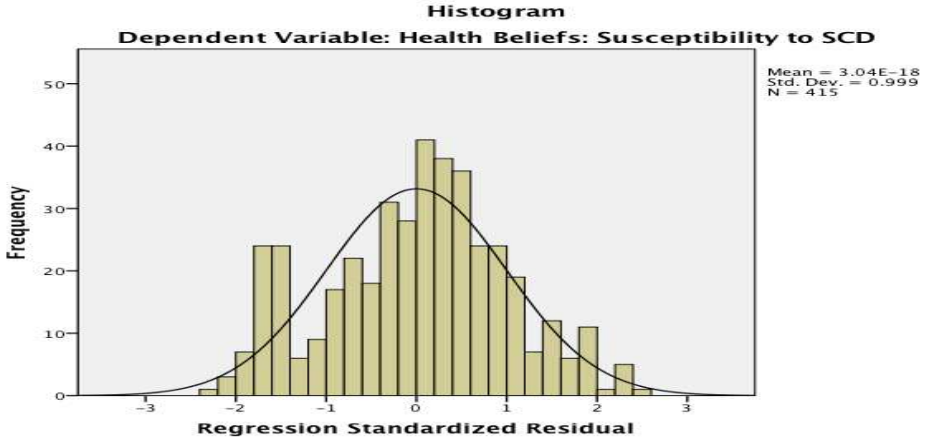

Figure 5-22 Knowledge Predicting Susceptibility with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were

computed for each of the Susceptibility distributions. In the first Susceptibility distribution, 11 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the second Susceptibility distribution, 15 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Susceptibility distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both the Susceptibility distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .01 and .03 using the formula h > 2(k+1)/n with k representing the number of independent variables (1; 6) and n representing the sample size (415). There were no cases with a leverage that was greater than .01 or .03. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Susceptibility to SCD.

Two separate regression models were examined for Susceptibility of SCD (Table 5-17). The first model examined the influence of knowledge about SCD on perceptions of Susceptibility. The model was statistically significant $F_{(1, 413)} = 40.91$ $p < .001$, $R^2 = .09$. Knowledge about SCD accounted for 9% of the variance. Knowledge about SCD had a significant, negative relationship with perceptions of Susceptibility of SCD. A unit increase in knowledge about SCD resulted in .33-point decrease in Susceptibility scores. In the second step, a second model was examined and the control variables Asian, Black or Hispanic, familiarity with SCD, and age were entered with knowledge about SCD. The

model was statistically significant $F_{(6, 408)} = 14.99$ $p < .001$, $R^2 = .18$. Knowledge about SCD, race/ethnicity, age, familiarity, and family history of SCD accounted for 18% of the variance in perceptions of Susceptibility. Knowledge about SCD remained significant after controlling for race/ethnicity, age, familiarity, and family history of SCD.

Perceptions of benefits to SCD carrier screening

There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.87 for distribution and 1.893 for distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Benefits to SCD Carrier Screening (Figures 5-23 to 5-24) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

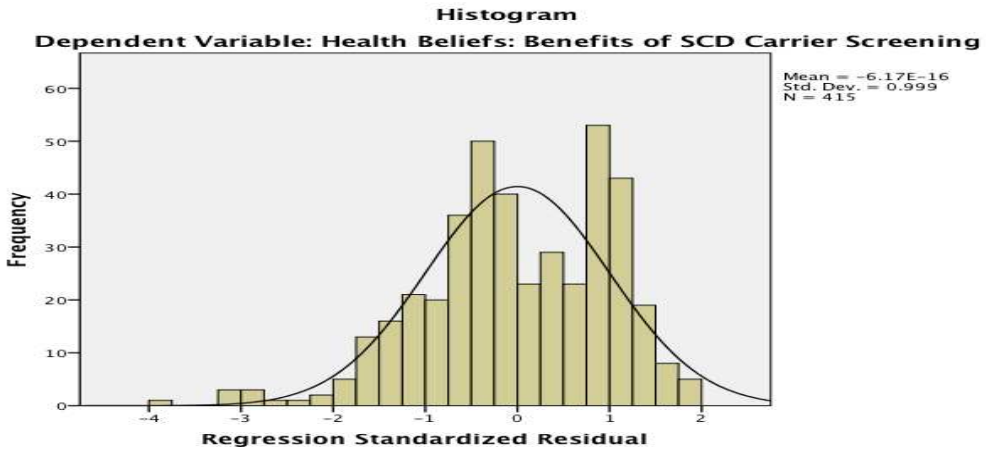

Figure 5-23 Standardized Residuals for Benefits

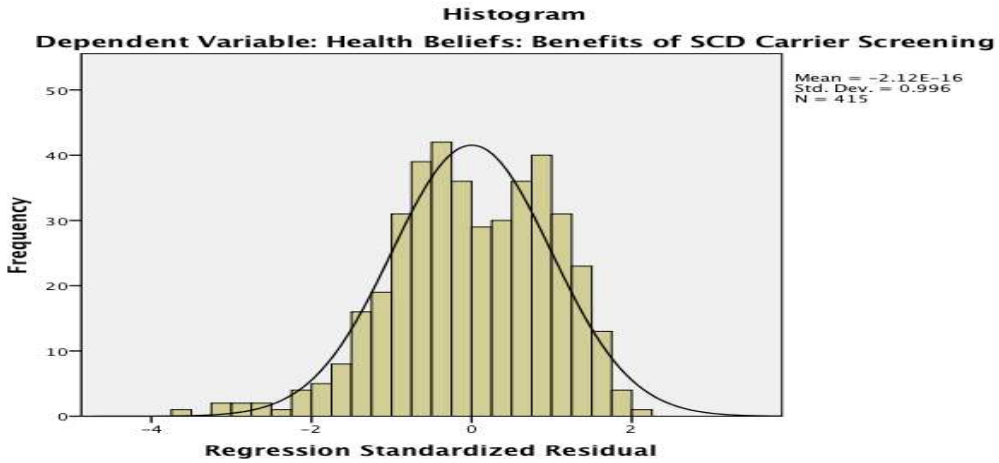

Figure 5-24 Standardized Residuals for Benefits

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Benefits distributions. In the Benefits distribution 1, 11 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the Benefits distribution 2, 13 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Benefits distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both the Benefits distribution, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .01 using the formula $h > 2(k+1)/n$ with k representing the number of

independent variables (1) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Benefits. However, for Benefits distribution 2, Leverage (h) was determined to have a maximum cutoff of .02 using the formula h > 2(k+1)/n with k representing the number of independent variables (3) and n representing the sample size (415). Based on these criteria, case 331 was noted as a potential outlier. Case 331 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .04; Cook's D = .07). Computations were performed to determine the degree of influence case 331 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Benefits to SCD Carrier Screening, predictor variable, and each control variables for case 331. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 331 was determined to be an influential outlier and was deleted from the analysis.

Linear regression analysis was conducted to evaluate this hypothesis (Table 5-17). Two separate regression models were examined for Benefits of SCD carrier screening. The first model examined the influence of knowledge about SCD on perceptions of Benefits. The model was statistically significant $F_{(1, 413)} = 50.65$ $p < .001$, $R^2 = .11$. Knowledge about SCD accounted for 11% of the variance. Knowledge about SCD had a significant, positive relationship with perceptions of Benefits of SCD carrier screening. A unit increase in knowledge about SCD resulted in .24-point increase in Benefits scores. In the second step, a second model was examined and the control

variables familiarity with SCD, and age were entered with knowledge about SCD. The model was statistically significant $F_{(3, 410)} = 21.16$ $p < .001$, $R^2 = .13$. Knowledge about SCD, familiarity with SCD, and age accounted for 13% of the variance in perceptions of Benefits. Knowledge about SCD remained significant after controlling for familiarity with SCD, and age.

Perceptions of barriers to SCD carrier screening

There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.11 the first distribution and 2.07 for the second distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Barriers to SCD Carrier Screening (Figure 5-25 to 5-26) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

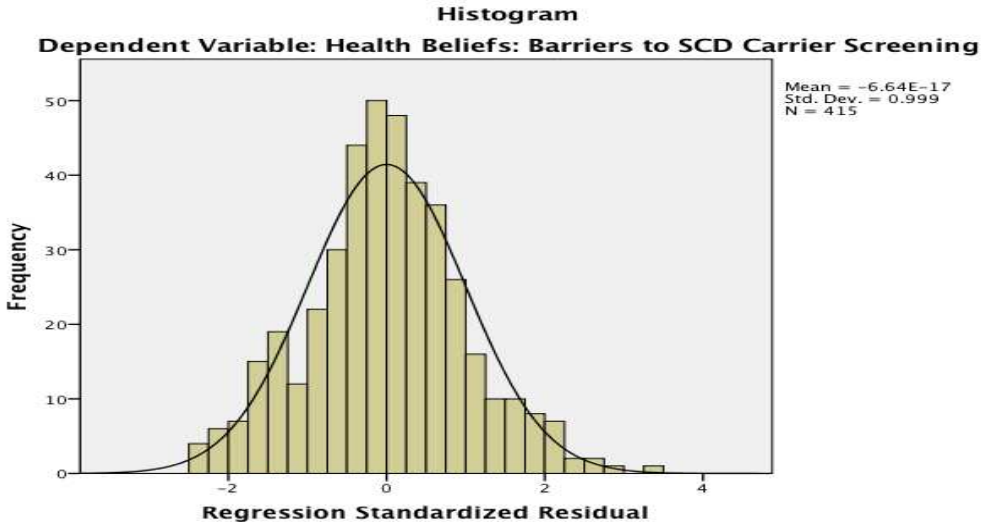

Figure 5-25 Standardized Residuals for Barriers

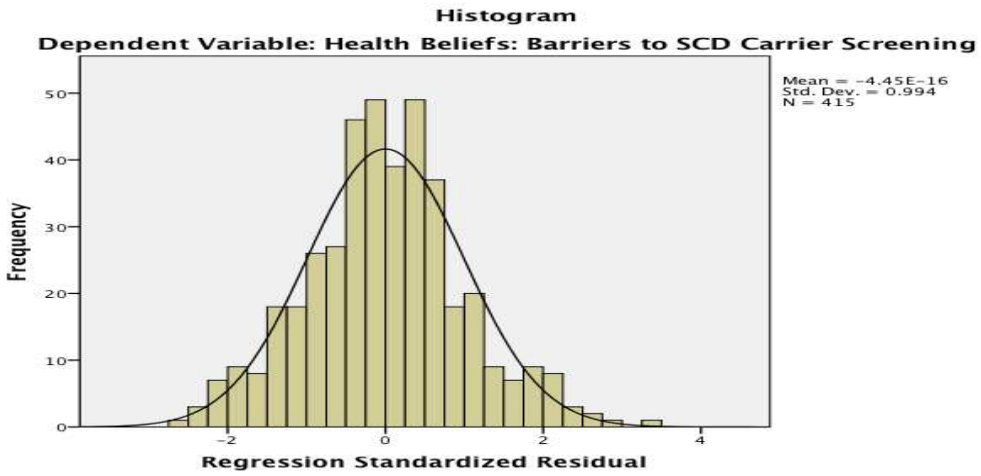

Figure 5-26 Standardized Residuals for Barriers with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the Barriers distribution, 23 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the Barriers distribution including the control variables, 26 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Barriers distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For the first Barriers distribution, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .01 using the formula $h > 2(k+1)/n$ with k

representing the number of independent variables (1) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Barriers. However, for Barriers distribution with control variables, Leverage (h) was determined to have a maximum cutoff of .03 using the formula h > 2(k+1)/n with k representing the number of independent variables (5) and n representing the sample size (415). Based on these criteria, case 95 was noted as a potential outlier. Case 95 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .07; Cook's D = .06). Computations were performed to determine the degree of influence case 95 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Barriers, predictor variables, and each control variables for case 95. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 95 was determined to be an influential outlier and was deleted from the analysis.

Linear regression analysis was conducted to evaluate this hypothesis (Table 5-17). Two separate regression models were examined for Barriers to SCD carrier screening. The first model examined the influence of knowledge about SCD on perceptions of Barriers. The model was statistically significant $F_{(1, 413)} = 121.86$ $p < .001$, $R^2 = .23$. Knowledge about SCD accounted for 23% of the variance. Knowledge about SCD had a significant, negative relationship with perceptions of Barriers. A unit increase in knowledge about SCD resulted in .65-point decrease in Barriers scores. In the second step, a second model was examined and the control variables familiarity with SCD, and

age were entered with knowledge about SCD. The model was statistically significant $F_{(5, 408)} = 36.03$ $p < .001$, $R^2 = .31$. Knowledge about SCD, Asian, Hispanic or Latino, familiarity of SCD, and family history of SCD accounted for 31% of the variance in perceptions of Barriers. Knowledge about SCD remained significant after controlling for race/ethnicity, familiarity with SCD, and family history of SCD.

Attitudes Toward SCD Carrier Screening

Linear regression analysis was conducted to evaluate this hypothesis (Table 5-17). There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.86 for distribution and 1.860 for distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Attitudes Toward SCD Carrier Screening (Figure 5-27; Figure 5-28) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

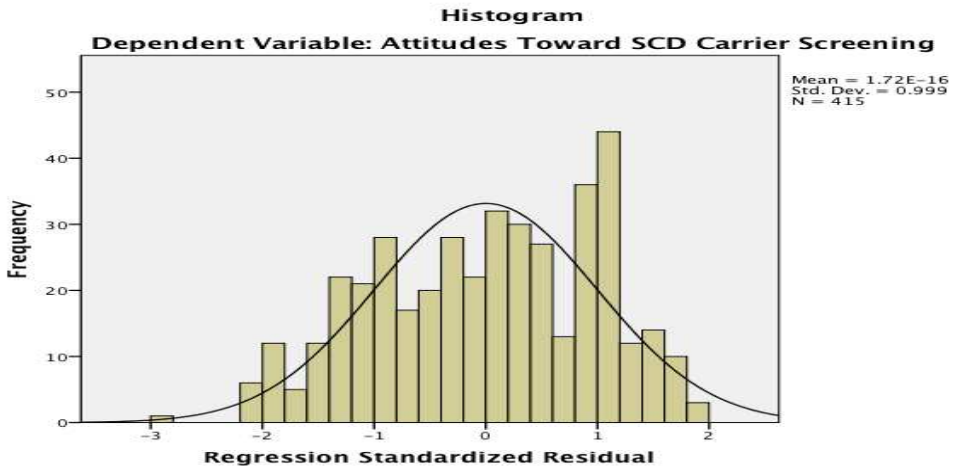

Figure 5-27 Standardized Residuals for Attitudes Toward SCD Carrier Screening

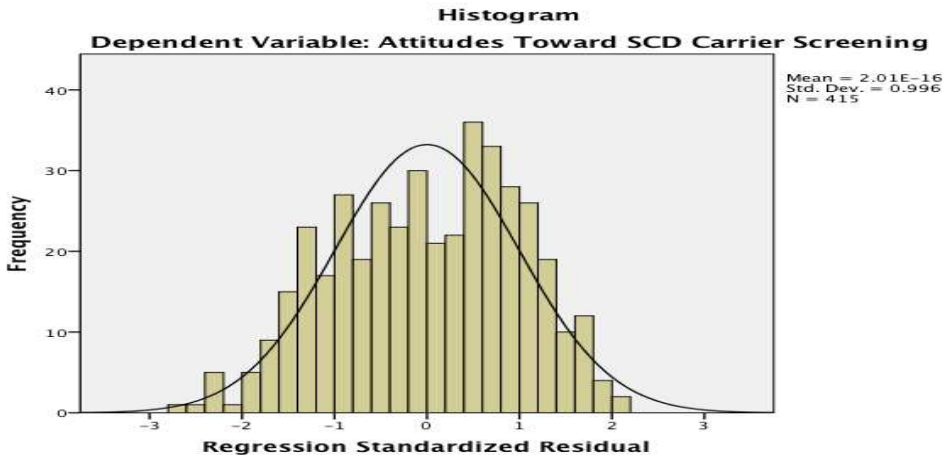

Figure 5-28 Standardized Residuals for Attitudes Toward SCD Carrier Screening with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Attitudes Toward SCD Carrier Screening distributions. In the Attitudes Toward SCD Carrier Screening distribution 1, 7 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the Attitudes Toward SCD Carrier Screening distribution 2, 5 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Attitudes Toward SCD Carrier Screening distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. For

distribution 1, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (1) and n representing the sample size (415). For distribution 2, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (2) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Attitudes Toward SCD Carrier Screening.

Two separate regression models were examined for Attitudes Toward SCD Carrier Screening (Table 5-17). In the first step, the first model examined the influence of knowledge about SCD on Attitudes Toward SCD Carrier Screening. The model was statistically significant $F_{(1, 413)} = 45.43$ $p < .001$, $R^2 = .10$. Knowledge about SCD accounted for 10% of the variance in Attitudes Toward SCD Carrier Screening. Knowledge about SCD had a significant, positive relationship with Attitudes Toward SCD Carrier Screening. A unit increase in knowledge about SCD resulted in .41-point increase in Attitudes Toward SCD Carrier Screening scores. In the second step, a second model was examined and race (Hispanic or Latino) and familiarity with SCD was entered with knowledge about SCD. The model was statistically significant $F_{(3, 411)} = 21.68$ $p < .001$, $R^2 = .14$. Knowledge about SCD, Race (Hispanic or Latino), and familiarity with SCD accounted for 14% of the variance in Attitudes Toward SCD Carrier Screening. Knowledge about SCD remained significant after controlling for race and familiarity with SCD.

Attitudes Toward Beta-Thalassemia Carrier Screening

Linear regressions were conducted to examine the relationship between Knowledge about SCD and Attitudes Toward Beta-Thalassemia Carrier Screening. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.96 for both distributions. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Attitudes Toward Beta-Thalassemia (Figures 5-29 to 5-30) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

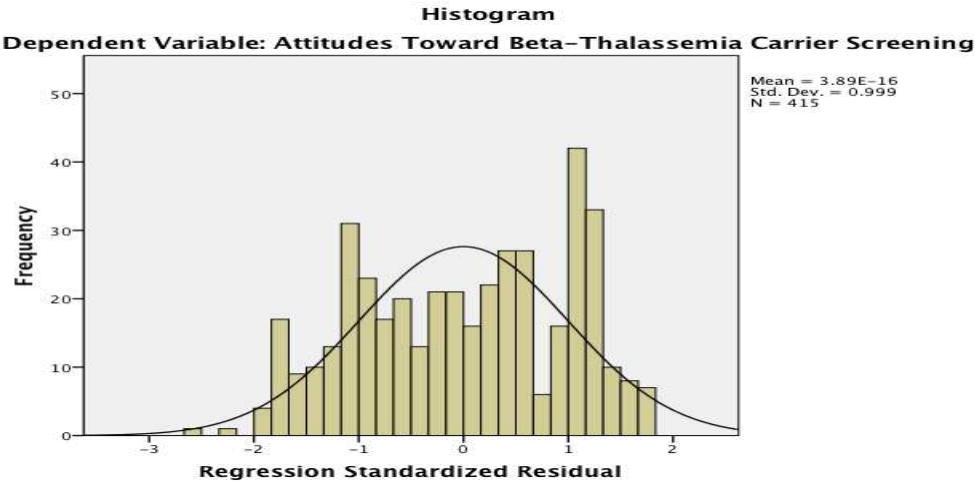

Figure 5-29 Standardized Residuals for Attitudes Toward Beta-Thalassemia Carrier Screening

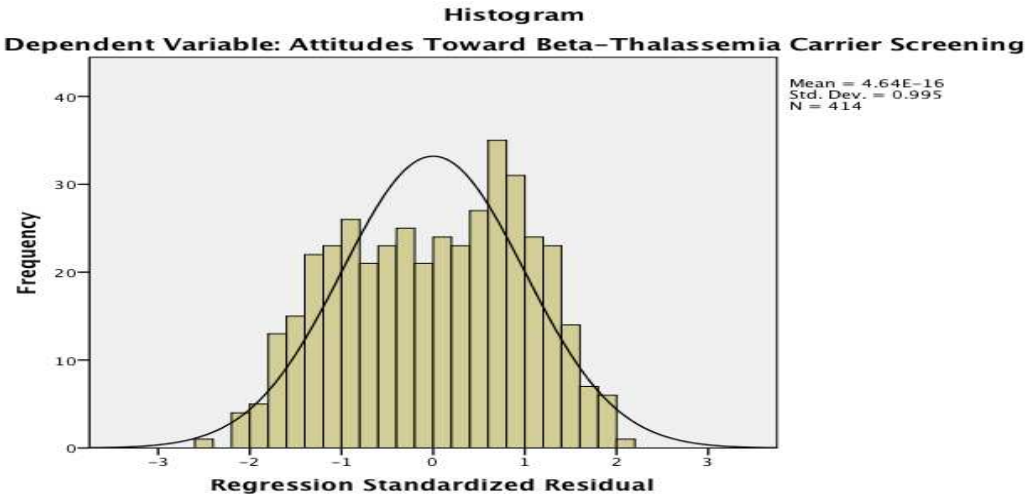

Figure 5-30 Standardized Residuals for Attitudes Toward Beta-Thalassemia Carrier Screening with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Attitudes Toward Beta-Thalassemia Carrier Screening distributions. In the Attitudes Toward Beta-Thalassemia distribution one, 2 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the Attitudes Toward Beta-Thalassemia distribution two, 6 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Attitudes Toward Beta-Thalassemia distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one,

indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (1) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Attitudes Toward Beta-Thalassemia Carrier Screening. However, for Attitudes Toward Beta-Thalassemia Carrier Screening distribution two, Leverage (h) was determined to have a maximum cutoff of .02 using the formula h > 2(k+1)/n with k representing the number of independent variables (4) and n representing the sample size (415). Based on these criteria, case 212 was noted as a potential outlier. Case 156 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .03; Cook's D = .03). Computations were performed to determine the degree of influence case 212 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Attitudes Toward Beta-Thalassemia, predictor variable, and each control variables for case 156. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 156 was determined to be an influential outlier and was deleted from the analysis.

Two separate regression models were examined for Attitudes Toward SCD Carrier Screening (Table 5-17). In the first step, the first model examined the influence of knowledge about SCD on Attitudes Toward SCD Carrier Screening. The model was statistically significant $F_{(1, 413)} = 26.40$ $p < .001$, $R^2 = .06$. Knowledge about SCD accounted for 6 % of the variance in Attitudes Toward Beta-Thalassemia Carrier

Screening. Knowledge about SCD had a significant, positive relationship with Attitudes Toward Beta-Thalassemia Carrier Screening. A unit increase in knowledge about SCD resulted in .33-point increase in Attitudes Toward Beta-Thalassemia Carrier Screening scores. In the second step, a second model was examined and the control variables race (Hispanic or Latino), and familiarity with SCD were entered with knowledge about SCD. The model was statistically significant $F_{(4, 409)} = 12.20$ $p < .001$, $R^2 = .10$. Knowledge about SCD, Hispanic or Latino, age, and familiarity of SCD accounted for 10% of the variance in Attitudes Toward Beta-Thalassemia Carrier Screening. Knowledge about SCD remained significant after controlling for race, age, and familiarity with SCD.

Attitudes Toward People with SCD

There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.81 for the first distribution and 1.82 for the second distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Attitudes Toward People with SCD (Figure 5.31-5.32) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

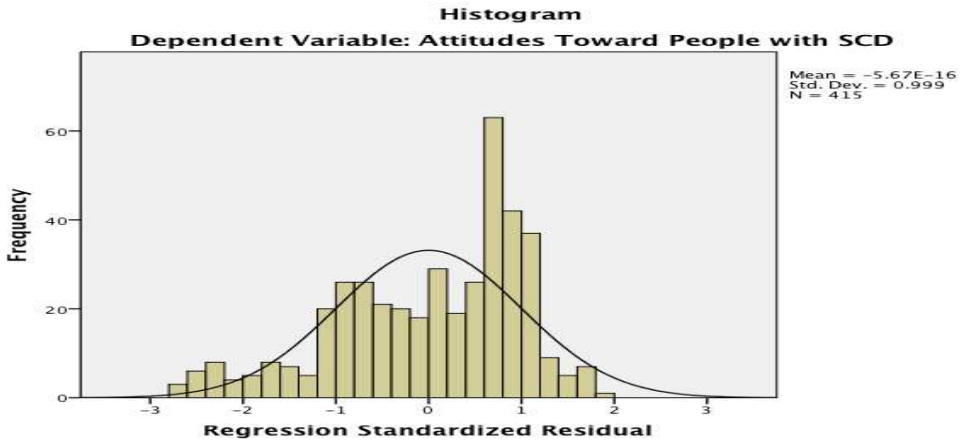

Figure 5-31 Standardized Residuals for Attitudes Toward People with SCD

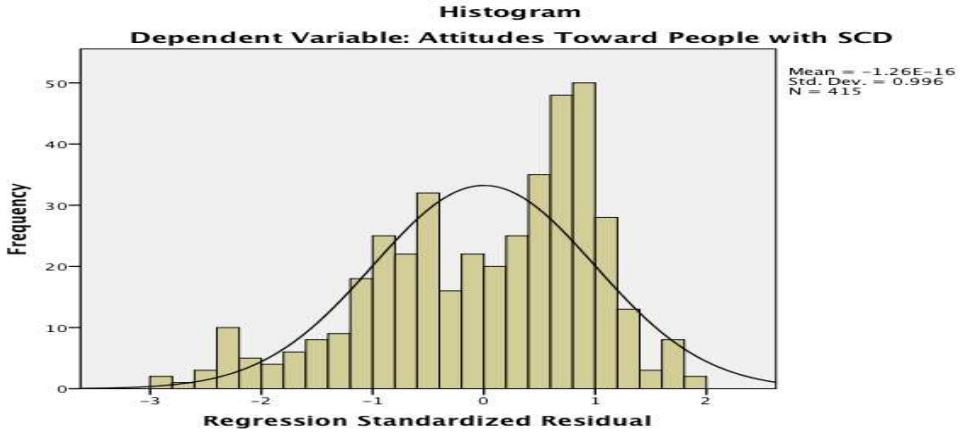

Figure 5-32 Standardized Residuals for Attitudes Toward People with SCD with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Attitudes Toward People with SCD distributions. In both the

Attitudes Toward People with SCD distributions 21 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Attitudes Toward People with SCD distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. For the first distribution, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (1) and n representing the sample size (415). For the second distribution, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (3) and n representing the sample size (415). There were no cases with a leverage that was greater than .02. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Attitudes Toward People with SCD.

Two separate regression models were examined for Attitudes Toward People with SCD. In the first step, the first model examined the influence of knowledge about SCD on Attitudes Toward People with SCD. The model was statistically significant $F_{(1, 413)} = 65.44$ $p < .001$, $R^2 = .14$. Knowledge about SCD accounted for 14% of the variance in Attitudes Toward People with SCD. Knowledge about SCD had a significant, positive relationship with Attitudes Toward People with SCD. A unit increase in knowledge about SCD resulted in .36-point increase in Attitudes Toward People with SCD scores. In the second step, a second model was examined and the control variables race (Asian), and

familiarity with SCD were entered with knowledge about SCD. The model was statistically significant $F_{(3, 411)} = 23.94$ $p < .001$, $R^2 = .15$. Knowledge about SCD, Asian, and familiarity of SCD accounted for 15% of the variance in Attitudes Toward People with SCD. Knowledge about SCD remained significant after controlling for race, and familiarity with SCD.

Knowledge As A Predictor Of Screening Behaviors

Screening Behaviors was not evaluated. Previous correlation matrix revealed no relationship between the dependent variable screening behaviors and the independent variable knowledge about SCD r (413) = -.02, p = .72.

Table 5-17 Knowledge as a Predictor of Health Beliefs and Attitudes

	B	SE	β
Severity			
Model 1			
Knowledge about SCD	.24	.02	.459***
Model 2			
Knowledge about SCD	.16	.03	.31***
[a]Family history of SCD (Unsure)	-.58	.28	-.09*
[b]Race/Ethnicity (Asian)	-.84	.25	-.15**
Familiarity with SCD	.14	.05	.14*
Susceptibility			
Model 1			
Knowledge about SCD	-.33	.05	-.30***
Model 2			
Knowledge about SCD	-.23	.07	-.21***
[a]Familiy history of SCD (Unsure)	2.91	.62	.21***
[b]Race/Ethnicity (Asian)	1.48	.58	-.12*
[c]Race/Ethnicity (Black or African American)	1.83	.62	.14**
Familiarity with SCD	.04	.12	.02
Age	-.07	.03	-.11*

Table 5-17 –*Continued*

Benefits			
Model 1			
Knowledge about SCD	.24	.03	.33***
Model 2			
Knowledge about SCD	.19	.04	.26***
Familiarity with SCD	.19	.08	.14*
Age	-.05	.02	-.12*
Barriers			
Model 1			
Knowledge about SCD	-.65	.059	-.477***
Model 2			
Knowledge about SCD	-.38	.07	-.28***
[a]Family history of SCD (Unsure)	-3.24	.28	-.11*
[b]Race/Ethnicity (Asian)	2.33	.67	-.16**
[d]Race/Ethnicity (Hispanic or Latino)	1.57	.70	.10*
Familiarity with SCD	-.59	.14	-.23***
Attitudes Toward SCD Carrier Screening			
Model 1			
Knowledge about SCD	.41	.06	.32***
Model 2			
Knowledge about SCD	.25	.08	.19**
[d]Race/Ethnicity (Hispanic or Latino)	1.64	.71	.11*
Familiarity with SCD	.54	.15	.22***
Attitudes Toward Beta-Thalassemia			
Model 1			
Knowledge about SCD	.33	.06	.25***
Model 2			
Knowledge about SCD	.18	.08	.13*
[d]Race/Ethnicity (Hispanic or Latino)	2.56	.75	.16**
Familiarity with SCD	.47	.15	.19**
Age	.07	.04	.08

Table 5-17 –*Continued*
Attitudes Toward People with SCD

Model 1			
Knowledge about SCD	.36	.04	.37***
Model 2			
Knowledge about SCD	.28	.06	.29***
[b]Race/Ethnicity (Asian)	-.94	.50	-.09
Familiarity with SCD	.16	.11	.09

*p < .05, **p < .01, ***p < .001
[a]Whether respondents were "unsure of family history of SCD" (coded 1) or not (coded 0)
[b]Whether respondents were "Asian" (coded 1) or not (coded 0).
[c]Whether respondents were "Black or African American" (coded 1) or not (coded 0).
[d]Whether respondents were "Hispanic or Latino" (coded 1) or not (coded 0).

Hypothesis 4

Research Hypothesis 4: Health Beliefs will be a predictive factor of SCD screening behaviors among college students.

Null Hypothesis 4: Health beliefs will not be a predictive factor of SCD screening behaviors among college students.

A two-step regression was conducted on this hypothesis. The second step in this hypothesis depended on the outcome of hypothesis 2; that is, a second regression was performed based on the statistical significance of gender, age, race/ethnicity ethnicity, family history, and familiarity with SCD, which were used as control variables. The variable Race/Ethnicity (African American, Caucasians, Asians, Hispanic or Latino, Other) was recoded African American = 1 if yes, otherwise = 0, Asians= 1 if Yes, otherwise = 0, Hispanic or Latinos= 1 if yes, otherwise = 0, and Other = 1 if yes, otherwise = 0. The category Caucasian was used as the reference category. Gender was coded Male = 1 and female = 0; the category females was used as the reference group. The variable Family history of SCD (no family history, unsure of family history,

family history of SCD) was recoded Unsure = 1 if yes, otherwise = 0 and family history of SCD = 1 if yes, otherwise = 0. The category No family history of SCD was used as the reference group.

Severity And Barriers As Predictor Of Screening Behaviors

Severity of SCD and Barriers to SCD Carrier Screening were not evaluated. Previous correlation matrix (table 5-4) revealed no relationship between the dependent variable Screening Behaviors and the independent variables Severity r (413) = .04, p = .41 and Barriers r (413) = -.03, p = .60

Susceptibility As Predictor Of Screening Behaviors

Linear regressions were conducted to examine the relationship between Susceptibility to SCD and Screening Behaviors. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.96 for the first distribution and 1.98 for the second distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Screening Behaviors (Figure 5-33 to 5-34) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

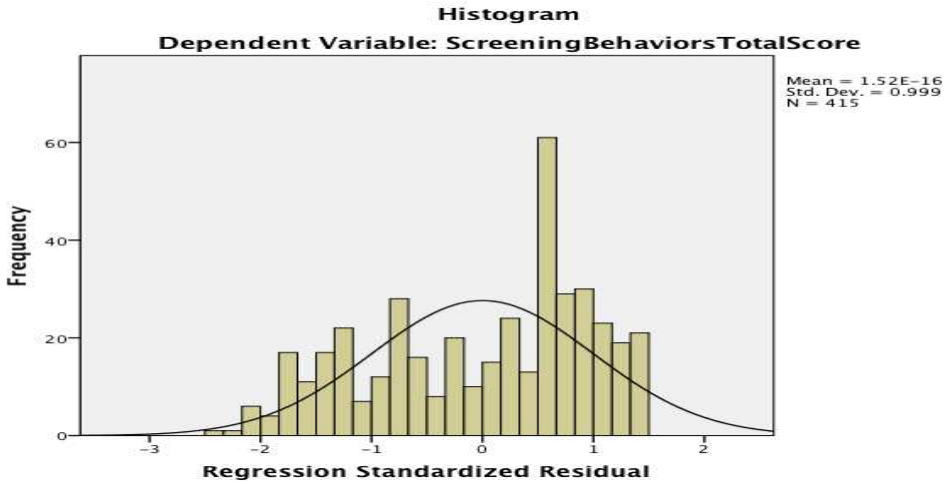

Figure 5-33 Barriers Predicting Screening Behaviors

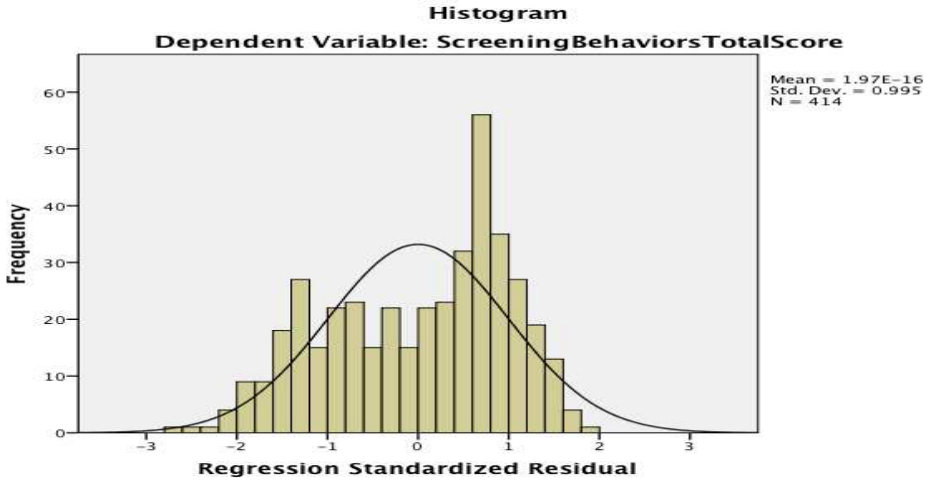

Figure 5-34 Barriers Predicting Screening Behaviors with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Screening Behaviors distributions. In the Screening Behaviors

distribution one, 8 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. In the Screening Behaviors distribution two, 8 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from Screening Behaviors distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. For distribution one, Leverage (h) was determined to have a maximum cutoff of .01 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (1) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Screening Behaviors. However, for Screening Behaviors distribution two, Leverage (h) was determined to have a maximum cutoff of .02 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (4) and n representing the sample size (415). Based on these criteria, case 282 was noted as a potential outlier. Case 282 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .03; Cook's D = .03). Computations were performed to determine the degree of influence case 282 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Screening Behaviors, predictor variable, and each control variables for case 282. Using the formula $3/\sqrt{n}$ where n is the number in the

sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 282 was determined to be an influential outlier and was deleted from the analysis.

Two separate regression models were examined for Screening Behaviors (Table 5-18). The first model examined the influence of perceptions of Susceptibility to SCD on Screening Behaviors. The model was statistically significant $F_{(1, 413)} = 44.93$ $p < .001$, $R^2 = .10$. Knowledge about SCD accounted for 10% of the variance. Susceptibility to SCD had a significant, positive relationship with Screening Behaviors. A unit increase in Susceptibility resulted in .10-point increase in Screening Behaviors scores. In the second step, a second model was examined and the control variables, age, familiarity with SCD, and family history (unsure) were entered with knowledge about SCD. The model was statistically significant $F_{(4, 409)} = 17.98$ $p < .001$, $R^2 = .15$. Perceptions of Susceptibility, age, familiarity with SCD, and family history accounted for 15% of the variance in Screening Behaviors. Susceptibility to SCD remained significant after controlling for age, family history, and familiarity with SCD.

Benefits As Predictor Of Screening Behaviors

Linear regressions were conducted to examine the relationship between Benefits to SCD Carrier Screening and Screening Behaviors. There was independence of residuals, as assessed by Durbin-Watson statistic of 1.87 for distribution one and 1.95 for distribution two. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Screening Behaviors (Figure 5-35 to 5-36) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

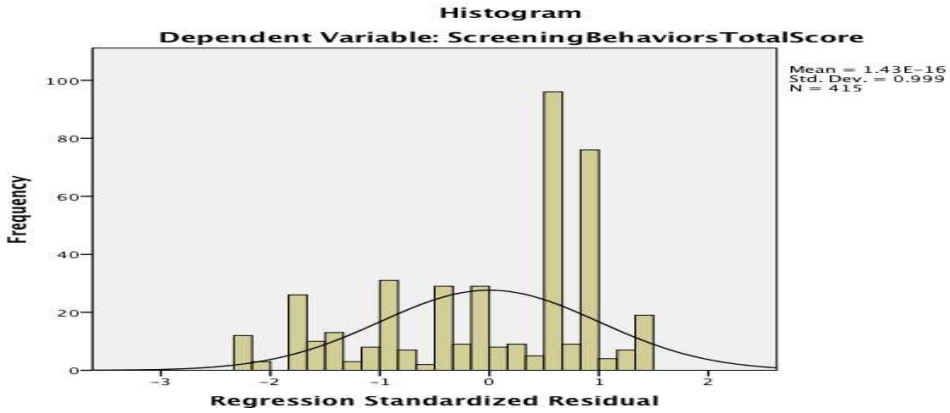

Figure 5-35 Benefits Predicting Screening Behaviors

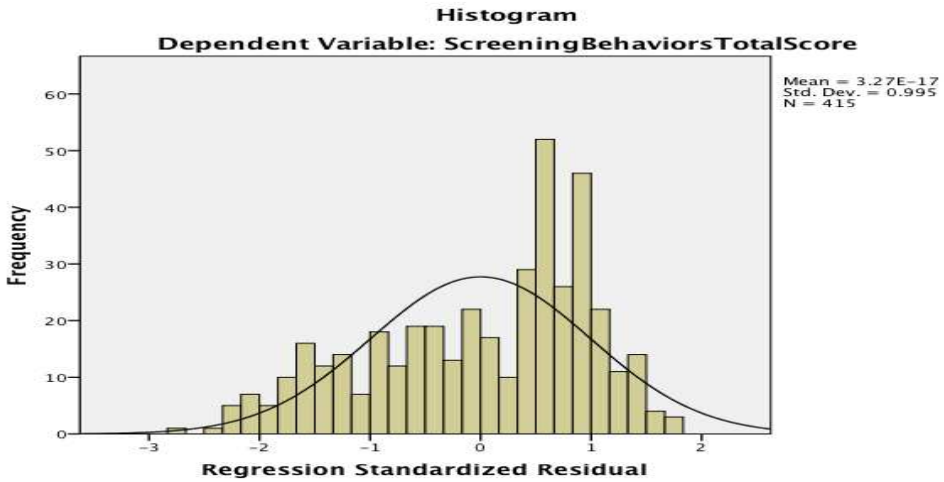

Figure 5-36 Benefits Predicting Screening Behaviors with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Screening Behaviors distributions. In each of the Screening

Behaviors distributions, 15 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Screening Behaviors distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. For the first distribution, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (1) and n representing the sample size (415). For the second distribution, Leverage (h) was determined to have a maximum cutoff of .02 using the formula h > 2(k+1)/n with k representing the number of independent variables (3) and n representing the sample size (415). There were no cases with a leverage that was greater than .01 or .02. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Screening Behaviors.

Two separate regression models were examined for Screening Behaviors (Table 5-18). The first model examined the influence of perceptions of Benefits to SCD Carrier Screening on Screening Behaviors. The model was statistically significant $F_{(1, 413)} = 45.70$ $p < .001$, $R^2 = .10$. Perceptions of Benefits accounted for 10% of the variance. Benefits to SCD Carrier Screening had a significant, positive relationship with Screening Behaviors. A unit increase in perceptions of Benefits resulted in .15-point increase in Screening Behaviors scores. In the second step, a second model was examined and the control variables race (Black or African American), age, and familiarity with SCD were entered

with Benefits to SCD Carrier Screening. The model was statistically significant $F_{(4, 410)}$ = 18.23 p < .001, R^2 = .15. Perceptions of Benefits, race, age, and familiarity with SCD, accounted for 15% of the variance in Screening Behaviors. Perceptions of Benefits remained significant after controlling for race, age, and familiarity with SCD.

Table 5-18 Health Beliefs As Predictor of Screening Behaviors

	B	SE	β
Model 1			
Susceptibility	.10	.02	.31***
Model 2			
Susceptibility	.09	.02	.28***
[a]Family history of SCD (Unsure)	.41	.20	.10*
Familiarity with SCD	.11	.03	.16**
Age	-.04	.01	-.17***
Model 1			
Benefits	.15	.02	.32***
Model 2			
Benefits	.14	.02	.30***
Familiarity with SCD	-.02	.03	-.02
[b]Race/Ethnicity (Black or African American)	.59	.19	.14**
Age	-.04	.01	-.18***

*p < .05. **p < .01. ***p < .001
[a]Whether respondents were “unsure of family history of SCD” (coded 1) or not (coded 0).
[b]Whether respondents were “Black or African American” (coded 1) or not (coded 0).

Hypothesis 5

Research Hypothesis 5: Attitudes about carrier screening will be a predictive factor of SCD screening behaviors among college students.

Null Hypothesis 5: Attitudes about carrier screening will not be a predictive factor of SCD screening behaviors among college students.

A two-step regression was conducted on this hypothesis. The second step in this hypothesis depended on the outcome of hypothesis 2; that is, a second regression was performed based on the statistical significance of gender, age, race/ethnicity ethnicity,

family history, and familiarity with SCD, which were used as control variables. The variable Race/Ethnicity (African American, Caucasians, Asians, Hispanic or Latino, Other) was recoded African American = 1 if yes, otherwise = 0, Asians= 1 if Yes, otherwise = 0, Hispanic or Latinos= 1 if yes, otherwise = 0, and Other = 1 if yes, otherwise = 0. The category Caucasian was used as the reference category. Gender was coded Male = 1 and female = 0; the category females was used as the reference group. The variable Family history of SCD (no family history, unsure of family history, family history of SCD) was recoded Unsure = 1 if yes, otherwise = 0 and family history of SCD = 1 if yes, otherwise = 0. The category No family history of SCD was used as the reference group.

Attitudes Toward SCD Carrier Screening Predicting Screening Behaviors

Linear regressions were conducted to examine the relationship between Attitudes Toward SCD Carrier Screening and Screening Behaviors. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.97 for the first distribution and 2.05 for the second distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Screening Behaviors (Figure 5-37 to 5-38) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

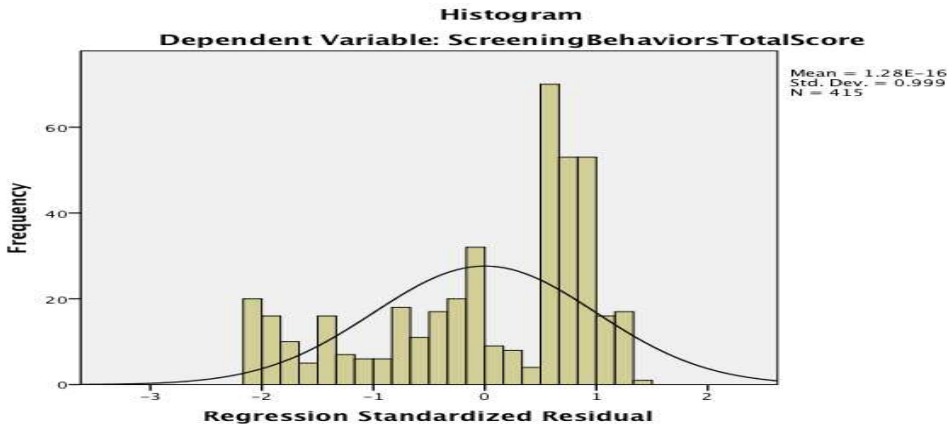

Figure 5-37 Attitudes Toward SCD Carrier Screening Predicting Screening Behaviors

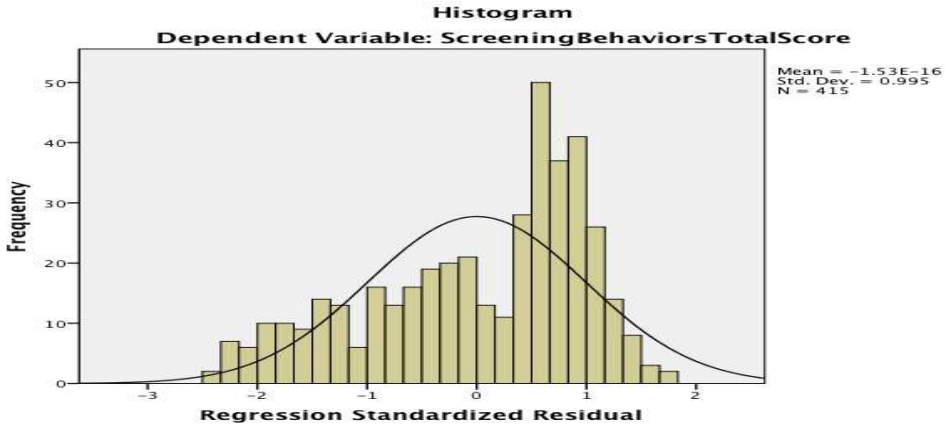

Figure 5-38 Attitudes Toward SCD Carrier Screening Predicting Screening Behaviors with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Screening Behaviors distributions. For the first Screening Behaviors distribution, 20 and for the second distribution, 16 of the observations were

detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Screening Behaviors distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. For the first distribution, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (1) and n representing the sample size (415). For the second distribution, Leverage (h) was determined to have a maximum cutoff of .02 using the formula h > 2(k+1)/n with k representing the number of independent variables (4) and n representing the sample size (415). There were no cases with a leverage that was greater than .02. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Screening Behaviors.

Two separate regression models were examined for Screening Behaviors (Table 5-19). The first model examined the influence of Attitudes Toward SCD Carrier Screening on Screening Behaviors. The model was statistically significant $F_{(1, 413)} = 21.88$ $p < .001$, $R^2 = .05$. Attitudes Toward SCD Carrier Screening accounted for 5% of the variance. Attitudes Toward SCD Carrier Screening had a significant, positive relationship with Screening Behaviors. A unit increase in Attitudes Toward SCD Carrier Screening resulted in .06-point increase in Screening Behaviors scores. In the second step, a second model was examined and the control variables familiarity with SCD and age were entered with Attitudes Toward SCD Carrier Screening. The model was statistically

significant $F_{(4, 410)} = 14.32$ $p < .001$, $R^2 = .12$. Attitudes Toward SCD Carrier Screening race (Black or African American), age, and familiarity with SCD accounted for 12% of the variance in Screening Behaviors. Attitudes Toward SCD Carrier Screening remained significant after controlling for race, age, and familiarity with SCD.

Attitudes Toward Beta-Thalassemia Carrier Screening Predicting Screening Behaviors

Linear regressions were conducted to examine the relationship between Attitudes Toward Beta-Thalassemia Carrier Screening and Screening Behaviors. There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.07 for both distributions. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Screening Behaviors (Figure 5-39 to 5-40) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

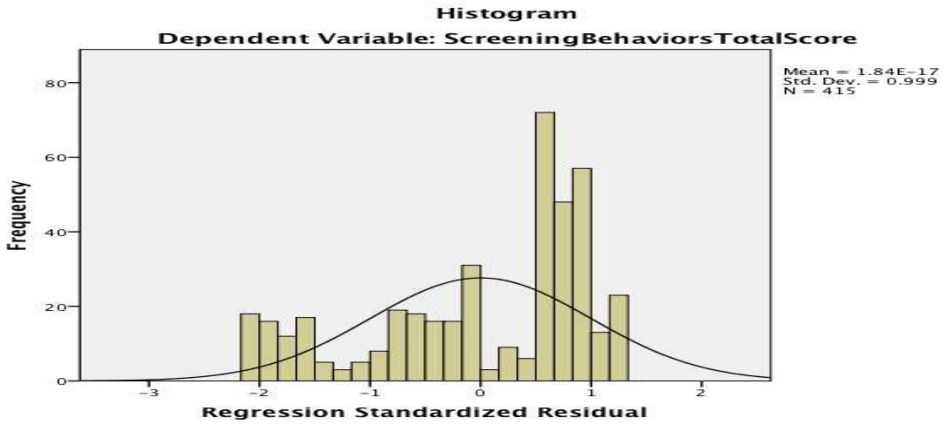

Figure 5-39 Attitudes Toward BT Carrier Screening Predicting Screening Behaviors

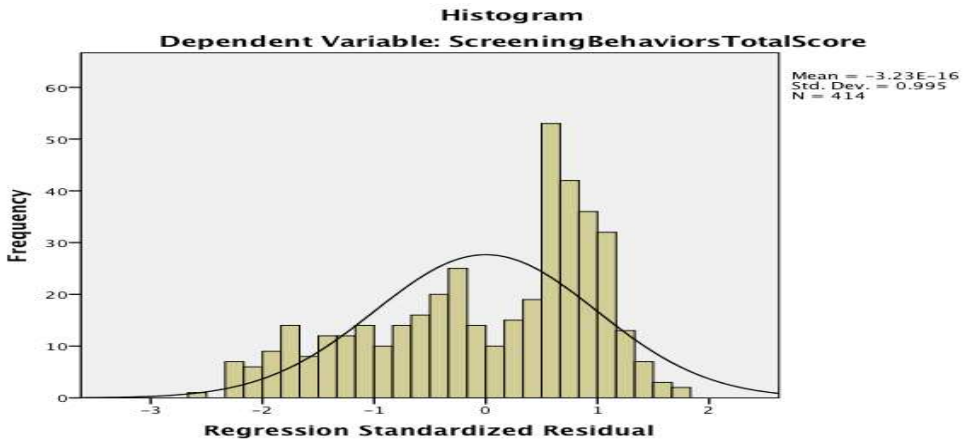

Figure 5-40 Attitudes Toward BT Carrier Screening Predicting Screening Behaviors with Control Variables

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the Screening Behaviors distributions. For the first Screening Behaviors distributions, 18 and for the second distribution, 14 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Screening Behaviors distributions, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For both distributions, there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. For the first distribution, Leverage (h) was determined to have a maximum cutoff of .01 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (1) and n representing

the sample size (415). For the second distribution, Leverage (h) was determined to have a maximum cutoff of .01 using the formula h > 2(k+1)/n with k representing the number of independent variables (2) and n representing the sample size (415). There were no cases with a leverage that was greater than .01. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Screening Behaviors. However, for Screening Behaviors distribution 2, Leverage (h) was determined to have a maximum cutoff of .02 using the formula h > 2(k+1)/n with k representing the number of independent variables (4) and n representing the sample size (415). Based on these criteria, case 43 was noted as a potential outlier. Case 43 exceeded the leverage criteria for outlier detection, but did not exceed the cutoff for Cook's D (Leverage = .03; Cook's D = .03). Computations were performed to determine the degree of influence case 43 had on the regression line. DFBETA (DFB) and Standardized DFBETA (SDFB) values were computed for the intercept, as well as for the variables Screening Behaviors, predictor variable, and each control variables for case 43. Using the formula $3/\sqrt{n}$ where n is the number in the sample (415), the standardized DFBETA values were compared to a threshold of .15. Based on the criteria, case 43 was determined to be an influential outlier and was deleted from the analysis.

Two separate regression models were examined for Screening Behaviors (Table 5-19). The first model examined the influence of perceptions of Attitudes Toward Beta-Thalassemia Carrier Screening and Screening Behaviors. The model was statistically significant $F_{(1, 413)} = 18.30$ $p < .001$, $R^2 = .04$. Attitudes Toward Beta-Thalassemia Carrier Screening accounted for 4% of the variance. Attitudes Toward Beta-Thalassemia Carrier Screening had a significant, positive relationship with Screening Behaviors. A unit

increase in Attitudes Toward Beta-Thalassemia Carrier Screening resulted in .05-point increase in Screening Behaviors scores. In the second step, a second model was examined and familiarity with SCD was entered with Attitudes Toward Beta-Thalassemia Carrier Screening. The model was statistically significant $F_{(4, 409)} = 13.73$ $p < .001$, $R^2 = .12$. Attitudes Toward Beta-Thalassemia Carrier Screening, race (Black or African American), age, and familiarity with SCD accounted for 12% of the variance in Screening Behaviors. Attitudes Toward Beta-Thalassemia Carrier Screening remained significant after controlling for race, age, and familiarity with SCD.

Table 5-19 Attitudes Toward Carrier Screening as a Predictor of Screening Behaviors

	B	SE	β
Model 1			
Attitudes Toward SCD Carrier Screening	.06	.01	.22***
Model 2			
Attitudes Toward SCD Carrier Screening	.06	.01	.24***
[a]Race/Ethnicity (Black or African American)	.58	.20	.14**
Familiarity with SCD	-.01	.03	-.01
Age	-.05	.01	-.24***
Model 1			
Attitudes Toward Beta-Thalassemia Carrier Screening	.05	.01	.21***
Model 2			
Attitudes Toward Beta-Thalassemia Carrier Screening	.06	.01	.23***
[b]Race/Ethnicity (Hispanic or Latino)	.43	.20	.01
Familiarity with SCD	.02	.03	.03
Age	-.05	.01	-.24***

*p < .05. **p < .01. ***p < .001
[a]Whether respondents were “Black or African American” (coded 1) or not (coded 0).
[b]Whether respondents were “Black or African American” (coded 1) or not (coded 0).

Hypothesis 6

Research Hypothesis 6: Of all the predictive factors race will be the best predictor of knowledge about SCD among college students.

Null Hypothesis 6: Of all the predictive factors, there will be no difference in the predictive effects of the different factors.

A multiple regression analysis was conducted to test this hypothesis. The variable Race/Ethnicity (African American, Caucasians, Asians, Hispanic or Latino, Other) was recoded African American = 1 if yes, otherwise = 0, Asians= 1 if Yes, otherwise = 0, Hispanic or Latinos= 1 if yes, otherwise = 0, and Other = 1 if yes, otherwise = 0. The category Caucasian was used as the reference category. Gender was coded Male = 1 and female = 0; the category females was used as the reference group. The variable Family history of SCD (no family history, unsure of family history, family history of SCD) was recoded Unsure = 1 if yes, otherwise = 0 and family history of SCD = 1 if yes, otherwise = 0. The category No family history of SCD was used as the reference group. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Knowledge about SCD (Figure 5-41) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

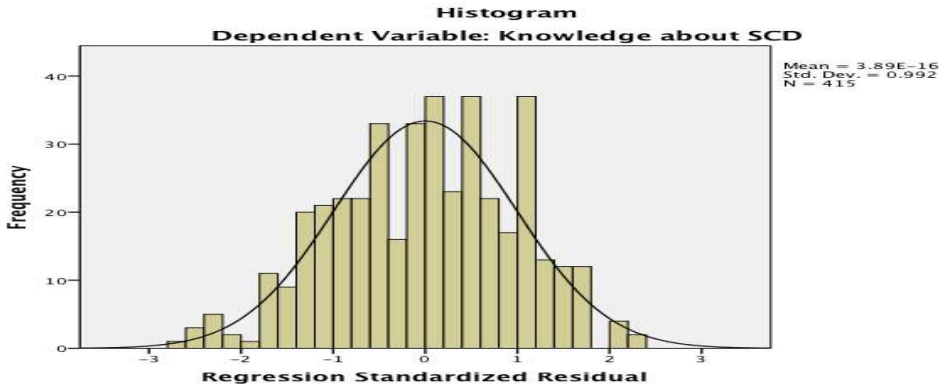

Figure 5-41 Best Predictor of Knowledge about SCD

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed for each of the distributions. In the knowledge about SCD distribution, 17 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the knowledge about SCD distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for both distributions to inform the researcher as to whether the possible outliers should be removed. For Knowledge about SCD there were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .04 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (7) and n representing the sample size (415). There were no cases with a leverage that was greater than .04. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not

exerting undue influence on the dependent variable Knowledge about SCD.

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted knowledge about SCD scores (Table 5-20). The seven independent variables regressed on the dependent variable showed a significant overall model $F_{(7, 407)} = 51.80$, $p < .001$, $R^2 = .47$. The predictor variables collectively accounted for 47% of the variance in Knowledge about SCD scores. As shown in Table (5.28), race (Asian) remained significant and was the best predictor of knowledge about SCD (B = -2.35). Family history of SCD (Unsure) was the second best predictor (B = -1.81).

Table 5-20 Best Predictor of Knowledge about SCD

	B	SE	β
Model 1			
[a]Family History of SCD (Unsure)	-1.81	.45	-.53***
[b]Race/Ethnicity (Black or African American)	-1.13	.48	-.09*
[c]Race/Ethnicity (Asian or Asian American)	-2.35	.45	-.21***
[d]Race/Ethnicity (Hispanic or Latino)	-1.44	.47	-.12**
[e]Race/Ethnicity (Other)	-1.36	.56	-.09*
Familiarity with SCD	.99	.07	.53***
[f]Gender	-1.24	.37	-.13**

*p < .05. **p < .01. ***p < .001

[a]Whether respondents were “unsure of family history of SCD” (coded 1) or not (coded 0).
[b]Whether respondents were “Black or African American” (coded 1) or not (coded 0).
[c]Whether respondents were “Asian” (coded 1) or not (coded 0).
[d]Whether respondents were “Hispanic or Latino” (coded 1) or not (coded 0).
[e]Whether respondents were “Other” (coded 1) or not (coded 0).
[f]Whether respondents were “male” (coded 1) or not (coded 0).

Hypothesis 7

Research Hypothesis 7: Of all the predictive factors knowledge about SCD will be the best predictor of health beliefs, attitudes, and behaviors regarding SCD among college students.

Null Hypothesis 7: Of all the predictive factors, there will be no difference in the predictive effects of the different factors.

The variable Race/Ethnicity (African American, Caucasians, Asians, Hispanic or Latino, Other) was recoded African American = 1 if yes, otherwise = 0, Asians= 1 if Yes, otherwise = 0, Hispanic or Latinos= 1 if yes, otherwise = 0, and Other = 1 if yes, otherwise = 0. The category Caucasian was used as the reference category. Gender was coded Male = 1 and female = 0; the category females was used as the reference group. The variable Family history of SCD (no family history, unsure of family history, family history of SCD) was recoded Unsure = 1 if yes, otherwise = 0 and family history of SCD = 1 if yes, otherwise = 0. The category No family history of SCD was used as the reference group.

Best Predictor of Severity of SCD

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Severity scores. The four independent variables regressed on the dependent variable showed a significant overall model $F_{(4, 409)} = 34.77$, $p < .001$, $R^2 = .25$. The predictor variables collectively accounted for 25% of the variance in Severity scores. As shown in (Table 5-21), knowledge about SCD remained significant but was not the best predictor of Severity (B = .162). Race was the best predictor of Severity scores (B= -.843).

Best Predictor Of Susceptibility to SCD

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Susceptibility to SCD. The seven independent variables regressed on the dependent variable showed a significant overall model $F_{(7, 406)} = 13.66$, $p < .001$, $R^2 = .19$. The predictor variables collectively accounted for 19% of the variance in Susceptibility scores. As shown in (Table 5-21), Knowledge about SCD remained significant however; family history (Unsure) (B = 2.96) was the best predictor of Susceptibility to SCD.

Best Predictor Of Benefits To SCD Carriers Screening

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Benefits to SCD Carrier Screening. The three independent variables regressed on the dependent variable showed a significant overall model $F_{(3, 410)} = 21.16$, $p < .001$, $R^2 = .13$. The predictor variables collectively accounted for 13% of the variance in Benefits scores. As shown in (Table 5-21), Knowledge about SCD was the best predictor of Benefits to SCD Carrier Screening (B = .19) along with familiarity with SCD (B = .19).

Best Predictor Of Barriers To SCD Carrier Screening

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Barriers to SCD Carrier Screening. The four independent variables regressed on the dependent variable showed a significant overall model $F_{(5, 408)} = 36.03$, $p < .001$, $R^2 = .31$. The predictor variables collectively accounted for 31% of the variance in Barriers scores. As shown in (Table 5.21), Knowledge about SCD remained significant however; family history of SCD was the best predictor of Barriers (B = -3.42). Race (Asian) was the second best predictor of Barriers (B = 2.33).

Best Predictor of Attitudes Toward SCD Carrier Screening

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Attitudes Toward SCD Carrier Screening scores. The two independent variables regressed on the dependent variable showed a significant overall model $F_{(3, 411)} = 21.68$, $p < .001$, $R^2 = .14$. The predictor variables collectively accounted for 14% of the variance in Attitudes Toward SCD Carrier scores. As shown in (Table 5.21), Knowledge about SCD remained significant however; race was the best predictor of Attitudes Toward SCD Carrier Screening (B = 1.64).

Best Predictor of Attitudes Toward Beta-Thalassemia Carrier Screening

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Attitudes Toward Beta-Thalassemia Carrier Screening scores. The four independent variables regressed on the dependent variable showed a significant overall model $F_{(4, 409)} = 12.20$, $p < .001$, $R^2 = .11$. The predictor variables collectively accounted for 11% of the variance in Attitudes Toward Beta-Thalassemia Carrier Screening scores. As shown in (Table 5.21), Knowledge about SCD remained significant however; race was the best predictor of Attitudes Toward Beta-Thalassemia Carrier Screening (B = 2.56).

Best Predictor of Attitudes Toward People with SCD

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Attitudes Toward People with SCD scores. The four independent variables regressed on the dependent variable showed a significant overall model $F_{(4, 409)} = 23.94$, $p < .001$, $R^2 = .15$. The predictor variables collectively accounted for 15% of the variance in Attitudes Toward People with SCD scores. As shown in (Table 5.21), although Race was a better predictor of Attitudes Toward People with SCD (B = -.94), it was not significant. Knowledge about SCD was the only significant predictor of Attitudes Toward People with SCD (B = .28).

Best Predictor of Screening Behaviors

A multiple regression analysis was conducted to evaluate how well all of the significant factors predicted Screening Behaviors. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.90 for the Screening Behaviors distribution. Normality, linearity, and homoscedasticity were examined using Histograms and scatterplots. The data for dependent variable Screening Behaviors (Figure 5-42) were approximately normally distributed. The linearity assumption was met as the scatterplot revealed a somewhat linear relationship. The homoscedasticity assumption

was satisfied as visual inspection of the scatterplot revealed no pattern of increasing or decreasing residuals.

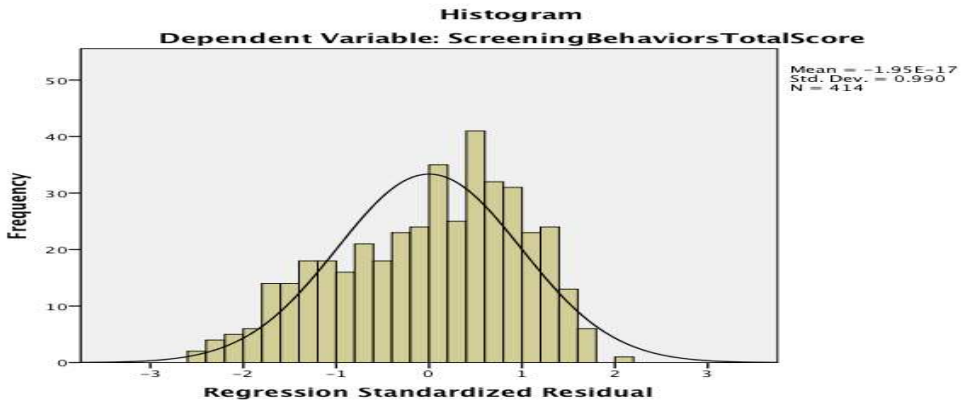

Figure 5-42 Standardized Residuals for Screening Behaviors

Multicollinearity was assessed using Variance Inflation (VIF) and Tolerance levels. " A common cut-off threshold is a tolerance value of .10 which corresponds to a VIF value of 10" (Hair et al., 2010, p. 204). Examination of the collinearity statistics revealed that the assumption of multicollinearity was met. Standardized residuals were computed the Screening Behaviors distribution. For the Screening Behaviors distributions, 12 of the observations were detected as possible outliers due to standardized residuals greater than the absolute value of two. Before removal of these potential outliers from the Screening Behaviors distribution, further diagnostics were completed. Influence (Cook's D) and leverage (h) were assessed for the distribution to inform the researcher as to whether the possible outliers should be removed. There were no values of Cook's D greater than the absolute value of one, indicating that none of the potential outliers exerted significant influence on the dependent variable. Leverage (h) was determined to have a maximum cutoff of .04 using the formula $h > 2(k+1)/n$ with k representing the number of independent variables (7) and n representing the sample size

(415). There were no cases with a leverage that was greater than .04. Though possible outliers were detected using standardized residuals, no observations were removed because tests for influence and leverage indicated that these possible outliers were not exerting undue influence on the dependent variable Screening Behaviors.

A multiple regression analysis was conducted to evaluate how well all of the significant demographic factors predicted Screening Behaviors (Table 5-21). Previous analysis revealed that there was no relationship between Knowledge about SCD and Screening Behaviors therefore; Knowledge about SCD was not included in the regression analysis. The seven independent variables regressed on the dependent variable showed a significant overall model $F_{(7, 405)} = 20.87$, $p < .001$, $R^2 = .27$. The predictor variables collectively accounted for 27% of the variance in Screening Behavior scores. As shown in (Table 5-21), race was the best predictor of Screening Behaviors (B = .31) however it was not significant. Perceptions of Benefits to carrier screening was the best significant predictor of Screening Behaviors (B = .11). Perceptions of Susceptibility to SCD was the second best predictor of Screening Behaviors (B = .09).

Table 5-21 Multiple Regression Model for Best Predictors of Health Beliefs, Attitudes, and Behaviors

	B	SE	β
Severity			
Model 1			
[a]Family History of SCD (Unsure)	-.58	.28	-.09*
[b]Race/Ethnicity (Asian)	-.84	.25	-.15**
Familiarity with SCD	.14	.05	.14*
Knowledge about SCD	.16	.03	.31***
Susceptibility			
Model 1			
[a]Family history of SCD (Unsure)	2.96	.62	.23***
[c]Family history of SCD (Yes)	2.32	1.22	.09

Table 5-21 –*Continued*

[d]Race/Ethnicity (Black or African American)	1.64	.65	.12*
[b]Race/Ethnicity (Asian)	1.51	.58	.13**
Familiarity with SCD	.01	.12	.01
Knowledge about SCD	-.23	.07	-.21***
Age	-.07	.03	-.10*
Benefits			
Model 1			
Familiarity with SCD	.19	.08	.14*
Age	-.05	.02	-.12*
Knowledge about SCD	.19	.04	-.26***
Barriers			
Model 1			
[c]Family history of SCD (Yes)	-3.24	1.34	-.10*
[b]Race/Ethnicity (Asian)	2.33	.67	.16***
[e]Race/Ethnicity (Hispanic or Latino)	1.57	.70	.10*
Familiarity with SCD	-.59	.14	-.23***
Knowledge about SCD	-.38	.07	-.28***
Attitudes Toward SCD Carrier Screening			
Model 1			
[e]Race/Ethnicity (Hispanic or Latino)	1.64	.71	.11*
Familiarity with SCD	.54	.15	.22***
Knowledge about SCD	.25	.08	.19**
Attitudes Toward Beta-Thalassemia Carrier Screening			
Model 1			
[e]Race/Ethnicity (Hispanic or Latino)	2.56	.75	.16**
Familiarity with SCD	.47	.15	.19**
Knowledge about SCD	.18	.08	.13*
Age	.07	.04	.08
Attitudes Toward People with SCD			
Model 1			
[b]Race/Ethnicity (Asian)	-.94	.50	-.09
Familiarity with SCD	.16	.11	.09
Knowledge about SCD	.28	.06	.29***
Screening Behaviors			
Model 1			
[c]Race/Ethnicity (Black or African American)	.31	.19	.07
[a]Family history of SCD (Unsure)	.28	.19	.07

Table 5-21 –*Continued*

Age	-.03	.01	-.15**
Familiarity with SCD	.07	.11	.03
Susceptibility	.09	.01	.30***
Benefits	.11	.02	.23***
Attitudes Toward SCD Carrier Screening	.05	.01	.19***

*p < .05. **p < .01. ***p < .001

[a]Whether respondents were “unsure of family history of SCD” (coded 1) or not (coded 0)

[b]Whether respondents were “Asian” (coded 1) or not (coded 0).

[c]Whether respondents had a “family history of SCD” (coded 1) or not (coded 0)

[d]Whether respondents were “Black or African American” (coded 1) or not (coded 0).

[e]Whether respondents were “Hispanic or Latino” (coded 1) or not (coded 0).

Summary of Hypotheses Findings and Research Questions

The guiding research question for this study was: What factors contribute to the knowledge, health beliefs, attitudes, and behaviors about SCD among college students? More specifically, three research questions and seven hypotheses guided this study. To evaluate the research questions and hypotheses, rigorous data analysis such as MANOVA and linear regression was conducted.

In regards to question 1, what are college students’ levels of knowledge about SCD; health beliefs about SCD and carrier screening; attitudes regarding carrier screening, those with the disease, and screening behaviors? Findings indicate that overall, participants had high perceptions of the severity of SCD and benefits of SCD carrier screening. Participants had moderate perceived susceptibility to SCD and barriers to carrier screening. Findings also indicated that overall, participants had positive attitudes toward carrier screening (SCD; Beta-Thalassemia), and people with SCD. Findings suggest that although most participants never had screening before, overall, participants were interested in screening.

In regards to research question 2, what differences do factors such as race/ethnicity; gender, age, family history, and familiarity with SCD have on knowledge, health beliefs,

attitudes, and screening behaviors regarding SCD among college students? Significant differences were found.

Hypothesis 1 was partially supported. MANOVA analyses revealed that there were statistically significant differences between genders in Knowledge about SCD, perceptions of severity of SCD, and attitudes toward SCD carrier screening. There were statistically significant differences in race/ethnicity for all dependent measures except Benefits to SCD Carrier Screening. Findings also revealed that there were statistically significant differences between age in Knowledge, Health Beliefs (Severity; Susceptibility), and screening behaviors. There were significant differences in familiarity with SCD for all except screening behaviors. There were statistically significant differences for all except Benefits to SCD Carrier Screening and attitudes toward SCD carrier screening.

In regards to research question 3, what are the relationships among knowledge about SCD, health beliefs about SCD, attitudes towards carrier screening, attitudes toward people with SCD and screening behaviors among college students? Significant relationships were found.

Research Hypothesis 2 was partially supported. Gender was only a predictive factor of Knowledge about SCD. Race/Ethnicity was a predictive factor of knowledge, health beliefs (Severity, Susceptibility, Barriers), attitudes, and screening behaviors. Age was a predictive factor of Health beliefs (Susceptibility, Benefits, Barriers), attitudes toward Beta-Thalassemia carrier screening, and screening behaviors. Familiarity with SCD was a predictor of knowledge, health beliefs, attitudes, and behaviors. Family history of SCD was a predictive factor of knowledge, health beliefs (Severity, Susceptibility, Barriers), and screening behaviors.

Research Hypothesis 3 was partially supported. Knowledge was a predictive factor of health beliefs and attitudes, however, there was no relationship between knowledge about SCD and screening behaviors among the college students.

Research Hypothesis 4 was partially supported. Health Beliefs (Susceptibility and Barriers) were predictive factors of SCD screening behaviors among the college students. However, Health Beliefs (Severity and Benefits) were not predictors of screening behaviors.

Research Hypothesis 5 was supported. Attitudes toward SCD and Beta-Thalassemia carrier screening were predictive factors of screening behaviors among the college students.

Research Hypothesis 6 was supported. Of all the predictive factors race was the best predictor of knowledge about SCD among the college students.

Research Hypothesis 7 was partially supported. Of all the predictive factors knowledge about SCD was only the best predictor of attitudes toward people with SCD and Benefits to SCD Carrier Screening. Family history of SCD was the best predictor of Susceptibility to SCD; race/ethnicity was the best predictor of health beliefs (Severity), attitudes, and behaviors regarding SCD among college students.

Conclusion

This chapter provided a description of the sample in regards to SCD knowledge, health beliefs, attitudes, and behaviors. Findings from the study revealed significant differences in gender, race/ethnicity, age, familiarity, and family history of SCD among the college students. Of the seven hypotheses tested, two were fully supported and five were partially supported. Detailed discussions of major findings and implications are presented in the next chapter.

Chapter 6

Discussion

The primary purpose of this study was to assess the knowledge, health beliefs, attitudes, and behaviors regarding SCD among college students. A non-experimental, cross-sectional research design was used for this study to obtain exploratory and descriptive data. It is evident from the analyses conducted that significant group differences and relationships exist among factors that contribute to college students' knowledge, health beliefs, attitudes, and behaviors regarding SCD. Findings from this study revealed four important considerations in the area of SCD prevention including knowledge of carrier status, demographic differences (gender; race/ethnicity; age), continued misconceptions that SCD only affects African Americans, and improved knowledge to increase screening. The findings of this study are important given the limited knowledge and significant gaps in the literature in the area of SCD prevention and will aid in the planning, development, and implementation of effective SCD prevention programs. This chapter discusses findings from the study, limitations, and implications for social work, practice, policy, and research are also presented.

Discussion of Major Findings

Knowledge of one's carrier status and understanding the reproductive implications of being a carrier of SCD are key to SCD prevention. A significant finding from this study was that only 26% of the participants knew their carrier status. This study also showed that participants were lacking knowledge about the reproductive implications of SCD highlighting the need for improved education and screening. Knowledge about carrier status and reproductive implications would provide individuals with informed reproductive choices. The HBM can provide important information for screening programs. According to the HBM, people with improved knowledge make better health

choices (Hollister & Anema, 2004). The HBM suggests that the individual has to believe that SCD is serious; they are at risk of the disease; and there are benefits and few barriers to the interventions. Findings from this study revealed that health beliefs were the best predictors of screening behaviors supporting the HBM. Participants who believed that they were susceptible to SCD and believed that there were benefits to SCD carrier screening had more favorable screening behaviors. These findings are important for prevention programs demonstrating the need for improved education on susceptibility of SCD and benefits of carrier screening.

Another important consideration for prevention planning relates to demographic differences. Findings from the study showed a negative relationship between age and perceived susceptibility to SCD, perceived benefits to carrier screening, and screening behaviors. These findings are important for program planning and implementation. For instance, participants in this study indicated that they were not interested in screening because they were either married or not having any more children so they were not susceptible and perceived no benefits to screening. It is more than likely that as age increased, participants would be married or did not plan on having more children. This finding highlights the importance of screening at a young age and emphasizes the importance of directing SCD prevention at young adults.

Consistent with findings from other studies (Ani et al., 2012; Arrayed & Hajeri, 2010; Stewart, 2007; Treadwell et al., 2006), males in this study had less knowledge about SCD than females. This is important to consider for program planning. Given the inherited nature of SCD, it is important that both genders are knowledgeable about the disease—particularly the reproductive implications. Males in this study also perceived SCD to be less severe than females highlighting the need for improved education. This study also revealed that males had more negative attitudes toward SCD carrier screening

compared to females. Although not surprising, this finding has several considerations for prevention programs. First, findings from this study showed a positive relationship between knowledge and attitudes toward screening. Given that males had less knowledge about SCD, it is not surprising that females had more positive attitudes toward SCD carrier screening. Second, the HBM suggests that the individual must perceive SCD to be severe in order to seek screening. Given that males in this study believed SCD to be less severe than females, it is not surprising that males would be less interested in screening. Moreover, females are generally more concerned with their health and that of their families (Molina-Barcelo et al., 2011).

Another important finding from the study was related to racial/ethnic differences. Minorities in the sample had less knowledge about SCD than Caucasians. Although not surprising given past research, this finding is concerning given the higher prevalence of SCD among minorities, specifically African Americans. Research has shown that African Americans do not have enough knowledge about SCD (Acharya et al., 2009; Boyd et al., 2005; Treadwell et al., 2006). This finding is important in terms of social justice. Research shows that African Americans are disproportionally affected by SCD, yet this population had less knowledge about SCD, highlighting the need for improved education for this population using the selective prevention approach. Asians and Hispanics or Latinos perceived higher barriers to SCD carrier screening. Although not surprising given that research suggests that minorities are less likely to participate in genetic screening (Weiner, Silk, & Parrott, 2005; Zimmerman et al., 2006), this finding is important for screening programs. Hispanics or Latinos are at greater risk of SCD therefore the need to reduce barriers to screening for these populations would be necessary to improve screening.

There is a misconception that SCD only affects African Americans (Bediako & Moffitt, 2011; Gallo et al., 2010; Smith & Aguirre, 2012), and although the prevalence of SCD is much higher for African Americans, other populations are also affected and should be concerned. Caucasians in this study believed that they were not at risk for SCD and would not be interested in screening. These findings provide important implications for future education and screening programs. Given the increasing rates of interracial marriages (Hayes, 2012; "Interracial Marriages", 2012; Jayson, 2012), SCD may become a huge problem for everyone. Thus, programs need to address these misconceptions by providing accurate information regarding prevalence of SCD using the Universal prevention approach.

A final important finding from this study was that there was a significant relationship between knowledge, health beliefs, and attitudes regarding SCD even after controlling for demographic factors. Findings from the study showed that better knowledge about SCD was related to better health beliefs and attitudes regarding SCD. Consistent with the Gustafon et al., (2007) study, this study showed that knowledge had a positive relationship with perceived benefits to SCD carrier screening and a negative relationship with perceived barriers to screening highlighting the importance of screening education. This finding highlights the importance of SCD education and should be an important factor to consider in the development of prevention programs. Although, findings from this study showed no relationship between knowledge and screening behaviors, findings showed that health beliefs and attitudes had a positive relationship with screening behaviors. These findings were consistent with Abioye-Kuteyi et al. (2009). Therefore, knowledge may have an indirect influence on screening behaviors. Findings from this study suggest that knowledge improved health beliefs, which improved screening behaviors. Therefore in order to improve screening behaviors, health beliefs

and attitudes have to be improved which further emphasizes the need to improve knowledge.

Limitations and Strengths

There were several limitations and strengths in this study, but it is important to mention that any study that provides researchers with any opportunity to learn more about the factors that influence the knowledge, health beliefs, attitudes, and behaviors regarding SCD is a benefit given the limited research.

Limitations

There were several limitations to this study that should be considered. The data was self-reported, which creates vulnerability to response bias (Creswell, 2009; Leedy & Ormrod, 2010; Mitchell & Oltean, 2007). To lessen response bias, participants were informed that responses would remain anonymous and no identifying information was collected except for the gift card drawing, which was collected separately from the survey responses, preventing any link between identity and responses. Furthermore, the online nature of the survey allowed for anonymity (VanSelm & Janowski, 2006).

Another limitation was the study design. Due to the cross-sectional research design, causality cannot be assumed (Rubin & Babbie, 2001). Another limitation includes the sampling and recruitment method. Since the current study used a convenience non-probability sample, it was not possible to generalize to the university population beyond the participants in this study. Replication using random sampling would increase generalizability. A final limitation to consider was that 34.5% of the participants were nursing students. Nursing students may be more knowledgeable about SCD than other students and could have influenced the results of this study.

Strengths

Although there were some limitations to the current study, this dissertation has several strengths. First, it adds to the limited research in the area of SCD knowledge, health beliefs, attitudes and behaviors. The current study adds to our knowledge of the factors that affect knowledge, attitudes, and behaviors regarding SCD among college students. Furthermore, it revealed that there might be other important factors not examined in this study that influence SCD knowledge, health beliefs, attitudes, and behaviors that need to be looked at. Given the limited research in this area, qualitative studies exploring people's SCD knowledge, health beliefs, attitudes, and behaviors would provide a deeper understanding of the influences. The study design also had some strength as the cross sectional design allowed multiple variables to be examined at once. The online nature of the survey provided benefits of cost effectiveness, time efficiency, and quality control. Given the online nature of the survey, there was a benefit in reaching a larger number of participants, allowing participants to complete at a time and pace most convenient to them. The study design also required fewer resources and did not demand additional time of the researcher to observe or administer the survey. Moreover, another benefit included easier data management as it eliminated the need to manually input each participant's responses (VanSelm & Janowski, 2006).

Implications for Social Work

There are several implications for social work practice, policy, and research based on the study results. This section presents these implications to guide social workers in the area of SCD prevention.

Practice

An important finding from the study was the significant relationship between knowledge about SCD and participant's health beliefs and attitudes regarding SCD. This

finding shows the importance of SCD education. Although the majority of participants (79%) reported that they have heard of SCD before, 21% of the participants reported that they have never heard of SCD. This is not surprising given the literature (Boyd et al., 2005; Burnes et al., 2008; Vassava et al., 2009) showing 30 to 54% had never heard of SCD. Approximately 30% of the participants in the current study answered less than half of the questions correctly. Most of the participants seemed to know that SCD is an inherited disease however, 14% still believed SCD could be transmitted through blood transfusions. Results from this study were slightly lower than Treadwell et al. (2006) who found that 17% and Stewart (2007) who found that 40% incorrectly believed SCD could be transmitted through blood transfusions. There were several aspects of SCD that participants were less knowledgeable about which is an important implication for prevention program development. Participants were less knowledgeable about the distinction between SCD and SCT, testing interpretation, prevalence, reproductive implications of SCD, and prevention. These findings highlight the need for improved SCD education. The Universal prevention approach would be useful to improve knowledge about SCD. The goal of the Universal prevention approach is to reach everyone in the population regardless of their risk level. With this approach, the intervention is delivered to the entire population (e.g., neighborhood, schools; community, local county, state, nation) (Nordentoft, 2011; TDSHS, 2012). Adequate knowledge and awareness about SCD and the inheritance of the disease is important for prevention

In order to develop culturally effective educational programs for universal prevention, social work professionals should consider several factors that may influence the effectiveness of such programs. For instance, this study found significant demographic differences (gender; race/ethnicity; age) in SCD knowledge, health beliefs, attitudes, and behaviors and should be considered for program development. Cultural

competence is important to create appropriate prevention programs when addressing SCD/SCT. SCD is a global issue affecting all races (Nelson & Hackman, 2013); however, this dissertation along with other research supports that the misconception that SCD only affects African Americans is still widely believed (Bedaiko et al., 2011; Gallo et al., 2010; Royal, Jonassaint, Jonnassaint & Castro, 2011). Therefore the Universal Prevention approach would improve knowledge among all racial ethnic groups. Knowledge on distinct information about cultural groups allows social workers to be culturally sensitive and competent when working with different cultures. For example, African Americans seem to be very religious and have strong family bonds (Johnson & Munch, 2009); practitioners can focus on these values to implement programs in churches. Acculturation, past health experiences, and health care access are important factors to consider when working with Hispanics or Latinos (Sanderson, 2013). For Asians, gender role, family support, and beliefs in God were factors influencing health behaviors (Lim, Baik, & Ashing-Giwa, 2012).

Findings from this study suggest that young adults had more favorable screening behaviors than middle adults. Screening programs using the Selective prevention approach should target the younger population, not only because they may be more willing to undergo screening, but also because it would be beneficial to detect carrier status early. Although the majority of the participants believed that everyone should know their carrier status, less than one third of the college students in this study indicated that they knew their carrier status. This finding highlights the need for screening programs. The study showed that overall, participants had positive attitudes toward SCD carrier screening. Social work professionals could take advantage of these positive attitudes to implement accessible voluntary screening programs. The Selective prevention would be an appropriate approach to target young adults for screening for

early detection of carrier status. Selective prevention approaches aim to reach a subset of the population determined to be at risk of passing on the genetic condition to their offspring (TDSHS, 2012). Thus recipients of selective SCD prevention approaches would include young adults since detecting carrier status early prior to marriage or having children, could reduce the risk for passing on the disease to their unborn children or at least prepare them to make informed reproductive choices.

Policy

Important implications for policy include a need for educational programs for universal prevention regarding SCD with an emphasis on the reproductive implications of being a carrier of SCD. Findings from the study showed that knowledge about SCD was a significant predictor of health beliefs and attitudes regarding SCD and carrier screening. Therefore, policies creating SCD educational programs using the Universal Prevention approach would increase knowledge about SCD and in turn improve health beliefs and attitudes.

A new National Collegiate Athletic Association (NCAA) legislation effective in 2013 required schools to provide SCT education for all student athletes as well as additional mandatory education for students who fail to confirm their carrier status. Furthermore, schools must confirm SCD carrier status of all incoming student athletes prior to participation in intercollegiate athletics (Middlebury, n.d.; NCAA, 2013). Although this is a great way to improve SCD knowledge among college students, the policy does not include non-athletes. Therefore, there need to be additional policies that are more inclusive. A good solution would be to have a policy addressing SCD/SCT in schools using the Universal Prevention approach to reach every student regardless of their perceived risk. The key to SCD prevention is to address the problem before it begins. Teens start dating as early as middle school (Noonan & Charles, 2009). Thus it would be

beneficial to include age appropriate education and awareness programs in schools, coupled with voluntary screening programs.

In addition, policies should be implemented around voluntary genetic testing and counseling for couples before marriage. Findings from this study showed that the majority of participants believed that everyone should know their carrier status, yet only a few (26%) knew their carrier status. Younger participants had more favorable screening behaviors. Participants who were not interested in screening reported that they did not believe they were at risk of SCD, they were already married, or that they were not planning to have any more children so they did not feel that screening would benefit them. This is why education and screening programs should target people at a young age, before dating begins especially before marriage. Here the Universal, Selective, Indicative Prevention Framework would be useful to provide different levels of prevention. The Universal approach would provide education for everyone regardless of age or marital status, as SCD education would still benefit married couples or parents since it is possible that their children may be carriers. The Selective approach could then be used to target select groups such as the young population to improve screening behaviors before marriage. Finally, once discovered through the Selective approach, the Indicative approach could then be applied to provide services to those found to be affected by SCD.

Another important policy implication involves social justice in terms of funding for SCD prevention, especially for the universal (education) and selective (screening) levels of prevention. SCD is the most common hereditary disease yet there is little support and funding for care or research (Nelson & Hackman 2012). There need to be policies supporting funding for programs aiming to increase education and awareness using the Universal Prevention approach. Funding and support for SCD is limited and having policies that allocate funding specifically to organizations dedicated to SCD prevention

might aid in increasing educational efforts and improve SCD knowledge, health beliefs and attitudes. Social workers have an obligation to strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people through advocacy, policy development and implementation (NASW, 2008, p. 22-26).

There also need to be policies supporting Screening programs using the Selective Prevention approach. Participants reported that they would not want to participate in screening if it was not covered by insurance. A solution would be to have policies ensuring that all insurance providers cover SCD screening or to provide specific funding to organizations allowing them to provide screening programs at no cost. For example the CDC and Department of Health and Human Services provide similar services for HIV prevention (Beckwith et al., 2005; Brown et al., 2007).

Research

This study has several implications for research. First, the literature on knowledge, health beliefs, attitudes, and behaviors regarding SCD is limited. Furthermore, the majority of existing literature on SCD is based on people of African decent. There is a pressing need for research with other populations. This is especially important given the diverse groups that are not traditionally considered at risk including Portuguese, Spaniards, French Corsicans, Sardinians, and Sicilians and Groups from countries such as Greece, Italy, Lebanon, Israel, Saudi Arabia, Kuwait and Yemen (NHLBI, 2012; SCDAA, 2012). Literature on other racial/ethnic groups is limited or non-existent. Findings from this study suggest that there were significant race/ethnicity differences in SCD knowledge, health beliefs, attitudes, and behaviors. Consistent with other studies (Gallo et al., 2010; Gustafon et al., 2007), this study revealed the need for more research including a more diverse population. Given the diverse racial and ethnic

groups affected and the increase in biracial and multi-ethnic marriages, (Locock & Kai, 2008) before long SCD may be a huge concern for everyone as they intermarry. Research shows that interracial marriages are increasing (Hayes, 2012; “Interracial Marriages”, 2012; Jayson, 2012) however, there are no studies exploring SCD among interracial marriages. Further research is needed to determine the risk of SCD among interracial couples. Therefore selective prevention education about carrier screening and universal early childhood education about SCD are important to improve knowledge and attitudes about the disease and its reproductive implications leading to informed partner choice and reproductive decisions.

Another important implication is that there needs to be more inclusion of males in future research; the majority of studies assessing SCD knowledge or attitudes include majority or all female samples. According to Alford et al. (2011), minority groups and males are underrepresented in genetic research. Given the significant gender differences found in the current study, there is a need for more studies exploring gender differences in SCD knowledge, health beliefs, attitudes and behaviors.

Family history of SCD was low for this study and findings were not clear as to the influence of family history on SCD knowledge health beliefs, attitudes, and behaviors. Future research should include a larger sample of participants with a family history of SCD to help us better understand the relationship between family history and knowledge, health beliefs, attitudes, and behaviors regarding SCD. A little over 20% of participants indicated that they would not be interested in carrier screening. Further research should be conducted to explore the reasons for not wanting screening to improve screening attitudes.

Conclusion

The purpose of this dissertation was to add to the limited research on Universal and Selective SCD prevention by exploring the knowledge, health beliefs, attitudes, and behaviors regarding SCD among a diverse group of college students. Findings from this study revealed several demographic differences, which are important for prevention planning. A key finding from the study was that improved knowledge was related to improved health beliefs and attitudes—supporting a universal prevention approach. This highlights the need for improved education and awareness among young adults. The Selective Prevention approach would be the best approach to target the younger population toward increased screening. SCD is a serious genetic disorder with physical, psychological, and psychosocial effects requiring more attention and awareness. Improved education is the key to improving health beliefs, attitudes, and behaviors regarding SCD. The Universal, Selective, and Indicated Prevention Framework seems to be an appropriate approach for SCD prevention and social workers can be instrumental in using this approach to provide different levels of prevention.

Appendix A

Invitation Emails

Student Invitation Email

Dear Student,

My name is Marcella Smith. I am a doctoral candidate in the School of Social Work at the University of Texas at Arlington. I am conducting a research study as part of the requirements of my degree in Social Work, and I would like to invite you to participate. I am conducting a study, surveying college students to assess their knowledge, beliefs, attitudes, and behaviors regarding sickle cell disease to inform sickle cell disease prevention.

As a student, you are in an ideal position to give us valuable first hand information from your own perspective. Even if you feel that you probably won't benefit directly from participating in this study, your participation will be a valuable addition to our research and findings could contribute to sickle cell disease prevention. In addition, participation could potentially satisfy service learning or volunteer hours

Participation is anonymous, which means that no one (not even the research team) will be able to link your answers to your name. So, please do not write your name or other identifying information on any of the study materials. We estimate that it will take you approximately 30 minutes to complete the survey. You will be entered into a drawing for a chance to win 1 out of 5 $25 visa gift card for participating in this study.

If you are willing to participate in the study, simply click on the link below, or cut and paste the entire URL into your browser to access the online survey.

Survey link: https://www.surveymonkey.com/s/SCDPrevention

If you have any questions please email me at marcella.smith@mavs.uta.edu or my faculty advisor, Dr. Aguirre, at rtpaguirre@uta.edu.

Sincerely,
Marcella Smith, MSW
Doctoral Candidate
School of Social Work
The University of Texas at Arlington
211 S. Cooper St
Arlington, TX 76019
marcella.smith@mavs.uta.edu

Student Organizations Invitation Email

Dear Student Organization Officers:

I hope this email finds you well. My name is Marcella Smith. I am a Doctoral candidate at the University of Texas at Arlington. I am interested in sickle cell disease prevention. I am conducting a study surveying college students to assess their knowledge, beliefs, attitudes, and behaviors regarding sickle cell disease to inform sickle cell disease prevention.

Given your position within the student organization, would you consider making my survey available to your student members as one of your service/volunteer hours options? Participation involves completing an online survey taking approximately 30 minutes. The survey is anonymous. Your student members are in an ideal position to give us valuable, first hand information from their own perspective. Even if you feel that you or your members probably won't benefit directly from participating in this study, their participation will be a valuable addition to our research and findings could contribute to sickle cell disease prevention. Also participation can count towards service learning or volunteer hours.

If you do not require volunteer hours or cannot include my survey as one of your volunteer hours option, would you mind sharing the details of my study with your student members through your listserv or Facebook page? Students not receiving volunteer hours can still complete the survey and be entered for a $25 Visa gift card drawing.

If you have any questions, or would like to use my survey as volunteer hours, or simply want to share with your student members, please email me at marcella.smith@mavs.uta.edu or my faculty adviser, Dr. Aguirre, at rtpaguirre@uta.edu and we will provide you with additional information and/or the link to the survey.

Thank you for your consideration- I appreciate your time and look forward to hearing from you soon.

Sincerely,
Marcella Smith, MSW
Doctoral Candidate
School of Social Work
The University of Texas at Arlington
211 S. Cooper St
Arlington, TX 76019
marcella.smith@mavs.uta.edu

Instructor Invitation Email: Extra Credit Option

Dear Professor/Instructor:

I hope this email finds you well. My name is Marcella Smith. I am a Doctoral candidate at the University of Texas at Arlington. I am interested in sickle cell disease prevention. For my dissertation, I am conducting a study, surveying college students to assess their knowledge, beliefs, attitudes, and behaviors regarding sickle cell disease to inform sickle cell disease prevention.

Given your position as a professor or instructor, would you consider making my survey available to your students as one of your extra credit assignment options? There must be alternatives the students can choose to complete for the exact same amount of credit as the survey. Participation involves completing an online survey taking approximately 30 minutes. The survey is anonymous. As a professor/instructor, you are in an ideal position to help us collect valuable information. Even if you feel that you or your students probably won't benefit directly from participating in this study, your participation will be a valuable addition to our research and findings could contribute to sickle cell disease prevention.

If you do not provide an extra credit option or cannot include my survey as one of your extra credit options, would you mind sharing the details of my study to your students? Students not receiving extra credit can still complete the survey and be entered for a $25 visa gift card drawing.

If you have any questions, or if you would like to use the survey as an extra credit option for any of your classes, or simply want to share the information with your students, please email me at marcella.smith@mavs.uta.edu or my faculty advisor, Dr. Aguirre, at rtpaguirre@uta.edu and we will provide you with additional information and/or link to the survey.

Thank you for your consideration- I appreciate your time and look forward to hearing from you soon.

Best,
Marcella Smith, MSW
Doctoral Candidate
School of Social Work
The University of Texas at Arlington
211 S. Cooper St
Arlington, TX 76019
marcella.smith@mavs.uta.edu

Student Invitation Email: Extra Credit Option

Dear Student,

My name is Marcella Smith. I am a doctoral candidate in the School of Social Work at the University of Texas at Arlington. I am conducting a research study as part of the requirements of my degree in Social Work, and I would like to invite you to participate. I am conducting a study, surveying college students to assess their knowledge, beliefs, attitudes, and behaviors regarding sickle cell disease to inform sickle cell disease prevention.

As a student, you are in an ideal position to give us valuable first hand information from your own perspective. Even if you feel that you probably won't benefit directly from participating in this study, your participation will be a valuable addition to our research and findings could contribute to sickle cell disease prevention.

Participation is anonymous, which means that no one (not even the research team) will be able to link your answers to your name. So, please do not write your name or other identifying information on any of the study materials. We estimate that it will take you approximately 30 minutes to complete the survey. You will receive extra credit predetermined by your instructor for participating in this study, so please print certificate of completion and return to your instructor for credit.

If you are willing to participate in the study, simply click on the link below, or cut and paste the entire URL into your browser to access the online survey.

Survey link: https://www.surveymonkey.com/s/SCDPrevention

If you have any questions please email me at marcella.smith@mavs.uta.edu or my faculty advisor, Dr. Aguirre, at rtpaguirre@uta.edu.

Thank you for your consideration, I appreciate your time and look forward to your participation.

Sincerely,
Marcella Smith, MSW
Doctoral Candidate
School of Social Work
The University of Texas at Arlington
211 S. Cooper St
Arlington, TX 76019
marcella.smith@mavs.uta.edu

Appendix B

Informed Consent

1. Informed Consent

PRINCIPAL INVESTIGATOR NAME
Marcella Smith, MSSW, Doctoral Candidate

TITLE OF PROJECT
Factors That Contribute To Knowledge, Beliefs, Attitudes, and Behaviors Regarding Sickle Cell Disease Among College Students

INTRODUCTION
You are being asked to participate in a research study. Your participation is voluntary. This survey is part of a study being conducted by Marcella Smith at the University of Texas at Arlington in partial fulfillment of dissertation requirements. IRB approval was granted _____. Please ask questions by emailing Marcella Smith (marcella.smith@mavs.uta.edu) if there is anything you do not understand or if you have any questions or concerns regarding your participation in this survey. If you would like to receive a copy of the results of this study, please send an email to Marcella Smith at the above address.

OBJECTIVE
The objective of this survey is to assess the knowledge, beliefs, attitudes, and behaviors regarding Sickle Cell Disease (SCD) in order to develop effective prevention programs. Your participation will involve completing an online survey. If you have already participated in this survey or are not a college student at the University of Texas at Arlington please exit this survey now. DURATION This survey will take approximately ____ minutes to complete. If at any time you experience discomfort you may exit the survey.

PROCEDURES
The procedures, involving you as a research participant, include you completing an online survey based on your own knowledge, beliefs, attitudes and behaviors. This is not a test and there are no right or wrong answers. Your responses will provide the researcher with information to inform Sickle Cell Disease (SCD) prevention.

ELIGIBILITY
You must be a college student currently enrolled at the University of Texas at Arlington (UTA) to participate in this survey.

POSSIBLE BENEFITS
There are no direct benefits for participating in this study; however, you will be contributing to the broader body of evidence on improving Sickle Cell Disease knowledge, beliefs, attitudes, and behaviors among college students.

COMPENSATION
Optional compensation for participation in this study includes: extra credit predetermined by your instructor and a drawing for a chance to win 1 out of 5 $25 Visa gift cards. Compensation will be dependent upon your affiliation as a student at UTA. You will be asked to provide additional information about your affiliation as a student. If you are completing this survey as a student in a class in which your instructor will offer extra credit, you will be asked to provide the name of the instructor and course. You will be provided with a completion certificate to turn in to your instructor for predetermined credit. Please contact instructor for specific credit. If not in a class offering extra credit, you can provide your contact information (name and email address) to enter a drawing for a chance to win 1 out of 5 $25 Visa gift cards. Your contact information will be kept separate from your responses, which means no one will be able to link your answers to your name. You must demonstrate a genuine effort to be awarded compensation.

POSSIBLE RISKS/DISCOMFORTS
There are no perceived risks for participating in this research study. If at any time you experience discomfort you may exit the survey.

ALTERNATIVE PROCEDURES
There are no alternative procedures offered for this study. However, you can elect not to participate in the study or quit at any time with no negative consequences. WITHDRAWAL FROM THE STUDY Participation in this study is voluntary. You may refuse to participate or quit at any time by closing the survey window. NUMBER OF PARTICIPANTS: We expect 1000 participants to enroll in this study.

CONFIDENTIALITY
This is an anonymous survey. The survey data will be kept anonymous and confidential, and you will not be asked to identify yourself in any way. If you choose to participate in this survey, please proceed. If you do not choose to participate, you may close this window to exit the survey at any time. Every attempt will be made to see that your study results are kept confidential. The results of this survey will only be available to Marcella Smith and her supervising professor, Dr. Regina Aguirre. A copy of the data from this study will be stored on the password protected computer of Dr. Aguirre, 2 encrypted USB drives, and in a password protected online data backup program administered by the University of Texas at Arlington for at least three (3) years after the end of this research. The results of this study may be published and/or presented at meetings. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. If you contact the researcher with questions or discomfort, your identity will be kept separate from your answers on the survey. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, then The University of Texas at Arlingto

***CONSENT:**

As a representative of this study, I, Marcella Smith, have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study.

By answering "Yes" below, you confirm that you have read or had this document read to you, that you are 18 or older, and that you are a student at the University of Texas at Arlington.

You have been informed about this study's purpose, procedures, possible benefits and risks through this form. You have been given the opportunity to ask questions before you answer "Yes" in agreement, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By answering "Yes" below, you are not waiving any of your legal rights. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled, and you may discontinue participation at any time without penalty or loss of benefits, to which you are otherwise entitled.

◯ Yes, I consent to complete this survey.

◯ No, I do not consent to completing this survey.

2. Informed Consent

This survey is intended to collect information on knowledge, beliefs, attitudes, and behaviors regarding Sickle Cell Disease. If you have already participated in this survey or are not a college student at the University of Texas at Arlington please exit this survey now. This survey contains questions about your views and experience regarding Sickle Cell Disease.

The survey data will be kept anonymous and confidential, and you will not be asked to identify yourself in any way. If you choose to participate in this survey, please proceed. If you do not choose to participate, you may close this window to exit the survey at any time.

This survey is part of a study being conducted by Marcella Smith at the University of Texas at Arlington in partial fulfillment of dissertation requirements. IRB approval was granted _____. If you have any questions or concerns regarding your participation in this survey please contact Marcella Smith (Marcella.smith@mavs.uta.edu). If you would like to receive a copy of the results of this study, please send an email to Marcella Smith at the above address.

Every attempt will be made to see that your study results are kept confidential. All study data will be electronically stored for at least 3 years after the study is completed using encrypted USB thumb drives. Only the researcher and supervising committee chair will have passwords to access the data for research purposes. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA IRB, and personnel particular to this research have access to the study records. Your results will be kept completely confidential according to the current legal requirements. They will not be revealed unless required by law, or as noted above.

This survey is expected to take _____ minutes. If at any time you experience discomfort you may exit the survey.

By clicking "Next" you confirm that you have read or had this document read to you and that you freely and voluntarily

Appendix C

Certificate of Completion and Gift Card Drawing Contact

Please provide your contact information if you would like to be entered in the $25 Visa card drawing. Your information will remain confidential and will only be used to contact you after the completion of the study in case you are a winner of one of the $25 Visa gift cards. If you do not wish to be entered into the drawing or contacted you may close your browser to exit this page.
Note: Only your name and email address are required

Name: Email Address:

Appendix D

Measures

choose to be in this research project. Otherwise, please click "Exit This Survey" at the top of the page.

3. Thank You

We are sorry you have chosen not to participate in this study. Thank you for your time and interest. You can exit the survey by selecting the exit link or closing the browser window.

4. Demographics

***Are you a college student at The University of Texas at Arlington (UTA)?**

- ◯ Yes
- ◯ No

5. Thank You

Unfortunately, you must be a college student in order to participate in this survey. Thank you for your time and interest. You can exit the survey by selecting the exit link or closing the browser window.

6. Demographics

***How old are you?**

***What is your sex?**

- ◯ Male
- ◯ Female
- ◯ Intersex

***What is your race/ethnicity?**

- ◯ Black or African American
- ◯ White
- ◯ Asian American
- ◯ Hispanic or Latino
- ◯ Native Hawaiian or Other Pacific Islander
- ◯ American Indian or Alaska Native
- ◯ Multiracial
- ◯ Other

***What is your marital status?**

- ◯ single
- ◯ married
- ◯ divorced
- ◯ separated
- ◯ co-habiting

***Who do you live with?**

- ◯ partner
- ◯ spouse
- ◯ parents
- ◯ Other (please specify)

***How many children do you have?**

***What is your highest level of education?**

- ◯ unsergraduate freshman
- ◯ undergraduate sophomore
- ◯ undergraduate junior
- ◯ undergraduate senior
- ◯ graduate student Master's program
- ◯ graduate student PhD, MD, DO, JD or other terminal degree program
- ◯ non-degree seeking student undergraduate
- ◯ non-degree seeking student graduate

***What is your major?**

***What is your religion?**

- ◯ Christian
- ◯ Jewish
- ◯ Buddhist
- ◯ Muslim
- ◯ Unitarian/Universalist
- ◯ Hindu
- ◯ Unaffiliated

Other (please specify)

***Which option are you completing the study for?**

7.

Please provide the name of the course and instructor

Please provide the name of your student organization

8. Familiarity With SCD

***1. Have you ever heard of sickle cell disease (SCD)?**

- ◯ Yes
- ◯ No

***2. If yes, do you know if you personally, have Sickle Cell Disease (SCD)?**

- ◯ Yes, I have it
- ◯ No, I don't have it
- ◯ Don't know

***3. How do you know?**

***4. Does anyone in your family have Sickle Cell Disease (SCD)?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

5. If yes, what is your relation to that person? Check all that apply

- ☐ Mom
- ☐ Dad
- ☐ Brother
- ☐ Sister
- ☐ Aunt
- ☐ Uncle
- ☐ Cousin
- ☐ Niece
- ☐ Nephew
- ☐ Grandmother
- ☐ Grandfather
- ☐ Other (please specify)

***6. Do you know anyone outside your family with Sickle Cell Disease (SCD)?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

7. If yes, what is your relation to that person?

***8. Have you ever heard of sickle cell trait (SCT)?**

- ◯ Yes
- ◯ No

9. If yes, do you know if you personally, have Sickle Cell Trait (SCT)?

- ◯ Yes, I have it
- ◯ No, I don't have it
- ◯ Don't know

***10. How do you know?**

***11. Does anyone in your family have Sickle Cell Trait (SCT)?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

12. If yes, what is your relation to that person? Check all that apply

- ☐ Mom
- ☐ Dad
- ☐ Brother
- ☐ Sister
- ☐ Aunt
- ☐ Uncle
- ☐ Cousin
- ☐ Niece
- ☐ Nephew
- ☐ Grandmother
- ☐ Grandfather
- ☐ Other (please specify)

***13. Do you know anyone outside your family with Sickle Cell Trait (SCT)?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

14. If yes, what is your relation to that person?

***15. Have you ever heard of Beta-Thalassemia trait?**

- ◯ Yes
- ◯ No

16. If yes, do you know if you personally, have Beta-Thalassemia trait?

- ◯ Yes, I have it
- ◯ No, I don't have it
- ◯ Don't know

***17. How do you know?**

***18. Does anyone in your family have Beta-Thalassemia trait?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

19. If yes, what is your relation to that person? Check all that apply

- ☐ Mom
- ☐ Dad
- ☐ Brother
- ☐ Sister
- ☐ Aunt
- ☐ Uncle
- ☐ Cousin
- ☐ Niece
- ☐ Nephew
- ☐ Grandmother
- ☐ Grandfather
- ☐ Other (please specify)

***20. Do you know anyone outside your family with Beta-Thalassemia trait?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

21. If yes, what is your relation to that person?

***22. Have you ever heard of Hemoglobin C-trait?**

- ◯ Yes
- ◯ No

23. If yes, do you know if you personally, have hemoglobin C-trait?

- ◯ Yes, I have it
- ◯ No, I don't have it
- ◯ Don't know

***24. How do you know?**

***25. Does anyone in your family have Hemoglobin C-trait?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

26. If yes, what is your relation to that person? Check all that apply

- ☐ Mom
- ☐ Dad
- ☐ Brother
- ☐ Sister
- ☐ Aunt
- ☐ Uncle
- ☐ Cousin
- ☐ Niece
- ☐ Nephew
- ☐ Grandmother
- ☐ Grandfather
- ☐ Other (please specify)

***27. Do you know anyone outside your family with Hemoglobin C-trait?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

28. If yes, what is your relation to that person?

***29. Have you ever heard of carrier screening for Sickle Cell Disease (SCD)?**

- ◯ Yes
- ◯ No

***30. Have you ever heard of carrier screening for Beta-Thalassemia?**

- ◯ Yes
- ◯ No

***31. Have you ever had any Sickle Cell Disease (SCD) education in the past?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

32. If yes, please select the source of education you have had in the past.

- ◯ Brochures
- ◯ videos
- ◯ presentations
- ◯ online
- ◯ workshops
- ◯ Never had SCD education in the past
- ◯ Other (please specify)

***33. Have you ever had any Beta-Thalassemia education in the past?**

- ◯ Yes
- ◯ No
- ◯ Not Sure

34. If yes, please select the source of education you have had in the past.

- ◯ Brochures
- ◯ videos
- ◯ presentations
- ◯ online
- ◯ workshops
- ◯ Never had beta-Thalassemia education in the past
- ◯ Other (please specify)

9. Knowledge about SCD

This section consists of the questions assessing knowledge about Sickle Cell Disease (SCD). Please answer the question to the best of your ability. This is not a test and you will not be graded. Remember the survey is anonymous.

***Based on your understanding of Sickle Cell Disease, which definition best defines it?**

- ◯ An inherited blood disorder
- ◯ Sickle Cell Trait (SCT) usually turns into Sickle Cell Disease (SCD)
- ◯ An infectous disease
- ◯ A genetic disease only affecting African Americans

***Are there different types of traits that can lead to Sickle Cell Disease (SCD)?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***3. Which of the following are true of Sickle Cell Disease (SCD):**

- ◯ Sickle Cell Disease (SCD) is a blood disease
- ◯ There are many different types of Sickle Cell Disease (SCD)
- ◯ Sickle Cell Disease (SCD) can be identified by a blood test
- ◯ Blood transfusions are sometimes used to treat Sickle Cell Disease (SCD)
- ◯ All of the above

10. SCD Student Questionnaire -Knowledge of Personal and Partner Status

***Do you know your Sickle Cell Trait status?**

- ◯ Yes
- ◯ No

***Do you know your partner/spouse's Sickle Cell Trait status?**

- ◯ Yes
- ◯ No
- ◯ No partner/spouse

***Do you think it is possible that your partner may be a carrier of Beta-Thalassemia?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***Why or why not?**

***Do you think it is possible that you yourself may be a carrier of Beta-Thalassemia?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***Why or why not?**

***Do you think it is possible that you yourself may be a carrier of Sickle Cell Disease (SCD)**

- ◯ Yes
- ◯ No
- ◯ I don't know

***Why or why not?**

***Do you think it is possible that your partner/spouse may be a carrier of Sickle Cell Disease (SCD)?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***Why or Why not?**

11. SCD Student Questionnaire -Mode of Inheritance

***When both parents have Sickle Cell Trait, what is their chance with each pregnancy of having a child with Sickle Cell Disease?**

- ◯ 50% (1 in 2)
- ◯ 25% (1 in 4)
- ◯ 10% (1 in 10)
- ◯ 100%

***How many genes must someone get to have Sickle Cell Disease? -Zero, it is not caused by genes -One from their mom -Two, one from the mother and one from the father -Three, one from the mother and two from the father -None of the above -I don't know**

- ◯ Zero, it is not caused by genes
- ◯ One from their mom
- ◯ Two, one from the mother and one from the father
- ◯ Three, one from the mother and two from the father
- ◯ None of the above

***A baby can be affected by Sickle Cell Disease (SCD) if**

- ◯ One parent is a carrier or has Sickle Cell Disease (SCD)
- ◯ Neither parent is a carrier or has Sickle Cell Disease (SCD)
- ◯ Both parents are carriers or have Sickle Cell Disease (SCD)
- ◯ None of these
- ◯ I don't know how a baby can be affected

***A baby can be affected by Beta-Thalassemia if:**

- ◯ One parent is a carrier or has Beta-Thalassemia
- ◯ Neither parent is a carrier or has Beta-Thalassemia
- ◯ Both parents are carriers or have Beta-Thalassemia
- ◯ None of these
- ◯ I don't know how a baby can be affected

***Which gender do you think is more likely to catch these diseases?**

- ◯ Male
- ◯ Female
- ◯ Equally likely in males and females
- ◯ I don't knaoe

***The only way that you can get Sickle Cell Disease (SCD) is:**

- ◯ Dirty needles
- ◯ Bad blood transfusion
- ◯ From both your biological parents
- ◯ Hanging around with a person who has the disease
- ◯ Sexual transmission

***If you have a friend with Sickle Cell Disease (SCD), you can catch it from them by**

- ◯ Blood transfusions
- ◯ Drinking from the same glass
- ◯ Holding their hand
- ◯ Sitting together in class
- ◯ None of the above, you cannot "catch" Sickle Cell Disease (SCD)

***Based on your knowledge about sickle cell disease, you can only get sickle cell disease from:**

- ◯ Being around someone with sickle cell disease
- ◯ Inheriting it from both your parents
- ◯ Infected blood
- ◯ None of the above

***How do you think sickle cell disease (SCD) is passed from person to person?**

- ◯ By respiratory system
- ◯ By blood
- ◯ By digestive system
- ◯ By heredity
- ◯ By sexual transmission

*How do you think Beta-Thalassemia is passed from person to person?

- ◯ By respiratory system
- ◯ By blood
- ◯ By digestive system
- ◯ By heredity
- ◯ By sexual transmission

12. SCD Student Questionnaire -Distinguishing SCD from SCT

*People with Sickle Cell Trait (SCT) have a mild form of Sickle Cell Disease (SCD)

- ◯ True
- ◯ False
- ◯ I don't know

*Sickle Cell Trait (SCT) is an illness

- ◯ True
- ◯ False
- ◯ I don't know

*Sickle Cell Trait (SCT) can change to Sickle Cell Disease (SCD)

- ◯ True
- ◯ False
- ◯ I don't know

13. Understanding Trait Testing

*What is the only way to figure out if a person has Sickle Cell Trait (SCT)?

- ◯ Special blood test
- ◯ Physical examination
- ◯ Eye examination
- ◯ X-ray
- ◯ I don't know

***A negative Sickle Cell carrier test means:**

- ◯ The person is very unlikely to have the trait.
- ◯ The person definitely does not have the trait.
- ◯ I don't know

***If your results show that you have inherited a gene for Sickle Cell Disease (you are a carrier), this means:**

- ◯ No possibility that my baby has Sickle Cell Disease
- ◯ Possible that my baby has Sickle Cell Disease
- ◯ No, do not include this question (indicate reasoning in textbox below please)
- ◯ My baby definitely has sickle Cell Disease
- ◯ None of these
- ◯ I don't know what it means

***If your results show that you have inherited a gene for Beta-Thalassemia (you are a carrier), this means:**

- ◯ No possibility that my baby has Sickle Cell Disease
- ◯ Possible that my baby has Sickle Cell Disease
- ◯ No, do not include this question (indicate reasoning in textbox below please)
- ◯ My baby definitely has sickle Cell Disease
- ◯ None of these
- ◯ I don't know what it means

14. Major Complications of SCD

***People with Sickle Cell Disease (SCD) select the correct answer (more than one answer)**

- ☐ Can be cured
- ☐ Need medicines
- ☐ Need regular blood transfusions
- ☐ Cannot have children
- ☐ Have great pain
- ☐ I don't know about Sickle Cell Disease (SCD)

***Would you say that children with Sickle Cell Disease (SCD) are more likely to develop the following conditions due to the disease? (check all that apply)**

- [ ] Pain requiring hospitalization
- [ ] Life-threatening infections
- [ ] Kidney failure
- [ ] Stroke
- [ ] I don't know

***To what extent do you agree or disagree that "Sickle Cell Disease (SCD) can impact a child's school performance?"**

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree
- ◯ Don't know

***Would you say that adults with Sickle Cell Disease are more likely to develop the following conditions due to the disease? (Check all that apply)**

- [ ] Pain requiring hospitalization
- [ ] Can shorten life span
- [ ] Kidney failure
- [ ] Stroke
- [ ] I don't know

***Sickle Cell Disease is cured by:**

- ◯ Bone marrow transplant
- ◯ Liver transplant
- ◯ Blood transfusions
- ◯ Kidney transplant
- ◯ None of the above
- ◯ There is no cure
- ◯ I don't know

***Sickle Cell Disease can cause**

- ◯ Severe debilitating pain
- ◯ Strokes
- ◯ Infections
- ◯ Organ damage
- ◯ All of the above
- ◯ I don't know

***How often do people have medical complications from Sickle Cell Trait?**

- ◯ Frequently
- ◯ Occasionally
- ◯ Rarely
- ◯ Never
- ◯ I don't know

15. Incidence of SCD

***Who gets Sickle Cell Disease in the US?**

- ◯ Only African Americans
- ◯ Mostly African Americans
- ◯ All races are equally as likely
- ◯ Don't Know

***Thinking about how common Sickle Cell Disease is, among African Americans would you say it affects . . . -1 in every 100 blacks -1 in every 500 blacks -1 in every 1000 blacks d. 1 in every 10,000 blacks - I don't know**

- ◯ 1 in every 100
- ◯ 1 in every 500
- ◯ 1 in every 1000
- ◯ 1 in every 10,000
- ◯ don't know

***Among African Americans Sickle Cell Trait (SCT) occurs approximately in**

- ◯ 1 in 12
- ◯ 1 in 100
- ◯ 1 in 10,000
- ◯ 1 in 100,000
- ◯ don't know

***Who would you say is affected by Sickle Cell Disease (SCD)?**

- ◯ Only African Americans
- ◯ Mostly Latinos
- ◯ Sickle Cell Disease (SCD) can be found in persons from many nationalities
- ◯ None of the above

***The best way to prevent Sickle Cell Disease (SCD) is by?**

- ◯ Healthy eating habits
- ◯ Everyone knowing their trait status
- ◯ Avoiding anyone with Sickle Cell Disease (SCD)
- ◯ There's no way to prevent it
- ◯ I don't know how to prevent Sickle Cell Disease (SCD)

***How can Sickle Cell Disease (SCD) be prevented?**

- ◯ Premarital trait testing
- ◯ Two persons with Sickle Cell Trait not marrying each other
- ◯ Complete abstinence from sex
- ◯ I don't know

16. Beliefs about Sickle Cell Disease (SCD) and Screening

Please rate your level of agreement with each of the following statements on a 5-point scale where 1 means "strongly disagree" and 5 means "strongly agree."

***Sickle Cell Disease (SCD) is a serious disease**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***Having a child with Sickle Cell Disease (SCD) would be very scary**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***My life would change if my child had Sickle Cell Disease (SCD)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***My children are at risk for Sickle Cell Disease (SCD)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***Sickle Cell Disease (SCD) could happen in my family**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I may be a carrier of Sickle Cell Trait (SCT)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***My partner may be a carrier of Sickle Cell Trait (SCT)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I may be a carrier of Beta-Thalassemia**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***My partner may be a carrier of Beta-Thalassemia**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***It is useful to know if I have Sickle Cell Trait (SCT)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***It is useful to know if my partner has Sickle Cell Trait (SCT)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***It is useful to know if I have Beta-Thalassemia trait**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***It is useful to know if my partner has Beta-Thalassemia trait**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***Knowing the risk of having a child with Sickle Cell Disease (SCD) would change how I choose my partner**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***Knowing the risk of having a child with Sickle Cell Disease (SCD) would change how I plan a pregnancy**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I would rather not know if I had Sickle Cell Trait (SCT)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I would rather not know if I had Beta-Thalassemia Trait**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I am afraid of finding out if I have Sickle Cell Trait (SCT)**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I am afraid of finding out if I have Beta-Thalassemia Trait**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***Testing for Sickle Cell Trait (SCT) is painful and difficult**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***Testing for Beta-Thalassemia Trait is painful and difficult**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***My partner would be hard to convince to have testing**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I would not want to pay for Sickle Cell Trait (SCT) testing if it is not paid for by insurance**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

***I would not want to pay for Beta-Thalassemia Trait testing if not paid for by insurance**

◯ Strongly Disagree ◯ Disagree ◯ Neither Agree Nor Disagree ◯ Agree ◯ Strongly Agree

17. Attitude Questions

This section contains questions assessing your attitudes toward information about carrier status, carrier screening, and attitudes towards others with SCD. Please rate your level of agreement with each of the following statements on a 5-point scale. Remember there are no right or wrong answers.

***'I think information about carrier status for sickle cell disease is...'**

Bad				**Good**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Unimportant**				**Important**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Alarming**				**Reassuring**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Unwise**				**Sensible**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Undesirable**				**Desirable**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Unpleasant**				**Pleasant**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Discriminatory**				**A privilege**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Harmful**				**Beneficial**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5

***'I think information about carrier status for thalassemia is...'**

Bad				**Good**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
***Unimportant**				**Important**
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5

*Alarming				Reassuring
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Unwise				Sensible
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Undesirable				Desirable
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Unpleasant				Pleasant
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Discriminatory				A privilege
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Harmful				Beneficial
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5

'I think information about carrier testing for Sickle Cell Disease is...'

Bad				Good
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Unimportant				Important
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Alarming				Reassuring
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Unwise				Sensible
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Undesirable				Desirable
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Unpleasant				Pleasant
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
*Discriminatory				A privilege
◯ 1	◯ 2	◯ 3	◯ 4	◯ 5

*Harmful Beneficial

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*'I think information about carrier testing for Beta-Thalassemia is...'

Bad Good

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unimportant Important

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Alarming Reassuring

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unwise Sensible

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Undesirable Desirable

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unpleasant Pleasant

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Discriminatory A privilege

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Harmful Beneficial

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*I think participating in carrier screening for sickle cell disease is...'

Bad Good

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unimportant Important

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Alarming Reassuring

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unwise Sensible

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Undesirable — Desirable

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unpleasant — Pleasant

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Discriminatory — A privilege

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Harmful — Beneficial

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*'I think participating in a carrier screening for Beta-Thalassemia is...'

Bad — Good

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unimportant — Important

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Alarming — Reassuring

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unwise — Sensible

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Undesirable — Desirable

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Unpleasant — Pleasant

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Discriminatory — A privilege

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*Harmful — Beneficial

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

*

1. Do you think everybody should know their carrier status?

- ◯ Yes
- ◯ No
- ◯ I don't know

***2. Do you know your carrier status?**

- ◯ Yes
- ◯ No

3. If yes, what is your carrier status?

***4. Will a person's SCD carrier status influence your decision to be friends with him or her?**

- ◯ Yes, I would not be friends with him or her
- ◯ No, I would still be friends with him or her
- ◯ I don't know

***5. Will a person's beta-thalassemia carrier status influence your decision to be friends with him or her?**

- ◯ Yes, I would not be friends with him or her
- ◯ No, I would still be friends with him or her
- ◯ I don't know

***6. Will a person's SCD carrier status influence your decision to date him or her?**

- ◯ Yes, I would not be date him or her
- ◯ No, I would still date him or her
- ◯ I don't know

***7. Will a person's Beta-Thalassemia carrier status influence your decision to date him or her?**

- ◯ Yes, I would not date him or her
- ◯ No, I would still date him or her
- ◯ I don't know

***8. Will partner's SCD carrier status influence your decision to marry him or her?**

- ◯ Yes, I would not marry him or her
- ◯ No, I would still marry him or her
- ◯ I don't know

***9. Will partner's beta-thalassemia carrier status influence your decision to marry him or her?**

- ◯ Yes, I would not marry him or her
- ◯ No, I would still marry him or her
- ◯ I don't know

***10. If a person has SCD would you be friends with him or her?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***11. If a person has SCD would you date him or her?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***12. If a person has SCD would you marry him or her?**

- ◯ Yes
- ◯ No
- ◯ I don't know

***13. What should be done by a couple when they discover that their carrier status predispose them to having children with SCD?**

- ◯ Discontinue their relationship
- ◯ Continue their relationship and damn the consequences
- ◯ Seek genetic counseling and make informed consent
- ◯ Don't know

18. Screening Behaviors

This section contains questions regarding carrier screening particiaption.

*1. Have you ever undergone carrier screening for Sickle Cell Disease (SCD)?

- ◯ Yes
- ◯ No
- ◯ Don't Know

*2. Why or why not?

3. If No, would you be interested in undergoing carrier screening for Sickle Cell Disease (SCD)?

- ◯ Yes
- ◯ No
- ◯ Don't Know

*4. Why or why not?

*5. Have you ever had a carrier screening for Beta-Thalassemia?

- ◯ Yes
- ◯ No
- ◯ Don't know

*6. Why or why not?

7. If No, would you be interested in participating in carrier screening for Beta-Thalassemia?

- ◯ Yes
- ◯ No
- ◯ Don't know

*8. Why or why not?

19. End of Survey

Thank you for completing the survey.

If you are taking this survey as part of an extra credit option in one of your classes, please provide the name of the instructor along with the name of the course. Please click here to print certificate of completion to turn in to instructor for credit. You can also print the certificate and turn in to your student organization's officer if participation in this survey satisfies volunteer hours. You may close your browser to exit this page.

OR

If you would like to be entered in the $25 Visa gift card drawing, please click here to provide your contact information. Your information will remain confidential and will only be used to contact you after the completion of the study in case you are a winner of one of the $25 Visa gift cards. If you do not wish to be entered into the drawing or contacted you may close your browser to exit this page.

Appendix E

Expert Panel IRB

Office of Research Administration
Regulatory Services
817-272-3723
regulatoryservices@uta.edu
http://www.uta.edu/research/administration

Institutional Review Board
Notification of Exemption

July 8, 2013

Marcella Smith
Dr. Regina Aguirre
School of Social Work
19129

Protocol Number: 2013-0654

Protocol Title: *Sickle Cell Disease Prevention Program for College Students*

EXEMPTION DETERMINATION

The UT Arlington Institutional Review Board (IRB) Chair, or designee, has reviewed the above referenced study and found that it qualified for exemption under the federal guidelines for the protection of human subjects as referenced at Title 45CFR Part 46.101(b)(2).

- (2)Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:(i) information obtained is recorded in such a manner that human subjects can be identified, either directly or through identifiers linked to the subject; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation

You are therefore authorized to begin the research as of **July 6, 2013**.

Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, "promptly report to the IRB ***any*** proposed changes in the research activity, and to ensure that such changes in approved research, during the period for which IRB approval has already been given, are **not initiated without prior IRB review and approval** except when necessary to eliminate apparent immediate hazards to the subject." Please be advised that as the principal investigator, you are required to report local adverse (unanticipated) events to the Office of Research Administration; Regulatory Services within 24 hours of the occurrence or upon acknowledgement of the occurrence. All investigators and key personnel identified in the protocol must have documented Human Subject Protection (HSP) Training on file with this office. Completion certificates are valid for 2 years from completion date.

Office of Research Administration
Regulatory Services
817-272-3723
regulatoryservices@uta.edu
http://www.uta.edu/research/administration

The UT Arlington Office of Research Administration; Regulatory Services appreciates your continuing commitment to the protection of human subjects in research. Should you have questions, or need to report completion of study procedures, please contact Robin Dickey at 817-272-9329 or robind@uta.edu. You may also contact Regulatory Services at 817-272-3723 or regulatoryservices@uta.edu.

Appendix F

Expert panel Email Invitation

Expert Panel Invitation Email

Dear Panelist:

I hope this email finds you well. I am a Doctoral student at the University of Texas at Arlington. I am interested in sickle cell disease prevention thus, I am hoping to develop and evaluate the effectiveness of an online educational prevention program in increasing the knowledge and awareness of sickle cell disease.

I am conducting a 2-part study, surveying college students to get a sense of their level of knowledge about sickle cell disease. The first part of the study will assess current knowledge and attitudes about sickle cell disease and carrier status. The second part will consist of developing an online seminar to improve knowledge and attitudes about sickle cell disease and carrier status.

After reviewing the literature, I have identified topic areas I wish to include in my study specifically from DeBaun's (2012) work. The instrument I will be using was the one modified by DeBaun, (2012). Thus, I will be building upon Dr. DeBaun's work but also going further. My study will focus specifically on young adults in a college setting. I will also include a panel of multidisciplinary and multinational members to get a more extensive perspective of content.

Given your experience and expertise, I am writing to ask if you would consider serving as a member of the expert panel by filling out the attached survey. This commitment involves reviewing the proposed questionnaire and providing feedback. The survey will be given to college students to inform creation of the online prevention class.

Thank you for your consideration- I appreciate your time and look forward to hearing from you soon.

Best,
Marcella Smith, MSW
Doctoral Student
School of Social Work
The University of Texas at Arlington
211 S. Cooper St
Arlington, TX 76019
marcellasmith@uta.edu

Appendix G

Current Study IRB Approval

Institutional Review Board
Notification of Exemption

September 17, 2014

Marcella Smith
Dr. Regina Aguirre
School of Social Work

Protocol Number: 2014-0804

Protocol Title: *Factors That Contribute to Knowledge, Beliefs, Attitudes, and Behaviors Regarding Sickle Cell Disease Among College Students*

EXEMPTION DETERMINATION

The UT Arlington Institutional Review Board (IRB) Chair, or designee, has reviewed the above referenced study and found that it qualified for exemption under the federal guidelines for the protection of human subjects as referenced at Title 45CFR Part 46.101(b)(2).

- (2)Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:(i) information obtained is recorded in such a manner that human subjects can be identified, either directly or through identifiers linked to the subject; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You are therefore authorized to begin the research as of **September 12, 2014**.

Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, "promptly report to the IRB ***any*** proposed changes in the research activity, and to ensure that such changes in approved research, during the period for which IRB approval has already been given, are **not initiated without prior IRB review and approval** except when necessary to eliminate apparent immediate hazards to the subject." Please be advised that as the principal investigator, you are required to report local adverse (unanticipated) events to the Office of Research Administration; Regulatory Services within 24 hours of the occurrence or upon acknowledgement of the occurrence. All investigators and key personnel identified in the protocol must have documented Human Subject Protection (HSP) Training on file with this office. Completion certificates are valid for 2 years from completion date.

The UT Arlington Office of Research Administration; Regulatory Services appreciates your continuing commitment to the protection of human subjects in research. Should you have questions, or need to report completion of study procedures, please contact Robin Dickey at 817-272-9329 or robind@uta.edu. You may also contact Regulatory Services at 817-272-3723 or regulatoryservices@uta.edu.

Appendix H

Revised Scale Reliability

Table 5-22 Reliability for Measures

	Item-Total Correlation	If Item Deleted
Familiarity		
1. Have you ever heard of SCD?	.36	.75
2. Does anyone in your family have SCD?	.20*	.76
3. Do you know anyone outside your family with SCD?	.35	.75
4. Have you ever heard of SCT?	.52	.74
5. Does anyone in your family have SCT?	.25	.76
6. Do you know anyone outside your family with SCT?	.43	.75
7. Have you ever heard of Beta-thalassemia trait?	.52	.74
8. Does anyone in your family have Beta-Thalassemia trait?	.08*	.77
9. Do you know anyone outside your family with Beta-Thalassemia trait?	.19*	.76
10. Have you ever heard of Hemoglobin C-trait?	.24*	.76
11. Does anyone in your family have Hemoglobin C-trait?	.14*	.77
12. Do you know anyone outside your family with Hemoglobin C-trait?	.09*	.77
13. Have you ever heard of carrier screening for SCD?	.51	.74
14. Have you ever heard of carrier screening for Beta-Thalassemia?	.52	.74
15. Have you ever had any SCD education in the past?	.55	.73
16. Have you ever had any Beta-Thalassemia education in the past?	.52	.74
Knowledge		
1. Based on your understanding of SCD, which definition best defines it?	.26*	.84
2. Are there different types of traits that can lead to SCD?	.21*	.85
3. Which of the following are true of SCD:	.29*	.84
4. Do you know your partner/spouse's SCT?	.26*	.84
5. Do you think it is possible that you yourself may be a carrier of Beta-Thalassemia?	.05*	.85
6. Do you think it is possible that you yourself may be a carrier of SCD?	.04*	.86
7. Do you think it is possible that your partner/spouse may be a carrier of SCD?	-.03*	.85
8. When both parents have sickle cell trait, what is their chance with each pregnancy of having a child with SCD	.31	.84
9. The only way that you can get SCD is:	.45	.84
10. If you have a friend with SCD, you can catch it from them by:	.35	.84
11. How many genes must someone get to have SCD	.44	.84
12. A baby can be affected by sickle cell disease (SCD) if:	.44	.84
13. A baby can be affected by beta-thalassemia if:	.24*	.84
14. How do you get SCD?	.50	.84
15. How do you think Beta-thalassemia is passed from person to person?	.49	.84
16. How do you think SCD is passed from person to person?	.48	.84
17. Which gender do you think is more likely to have these diseases?	.18*	.85

Table 5-22 –*Continued*

18. Persons with SCT often develop SCD	.49	.84
19. Sickle Cell Trait (SCT) is an illness	.44	.84
20. People with SCT have a mild form of SCD	.33	.84
21. What is the only way to figure out if a person has SCT or Beta-Thalassemia trait?	.58	.84
22. If your results show that you have inherited a gene for SCD this means	.48	.84
23. If your results show that you have inherited a gene for Beta-Thalassemia, this means	.19*	.85
24. A negative sickle cell carrier test means:	.28*	.84
25. Sickle Cell Disease (SCD) can cause	.50	.84
26. To what extent do you agree or disagree that SCD can impact a child's school performance?	.53	.84
27. Sickle Cell Disease (SCD) is cured by:	.15*	.85
28. Who would you say is affected by SCD?	.34	.84
29. Who gets SCD in the U.S.?	.47	.84
30. Thinking about how common SCD is, among African Americans in the U.S., would you say it affects...	.15*	.85
31. Among African Americans SCT occurs approximately in	.21*	.84
32. How can Sickle Cell Disease (SCD) be prevented?	.41	.84
33. The best way to prevent Sickle Cell Disease (SCD) is by?	.41	.84
34. How often do people have medical complications from SCT?	.16*	.85
35. Do you think it is possible that your partner/spouse may be a carrier of Beta-Thalassemia?	.03*	.85
36. Do you know your SCT status?	.38	.84
Health Beliefs		
Severity		
1. Sickle Cell Disease (SCD) is a serious disease	.66	.83
2. Having a child with SCD would be very scary	.76	.75
3. My life would change if my child had SCD	.73	.77
Susceptibility		
4. My children are at risk for Sickle Cell Disease (SCD)	.63	.89
5. Sickle Cell Disease (SCD) could happen in my family	.65	.89
6. I may be a carrier of Sickle Cell Trait (SCT)	.78	.87
7. My partner may be a carrier of Sickle Cell Trait (SCT)	.78	.87
8. I may be a carrier of Beta-Thalassemia	.74	.87
9. My partner may be a carrier of Beta-Thalassemia	.74	.87
Benefit		
10. It is useful to know if I have Sickle Cell Trait (SCT)	.84	.82
11. It is useful to know if my partner has Sickle Cell Trait (SCT)	.88	.81
12. It is useful to know if I have Beta-Thalassemia trait	.84	.82
13. It is useful to know if my partner has Beta-Thalassemia trait	.87	.82
14. Knowing the risk of having a child with SCD would change how I choose my partner	.24*	.88

Table 5-22 –*Continued*

15. Knowing the risk of having a child with SCD would change how I plan a pregnancy		.28*	.96
Barriers			
16. I would rather not know if I had Sickle Cell Trait (SCT)		.60	.81
17. I would rather not know if I had Beta-Thalassemia Trait		.60	.81
17. I am afraid of finding out if I have Sickle Cell Trait (SCT)		.63	.81
18. I am afraid of finding out if I have Beta-Thalassemia Trait		.65	.81
19. Testing for Sickle Cell Trait (SCT) is painful and difficult		.58	.82
20. Testing for Beta-Thalassemia Trait is painful and difficult		.55	.82
21. My partner would be hard to convince to have testing		.52	.82
22. I would not want to pay for Sickle Cell Trait (SCT) testing if it is not paid for by insurance		.42	.84
23. I would not want to pay for Beta-Thalassemia Trait testing if not paid for by insurance		.41	.84
Attitudes Toward Screening			
I think participating in a carrier screening for sickle cell disease is...'			
Bad	Good	.79	.91
Unimportant	Important	.80	.91
Alarming	Reassuring	.75	.91
Unwise	Sensible	.81	.91
Undesirable	Desirable	.75	.91
Unpleasant	Pleasant	.58	.93
Discriminatory	A privilege	.69	.92
Harmful	Beneficial	.82	.91
2. 'I think participating in a carrier screening for Beta-Thalassemia is...'			
Bad	Good	.81	.92
Unimportant	Important	.83	.92
Alarming	Reassuring	.82	.92
Unwise	Sensible	.83	.92
Undesirable	Desirable	.78	.92
Unpleasant	Pleasant	.57	.94
Discriminatory	A privilege	.72	.93
Harmful	Beneficial	.83	.92
Attitudes Toward People With SCD			
1. Do you think everybody should know their carrier status?		.10*	.88
2. Do you know your carrier status?		.13*	.85
3. Will a person's SCD carrier status influence your decision to be friends with him or her?		.47	.85
4. Will a person's beta-thalassemia carrier status influence your			

Table 5-22 –*Continued*

decision to be friends with him or her?	.50	.85
5. Will a person's SCD carrier status influence your decision to date him or her?	.77	.83
6. Will a person's beta-thalassemia carrier status influence your decision to date him or her?	.75	.83
7. Will partner's SCD carrier status influence your decision to marry him or her?	.76	.83
8. Will partner's beta-thalassemia carrier status influence your decision to marry him or her?	.76	.83
9. If a person has SCD would you be friends with him or her?	.36	.82
10. If a person has SCD would you date him or her?	.72	.84
12. What should be done by a couple when they discover that their carrier status predispose them to having children with SCD?	.41	.86
Screening Behaviors		
1. Have you ever undergone carrier screening for SCD?	.18*	.65
2. If No, would you be interested in undergoing carrier screening for SCD?	.68	.25
3. Have you ever had a carrier screening for Beta-Thalassemia?	.21*	.65
4. If No, would you be interested in participating in carrier screening for Beta-Thalassemia?	.67	.26

* items deleted due to low correlations

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Biographical Information

Marcella Smith was born in Belize Central America in 1977. She graduated with honors from Louisiana State University in Shreveport in 2007 with a Bachelor of Science in Business Administration and her Master's Degree In Social Work with a concentration in Community and Administrative Practice from the University of Texas at Arlington in 2010. In the fall of 2010, she began her doctoral coursework at the University of Texas at Arlington School of Social Work. She has served as a Research Assistant working on several research projects regarding Trauma informed Practice and youth in foster care. She has also served as a Teaching Assistant and Adjunct Instructor for in Human Behavior in the Social Environment, Human Behavior in Diverse Populations, Brain and Behavior, Introduction to Social Work, Personal Relationships, Research and Evaluation Methods, and Advocacy and Social Policy. The doctoral degree will be conferred upon her in May 2015. While in the PhD program, she has worked on several manuscripts and has produced one scholarly publication on Sickle Cell Disease in *Health and Social Work,* has another under review in the *Journal of Social Work and Public Health*, and one under review in *Child & Adolescent Social Work*. She has also presented her research as well as other co-authored projects at the Council for Social Work Education Annual Program Meeting and the Society for Social Work Research Annual Conference-the profession's two leading conferences in academia, Society for Prevention Research, and the 7th International Conference on Social Work in Health and Mental Health. Her research interest includes minority and adolescent health, heath disparities, Sickle Cell Disease prevention, genetic counseling, and program and scale development and evaluation. She hopes to make a difference through her passion for teaching and research post graduation.