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## **An Examination Of African American College Students' Knowledge And Attitudes Regarding Sickle Cell Disease And Sickle Cell Disease Carrier Testing: A Mixed Methods Study**

Kai Anika Stewart  
*University of Alabama at Birmingham*

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AN EXAMINATION OF AFRICAN AMERICAN COLLEGE STUDENTS'  
KNOWLEDGE AND ATTITUDES REGARDING SICKLE CELL DISEASE AND  
SICKLE CELL DISEASE CARRIER TESTING: A MIXED METHODS STUDY

by

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A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,  
in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2007

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AN EXAMINATION OF AFRICAN AMERICAN COLLEGE STUDENTS'  
KNOWLEDGE AND ATTITUDES REGARDING SICKLE CELL DISEASE AND  
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KAI ANIKA STEWART

HEALTH EDUCATION AND HEALTH PROMOTION

ABSTRACT

Approximately, 80,000 Americans are affected by sickle cell disease (SCD) and it is the most common inherited blood disorder in the United States. SCD is most prevalent among individuals of African, Mediterranean, Middle Eastern, and Asian Indian ancestry; however, statistics suggest that in the United States, African Americans are disproportionately affected by SCD (Sickle Cell Disease Association of America (SCDAA), 2007). Nearly, 1 in 400 African Americans is born with SCD; in addition, 1 in 12 African Americans is born with sickle cell trait (SCT) (National Human Genome Research Institute (NHGRI), 2007). Two carriers of the trait have a 25% chance of having an unaffected child, a 50% chance of having a child who is also a carrier, and a 25% chance of having a child with SCD. However, many African Americans lack knowledge about SCD and SCT and are unaware of their carrier status.

The purpose of this two-phased sequential mixed methods study was to explore African American college students' beliefs, attitudes, and knowledge of sickle cell disease (SCD) genetics, and of sickle cell trait (SCT) and SCD carrier testing. This purpose was accomplished by surveying 191 African American men and women between the ages of 19 and 30 years and then exploring those results in more depth through follow-up interviews with 8 purposefully selected individuals from the first phase. In the 1st phase, quantitative research questions addressed the relationship of African American

college students' current level of knowledge and attitude about SCD and SCT, attitude toward SCD carrier testing, and their intention to participate in carrier testing at various sites. A stepwise multiple regression analysis was used to determine which of these variables contributed most significantly to the participants' decision to participate in carrier testing. In the 2nd phase, qualitative interviews with purposefully sampled individuals who participated in testing were used to explore the significance of participants' attitude toward carrier testing. There have been few studies published that examined the knowledge and beliefs of young adults regarding SCD and SCD carrier testing. It was determined that the major factors that contributed to the students' intention to participate in SCD carrier testing were attitude toward carrier testing, lack of knowledge regarding SCD and SCD carrier status, family history, cost, time and opportunity. It was revealed that the participants supported carrier testing and viewed SCD carrier testing for young adults as valuable. However, greater community health education about SCD and SCD carrier testing was desired. The implications for health education and promotion research are to a) increase the SCD genetic knowledge of young adults in the African American community and b) increase opportunities for minority populations to be informed of SCD carrier testing.

## DEDICATION

To my parents, Carlton and Barbara Stewart, for their constant, love, support, sacrifice, and prayers throughout my life. To my brother and sister, Chaka and Nini Stewart, for all of their love and support. This was all for them.

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## LIST OF ABBREVIATIONS

AMA	American Medical Association
ANOVA	Analysis of Variance
CF	Cystic Fibrosis
FCT	Feelings about Carrier Testing
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HOS	Health Orientation Scale
IOM	Institute of Medicine
IRB	Institutional Review Board
MMR	Mixed Methods Research
MRA	Multiple Regression Analysis
NIH	National Institutes of Health
QUAL	Qualitative
QUAN	Quantitative
SCD	Sickle Cell Disease
SCDF of GA	Sickle Cell Disease Foundation of Georgia
SCT	Sickle Cell Trait
TB	Tuberculosis
TRA	Theory of Reasoned Action
TSD	Tay- Sachs disease

## CHAPTER 1

### INTRODUCTION

In 2006, the National Human Genome Research Institute noted that in the United States, sickle cell disease (SCD) is the most common inherited blood disorder. Although approximately 80,000 Americans have SCD, about 1 in 400 African Americans is born with SCD; in addition, 1 in 12 African Americans is born with sickle cell trait (SCT), which means that they are carriers of the disease (National Human Genome Research Institute, 2007). SCD is particularly common among individuals of African, Mediterranean, Middle Eastern, and Asian Indian ancestry; however, statistics suggest that in the United States, African Americans are disproportionately affected by SCD (SCDAA, 2007).

Complications of SCD are also a major health problem worldwide for an estimated 120,000 to 250,000 affected infants born annually (Olney, 1999). Because the gene is passed down through the generations, both the mother and the father must pass on the defective form of the gene for the child to be affected. Two carriers of the trait have a 25% chance of having an unaffected child, a 50% chance of having a child who is also a carrier, and a 25 % chance of having a child with SCD (Bojanowski & Frey, 2006).

## Statement of the Problem

Public health issues and policies associated with SCD vary widely by population. Because SCD is not well known or recognized by many individuals as a significant health problem with major complications, a large number of African Americans are carriers of the trait but are unaware of their status. It is particularly important for individuals with SCT to understand the implications for reproduction.

After reviewing the sparse amount of literature available regarding African Americans and SCD, two significant gaps in the literature were found. First, few empirical studies examined the SCD carrier testing or identification practices among African Americans. Second, even fewer studies addressed the factors that would either enable or prohibit the participation of African Americans in SCD carrier testing. It has been inferred by researchers that the SCD education and screening programs of the past may have left a legacy of misinformation, mistrust, and disenchantment among African Americans that has greatly impacted individuals' current perspectives on SCD and has also affected SCT and SCD carrier testing utilization patterns (Hill, 1994; Markel, 1997; Wailoo, 2001). Because of the lack of recognition of the impact of SCD and SCT on reproductive health, it is important to build on the literature related to this population.

### *Current SCD Carrier Testing Programs*

The United States Preventative Services Task Force (1996) noted that screening for sickle cell disorders is usually discussed with respect to two target populations, those of neonates and adults of reproductive age. Although campaigns to increase SCD carrier

testing among women and men of reproductive age have been ongoing, far less attention has been given to the perspectives of young African American men and women of reproductive age who are possibly predisposed to SCT. It has been suggested that reproductive decision making in the area of recessive disorders is optimally made during the preconception period (Barlow-Stewart, Proos, & Howell, 2003); however, there are great difficulties in informing persons of childbearing age of the availability and relevance of genetic carrier testing (J. Andrews & Wilson, 1996). These difficulties include facilitating carrier testing, marketing to and attracting the target audience, and tracking future reproductive decision making.

There has been much debate surrounding the value of screening for sickle cell disorders in persons of reproductive age. Critics highlight the fact that, in the past, sickle cell screening programs have failed to adequately educate patients and the public about the significant differences between SCT and SCD (Bowman, 1983). In addition, little evidence that carrier testing, and subsequent genetic counseling of young adults will be remembered throughout the individual's reproductive life, influence partner selection, alter use of prenatal testing, or ultimately reduce the rate of births of affected children (Bowman; Gehlbach & Morgenstern, 1988).

Supporters of using carrier testing and subsequent genetic counseling argue that these outcomes should not be used as measures of effectiveness because the objective of such testing and counseling is to facilitate informed decision-making by prospective parents (Bowman, 1983; Gehlbach & Morgenstern, 1988; Steinberg & Embury, 1986). J. Andrews and Wilson (1996) noted that regardless of evidence suggesting that such

counseling does not reduce the number of affected offspring, health care providers, including primary care providers, obstetricians/gynecologists, and genetic counselors, are responsible for making individuals aware of their diagnoses, assessing and informing them of the risk to future offspring, and providing recommended methods for reducing that risk. Whitten (2001) argued that individuals with SCT deserve to have the option of being made aware that they have SCT and have the ability to make informed decisions that they believe are in their best interest. The failure to provide adequate services can be viewed as the abridgment of two rights: the right to know and the right to decide. Nonetheless, these issues are being debated by a variety of experts in the field (Duster & Beeson, 1998) who have not investigated the perspectives of young African American men and women possibly predisposed to SCT.

#### *History of SCD Carrier Testing*

The Sickle Cell Disease Control Act of 1972 initiated SCD education and screening programs in the United States. It is not clear whether the adverse history of the SCD education and screening programs has influenced the knowledge and beliefs of present-day young persons of color with regard to SCD genetics, carrier testing, and carrier testing practices. Researchers have suggested that the Sickle Cell Anemia Control Act of 1972 increased the knowledge and awareness of SCD among the general public, but it also provoked many new controversies (Hill, 1994; Wailoo, 2001). Wailoo speculated that the early sickle cell screening programs may have been criticized because of the apparent racism surrounding the disease (Wailoo, 2001). Atkin and Ahmad (1998) stated that public recognition of sickle cell disorders in the United States was

accompanied by the suggestion that the existence of SCD among African Americans proved genetic inferiority.

Because of the lack of funding and public support, among other issues, there is limited information about the knowledge, perceptions, and attitudes about SCD and SCT among individuals in high-risk groups who often do not know their own trait status (Boyd, Watkins, & Price et al., 2005; Treadwell, McClough, & Vichinsky, 2006). Because the purpose of carrier testing is to provide genetic information to individuals or couples about their carrier status with regard to genetic disorders, I examined African American knowledge, beliefs, and attitudes toward SCD and SCT and toward SCD carrier testing. Research indicates that, although SCD carrier testing has been available in the United States for over 30 years, carrier testing rates among adult African Americans have consistently been low (Beeson & Doksum, 2001; Duster & Beeson, 1998).

### Purpose Statement

The purpose of this two-phased sequential mixed methods study was to explore college-aged African Americans' beliefs, attitudes, and knowledge about SCD genetics, SCT, and SCD carrier testing. This investigation was accomplished by surveying 191 African American men and women 19-30 years old and then exploring those results in more depth through follow-up interviews with 8 purposefully selected individuals from the first phase. In the first phase, quantitative research questions addressed the relationship among African American college students' current level of knowledge and attitude about SCD and SCT, their attitude toward SCD carrier testing, and their intention to participate in carrier testing at various sites. A stepwise multiple regression analysis

was used to determine which of these variables contributed most significantly to the participants' decision to participate in carrier testing. In the second phase, purposefully sampled individuals who had participated in testing were engaged in qualitative interviews to explore the significance of participants' attitude toward carrier testing. There have been few studies published that examined the knowledge and beliefs of young adults regarding SCD genetics and carrier testing.

## Research Questions

### *Quantitative Research Questions*

Research Question 1: What is African American college students' level of knowledge about SCD, attitude regarding SCD and SCT and regarding SCD carrier testing, level of perceived susceptibility to SCT, and perceived severity of SCT?

Research Question 2: Is there a relationship between African American college students' level of knowledge about SCD, attitude regarding SCT and SCD carrier testing, level of perceived susceptibility to SCT, or level of perceived severity of SCT and their intention to participate in SCD carrier screening?

Research Question 3: Do African American college students with certain levels of (a) perceived risk for SCT and (b) concern for receiving a positive SCT result have greater intention to participate in SCD carrier testing?

Research Question 4: Is there a relationship between African American college students' support of SCD carrier testing and their intention to participate in SCD carrier testing?

*Qualitative Research Questions*

*Central Question*

Research Question 5: Why do African American college students participate in SCD carrier testing?

*Subquestions*

Research Question 5a: How did the statistically significant factors identified in Phase 1 contribute to African American college students' intention to participate in SCD carrier testing?

Research Question 5b: What are the perceptions of African American college students who test positive or negative for SCT?



## Theoretical Framework

Constructs derived from the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA) served as the theoretical framework for this study. These constructs are discussed in the next two subsections.

### *Health Belief Model*

The HBM was developed in the 1950s in an attempt to explain the failure of participation by individuals in preventative health behaviors such as various health screenings and immunization programs (Poss, 2001). Developed by Rosenstock, Hochbaum, Leventhal and Kegles (Rosenstock, 1974), the HBM is a value expectancy model that suggests that whether individuals choose to engage in a certain behavior such as being screened, depends on how much they value a particular outcome such as knowing their SCT status, as well as on their evaluation of how a particular behavior will achieve that outcome. If the outcome is the avoidance of a health condition such as having SCT, then the individual must feel vulnerable to the condition ( a vulnerability defined as *perceived susceptibility*), through family history of SCD and must judge it to be potentially serious (a judgment defined as *perceived severity*), the severity would be viewed as consisting of actually having SCT (Poss).

However, the HBM does not account for normative or cultural factors that may be important in explaining health-seeking behavior. Because the HBM lacks a culturally specific concept, Rubel and Garro (1994) questioned whether it can by itself explain behavior in various cultural settings because it lacks a culturally specific concept. The

experiences of African American women with SCT exposed the inferred assumptions of this model as it is applied to genetic screening in order to prevent diseases (Hill, 1994).

According to Hill (1994), the model, as it relates to SCD carrier testing, rests on several assumptions. These assumptions are as follows: (a) medical knowledge is accurate, accessible, and acceptable; (b) child-bearing occurs within marriage and is planned; (c) women have enough power in their lives and relationships to control the transmission of genetic diseases; and (d) education can override strong cultural values.

### *Theory of Reasoned Action*

The TRA emphasizes the relationship among attitudes, subjective norms, intentions, and behaviors. According to Fishbein (1979), behavior is a function of a specific intention. The author stated that attitudes (such as behavioral beliefs and outcome evaluation) and subjective norms (such normative beliefs and motivation to comply) toward a specific behavior influence intention. *Attitude* consists of a person's belief that a behavior leads to certain outcomes, as well as of the person's evaluation of these outcomes. Examining this theory in context with participation in carrier testing reveals that an individual's participation in the screening process leads them to knowing about their carrier status and to evaluating the results of the testing, whether favorable or unfavorable. The *subjective norm* is composed of the person's belief that specific individuals or groups think that he or she should or should not perform the behavior (e.g. being screened), as well as of the person's motivation to comply with these specific individuals. The conceptual model for the study is presented in Figure 1.

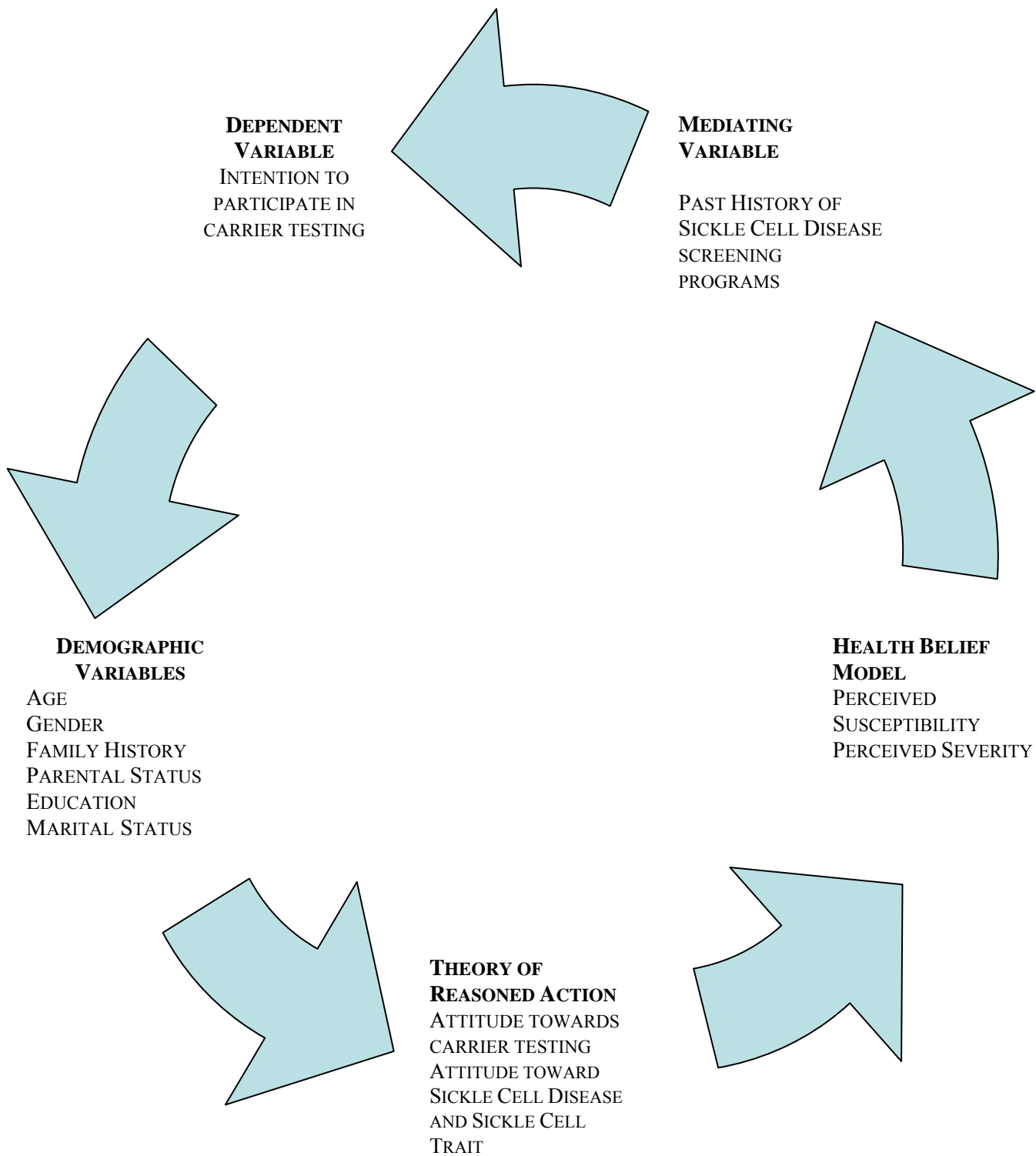


Figure 1. Conceptual Model

### *Study Model*

The HBM and TRA, along with proposed models combining the two, have been used successfully to study participation in screening programs, as well as to examine the health behaviors and beliefs of culturally distinct groups (Poss, 2001). Both have common characteristics and are based on a value expectancy theory of behavior. Likewise, both models also posit that beliefs about behavioral consequences should predict behavior (Poss).

Doukas, Localio, and Li (2004) conducted a quantitative study to determine the values, beliefs, and attitudes influencing the intention of men to undergo or defer genetic testing for prostate cancer risk. The authors who merged the HBM and TRA to form the model for genetic decision-making for their study, the researchers reported that the combined model allowed for a fuller understanding of how persons make decisions about behaviors on the basis of their values, attitudes, social influence factors, and beliefs (Doukas et al.).

Ham (2006) conducted a quantitative study to determine the factors affecting the intention of Korean women to receive a mammogram. The researcher also combined several constructs from the HBM and the TRA in development of the theoretical framework. It was determined that the model combining HBM and TRA was more effective in predicting future mammography intention than in explaining past experience. In a study conducted by Poss (2001), factors affecting Mexican migrant workers' participation in tuberculosis screening were investigated; the author found that variables

derived from both the HBM and TRA were necessary to best predict the dependent variable, screening.

The constructs from the HBM and TRA that were selected as the theoretical framework for this study were perceived susceptibility and perceived severity (HBM), along with attitude (TRA). The perceived susceptibility construct from the HBM was included in the model because of the nature of SCD. Because SCD is an inheritable disorder, an individual genetically predisposed to the sickle cell gene has a greater chance of having the disease or trait. For SCD and other genetic disorders, there are no risk factors or behaviors that can be modified to prevent being identified as a carrier. Perceived severity was important to include in the model, as well. Perception of individuals regarding the seriousness of being identified as a carrier may positively or negatively influence their decision-making process. If being a carrier has no profound impact on their daily living or functionality, identification of carrier status may not be a priority.

Because of the history of racism, discrimination and poor testing practices related to past SCD screening programs, the attitude construct was essential to this study. Assessing the behavioral beliefs of the individuals regarding SCD carrier testing and the way in which those beliefs are personally evaluated is a necessary component of the study model. On the basis of the literature review and theoretical framework, individual health beliefs were studied in relation to African American college students' intent to participate in SCD carrier testing. The constructs of perceived susceptibility, perceived severity, and attitude were chosen as the theoretical framework for this study because it is

believed that understanding the health and cultural beliefs that influence the meaning of genetic testing information may be an initial step in understanding the decision-making process leading to carrier testing.

### Significance of the Study

Sorenson and Chevront (1993) proposed that, with regard to genetic testing, there are four major areas of research that require contributions from health education and health promotion studies: (a) utilization of genetic services such as genetic testing and counseling, (b) effectiveness of genetic counseling, (c) emotional, attitudinal, and behavioral outcomes of genetic testing, and (d) sociological outcomes of genetic testing. It is believed that this study addressed two of these issues in relation to carrier testing for SCD; those issues are: (a) utilization of genetic testing and (b) emotional, attitudinal, and behavioral outcomes of genetic testing.

This study identified on a very small scale both the individuals who were interested in SCD carrier testing and the various reasons for participation. It is important to identify utilization patterns as a way of assisting SCD providers with developing marketing strategies and creating educational materials with tailored messages to a population in need. Additionally, the study identified individuals' preferences for where and how they receive testing, such as through participation in health fairs or other community events.

Second, the findings of this study revealed the cultural beliefs and values of some African Americans about, and SCD, SCT and about SCD carrier testing. This study

illustrated the value of using both quantitative and qualitative methods to gain a deeper understanding of the decision-making process of individuals participating in SCD carrier testing. Finally, this study provides support for the need to continue carrier testing for individuals of reproductive age, particularly in communities that have limited health resources. There has been a significant amount of literature published on the nuances of carrier testing for comparable diseases that affect specific populations, such as cystic fibrosis (CF) and Tay-Sachs disease (TSD); however, the amount of published research on carrier testing for SCT alone has been less than adequate. Moreover, the majority of published research that addresses attitudes toward genetic screening or carrier testing focuses on women (Doksum, Joseph, Watson, Kim & Brand, 2004). It is also important to understand how these issues affect men of reproductive age. Additionally, a large majority of research surrounding the social and behavioral aspects of carrier testing was centered on populations outside the United States. Also, most research available on carrier testing is quantitative in nature and may not reveal sensitive underlying themes that can best be captured by qualitative methods. It is essential for researchers in health education and promotion to assess the genetic knowledge, attitudes, and beliefs held by the public and to identify areas of misconception or concern that may benefit from public health intervention (Wang, Bowen, & Kardia, 2005).

#### Study Limitations

1. The study includes a small sample thus results may not be generalizable beyond the specific population from which the sample was drawn.

2. The sample was drawn from a limited geographic area (e.g., Atlanta, GA and Savannah, GA).
3. The measures used were developed for this study and therefore had not been validated previously.

#### Assumptions

1. Participants attending health fairs at scheduled sites are representative of the target population.
2. Participants comprehended and completed each survey to the best of their ability.
3. Participants responded honestly to each question on survey and interview protocol.



## Definition of Terms

*Sickle cell disease (SCD)* is an inherited blood disorder in which the red blood cells are shaped like a sickle as a result of a predominance of hemoglobin. The disease is most commonly found in African Americans in the United States.

*Sickle cell trait (SCT)* is an inherited condition in which both Hemoglobin A and Hemoglobin S are produced in the red blood cells. SCT is a carrier state and not a disease.

*Carrier testing* is a type of genetic testing used to determine whether an individual carries one copy of an altered gene for a particular recessive condition. Carrier testing is done because of a family history of a genetic disorder or because of racial or ethnic background.

*Genetic testing* is the laboratory analysis of DNA, RNA, or chromosomes. Genetic testing is done to predict risk of disease, screen newborns for disease, identify carriers of genetic disease, and establish prenatal or clinical diagnosis or prognosis, as well as to direct clinical care.

*Health Belief Model (HBM)* is a theory developed in the 1950s in an attempt to explain the failure of people to participate in preventative health behaviors such as screening and immunization programs. The theory was developed by Rosenstock, Hochbaum, and Leventhal (Rosenstock, 1974)

*Theory of Reasoned Action (TRA)* is a theory that emphasizes the relationship between attitudes, subjective norms, intentions, and behaviors. The TRA was developed by Fishbein and Azjen (1975).

*Tay-Sachs disease (TSD)* is an autosomal recessive disorder of the central nervous system in which symptoms develop within the first 6 months of life and end fatally 3 to 4 years later. Apparently normal at birth, most children with TSD show signs of neurological deterioration sometime in their first year of life. TSD is most common in individuals of Ashkenazi Jewish ancestry.

*Cystic fibrosis (CF)* is an autosomal recessive disorder characterized by chronic lung disease and pancreatic insufficiency and is the most common genetic disorder among the U.S. Caucasian population.

*Reproductive genetic testing* is a genetic test that is used to provide prospective parents with information about their chances of having a child with a specific genetic disorder or characteristic in a current or future pregnancy. It includes carrier testing, prenatal genetic testing (e.g., testing of fetal cells obtained through procedures such as amniocentesis) and preimplantation genetic diagnosis such as testing done on embryos produced through in vitro fertilization

## Chapter Summary

The purpose of this chapter was to present the research problem, give a brief overview of SCD and SCT, and discuss both the history of SCD carrier testing and current carrier testing practices. Also, this chapter introduced the purpose of the study, the research questions guiding the study, the rationale for utilizing a mixed method study design, the theoretical framework, and the significance of the study. The next chapter provides a review of published literature about: (a) carrier testing and psychosocial issues related to carrier testing, (b) carrier testing for genetic disorders in specific populations, and (c) SCD carrier testing.

## CHAPTER 2

### LITERATURE REVIEW

This chapter describes literature relevant to the research purposes of this dissertation. The chapter is organized into three main sections: (a) Overview of Carrier Testing, (b) Carrier Testing for Genetic Disorders in Specific Populations, and (c) Sickle Cell Disease and Carrier Testing

#### Overview of Carrier Testing

Genetics explores the manner by which specific traits are passed from generation to generation and the way in which they are expressed (Institute of Medicine [IOM], 1994<sup>b</sup>). Modes of inheritance of the altered gene can be autosomal dominant, autosomal recessive, or X linked. Autosomal recessive disorders such as SCD result in illness only if a person receives two copies of the abnormal gene, one from each parent; in this situation both parents are carriers. Individuals who carry only one copy of the abnormal gene are called heterozygotes, or carriers, and are generally without symptoms or illness (IOM, 1994). Screening or testing programs can be either universal, so that the whole population is covered or selective so that people satisfying certain parameters are screened or targeted programs, which certain individuals are screened based on a specific criteria (Davies & Oni, 2001).

Carrier testing specifically is a type of genetic testing used to determine whether an individual carries one copy of a gene-altered gene for a particular recessive condition. Carrier testing can be undertaken at a variety of times during life and for different purposes: (a) during the neonatal period to identify an infant with genetic disease and enroll the infant into a program of comprehensive care early enough to prevent mortality and reduce morbidity; (b) during the pregnancy period, to give an opportunity for informed genetic choice, offer access to prenatal diagnosis, and (where acceptable) provide facilities for termination of an affected fetus; and (c) during the preconception period to inform population of their genetic inheritance and the possible consequences and to enable premarital decision making (Davies & Oni, 2001). The current study focuses on adult carrier testing for SCD during the preconception period.

### *Benefits of Carrier Testing*

Most individuals seeking carrier testing are aware that they are related to an individual with the disease or to someone who is known to be a carrier or are aware that they are at higher risk because of racial or ethnic background. For some, the benefits of carrier testing include (a) the possibility of reassurance that they are not carriers of the gene or (b) information that may be used in prevention. Prevention may include avoiding marriage to (or reproduction with) another carrier or engaging in reproductive planning via prenatal diagnosis and selective abortion, artificial sperm insemination by a donor, ova or embryo donation, adoption, surrogacy, or experimental procedures (IOM, 1994<sup>b</sup>).

Current debates around carrier testing for SCD and other genetic disorders focus on whether the goals are best accomplished by screening preconceptional adults, pregnant

women, or by screening neonates. Some suggest that it would be better for individuals to know their risk before becoming pregnant. Adversely, others argue that individuals not facing a pregnancy will not value this information until they are planning or starting a family (IOM, 1994<sup>b</sup>).

Past carrier testing programs have illustrated the advantages of providing community education before testing people with no previous family history of the condition in question (Davies & Oni, 2001; Hegwer, Fairley, Charrow, & Ormond, 2006; IOM, 1994). For individuals considering carrier testing, genetic counseling provides information regarding what they need to know to determine whether testing is warranted, as well as facts about the risk status, the benefits and barriers of testing, the limitations of available testing, and the implications of the test results. Biesecker (2001) defined *genetic counseling* as a psychoeducational process centered on genetic information. Within a therapeutic relationship established between provider and client, the client is helped to personalize technical and probabilistic genetic information. In conjunction with carrier testing, genetic counseling has two goals; the first goal is to provide information to reduce birth defects and genetic disorders such as SCD, and the other goal is to improve the psychological well-being of clients adapting to a genetic condition or risk such as being a SCD carrier (Biesecker). Both goals emphasize that clients should make their own reproductive decisions; however, the former goal relies on individuals, making decisions that will reduce the impact of genetic disorders. Biesecker believed that the way in which this information is presented might have a profound effect on an individual's decision to participate in testing.

## *Barriers to Carrier Testing*

In general, substantial advances in genetics in recent decades have presented opportunities for understanding and promoting health, lowering mortality and morbidity, and preventing diseases. Integrating genetic services such as carrier testing into health programs can be a difficult task not only because of the lack of an appropriate infrastructure but also because of certain basic conceptual conflicts and dilemmas that must be addressed (Lin-Fu & Lloyd-Puryear, 1999). These issues include the lack of knowledge about carrier testing; the accessibility of carrier testing, beliefs about carrier testing; and the social, ethical, and legal implications of carrier testing.

### *Lack of genetics knowledge*

Past research has suggested that the lack of knowledge of the general public regarding genetics and genetic testing is a major problem in providing genetic services. Consequently, promoting access to genetic services for a population that has little or no knowledge of genetics has little value. Without some degree of genetics knowledge and a clear understanding of the limitations and potential risks associated with genetic testing, truly informed decisions could not be made (Lin-Fu & Lloyd-Puryear, 1999).

Kalfoglou, Suthers, Scott, and Hudson (2004) conducted a multimethod study that utilized focus groups, telephone interviews, and Internet surveys nationwide to assess Americans' awareness, knowledge, and attitudes about reproductive genetic testing. A sample of 6,957 participants consisted of Black, White, and Hispanic men and women, ages 18 to 50. The researchers reported that the majority of participants 83 % had not

heard of carrier testing and that 89% had heard of prenatal genetic testing in general. Kalfoglou et al. reported that focus group participants generally understood that genetic testing could be used to make reproductive decisions; however, there were some misconceptions about the use of carrier testing. One third of the participants in the 21 focus groups believed that carrier testing is unnecessary unless there is some family history of genetic disease. Additionally, the participants believed that carrier testing was a routine part of prenatal care (i.e., was not requested) and that patients do not have a choice. The participants also held the belief that carrier testing is done to diagnose a condition in the fetus, rather than to provide information about the individual tested and the risk for current or future pregnancy. Also, one third of the focus group participants believed that carrier testing is a routine part of premarital blood testing.

### *Beliefs about Carrier Testing*

Telfair and Nash (1996) proposed that a major component in delivering effective genetic services is the understanding of what factors contribute to how services are offered and received. It has been suggested that the way in which carrier testing is offered and the timing (i.e., preconceptional or prenatal) determine participation in testing and the reasons for participation. Some research suggests that as opposed to carrier testing offers made by mailed invitation or poster announcement testing offered face to face with the possibility of immediate testing can positively influence decision making (Henneman, et al. 2001). Preconception carrier testing (i.e. testing of individuals of reproductive age) does have its theoretical challenges in that general interest in carrier identification is limited because most people who have not had direct contact with a



person who has the condition (i.e., a family member) do not see themselves as being at risk for genetic conditions. Richards (1993) contended that one possible explanation is that individuals typically believe that they could not be carriers if they do not have close relatives with the disease.

Some researchers proclaim that the thought of being identified as a carrier of a genetic disorder can prohibit one from participating in carrier testing. Emery (2001) stated that conceptualizing carrier status can be problematic and that being identified as a trait carrier can have psychological consequences. Although everyone can carry unhealthy recessive genes, actual knowledge that one is a carrier of such a gene can be distressing (Fost, 1992). L. Andrews (1996) determined in a study of individuals' feelings toward carrier identification that being identified as a carrier of a recessive disorder like SCD generates anxiety, which can have a lasting impact on the individual. Moreover, women tended to exhibit more anxiety when they or their spouses were identified as carriers. L. Andrews also implied that, in some cases, learning genetic information about oneself had an impact on the participants' emotional well being and self-concept. Carriers typically have more negative feelings about their future health than members of the general population do. Some of the participants felt "defective" after obtaining unexpected information through genetic testing.

The health practices and circumstances of some cultures, (e.g., African Americans culture) may affect the access to or use of genetic testing (Doksum et.al, 2004). Some health-related studies of African Americans have proposed less frequent use of preventative care or tests (Hughes et al., 1997). Doksum and colleagues (2004) found that

African American women tended to have more positive attitudes about the benefits of genetic testing but that they also had more concerns about limitations and risks than women of other backgrounds (e.g., Caucasian and Hispanic) did; the researchers also indicated that the level of interest in genetic testing for breast or ovarian cancer susceptibility among African American women was high and was similar to that of the general population. In contrast, the interest level was low for actual use of carrier testing for SCD. Beeson and Doksum (2001) concluded in their study of African American SCT carriers and White CF carriers that in comparison with Whites and African Americans of higher socioeconomic status, African Americans of lower socioeconomic status were more concerned about limitations and risks of testing. Some investigations have found more negative attitudes about the medical community among African Americans than among Whites and Latinos; this difference was more evident in qualitative studies than in quantitative studies (Culver, Burke, Yasui, Duffy, & Press, 2001; Hill, 1994; Matthews et al., 2000). However, it was concluded that mistrust of the medical community was categorized differently by Black men and women; Black women did not show more distrust of the medical community but were more concerned about confidentiality. Black men were more likely to voice mistrust of the medical community (Beeson & Doksum; Duster & Beeson, 1998).

### *Accessibility to Carrier Testing*

No matter what aspect of genetics is discussed, it is impossible not to discuss the cost and financial issues related to genetic services such as carrier testing. Equity and access to genetic services in the United States is profoundly affected by cost and the role

of health insurance (IOM, 1994<sup>a</sup>). The United States is the only developed country that is without a social insurance plan or universal health care system that would provide basic healthcare for most or all of its citizens (IOM, 1994<sup>a</sup>). This deficit perpetuates problems of access and equity, especially for low- income or high- risk individuals who are self-employed, work part time, or are employed by small businesses and who may not be able to afford or obtain health insurance. Currently, access to and cost of genetic services has been skewed in favor of well-educated couples from the middle and upper income levels (American Medical Association [AMA], 1991). There are a disproportionate number of African Americans represented among individuals with low socioeconomic status and no insurance. For this subgroup, the substantial cost of genetic services and the lack of coverage from health insurance companies can limit access to these services. Lack of access by monetary means is not the only issue. As with other medical treatments, genetic services are generally not accessible to individuals who reside in rural communities. Some individuals seeking genetic testing and/or counseling pay out of pocket, either because they do not have insurance coverage for such services or because they fear improper use of the information by insurance companies or others. The cost for genetic diagnosis and testing is often a substantial sum. According to the National Institutes of Health [NIH], (2007) testing for genetic disorders can run from \$100 to \$2,000, depending on the nature and complexity of the test. Typically, SCD carrier testing is provided for free or at little cost by SCD community providers, county health departments, hospital-based programs, or private physicians.

## *Social, Ethical and Legal Implications of Carrier Testing*

*Social implications of carrier testing.* Some schools of thought proposed that genetic risks are a part of an individual's makeup; therefore, it is the individual's responsibility to act to protect his or her health and the health of future generations (Hallowell, 1999). Petersen (1998) argued that this responsibility is emphasized through carrier testing and genetic counseling. Both Hallowell (1999) and Petersen(1998) further contended that carrier testing and genetic counseling not only identify the precise risks to an individual's health (or to the health of their offspring) but, by promoting self-surveillance, also promise individuals control over these uncertainties. Hallowell suggested that it can be debated that, by labeling individuals as being "at-risk" and by presenting genetic risks as being manageable, carrier testing and genetic counseling imply that individuals are obligated to attempt to modify these risks.

*Ethical implications of carrier testing.* The dual themes of identification and cure that are evident in scientific medicine and public health could be seen as to implying a concern with prevention rather than as implying a concern with informed decision making (IOM, 1994<sup>c</sup>). Typically, the public health model is appropriate for the prevention of disease because it includes the requirement of certain interventions such as immunization, health communication strategies that warn individuals of health risk, or surveillance mechanisms. However, when the public health model is applied to genetics, many ethical conflicts arise; this is evident with infectious diseases such as HIV or TB, which can put society at large at risk by rapidly spreading to a number of people in a

limited period. In contrast, genetic diseases do not pose an immediate threat to society. The transmission of a genetic disorder to offspring does not have an immediate impact on society, but does create increased risk for future generations (IOM, 1994<sup>c</sup>). Thus, the concept of prevention does not fit most genetic disorders, because the disease itself is not being prevented; instead, the birth of an individual with the disease is prevented. Furthermore, individuals with a certain genetic risk may perceive genetic testing (i.e., carrier testing) as being a way to prevent individuals like themselves and therefore a disavowal of their own worth (IOM, 1994<sup>c</sup>).

Atkin & Ahmad (1998) explored this emerging tension between informed decision making and prevention with regard to hemoglobin carrier testing in Blacks in the United Kingdom; the authors contended that a major principle in public health is that primary prevention is better than secondary or tertiary prevention. However, the primary prevention of genetic diseases, more specifically genotype prevention, may be perceived as being close to eugenics- the elimination of minority ethnic groups, disabled individuals, and those deemed as socially undesirable, with the goal of having a supposedly pure and superior race. Therefore, if the role of public health in providing genetic services is going to increase, policy makers in this field must alter their view of primary prevention in certain circumstances (Lin-Fu & Lloyd-Puryear, 1999).

Atkin (2003) further examined the circumstances surrounding ethnicity and the term the *new genetics*. This term is derived from scientific researchers' increasing concern with the genetic basis of disease and the development of ways in which to identify what genes lead to certain conditions. Because of this new reality, there is an

apparent tension that emerges between informed decision-making and prevention. It has been implied by Atkin that screening for inherited genetic disorders, especially those that are differentially distributed by race and ethnicity, such as SCD, may be a “back door” to eugenics. Thus, there is a need for sensitivity to the fear of eugenics and for the preservation of personal decision making.

Lin-Fu and Lloyd-Puryear (1999), Whitten (2001), and Emery (2001) supported the concept that the goal of carrier testing for recessive disorders such as SCD is not to prevent the births of individuals with these disorders or to reduce the incidence of disease but to provide information to enable couples to make an informed choice in reproductive decisions and to support and care for children born with the condition. Atkin (2003) stated that debates about carrier testing center around the conflict between support for informed decision making and support for a decrease in the number of affected births. The implicit understanding is that a significant number of prospective parents will use their informed choice to make the “right decision” and abort or avoid affected children (Petrou & Modell, 1995).

*Legal implications of carrier testing.* Although possessing genetic information provides the promise of early detection and treatment of certain illnesses and disorders, it also poses risks. The possibility of genetic discrimination is a fear for all members of American society. The rise in genetic research and technology, spurred largely by the Human Genome Project, has resulted in the continuing expansion of the range of genetic tests and other genetic information available to physicians, insurance companies, employers, and the general public (Miller, 1998). Genetic tests can provide medical

information about an individual, including an individual's increased risk of future disease, disability, or early death. In the case of sickle cell disease, these tests can reveal information about an individual's carrier status (i.e., the likelihood of parents passing on to their children a genetic condition) and about the health of the individual's family members (Miller). If employers were permitted to hire employees based on genetic information, people might be unfairly barred or removed from employment for reasons that are unrelated to their ability to perform their jobs (Miller). Simultaneously, an influx of legislation has been prompted by a number of cases of health, life, and disability insurers using emerging genetic information to deny coverage, raise rates, and limit coverage (M.A. Hall & Rich, 2000). These factors can be particularly alarming for individuals with SCT and SCD as well as others. As cited by M.A. Hall & Rich in 2000, President Clinton signed an executive order that prohibits federal agencies and departments from using genetic information in any hiring or promotion decision. Clinton also endorsed the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, a bill that would extend similar protections to the private sector and to individuals purchasing health insurance. In the context of genetic screening of the public, there is no lowered expectation of privacy. Individuals' refusals to participate in genetic screening because they fear genetic discrimination have negative consequences not just for those individuals but also for scientific research in this area (Miller).

### Carrier Testing for Genetic Disorders in Specific Populations

This section explores literature published on carrier testing knowledge, beliefs, and attitudes about other autosomal recessive disorders affecting individuals of specific

racial/ethnic populations in comparison with those affected by SCD or SCT. The section provides examples of empirical studies that address issues relevant to carrier testing for Tay Sachs disease in Ashkenazi Jewish persons, Cystic Fibrosis in Whites, and SCD in African Americans.

### *Tay Sachs Disease and Carrier Testing*

Tay Sachs disease (TSD) is a genetic disorder that has its onset during the infancy period. Infants with TSD appear to develop normally for the first few months of life. Then, as nerve cells become distended with fatty material, a relentless deterioration of mental and physical abilities occurs. The conditions that characterize the disease are blindness, deafness, inability to swallow, atrophied muscles, and subsequent paralysis (National Institute of Neurological Disorders and Stroke, 2007). Other neurological symptoms include dementia, seizures, and an increased startle reflex to noise. A much rarer form of the disorder occurs in patients in their 20s and early 30s and is characterized by an unsteady walk and progressive neurological deterioration (National Institute of Neurological Disorders and Stroke). The disorder is most common in people of Ashkenazi Jewish ancestry. In its most severe form, death (caused by respiratory infection) typically occurs before the child reaches the age of 5 years. Currently, no treatment is known to alter the natural history of this disease (Gason et al., 2003)

### *History of TSD Carrier Testing*

The American Medical Association (1991) proclaimed that the TSD carrier testing programs of the 1970s have been the most successful screening programs for



genetic disorders. It was suggested that there were several factors that contributed to the success of this endeavor. First, the programs targeted a very small and well defined group, Ashkenazi Jews. Moreover, the test for TSD was very simple, accurate, and inexpensive. Additionally, the screening programs were preceded by health education campaigns targeting a clearly defined population and addressing the need for and nature of carrier testing. The program activities were pilot tested to ensure proper planning, which included the active involvement of key stakeholders such as community leaders and institutions. Additionally, the severe nature of the disease played a significant role in increasing participation. Because of the fact that TSD is an incurable, progressively degenerative disease that is fatal at an early age, it was not difficult to encourage active efforts to prevent births of TSD children. All of these factors contributed to the high percentage of participation in testing among this group. The apparent success of these programs led health practitioners to use this model as a basis for developing subsequent screening programs for other genetic disorders such as SCD (AMA, 1991).

Edelson (1997) offered an opposing view; that research stated that, although there is evidence that the Tay-Sachs programs were effective in educating people about their risks of having children affected by the disease and although some of the programs led to a decline in the birth rate of children with TSD, historical records suggest that Tay-Sachs screenings were not the success that has been reported. Edelson argued that the Tay-Sachs model may not necessarily be the most appropriate model to use in designing programs for the control of other genetic diseases. The following reasons were expressed:

- (a) The programs developed were primarily aimed at young Ashkenazi Jewish married couples who had not yet completed their families.
- (b) Programs were organized on a

community- by- community basis, usually stimulated by academic physicians at a local institution who had professional interests in TSD. (c) Programs were supported by both public and private funds; however, the programs were nearly always carried out under the guidance of local Jewish community groups, who were financial and social sponsors of the programs (Edelson).

Others have suggested that higher educational levels in a community generally translate into greater cooperation with mass screening programs. However, few, if any, data, exist that actually pertain to this idea. Furthermore, the information that is available suggests that other factors, specifically gender, played a much greater role in motivating cooperation. Gason and colleagues (2003) implied that the programs were highly supported by women who not only participated in carrier testing but also served as community advocates for TSD carrier testing. It has been documented that the experience in the TSD screening programs was nearly the opposite of what occurred in the SCD screening programs that were taking place simultaneously. There was little community education about SCD, programs were often led by government agencies, and providers frequently lacked training in testing procedures (Gason et al., 2003).

#### *Current Perspectives on Carrier Testing for TSD*

Gason et al., (2003) noted the vast amount of information available about the acceptability of TSD carrier testing done in the early 1970s. However, Gason and colleagues were interested in investigating the introduction of a TSD screening program in present times, because of the greater community interest in and concern with genetic testing; thus, they conducted a study with 710 male and female students, ages 15-18, who

attended Jewish day schools in Australia between 1998 and 2000. The participants attended multiple educational sessions during schooltime with the permission of the school. The educational sessions presented information on TSD, genetics, inheritance, prevalence in population, interpretation of results, and reproductive options. In addition, the participants were shown a 5- min. video illustrating parents' experiences of having a child with TSD. Within 2-10 days, the participants were offered an opportunity to get tested. A questionnaire was used to assess the participants' understanding of TSD and TSD genetics, and to evaluate their attitudes toward genetic testing for TSD. Also, the questionnaire measured the participants' predicted feelings should they be found to be a carrier, reasons for their decision to test, and choice of source for seeking further information. Gason et al., concluded that only 54% of the students answered all of the TSD knowledge, importance of TSD, and general genetics questions correctly. There were significant associations between level of knowledge and gender, attitudes about TSD genetic testing, their predicted feelings should they be found to be a carrier, and their decision to be tested. The students' decision to be tested was associated with a higher knowledge level. Female participants displayed a higher level of knowledge and were more likely to undergo carrier testing. Higher knowledge levels about TSD and TSD carrier testing were associated with lower levels of predicted anxiety about having a positive carrier status. Fear was the most common predicted feeling reported among 30% of the participants; they believed that they would be afraid if they tested positive for the TSD carrier trait. Ninety-one percent of the participants responded that they had a high level of acceptance about TSD genetic testing. The two most relevant reasons given for participants' decisions to get tested were identification of carrier status and desire to

have information for use with future partner. Ultimately, Gason et al., reported that the favorable attitudes toward TSD testing found among students in the 1970s were also found in their participants; however, there was a lack of community knowledge and concern about genetic testing. The strengths of that study were the large sample size and the low attrition rate of participants. A weakness of the study was the possible bias presented by the researchers. The study was conducted with high school students, under the age of 18, during their school day. The students may have felt coerced into participating in the study by researchers or school personnel. Depending on their beliefs about TSD testing, the students' parents may have also had an influence on their decision to participate in the study.

D'Souza et al. (2000) presented the findings of a community-based carrier-screening program for TSD; this program was implemented on the University of Wisconsin-Madison campus from 1978 to 1999. The Madison Community Tay-Sachs Screening Program was a collaborative, interdisciplinary program that organized and conducted periodic screening for TSD for the purpose of identifying Tay-Sachs carriers. The program tested 1,599 Ashkenazi Jewish men and women, ages 18-40, from 1978-1999. In 2000, surveys were administered to 102 individuals to assess current knowledge of TSD, awareness of screening program, and factors that influenced their decision about whether to undergo carrier testing. It was concluded that less than 15% of the Jewish students who were aware of the screening program in 1999 chose to be tested. The survey indicated that more than half (56%) of the students did not think that their parents had been screened and that 14% thought that their parents had been tested but did not recall the results. D'Souza et al. found that motivating individuals to get tested has

been a significant challenge over the years. The number of individuals getting tested in this population decreased steadily over the years. The following reasons were given for individuals' lack of participation in the screening program: lack of awareness of the program and couples' preference to have carrier testing conducted by their own medical provider. A major factor in the decision to participate was family history of TSD. However, 22% of the 102 individuals surveyed knew that they were not at risk of being carriers because their parents tested negative for the condition; 56% had parents who were untested or they were unsure whether their parents had been tested; 4% had parents who were carriers; and 14% had parents who were tested, but they were unsure of the parents' test result.

Hegwer et al. (2006) assessed the knowledge and beliefs of 174 men and women of Jewish ancestry who participated in a TSD educational program from 2002 to 2003. Site locations included universities in the Chicago and Champaign/Urbana, Illinois, areas as well as the Jewish Federation meetings and Anshe Emet synagogue. The goals of the study were to (a) document the demographic characteristics of individuals who attend the free screening program, (b) determine how the study participants perceive their genetic risk before and after educational intervention, and (c) learn how the individuals attending the educational program and testing sessions knowledge and attitudes changed by learning more about the disorder. Hegwer et al. concluded that there was a statistically significant difference in the participants' level of knowledge from the before and after education. Women reported a significantly higher level of concern about the disorders and about their carrier status before the education, as well as about their carrier status after the education. Finally, having one or more parent affiliated with Orthodox Judaism

was related to higher knowledge before the education program. In conclusion, the results of the Hegwer et al. study demonstrated that the educational program increased knowledge about the disorders and also produced mild anxiety regarding personal and reproductive risks.

In summary, the literature mentioned in this subsection suggests that the Tay Sachs carrier testing programs of the 1970s were deemed successful for several reasons. However, these factors that contributed to the success of the endeavor were unique to the target population. Although the TSD screening program appeared to be a useful model for the identification of genetic disorders in specific populations, perhaps it was not the best model to be applied to the identification of genetic disorders in other populations, such as SCD within the African American community. There is still a high level of acceptability regarding TSD carrier testing among the Jewish community. There are high levels of concern for individuals who are found to be carriers. Attitudes toward carrier testing and predicted feelings about test results were significantly associated with the decision to get tested.

All of the studies reviewed used quantitative designs. The participants' true feelings about carrier testing in this population may have been better assessed by a mixed method approach. Cultural implications are not always revealed via quantitative methodology alone.

### *Cystic Fibrosis and Carrier Testing*

Cystic Fibrosis (CF) is a potentially lethal autosomal recessive disorder characterized by lung infections and subsequent damage, problems with intestinal

absorption and obstruction, vitamin and mineral deficiencies, inflammation of the liver, and male infertility and reduced female fertility (O'Connor & Cappelli, 1999). It is the most common serious genetic disorder among the United States Caucasian population. Approximately 1 in 25 people of European heritage are carriers of CF. If random selection is assumed, 1 in 400 Caucasian couples will be a two-carrier couple. CF is relatively rare in other non-Caucasian populations. Currently, the average age of survival for a person with CF is 25-27 years, with some individuals reaching 40 or greater (AMA, 1991). CF and SCD are often compared in the literature because they are both autosomal recessive disorders, have the onset of disease in early childhood, continue through the life span, and affect specific racial populations.

#### *History of Carrier Testing for CF*

Unlike TSD and SCD, CF could not be directly detected was not possible until the early 1990s. Thus, CF does not possess the extensive history of carrier testing found with TSD and SCD. Before the location of CF chromosome mutations in 1989, the only methods of carrier detection were (a) giving birth to a child with CF or (b) estimating carrier risk by how closely related the individual is to an affected family member.

Testing for CF is different from other testing programs in that it cannot be limited to a relatively small, well-defined population that is at an elevated risk. Because of the absence of specific indications for testing besides European ancestry, the entire Caucasian population is essentially at risk for being a CF carrier (AMA, 1991). In 1997, NIH recommended that carrier testing be offered to adults with a family history of CF, couples in which a partner belongs to a CF family, couples currently planning a

pregnancy, and couples seeking prenatal testing. A critical problem of population-wide screening for CF is the reduced sensitivity of the carrier test for persons who have no family history of CF. The lack of genetic education of the general population is also an impediment to large-scale screening. Other issues are (a) the impact of carrier detection on the emotional, psychological, and social well-being of the tested person and (b) the reactions of employers and insurance companies to CF carriers with regard to possible employment discrimination and increased insurance premiums.

#### *Current Perspectives on CF Carrier Testing*

Carrier testing is a relatively new area of discussion. As a result, there has been a plethora of information published addressing the benefits and barriers of CF testing, as well as the target population's perspectives of CF and CF carrier testing.

In a study by Loader et al., (1996), 4,879 patients in Rochester, NY, were surveyed to determine their receptivity to carrier testing for CF. The intervention included free carrier screening for patients of reproductive age, pregnant or not, and genetic counseling of patients found to be carriers. The acceptance rate among pregnant women was approximately 57%. The most common reasons for accepting screening were to obtain reassurance (50.7%) and to avoid having a child with CF (27.8%). The most common reasons for declining screening were (a) not intending to terminate a pregnancy for CF (32.4%) and (b) believing that the chance of having a CF child was very low (32.2%). In comparison with decliners, acceptors were more likely to have not had children, to regard having a child with CF as being more serious, to believe themselves more susceptible to having a child with CF, to know more about CF, to terminate a



pregnancy if the fetus were shown to have CF, and to strongly support offering CF screening to women of reproductive age. Of 4,879 women on whom results were obtained, 124 were found to be carriers. Of the 124 women who were found to be carriers, 106 had a partner who was tested. Of the five at-risk couples, four requested prenatal diagnosis, and one requested neonatal diagnosis. No woman found to be a carrier whose partner tested negative requested prenatal diagnosis. The Loader et al. study has different implications because the majority of the participants were pregnant as opposed to planning for children. The participants in this study were already pregnant; thus, there was no opportunity to prevent the conception of a child with CF if prevention was the desire of the parents.

Results of pilot studies of CF screening through primary health care services (Bekker et al., 1993; Tambor et al., 1994; Watson et al., 1991) demonstrated that the method of presentation was critical in determining participation rates. An invitation by letter or leaflet resulted in lower response rates; however, when the offer of screening was made during a personal contact with a health professional, the acceptance rate was significantly higher. Using both a personal approach, and the offer of “immediate” testing resulted in even higher participation rates.

Clayton et al., (1996) examined the reasons for the lack of interest of nonpregnant couples in carrier testing for CF. The eligible participants were 873 individuals in stable relationships who visited clinical and nonclinical health care sites in a southern urban city. Questionnaires were used to assess individuals' attitudes about genetic testing in general and about CF carrier screening in particular. Participants expressed conflicting views about carrier screening. Clayton et al. concluded that the most important factors for

lack of interest in carrier testing were as follows: risk of losing their health insurance (60%), low perceived risk of being a carrier (50%), religious beliefs (50%), concern about what they would need to learn (50%), the opinion of the partner (45%), and opposition to abortion (40%), preference for providing DNA by swab not a part of the study's protocol rather than by finger stick (25%), and belief that genetic testing was "meddling in God's plan". Sixty-six percent of those who participated in screening were more educated, more often worked outside the home, more often worked in health care, more often were Whites, and more frequently had a family history of CF. One significant finding was that the participants felt that physicians should not incorporate CF carrier screening into the routine medical care of nonpregnant people who do not have a family history of CF. The Clayton et al., study assessed the perspectives of couples only. Persons who are in stable relationships and considering children may have a different perspective from those who are single.

Evers-Kiebooms, Denayer, Welkenhuysen, Cassiman and Van de Berghe (1994) evaluated the emotional impact of carrier testing for CF in a sample of 139 men and women (90% were CF relatives and their partners) by utilizing the Health Orientation Scale; they found that (a) carriers of the CF gene had significantly fewer positive feelings about themselves than noncarriers did, and (b) carriers and noncarriers attributed significantly more negative feelings to carriers than to non-carriers. These findings are an indication of social and self-stigmatization of CF carriers. However, carriers of the CF gene attributed significantly more negative feelings to other carriers of the CF gene than to themselves.

Studies conducted in the United Kingdom (Axworthy, Brock, Bobrow & Marteau, 1996; Bekker, Denniss, Modell, Bobrow, & Marteau, 1994; Marteau, Dundas & Axworthy, 1997) showed that anxiety levels increased when people were told they were CF carriers but had decreased 3 months later during follow-up sessions. Axworthy et al. reported small proportions (16%) of the 280 identified carriers were still worried about their test result 3 years later. Marteau et al. indicated that informing people that they are carriers did not produce severe levels of anxiety. However, carriers were less likely to report positive feelings and more likely to report troubling thoughts about their test result than persons with a negative result were found to be. In comparison with male carriers female carriers were more likely to report more negative feelings when thinking about their result.

O'Connor and Cappelli (1999) utilized the HBM as their framework for predicting intent to use carrier screening for CF. A cross-sectional survey design was used to collect demographic variables and information about health beliefs from a sample of 133 White men and women who were aged 18-45 years old in Canada. A model using the HBM constructs perceived severity, beliefs, and benefits was designed and tested for efficacy in distinguishing between respondents who indicated that they would and those who indicated that they would not consider carrier screening. Sixty percent of the participants had not heard of the CF carrier testing before completing the questionnaire. More than half (56%) of the participants indicated that they would not consider testing. The two most commonly cited reasons for the decision not to consider CF carrier testing included having no family history of the disease (41%) and not wanting any more children (38%). Persons who indicated that they would consider testing (44%) most

frequently cited the following reasons for doing so: (a) finding out their chance of being a carrier (29%) and (b) identifying their children's risk of being carriers (28%). The situations cited as being most influential in one's decision to undergo carrier screening were having a family member diagnosed with CF (65%), finding out that a family member is a carrier (64%), and being pregnant (26%). Despite the fact that a majority of individuals indicated that they would not consider testing for themselves, 87% of the sample said that they would tell others about the availability of testing, including people in general (53%), siblings (50%), and their spouse (48%).

Henneman et al. (2001) investigated why some couples participated in preconceptional carrier testing, whereas others declined. Screening was offered to 5,414 Caucasian individuals, ages 25 to 35, receiving services from five health care providers in the Netherlands between 1997 and 1998. Seventy-six couples participating in the educational sessions were offered and consented to CF carrier testing. Henneman et al. reported that 85% of the couples made the decision to get tested jointly and that 15% indicated that the women had more influence on the decision to participate. It was concluded that the main reason given by couples for taking the test was wanting to know whether they were a carrier couple (97%) with a high risk of having a child with CF. The reasons nonparticipants gave for not responding to the invitation for testing varied, but the most common response given was lack of time (53%); other responses given were that test results would not influence attitudes toward family planning (21%), and that the couple was not concerned. Factors associated with participation were as follows: Participating couples scored higher than non-participating couples did on the knowledge questionnaire and perceived higher benefits of testing. Participating couples were more

likely to have a lower level of perceived discomfort about testing and to have fewer perceived barriers to testing. No associations were found between participation in testing and familiarity with CF, perceived susceptibility, or perceived severity or seriousness. The strongest predictors for participation were perceived discomfort about testing and perceived benefits of testing. Again, all of these studies were conducted on the basis of a quantitative design. It is believed that a more in-depth understanding of participants' knowledge, beliefs, and attitudes about carrier testing might be revealed with a quantitative and qualitative approach. Moreover, several of the studies that addressed knowledge and belief patterns related to CF were conducted with populations outside the United States.

J. Hall, Fiebig, King, Hossain, and Louviere (2006) explored factors that influence participation in genetic carrier testing in Australia; they reported consumer preferences for testing for carrier status for two particular conditions, TSD and CF. The sample consisted of 210 participants from the Jewish community and 261 participants from the general community. The participants reviewed 16 scenario cards and identified the thoughts or feelings elicited by the situation presented on each card.

J. Hall et al. concluded that Jewish participants were more likely to be tested and more likely to test for TSD. The results of the study suggested that being tested for TSD was part of one's responsibility to the Jewish community. Both Jewish and general population participants preferred to receive genetic information as a couple. In both populations, participants expressing the intention to have more children had a greater likelihood of participation in testing for TSD and CF. Convenience of testing was not an

issue for any of the participants. It was reported that the participants preferred to go to a specialized clinic for testing as opposed to going to any doctor or clinic available. It was stated by the authors, in regard to this type of genetic service, that the participants associated specialized care with a higher quality of care. J. Hall et al. contended that, although both disorders are recessive they differ in severity and in the availability of treatment. Furthermore, the prevalence of these diseases and the awareness of their prevalence and consequences also differ by population group, and these differences allow an investigation of the extent to which different cultures and expectations affect attitudes towards screening.

In Australia, Barlow-Stewart et al. (2003) conducted an evaluation of a genetics carrier screening program for TSD and CF, between 1995 and 1998. The program consisted of mandatory on-site education, followed by voluntary on-site genetic carrier testing. The sample was 629 senior high school students, ages 15-17, at four Jewish community schools. Questionnaires were used to assess knowledge, attitude, and self-reported concern about positive test results for carrier status and were administered before and after the educational sessions, as well as annually. From 1995 to 1998, uptake for testing increased from 54% to 94%, with more females than males participating. The participants indicated the following reasons for engaging in carrier testing: to use with future partner, just want to know, advice of the Jewish community, parents' influence, and peer pressure. The following reasons for not testing were also discussed: not at this time of life, hate needles, not personally at risk, don't want to know carrier status, cost, test outside of school, parents' influence, and not in a high-risk group. The factors were listed according to how strongly they influenced their decision.

In comparison, Beeson and Doksum (2001) examined the social processes that occur as families at risk for SCD and CF encounter carrier testing. The study used a qualitative approach, which the authors suggested allowed an additional lens to be focused on the role of culture in integrating genetic testing into family life and reproductive planning. The data were collected during focused interviews with 369 individuals from families in which at least one member had been identified as having SCD or CF or the trait for the disorder. Interviews were conducted in person, at community sites, in churches, and by telephone. There were 189 participants in the SCD group and 180 in the CF group; and there were 15 focus groups conducted, as well.

Beeson and Doksum found that only a few participants had pursued carrier testing; this lack of response resulted primarily from religious values or values of romantic love. African Americans who had been tested rejected the relevance of testing in selecting a partner and failed to mention carrier status to partners. This attitude toward partner selection existed among Caucasian participants, as well. The Caucasian participants were less likely to express feelings of mistrust toward the medical community but also were less enthusiastic about screening or testing, even when they utilized them. Beeson and Doksum concluded that the decision making process for carrier testing is complex and is often determined by cultural factors (e.g., high value placed on motherhood, mistrust of medical community) that conflict with health care research. Low levels of SCD carrier testing among African Americans may reflect these cultural factors instead of irresponsibility or a lack of knowledge (Duster & Beeson, 1998).

## *Sickle Cell Disease and Carrier Testing*

### *Overview of Sickle Cell Disease and Sickle Cell Trait*

SCD is a term used to describe a group of autosomal recessive (inherited) disorders characterized by the production of abnormal, S or sickled, hemoglobin (Olney, 1998). Some of the medical complications associated with SCD include vaso-occlusion which results in intense episodes of pain and physical dysfunction; damage to organs, including kidneys, spleen, and liver; acute chest syndrome, including life-threatening chest pain, shortness of breath, and fever; stroke caused by the reduction of oxygen to the brain as result of sickled blood cells; and delayed growth at puberty because of the production of blood cells (Bojanowski & Frey, 2006).

SCT is not regarded as a disease state because it has complications that are neither uncommon nor mild. As with SCD, there are several health conditions that are associated with SCT, including inadequate spleen function at high altitudes; inability to engage in sustained exercise; and hypoxemia, which is a deficient level of oxygen in the blood. Other health problems include compromised kidney function exercise induced, heat stroke or death, and sudden idiopathic (i.e., unknown cause) death (Kark, 2000).

More than half of individuals with SCD are, at any one time, asymptomatic and lead normal lives but must still face ecological issues such as discrimination in jobs, access to life and health insurance, and stigmas associated with having an invisible chronic condition (Telfair, 1997). The financial aspects of SCD, are revealed by the most recent statistics (reported nearly a decade ago) which indicate that, in 1997, there were



75,000 hospitalizations annually for SCD and that these hospitalizations resulted in a direct cost of more than \$475 million dollars (Davis, Moore, & Gergen, 1997). However, in comparison with studies of similar genetic disorders such as CF, the numbers of empirical studies that have been conducted to address the health complications and related issues regarding SCD and SCT have been less than adequate. Moreover, the available SCD literature focuses primarily on the clinical and treatment aspects of SCD or on practices for screening newborns.

In a study completed by Smith, Okeyu, Homer, and Zuckerman (2006), it is posited that the paucity of research produced on SCD is a result of the lack of federal funding and general public support for SCD investigations. The dearth in general public support may be attributed to the restricted funding available to SCD community organizations; increased funding would enable the provision of educational programming and community outreach to high risk populations such as the African American community. In 2003, the total revenue for the Sickle Cell Disease Association of America was \$498,577, which is significantly less than the \$152 million dollars in total revenue reported by the Cystic Fibrosis Foundation for CF, a comparable disease (Smith et al.).

Carrier testing for SCT has been available for several years in the United States; however, testing rates among African Americans remain low (Beeson & Doksum, 2001). As mentioned previously, there have been few studies published that examined the current level of knowledge, beliefs and attitudes of African Americans about SCD carrier testing and, subsequently, what factors contribute to their decision to participate in carrier testing.

### *SCD Genetic Knowledge*

Before 1970, few programs were dedicated to providing the public with information on SCD. Whitten (1992) reported that before the 1970s, most African Americans learned of SCD and their sickle cell carrier status by bearing children with SCD. Past studies conducted in large urban areas illustrated limited awareness of SCD among African Americans in those communities (Lane & Scott, 1969; Young, Peters, & Houser, 1974). In a 1968 survey, approximately 70% of African Americans responded that they were not aware of SCD (Lane & Scott). Nearly 6 years later only 38% of African Americans participating in a comparison study responded that they were not aware of SCD (Young et al.). It is believed by researchers that the Sickle Cell Control Act of 1972 significantly increased awareness about SCD among the African American community (Hill, 1994; Ogamdi, 1994). SCD education typically has two objectives. The first is a focus on how to reduce crisis-triggering situations, such as the prevention of dehydration; hypoxia (loss of oxygen to the organs); bacterial infections; excessive stress at home, work, or school; overexertion; and sudden temperature variations. The second objective is an emphasis on understanding the genetic transmission of the disease and on the reproductive decisions about childbearing that those persons will need to make with full knowledge, understanding, and acceptance of possible challenges (Ogamdi).

Ogamdi (1994) conducted a quantitative investigation to determine the level of knowledge about SCD among students at a Texas university with predominantly Black enrollment. The researcher found that, of the 334 participants, 72% correctly answered the question about how the disease is transmitted. However, approximately 81% of the

participants did not know that the genotype describing SCD, and more than 60% of the students did not know the disease could be prevented if individuals made “responsible” reproductive choices. Only 40% of the participants in the survey believed that, because of added risk, contraceptive choices of those who carry the sickle cell trait or disease should be made in close consultation with a physician. About 52% of the participants recognized that pregnancy in SCD is a high-risk endeavor and must be carefully monitored.

Boyd et al. (2005) conducted a community survey to assess the existing knowledge about SCD in 264 African American women in St. Louis, Missouri. Although most of the respondents had a basic understanding of SCD, 30% of the women of childbearing age in the study were still unaware of SCD. Boyd et al. maintained that African American women in general have not been equipped with adequate information about the incidence and inheritance patterns of SCD to make informed decisions. Fifty-two percent of women surveyed did not know that there were various types of SCD; 6% believed that SCD is transmitted via blood transfusions. Less than 10% understood the inheritance patterns of the disease and, subsequently, the probability of transmission. The respondents specified several approaches for increasing awareness about SCD. They contended that the following routes would be most effective in educating African Americans about SCD: SCD pamphlets, educational meetings, and television and radio announcements.

More recently, Treadwell et al.,(2006) conducted a mixed methods study to evaluate knowledge and perceptions about SCT and SCD, to investigate the effectiveness of different sources of information about SCT and SCD, and to determine individual

knowledge of SCT status. Twenty-eight individuals participated in three focus groups (i.e., health care providers) [10], individuals with SCD or SCT [8], and community members [10]. Additionally, 282 surveys were administered in an interview format to participating individuals. Sixty-six percent of respondents were women, mean age was 32.7 years, 64.9% were single, and 23.8% were married. Treadwell et al.(2006) found that the common themes across the three focus groups included the limited general awareness of SCD and SCT, an emphasis on the benign nature of SCT rather than on future implications (i.e., reproductive decision making), and the need for public health education campaigns about SCD and SCT involving media strategies. A large majority of individuals who completed the survey ( $n = 243$ , 86.2%) had correct general knowledge about the genetic basis and severity of SCD, but only 16% ( $n = 45$ ) knew their own carrier status.

#### *Beliefs and Attitudes About SCD Carrier Testing*

To date, there have been four studies published that address health beliefs about SCD carrier testing as it relates to reproductive decision making. However, no studies have pertained to factors contributing to participation in SCD carrier testing or to belief patterns.

Rowley, Loader, Sutera, Walden, and Kozyra (1991) examined a comprehensive prenatal hemoglobinopathy-screening program in the northeastern region of the United States. The study participants were Southeast Asian ( $n=50$ ), Caucasian ( $n=96$ ) and Black ( $n=576$ ) women at less than 18 or greater than 18 weeks of gestation. Rowley et al. suggested that a woman identified as being a SCD carrier or beta-thalassemia carrier may

face three decisions: whether to accept the offer of counseling; whether to have her partner tested; and, if her partner tested positive, whether to accept the offer of prenatal diagnosis. The study involved analyzing the factors affecting her decision, with special focus given to those factors that were derived from the HBM. Rowley et al. concluded that factors predicting that a woman identified as a carrier would attend counseling included having no prior knowledge that she is a carrier, being at less than 18 weeks of gestation, and being Caucasian. For SCT counselees, factors found to predict a patients intent to have her partner tested were as follows: a greater post counseling knowledge of the disease, a lesser perceived burden of intervention, and a belief that her partner is also a carrier. For SCT counselees, factors found to predict patients who actually had their partner tested were as follows: gestational age at identification less than 18 weeks, perceived seriousness (i.e., knowledge of the disease), perceived burden of intervention (i.e., perception of prenatal diagnosis as being dangerous), and living with their partner. Between the two groups at greatest risk for SCT or beta-thalassemia, African Americans and Asians, there were several differences. African American participants indicated that they could not terminate a pregnancy for any reason and declined prenatal diagnosis for that reason. Rowley et al. stated that, for some African Americans, the prospect of a child with a severe illness was considered one more adverse event in their lives, in which they perceived themselves to have little control. In comparison, the researchers concluded that the Asian participants appeared to be more open to intervention, reacted promptly when notified of an abnormal test result, often brought their partner to the first visit, did not object to abortion in principle, and usually wanted prenatal diagnosis when offered. Rowley et al. suggested that special efforts toward being tested before pregnancy and

toward learning one's partner's carrier status before reproduction should be encouraged as an alternative strategy in the African American community.

Wright, Zeldin, Wrenn, and Miller (1994) investigated the SCD awareness of 147 African American men and women receiving services in the emergency department of a large urban university hospital. The objective of the study was to determine whether young adult African American patients in an emergency department were familiar with SCD and how many knew their own SCT status. The participants were interviewed to determine their knowledge base regarding SCD, as well as to ascertain how many participants knew their carrier status; and those who were unsure of their carrier status were tested for SCT. Ninety-eight percent of the participants had heard of SCD, and 73% knew that it was a genetic disorder; however, only 31% knew their own carrier status. Women were more likely than men to know their carrier status. Approximately half of the participants who had family histories of the trait of the disease knew their own status. Two (4%) of the 47 participants who were tested had positive results. In summary, most of the childbearing- aged African American men and women presenting to the emergency department had heard of SCD and knew that it was inherited, but few had been tested and knew their own trait status.

Hill (1994) conducted a qualitative study of 29 African American mothers of children with SCD. The purpose of the study was to explore the factors that contributed to these participants' decision to have children despite knowing their SCD or carrier status. Several themes emerged from the interviews. First, Hill concluded that the lack of SCD medical information was not the key factor in having a child with SCD. The author

believed that the mothers in the study obfuscated, confused, or blurred facts about SCD to evade the issue and legitimize their reproductive behaviors. Hill inferred that, if the women accepted accurate SCD information, then they were aware of the possible outcomes: having a child with SCD and contributing to the increase of SCD. For example, SCD screening programs were built on the premise that, once informed about the risk of having a child with SCD, a person would engage in preventative health behaviors. Despite knowing their trait status and the risk of having a child with SCD, the participants had not pursued options to avoid having a child with SCD, such as using birth control or termination. Mothers justified their decisions by stating that the historic neglect of and misinformation about SCD left them misinformed and/or unable to trust the accuracy of SCD medical knowledge. The second theme illustrated in the study was the high value placed on family and motherhood in the African American culture. This value may significantly influence the attitudes of some with regard to reproductive and other genetic testing; thus, having carrier information before pregnancy or during pregnancy might not have an influence on partner selection or on the decision to have children. Because women tend to be diagnosed while seeking care for other health matters, they were more likely to know that they had SCT. For these women, persuading their partners to get tested was a significant challenge. Childbirth outside marriage and the gender imbalance of power nullified the efforts of these Black women to have their male partners tested.

In a qualitative study conducted in the United Kingdom, Asgharian and Anie (2003) explored, via semi-structured interview, the views and feelings of 35 African American and African Caribbean women about their SCD carrier status and the timing of

being told their trait status. Eighteen of the women had partners who were also SCD carriers, and these women were therefore characterized as being members of an at-risk couple; 3 of the women were unaware of their partner's status at the time of the interview; 14 of the women were single or had partners who were not carriers; and 14 of the women already had children with SCD. Asgharian and Anie found that, in response to learning their carrier status, the women displayed a wide range of reactions from indifference to shock, surprise, worry, and being upset. The effect of the timing of learning trait status was studied by categorizing answers according to whether women found out in childhood or in adulthood and, in the latter case, whether they found out before or after conception. Seven of 14 women who were told their trait status during pregnancy stated that finding out any earlier would not have made any difference in their lives. Their findings indicated that, of the 35 women studied, 57% wanted to find out their partners' carrier status once they were diagnosed. The remaining 43% did not want to find out their partner's status before becoming pregnant. The reasons for not wanting to know fell into two categories: (a) this issue was too awkward and sensitive for the women to ask their partner, and (b) they did not realize the importance of both partners' being tested. In addition, the women stated that inquiries about the partner's trait status at an inappropriate time during the relationship could bring about problems. Consequently, 54% of the women stated that having SCT had not affected their choice of partner and that love and the relationship were more important than they believed the risk of disease to be. Nonetheless, 17% stated that they were aware of the risk and that the relationship would cease to exist, if their partner was a carrier. Last, the women were



afraid of revealing that they themselves were carriers and of being faced with the social stigma of being a carrier.

There is a paucity of research available that both focuses on the factors that contributes to individuals' intentions to participate in SCD carrier testing and focuses on their perspectives on carrier testing. The goal of this dissertation study was to begin to examine these areas of research.

### Chapter Summary

The purpose of this chapter was to review pertinent literature and issues related to carrier testing in general, carrier testing in other populations, and SCD carrier testing. The intent was to provide background information to illustrate the depth of information available on carrier testing for comparable genetic disorders and then, to support the need to examine African American men's and women's perspective on SCD, SCT, and SCD carrier testing given the absence of such an examination in the literature.

The next chapter includes a description of the application of the mixed methods research design, which frames the study. The chapter also contains discussions on the sampling strategies, data collection procedures and instruments, and data analysis procedures for Phases 1 and 2 of the study.

## CHAPTER 3

### RESEARCH METHODS

The aim of this chapter is to discuss the research methodologies involved in conducting this study. The chapter begins with an overview of the mixed methods research approach and sequential explanatory design. The chapter continues with discussions of the two phases of the study. Phase 1, which is the quantitative phase, includes a discussion on sampling strategies; data collection, including procedures and instrument development; and data analysis. Phase 2, which is the qualitative phase, includes a discussion on sampling strategies; data collection, including procedures and instrument development; and data analysis. Additionally, the chapter includes a description of the integration of Phase 1 and Phase 2, as well as a discussion of the validity, credibility and legitimation procedures used.

#### Mixed Methods Research Approach

For the current study, a mixed methods approach was adopted to assess the beliefs and attitudes of college-aged African Americans about SCD and SCT and about SCD carrier testing. The mixed methods approach refers to the use of multiple methods, and is typically a combination of quantitative and qualitative research. Several terms have been used to denote the mixed methods approach such as mixed method studies, mixed model

studies, multi-methodology, and integrated, or combined quantitative and qualitative methods. Teddlie and Tashakkori (2006) have provided one of the most recent definitions of mixed methods research; the authors state that it is the process in which an investigator collects and analyzes data, integrates the findings and draws inferences by using quantitative and qualitative approaches or methods in a single study or program of inquiry.

Mixed methods research initially emerged in the early 20<sup>th</sup> century, within the context of social science fieldwork. However, in 1959 Campbell and Fiske were among the first to discuss using multiple quantitative methods in psychological studies (Tashakkori & Teddlie, 2003). Years later, discussions continued around the idea of merging fieldwork or in-depth case studies and surveys at the site or location of the study. It was determined that this new style research and the integration of research techniques within a single study provided significant opportunities for mutual advantages in each of three major phases of research, including design, data collection, and data analysis (Tashakkori & Teddlie, 2006). Johnson and Onwuegbuzie (2004) suggested that mixed methods research is the third research movement because it moves past the paradigm wars (i.e., debates about quantitative versus qualitative methods) by offering a logical and practical alternative. The mixed methods framework utilizes induction (i.e., the discovery of patterns), deduction (i.e., the testing of theories and hypotheses), and abduction (i.e., uncovering and relying on the best of a set of explanations for understanding one's results); Johnson & Onwuegbuzie.

Over the years, the mixed method approach has been adopted in diverse fields of study such as health, social and behavioral science, education, sociology, management

and organizational research, counseling psychology, and law (Collins, Onwuegbuzie, & Sutton, 2006). Many researchers are using the mixed methods approach to expand the scope of and deepen insights from their studies because neither quantitative nor qualitative methods independently provide a complete picture (Sandelowski, 2000). Typically, quantitative data are more objective and can represent all participants; however, they do not create in-depth information. Qualitative data, on the other hand, provide more in-depth insight about a phenomenon but it may be less objective and may not be representative of a population. For this reason, an approach that uses several methods may better address certain research problems and provide a more comprehensive view of the phenomenon being investigated (Sandelowski, 2000).

In this study a mixed methods approach was adopted to assess the knowledge, beliefs, and attitudes of African American college students about SCD and SCT and about SCD carrier testing. The quantitative research approach (Phase 1), which included a cross-sectional survey, provided a current snapshot of the characteristics of individuals who participate in SCD carrier testing, their level of knowledge related to SCD and SCT, their awareness of current carrier status, and their general feelings about carrier testing. Once these elements were identified, the qualitative research approach (Phase 2), which included the follow-up interviews, explored how these factors were influenced by participants' health and cultural beliefs.

For several reasons the mixed methods approach was well suited for a study of health beliefs and genetic testing, specifically carrier testing among African Americans. The practice of genetic testing is generally associated with biomedical research. Biomedical research is an issue that has deep-rooted racial and political underpinnings in

the African American community. It has been documented in the literature that some African Americans hold negative opinions of biomedical research and the medical community (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Harris, Gorelick, Samuels, & Bempong, 1996; Laskey et al., 2003). Negative attitudes toward biomedical research have been attributed to the SCD screening programs of the 1970s as well as to other factors (Laskey et al.). The mixed methods approach used in this study provided a comprehensive framework in which current perspectives on SCD and SCT and on SCD carrier testing were identified and then explained in greater detail. Stronger inferences were obtained from the combination of results from the quantitative and qualitative methods than would have been obtained from results from one independent method. However, the general limitations of this approach were as follows: the legitimization of findings, the time and budget necessary for full implementation of the study.

### Sequential Explanatory Design

The specific type of mixed methods research design applied to this study was the sequential explanatory design. This design is characterized by collection and analysis of quantitative data, followed by collection and analyses of qualitative data (Creswell et. al., 2003). The purpose of the sequential explanatory design was to use qualitative results to assist in explaining and interpreting the findings of a primarily quantitative study (Creswell, Plano, Clark, Guttman, & Hanson, 2003). The sequential explanatory design was appropriate for this study because it was essential to first identify the knowledge, attitudes, and beliefs of college-aged African Americans before discussing the

determinants of their perspectives regarding SCD carrier testing.

The sequential explanatory approach has several advantages. Of the major mixed methods approaches, the sequential explanatory design is the most straightforward. The steps of the model fell into clear and concise stages, which facilitated study implementation. Additionally, the distinct stages made the data analysis and final reporting less complicated. However, the disadvantage of using this approach is the time needed to conduct both Phase 1 and Phase 2 of the design (Creswell, 2003). This disadvantage had significant implications for the timeline and budget of this study, which will be discussed in greater detail in chapter 5 along with other study limitations. As suggested by Creswell et al. (2003), three factors were considered in conducting this mixed method study: which included implementation, priority, and integration.

### *Implementation*

Implementation refers to whether the quantitative and qualitative data for the study were collected in phases (sequentially) or at the same time (concurrently). When the data are collected in phases, either the quantitative data or the qualitative data can be introduced first. In a sequential explanatory design the quantitative phase is always presented first. Thus in the present study the quantitative phase was implemented first through the collection of cross-sectional survey data from African American college students. The aims in this phase were to identify variables that most significantly contributed to the participants' intention to participate in carrier testing and to identify important trends that would be explored in greater detail with participants selected for

Phase 2. Next, semi-structured interviews were used to obtain data from a subgroup of individuals who had participated in the first phase of the study. The aim in this phase was to further explore the variables that were significant in contributing to the students' decisions to participate in carrier testing.

### *Priority*

Priority refers to whether greater weight is given to the quantitative approach or to the qualitative approach in this study. Priority was given to the quantitative approach for the present study because the cross-sectional survey data provided basic information on a large number of participants at a single point in time. In this design, quantitative data collection began first and represented a significant portion of the mixed methods data collection procedures. The second phase consisted of a smaller qualitative data collection process. The goal of the qualitative or second phase was to further elaborate and interpret the statistical findings of the first phase through qualitative methods. In-depth interviews were used to explore why African American men and women participated in SCD carrier testing, as well as their experiences with SCD carrier testing.

### *Integration*

Integration refers to the process of mixing or connecting data at different stages during the research process. In the current study, the quantitative and qualitative data were mixed at five different points. The first point at which quantitative and qualitative

data were mixed was at the research design stage, when the quantitative and qualitative research questions were introduced together. The second point occurred during the data collection stage of Phase 1, when participants were asked open-ended questions on the quantitative instrument; the results were interpreted during the discussion stage. The quantitative and qualitative data sets were connected at the intermediate stage by sampling. The very nature of the sequential explanatory design dictated that the participants of Phase 2 be a subgroup, which was selected from Phase 1 participants. Also, the fourth point of connection was during the intermediate stage. The interview protocol questions for Phase 2 were developed or guided from Phase 1 statistical analysis results. The fifth point of mixing occurred when the quantitative and qualitative data were integrated. The results were addressed according to the quantitative or qualitative questions that participants answered. A visual model for the mixed methods sequential explanatory design procedures is illustrated in Figure 2. The figure is adapted from Ivankova, Creswell, and Stick, 2006.



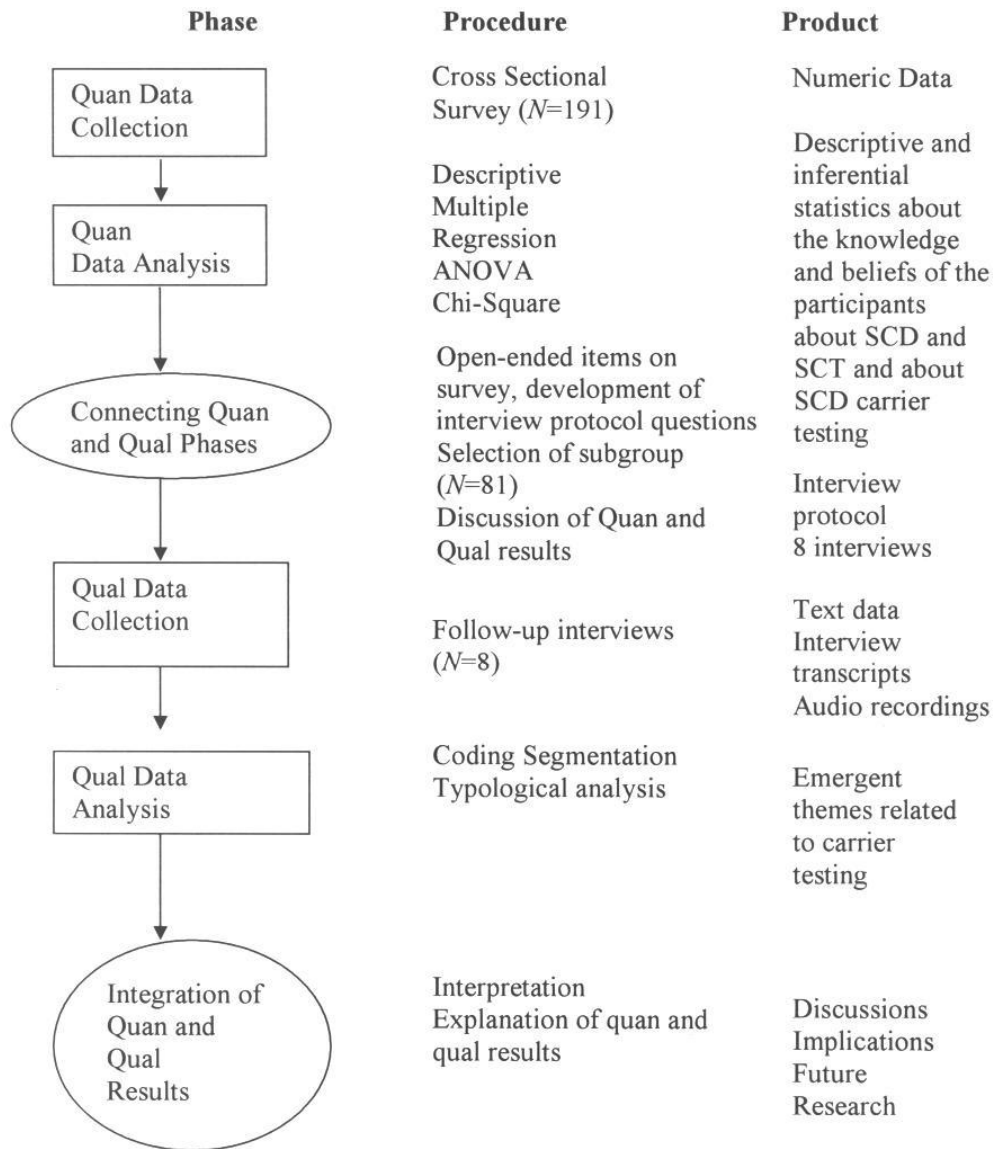


Figure 2 Visual model for mixed methods sequential explanatory design procedures

## Phase 1: Quantitative Research

### *Target Population*

The target population for this study was African American college students attending health fairs sponsored by several universities and a national conference. The universities and national conference contacted the Sickle Cell Foundation of Georgia (SCDF of GA), to ask the foundation to participate by providing the mobile testing program for the health fairs. The universities included Savannah State University (SSU), Clayton State University (CSU), Clark Atlanta University (CAU), Georgia State University (GSU), and Emory University (Emory). The national conference was the 20<sup>th</sup> Annual 100 Black Men of America Conference, sponsored by the 100 Black Men of America, Inc.

SSU, located in Savannah, GA, and CAU, located in Atlanta, GA, are historically black 4-year universities with student populations of 2,975 and 3,667, respectively. CSU, located in Morrow, GA, is a 4-year university with a varied student population of 6,000. GSU and Emory, both located in Atlanta, GA, are 4-year universities with varied student populations of 23,800 and 12,338, respectively. The 20<sup>th</sup> Annual 100 Black Men of America Conference was also held in Atlanta, GA on June 7-11, 2006. Inclusion criteria for selecting the participants were: (a) identified race as African American, (b) being between the ages of 19 and 30, and (c) currently enrolled as a student.

## *Data Collection*

### *Procedures*

In March 2006, the University of Alabama at Birmingham (UAB) Institutional Review Board for Human Use (IRB) approved the study (see Appendix A). The President and CEO of the SCDF of GA had granted approval for the study in January of that year (see Appendix B).

Convenience sampling methods were used to recruit potential participants at health fairs in which the SCDF of GA made SCD carrier testing available. During the health fairs, the health fair staff and the researcher distributed flyers about the study to potential participants who met the inclusion criteria (see Appendix C). Potential participants were instructed to visit the table sponsored by SCDF of GA if they were interested in participating in the study. The individuals were instructed that being tested for carrier status was not necessary and completing a survey was not necessary to get tested but if they wished they could both complete a survey and get tested. Individuals who agreed to participate in the study were given a survey and two copies of the Phase 1 consent form, one to sign and return to me and to keep one for their records. All of the components of the consent form were explained, and participants were given verbal instructions for completing the survey.

The surveys took the participants approximately 10-30 min. to complete. If the participants decided to get tested, they would complete the survey while they were waiting to have their blood drawn. In exchange for completing the survey, each participant received a \$10.00 cash incentive for his or her cooperation and time.

Overall, 235 survey packets were distributed between March and June 2006; however, only 225 of the survey packets were returned to the researcher.

### *Instrument*

The Sickle Cell Disease Assessment Survey (SCDAS) was used in this phase of the study. The SCDAS was a 31-item self-developed survey used to measure demographic variables, including age, gender, marital status, years of education, and parental status (see Appendix D). The survey is divided into eight sections, which include SCD Genetics Knowledge, Attitudes about Carrier Testing, Perceived Severity of SCT, Perceived Susceptibility of SCT, Carrier Status, and Health Orientation Scale (HOS). The SCD Genetics Knowledge subscale was self-developed from information adapted from various sources including the Knowledge and Beliefs about Cystic Fibrosis Scale (Surh, Cappelli, McDonald, Mettler, & Dale, 1994; O'Connor & Cappelli, 1999); *The Management of Sickle Cell Disease Publication* (National Heart, Lung and Blood Institute, 2002), the Attitudes about Tay Sachs Disease and Cystic Fibrosis Carrier Testing Scale (Barlow-Stewart et al., 2003), and the Perceived Severity subscale (Henneman et al., 2001) and the Health Orientation Scale (Wooldridge & Murray, 1988). The survey was pilot tested with 15 students from Georgia State University. Information related to the reliability and validity of the instrument will be discussed later in this chapter.

*Section 1: Demographics.* The survey began with six demographic items: (a) highest level of education completed, (b) age, (c) gender, (d) marital status, (e) parental status, and (f) family history of SCD and SCT. Gender referred to the participant's self-

reported description of themselves as male or female. Age referred to the chronological age of the participant at the time of the study. Years of education referred to the number of years that the participant attended school. Parental status referred to the number of children reported by the participant. Marital status referred to the participants' self-reported description of themselves as married, single, divorced, separated, or widowed. Family history of SCD or SCT referred to participants' knowledge of any family members with either SCD or SCT.

Demographic information was obtained by questions such as:

Which best describes your marital status? The response format was: "married", "widowed", "single", "separated" and "divorced".

*Section 2: General knowledge of SCD and SCT (Questions 1-10).* These items were developed from information obtained from the National Heart, Blood and Lung Institute's 2002 publication on managing SCD. The statements were derived from the genetic counseling chapter in the *Management of Sickle Cell Disease* publication. This work recommended that several topics be covered in genetic counseling sessions before or after SCD carrier testing. The topics included: a) how sickle cell conditions are acquired-genetic basis, b) difference between SCT and SCD, c) health problems that can occur in SCD, d) variability of and inability to predict occurrence and frequency of health problems in SCD, e) potential outcome of each pregnancy if one or both partners has SCT, f) family planning options, g) racial groups who have SCD and the percent of individuals in the counselee's racial group who have SCT and SCD and h) average life span of individuals with SCT and SCD. From these topics a 14-item scale was developed

that had a true/false response format. Participants were presented statements about inheritance patterns for SCD (7 items) for example “If one parent has SCD and the other is normal, all of their children will have SCT”? Knowledge of the difference between SCT and SCD was examined by 1 item, “There is no difference between having SCD and SCT”. The prevalence of SCD and SCT among African Americans was assessed using 2 items. For example, “SCD occurs in 1 out of 12 African Americans.” General knowledge of SCD and SCT included 4 items. For example, “There are several different types of SCD”. Each correct answer was worth 10 points, for a possible total of 100 points. Because the SCD Genetics Knowledge subscale was self-developed a separate psychometric analysis was conducted after a pilot testing of the subscale with 15 college students. The analysis included a calculation of descriptive statistics [mean, standard deviation (SD), and range] and validation procedures, an examination of the factor structure of the 14 items, and an examination of the instrument’s internal consistency reliability and validity. The internal consistency reliability of the subscale was assessed using the Cronbach alpha coefficient. The alpha coefficient that was produced from the pilot testing was .32. Items were deleted if their removal increased the alpha coefficient. Four items were deleted. The alpha coefficients with items deleted ranged from .37 to .51. The corrected item-total correlations were variable ranging from .06 to .38.

Additionally, content validity was assessed by submitting the items to staff persons at the SCDF of GA. The staff gave feedback via email on the remaining 10 items. Two of the items were reworded for clarity. The original statement read “both parents must have SCT for the child to have SCD (True/False)”. It was rewritten to read “when both parents have SCT, they have a 25% chance (1 out of 4) of having a baby with SCD”.

The second item stated, “there is no difference between SCD and SCT”. It was rewritten to read “there is no difference between people with SCD and SCT”. Construct validity was explored using the Spearman inter-item correlations. Only two of the items were correlated at the .05 level of significance.

*Section 3: Attitude toward carrier testing (Questions 11-16):* The Feelings about Carrier Testing subscale was adapted from the Attitudes about Tay Sachs Disease and Cystic Fibrosis Carrier Testing scale, a four-item scale developed to measure the attitude of Australian Jewish high school students about genetic testing and the use of test results (Barlow-Stewart et al., 2003). This scale was used as an assessment tool for a study of a school-based carrier screening program for TSD and CF. The questions were adapted to measure the attitudes or feelings of the participants about SCD carrier testing. There was no evidence that this subscale had been used in the African American population before the current study. The reported internal consistency score for the attitude scale was 0.55. Two items asked whether participants were in support of SCD carrier testing, and one item asked whether participants were in support of partner testing.

Example: “Do you support SCD carrier testing in the African American community?” The response format was “agree” or “disagree”.

The remaining items asked participants to evaluate their beliefs about carrier testing. The response format for these questions was “good” or “bad”. Each item that was answered with a favorable response received a +1, and each item that was answered with an unfavorable response received a -1. Positive scores were ranked as follows: 1-2, favorable; 3-4, mostly favorable; and 5-6, very favorable. Negative scores were ranked

similarly: -1 to -2, unfavorable; -3 to -4, mostly unfavorable; and -5 to -6, very unfavorable.

Example: “Do you think that SCD carrier testing in the African American community is...?” The response format was “good” or “bad”.

*Section 4: Carrier status (Question 17).* This item asked participants to report their carrier status if they knew it.

Example: “What is your carrier status?” The response format was “have SCT”, “do not have SCT”, and “don’t know”

*Section 5: Intention to participate in carrier testing (Questions 18-19).* The first item asked participants how likely it was that they would participate in SCD carrier testing.

Example: “How likely are you to participate in SCD carrier testing today?” The response format was a Likert-type scale ranging from *1 very likely* to *5 very unlikely* and included “don’t know”.

The second item asked participants whether they participated in carrier testing that was performed on the day that the survey was given. A score was given to indicate participants’ actual participation in testing.

Example: “Did you participate in SCD carrier testing today?” The response format was “yes” or “no”

If the individuals responded that they were very likely to participate in testing, a score of 5 was given; if they actually participated in testing, a +1 was added to the score of 5, for an intention to participate in testing score of 6. If the individuals indicated that they were unlikely (score of 2) to participate in testing and did not get tested a -1 one was added to



the likelihood score, for an intention score of 1. The scores ranged from 0, representing a low intention to participate in testing, to 6, representing a high intention to participate in testing.

*Section 6: Factors for or against testing (Questions 20-21).* These items were open-ended questions that asked the participants to identify factors that would contribute to their intention to participate or not to participate in SCD carrier screening.

Example: “What factors would contribute to your decision to be tested?”

*Section 7: Perceived susceptibility (Questions 22-23).* These items were adapted from the Cystic Fibrosis Carrier Testing Survey (O’Connor & Cappelli, 1999; Surh et al., 1994). The original subscale was developed by Surh et al. to assess the health beliefs and carrier testing practices of relatives of individuals with CF and spouses of identified carriers or patients with CF, as well as to measure their perceived susceptibility to being CF carriers. O’Connor & Cappelli revised the subscale for their study about health beliefs and the intent to use predictive genetic testing for cystic fibrosis carrier status. In both studies, the target population was Caucasian women between the ages of 18 and 34. This perceived susceptibility scale has not been used with African Americans or other populations of color.

The original survey asked the respondents to (a) indicate the probability that they are a CF carrier and (b) how concerned they are about being a CF carrier ( Surh et al., 1994). O’Connor and Cappelli (1999) added two additional items that asked the participants to (1) indicate their perceived risk of being a carrier and (2) indicated their level of perceived risk. The internal reliability score for the original study by Surh et al., was 0.8, whereas the score for the study completed by O’Connor and Cappelli was 0.48.

There was been no evidence to suggest that this scale has been used with African Americans. O'Connor and Cappelli's two additional items were re-written to measure the perceived susceptibility to being a SCD carrier.

One item asked the participants to indicate the likelihood that they were SCD carriers instead of CF carriers.

Example: "How likely is it that you are at risk for SCT?" The response format was a Likert scale ranging from 1 *very likely* to 5 *very unlikely* and included "don't know".

A second item asked the participant to rate their risk of being a SCD carrier.

Example: "What is your level of risk?" The response format was a Likert-type scale ranging from 1 *very high* to 5 *very low* and included "don't know".

The composite score for the two items ranged from 0 to 10. A score of 1 indicated a very high perceived susceptibility whereas a score of 10 indicated a very low perceived susceptibility.

*Section 8: Perceived severity (Questions 24-25).* These items were adapted from the Health Belief Questionnaire (Henneman et al., 2001). The items on this scale were used by Henneman et al. to examine the perceived severity of reproductive outcomes associated with being a CF carrier. These items were re-written to measure the participants' perceived severity of having SCT. One item asked about their level of concern for testing positive for SCT.

Example: "What would be your level of concern if you tested positive for SCT?"

The response format for this item was a Likert-type scale ranging from 1 *very high* to 5 *very low* and included "don't know".

Another item asked about their perceptions regarding whether they would feel less healthy than others if they learned that they had SCT.

Example: “Would you feel less healthy than others if you learned that you had SCT?” The response format for this item was Likert scale ranging from 1 *very likely* to 5 *very unlikely* and included “don’t know”.

The composite score for the two items ranged from 0 to 10. A score of 1 indicated a very high perceived severity while a score of 10 indicated a very low perceived severity.

*Section 9: Attitude toward SCD/SCT (Questions 27-30)* Woodridge and Murray (1988) developed an instrument entitled: The Health Orientation Scale: A Measure of Feelings about SCT. In the HOS the semantic differential technique was used for the general measure of attitudes. The scale was developed to objectively appraise the psychological implications of being identified as a sickle cell gene carrier. Woodridge and Murray’s study focused on a comparison of noncarrier and carrier reactions to situations involving the diagnosis of SCD and SCT among African Americans.

The Pearson product-moment correlation coefficient obtained for the original scale was 0.82, indicating that the HOS is a stable measurement instrument. A coefficient alpha of 0.97 was obtained for a subdivision of those situations addressing SCD and SCT only. The HOS provided a measure of attitudes toward nine situations. Only the four situations that addressed SCD and SCT were included in the current analysis.

The following five of the situations were eliminated from the analysis:

“How would you feel if you were diagnosed with cancer?”

“How would you feel if you were diagnosed with high blood pressure?”

“The following terms best describe me.”

“How would you feel if you were in charge of 50 people who do different kinds of jobs and you learned that several of your employees have SCT?”

“As the boss, I imagine that SCT carriers might feel...”

The items related to high blood pressure and cancer were not included in the current data analysis because they were not relevant to SCD or SCT. The other three other items were related to SCT but were considered incompatible with the study population.

Each of the situations is followed by the same 12 semantic bipolar differential scales: (a) Bad-Good; (b) Afraid-Unafraid, (c) Not guilty –Guilty, (d) Ashamed-Unashamed, (e) Strong-Weak, (f) Sad-Happy, (g) Pleased-Angry, (h) Sick-Healthy, (i) Shocked-Relieved, (j) Unmarked-Marked, (k) Unable-Able, and (l) Inactive-Active. Mean scores from these bipolar scales ranged from 1 to 5. As illustrated by Woodridge and Murray (1988), an extreme score of 1 indicated an extreme left position, which is represented by a very negative/unfavorable rating on the bipolar continuum. An extreme score of 5 indicated an extreme right position, which is represented by a very favorable/positive rating on the continuum. A mean of 3 was the midpoint of the continuum, suggested neutrality. The situation means ranged from 12 to 60. The scores represented the following categories: very unfavorable (0-12), unfavorable (13-24), ambivalent (25-36), favorable (37-48), and very unfavorable (49-60).

Example: Situation F: “Your doctor has just told you that you have SCD, you feel...” The response format was “Bad...Good”, “Afraid...Unafraid”, “Not guilty... Guilty”, “Ashamed...Unashamed”, “Strong...Weak”, “Sad...Happy”,

“Pleased...Angry”, “Sick....Healthy”, “Shocked...Relieved”,  
“Unmarked...Marked”, “Unable...Able”, and “Inactive...Active”.

### *Pilot Testing of Instrument*

Before the first administration of the SCDAS, it was pilot tested with 15 African American students at the Georgia State University School of Social Work. During the initial visit to the class the researcher discussed the dissertation topic, the purpose of the research and the survey that was being developed to collect data. The researcher recorded all of the verbal comments made by the students. In addition, the researcher reviewed and made notes regarding the comments written by the students. The students suggested several revisions such as increasing the font size from 10 point to 12 point, providing more space for Likert-type scale response formats to avoid confusing respondents, and adding “don’t know” to the response format for Items 22 through 25. On the basis of their suggestions, the instrument was revised and the students class was visited a second time four weeks later. The purpose of the second visit was to have the students complete the survey again to assess whether the students scores remained consistent over time however, the same group of students were not available for the second administration of the test. Additionally, the survey was given a second time to ensure clarity of the concepts, as well as to estimate the amount of time that students took to complete the surveys.

### *Reliability of Instrument*

The internal consistency of the instrument was tested; after the pilot and major study. The internal consistency statistic was used to assess the extent to which the items

within the instrument measure consistently. The alpha coefficients presented are based on the major study and include, .55 for the SCD/SCT Genetics Knowledge subscale, 0.64 for the Feelings about Carrier Testing subscale, .81 for the Perceived Susceptibility subscale, .62 for the Perceived Severity subscale, .94 for the HOS and .73 for the total inventory. These estimates of reliability suggest that Perceived Severity and Feelings About Carrier Testing were just below the recommended alpha level of .70. This issue speaks to the true reliability of the responses on those scales. However, the alpha coefficient for the entire instrument was .73, which above the recommended score. Table 1 depicts the alpha coefficients for the SCDAS items. The table illustrates the alpha coefficients for the items obtained by the authors of the original studies, the pilot study and the major study.

Table 1

*Internal Consistency Reliability Scores for Sickle Cell Disease Assessment Survey Subscales*

Subscales	Original study $\alpha$	Pilot study $\alpha$ (N=15)	Major Study $\alpha$ (N=191)
Sickle Cell Disease Genetics Knowledge subscale	Self-developed	0.44	0.55
<sup>a,b</sup> Perceived Susceptibility subscale	0.83, 0.48	0.95	0.81
<sup>c</sup> Perceived Severity subscale	0.64	0.85	0.62
<sup>d</sup> Feelings about Carrier Testing subscale	0.55	0.63	0.64
<sup>e</sup> Health Orientation Scale	0.97	0.91	0.94

*Note.* <sup>a</sup>Surh, Cappelli, et al, 1994; <sup>b</sup>O'Connor & Cappelli, 1999; <sup>c</sup>Henneman, Bramsen, Van der Ploeg, Van der Horst, & Gille, 2001; <sup>d</sup>Barlow-Stewart, Burnett, Proos, Howell et al., 2003; <sup>e</sup>Wooldridge & Murray, 1988

### *Validity of Instrument*

Content validity was established during the pilot testing of the survey. Content validity refers to the assessment of the degree to which items on a test measure the intended instructional objectives or the content (Tashakkori & Teddlie, 1998). Relevant staff persons at the SCDF of GA were sent the instrument via e-mail. The Delphi technique was applied to this process; that is, the instrument was reviewed several times, and additional feedback was solicited each time in response to edits. It was recommended that a category for “don’t know” be added to the response format for Items 23 –25, which measured perceived susceptibility and perceived severity. During the pilot testing, student reviewers suggested that this option be added, as well. I approached experts for confirmation.

Construct validity was established during the instrument development phase. Construct validity is concerned with the degree to which the test measures the construct (Heppner & Heppner, 1998). This validity was assessed by obtaining inter item correlations for the 24 items that were used on the survey to measure the independent variables: SCD genetics knowledge (SCD Genetics Knowledge subscale), attitudes about carrier testing (FCT subscale), perceived susceptibility (perceived susceptibility subscale), perceived severity (perceived severity subscale) and attitudes toward SCD and SCT (HOS subscale). The Pearson  $r$  coefficient and level of statistical significance were examined on the correlation matrix for all of the items. Three of the five subscales, HOS, Perceived Susceptibility, and Perceived Severity, had items that were all correlated at the statically significant level ( $p < .05$ ). The other two subscales had items that did not reveal

statistical significance. The FCT subscale items that were not correlated were as follows: Item 11 did not correlate with Items 13 and 14 and Item 14 did not correlate with Items 13 and 15. The following SCD Genetics Knowledge subscale items were not correlated: Item 2 which did not correlate with Items 3 or 6, Item 3 did not correlate with Items 5 or 10, Item 1 did not correlate with Item 4, and Item 9 did not correlate with Item 6 or 7. These items were not eliminated from the survey.

## Data Analysis

### *Data Screening*

Before the preliminary analysis was begun, the data set was screened for accuracy, missing data, outliers, and the normality of distributions by using SPSS-PC Statistical Package Version 12. To check the accuracy of the data entered, the researcher performed a visual inspection to determine whether there were any inconsistent or improbable scores. Frequency tables were printed to find improbable scores across all variables. Subsequently, a frequency table and histogram were produced to check the adequacy of the scores. Of the 235 survey packets that were distributed, only 225 were returned.

*Missing Data.* In addition to being screened, the data were also checked for missing items. Before entering the data, I discovered that because of an error items 27-30 from the HOS were not included in 23 surveys. These surveys were eliminated from the data, and only 202 surveys were entered. After further examination, it was found that approximately 23% (48) of participants did not respond to Item 20 and that



approximately 16% (33) did not respond to Item 21. These items were open-ended questions that asked the participants to identify the factors that they felt would contribute to their decision to participate in carrier testing. Outliers were sought by reviewing stem-and-leaf diagrams for each quantitative variable, and none were found.

Items 24 and 25 referred to the participants' perceived severity of having SCT and perceived level of concern for testing positive for SCT, respectively. Approximately 7.9% (16) of responses from Item 24 were missing, and approximately 8.9% (18) of responses from Item 25 were missing. Responses of "don't know" were not counted as missing data.

To maintain the sample size of the study, the researcher followed the Hair, Anderson, Tatham, and Black (1998) suggestion and replaced the responses missing from Items 24 and 25 with the group means. Eleven cases were also eliminated from the data set because they did not meet the inclusion criteria. Specifically, these eliminated cases included participants reporting less than 13 years of education, which indicated that their level of education was not beyond high school. In total, 191 cases were used in the analysis.

*Descriptive Statistics.* Descriptive statistics for all predictor variables were calculated, and all of the statistics had reasonable values. The means and standard deviations for the predictor variables were knowledge,  $M=58.27$  and  $SD=16.11$ ; attitudes carrier testing,  $M=5.54$  and  $SD=1.03$ ; Perceived Severity,  $M=7.13$  and  $SD=2.33$ ; perceived susceptibility,  $M=6.20$  and  $SD=3.52$ ; and attitude toward SCD and SCT,

$M=28.20$  and  $SD=12.84$ . Table 2 illustrates the predictor variables that were assessed for mean, standard deviation, skewness, and kurtosis.

Table 2

*Mean, Standard Deviation, Skewness and Kurtosis for the Predictor Variables*

Variable	<i>M</i>	<i>SD</i>	Skewness <sup>a</sup>	Kurtosis <sup>b</sup>
SCD/SCT Genetics Knowledge	58.27	16.11	-.318	.035
Attitude towards Carrier Testing	5.64	1.03	-2.47	4.75
Perceived Severity	7.13	2.33	-.175	-.263
Perceived Susceptibility	6.20	3.52	.520	-1.02
Attitude towards SCD/SCT	28.20	12.84	-.217	.183

*Note.*  $N=191$  SCD= sickle cell disease; SCT=sickle cell trait.

<sup>a</sup> Transformed skewness = .763; <sup>b</sup> Transformed kurtosis = .843

Only one variable, attitude toward carrier testing (FCT score) was not univariate normal in that the skewness and kurtosis were greater than 2. Data transformation provides a means of modifying variables for one or two reasons: (a) to correct violations of the statistical assumptions underlying the univariate or multivariate techniques, or (b) to improve the relationship (correlation) between the variables (Hair et al., 1998). This variable was transformed to achieve normality. The attitude towards carrier testing (FCT score) variable was a skewed distribution. The skewed distribution was transformed by taking the logarithm of the variable. After the data, were transformed the skewness and kurtosis of the transformed attitude toward carrier testing variable were less than 1; therefore, the scores from the sample could be normally distributed.

### *Variables in Quantitative Analysis*

There were several variables that were examined to gain an in-depth understanding of how individual variables or a combination of variables influenced participants' decision to participate in carrier testing. The independent variables included (a) knowledge level of SCD/SCT genetics, (b) attitude toward carrier status, (c) attitude towards carrier testing, (d) perceived severity, and (e) perceived susceptibility. The score received on the questions, which evaluated basic understanding of SCD, SCD inheritance patterns, and carrier testing, measured the participants level of knowledge. Beliefs about carrier testing were defined by the score received on questions that evaluated the perceived susceptibility of risk for having SCT and the perceived severity of feelings regarding SCT. The dependent variable was intention to participate in carrier testing; this variable was defined by the individual's decision to participate in SCD carrier testing. The control variables, which were the demographic variables, included (a) gender, (b) age, (c) years of education, (d) marital status, (e) parental status and (f) family history of SCD or SCT.

### *Statistical Procedures Applied to Research Questions*

*Research Question 1.* This question asked, what is African American college students' level of knowledge about SCD, attitude regarding SCD and SCT and regarding SCD carrier testing, level of perceived susceptibility to SCT, and level of perceived severity of SCT?

The scales used to answer research question 1 include the SCD Genetic Knowledge subscale, HOS, and the FCT Scale.

First, participants' level of knowledge was assessed through the scores obtained on the 10-item SCD Genetics Knowledge subscale. Descriptive statistics, specifically the frequency and mean, were developed to illustrate the scores obtained on the basis of a 10-point scale, for a total of 100 percentage points. The total scores ranged from 0 to 100%.

Next, the scores from the HOS, were used to assess participants' attitudes toward SCT carrier testing. Descriptive statistics were developed to illustrate the number of participants whose scores fell in the following categories: very unfavorable (0-12), unfavorable (13-24), ambivalent (25-36), favorable (37-48), and very favorable (49-60).

Participants' attitudes toward SCD carrier testing were determined by the scores calculated from the FCT subscale items. Descriptive statistics were developed to illustrate support or nonsupport of SCD carrier testing.

Additionally, descriptive statistics were calculated for Item 24, which asked, "What would be your level of concern if you tested positive for SCT?" Item 25 asked, "Would you feel less healthy than others if you learned that that you had SCT?" These items assessed the participants' level of perceived severity.

*Research Question 2.* This question asked, is there a relationship between African American college students' level of knowledge about SCD, attitude regarding SCT and SCD carrier testing, level of perceived susceptibility to SCT, or level of perceived severity of SCT and their intention to participate in SCD carrier screening?

Multiple regression analysis was used to answer this research question. Multiple regression analysis is a multivariate statistical technique used to examine the relationship between a single dependent variable (intention to participate in carrier testing) and a set of independent variables (attitude towards SCD and SCT, attitude towards carrier testing, perceived severity, and perceived susceptibility)(Hair et al., 1998). This analysis was applied to this research question because the aim was to objectively assess the degree and character of the relationship between the dependent variable and the independent variables. The independent variables, in addition to their collective prediction of the dependent variable, may also be considered for their individual contribution to the regression equation and its prediction.

The stepwise multiple regression procedure was used to select variables for this analysis. Stepwise regression was chosen because it allowed the identification of (a) how much total variance a set of independent variables can account for in a dependent variable and (b) which independent variables can explain more variance in the dependent variable. Each variable was considered for inclusion before the equation was developed. The independent variable with the greatest contribution was added first. Independent variables were then selected for inclusion on the basis of their incremental contribution over the variables already in the equation.

*Research Question 3.* This question asked, do African American college students with certain levels of (a) perceived risk for SCT and (b) concern for receiving a positive SCT result have greater intention to participate in SCD carrier testing?

An Analysis of Variance (ANOVA) was computed to determine differences between groups on the basis of the dependent variable. The perceived level of risk for SCT was addressed in Item 24. These categories were cross-tabulated with the dependent variable, intention of participating in SCD carrier testing. The level of concern about receiving a positive test result for SCT was addressed in Item 25. These categories were cross-tabulated with the dependent variable, intention to participate in SCD carrier testing.

*Research Question 4.* This question asked, is there a relationship between African American college students' support of SCD carrier testing and their intention to participate in SCD carrier testing?

A chi-square test was conducted to address the variable support for SCD carrier testing in young adults and its association with the variable intention to participate in SCD carrier testing. The independent variable is categorized by nominal level of measurement with participants who agree labeled as supporters of testing and those that disagree labeled as non-supporters of testing. Table 3 provides a summary of the statistical procedures that were conducted to answer each question.

Table 3

*Statistical Analyses Applied to Research Questions (RQs)*

RQ	Type of analysis	Rational for analysis
RQ 1: What is African American college students' level of knowledge about SCD and SCT, attitude regarding SCT and SCD carrier testing, level of perceived susceptibility to SCT and perceived severity of SCT?	Descriptive statistics	Describe the sample according to the IV
RQ 2: Is there a relationship between African American college students' level of knowledge about SCD and SCT, attitudes regarding SCT and SCD carrier testing, level of perceived susceptibility to SCT, and perceived severity of SCT and their intention to participate in SCD carrier screening?	Multiple regression	Examine the joint and separate effects of the IVs on the DV
	Stepwise analysis	Predict a DV from one or more IV's
RQ 3: Do African Americans college students with certain levels of (a) perceived risk and (b) concern for a positive SCT result have greater intention to participate in SCD carrier testing?	ANOVA	Determine group differences
RQ4: Is there a relationship between African American college students' support of SCD carrier testing and their intention to participate in SCD carrier testing?	Chi-square	Test two variables independence or dependence

*Note.* SCD= sickle cell disease; SCT=sickle cell trait; IV= independent variable; DV=dependent variable

Combining Quantitative and Qualitative Data in a Mixed Method Study

The purpose of Phase 2 was to use qualitative methods to complement a predominately quantitative research effort. In this case, the qualitative method used was semi-structured interviews, which typically provide interpretative resources for understanding the results from the quantitative research (Morgan, 1998). During the

intermediate phase (when Phase 1 and Phase 2 overlapped), the results from the statistical analyses conducted on the survey data in Phase 1 were used to inform Phase 2 in two ways. First, there was a selection of individuals to participate in follow-up interviews in order to further explain the statistical findings. Second, the interview protocol was developed with questions that guided the follow-up interviews with those students selected for continued participation.

### *Sampling Procedures*

The individuals chosen for this phase of the study were a subset of participants from Phase 1. Only individuals who underwent SCD carrier testing and completed an SCDAS were eligible to participate in Phase 2 of the study. The sample relationship used for this design was the nested relationship, which implied that sample members selected for one phase of the study represented a subset of those participants chosen for the other facet of the investigation (Onwuegbuzie & Collins, 2004). Initially, the maximum variation sampling strategy was proposed for the current study. Maximum variation samples include individuals selected to maximize the range perspectives investigated in the study (Onwuegbuzie & Collins).

It was anticipated that this sampling strategy would yield 12-15 participants. However, because of the realities of field research, there were a small number of respondents for this phase of the study and only 10 participants agreed to interviews.



## *Instrument*

### *Interview protocol development*

The sequential explanatory design dictates that the interview protocol be developed from the results of the statistical test conducted in Phase 1. The interview protocol was developed on the basis of information found during the literature review and on the basis of response patterns identified during analysis of the quantitative data.

The first question asked the participants to tell about themselves. This was asked as a way of learning characteristics of the participant and making the participant feel more at ease during the interview. The second question asked the participants to discuss what they knew about SCD and SCT. This was asked to explore assess the participants' familiarity with SCD and SCT, additional probing sub-questions were asked to probe the participants understanding of topics such as disease characteristics, inheritance patterns, and disease transmission. The average score on the survey was 56.8 %, which meant that most of the participants answered 6 out of the 10 items correctly. Many of the participants responded incorrectly to the facts specifically about SCD and SCT. Because of the closed ended questions on the cross-sectional survey in Phase 1, participants could not fully express their knowledge. The revised open-ended question was asked during Phase 2 as a way of obtaining a greater understanding of the participants' basic knowledge of SCD and SCT.

The third question asked the participant why he or she decided to participate in SCD carrier testing. This question was asked as a way of further exploring internal and external factors that contributed to the participant's decision to participate in testing. Also, asking this question allowed the researcher to compare the factors that were identified by participants open-ended responses in Phase 1 (e.g., family history, accessibility and being African American) with those identified by participants in Phase 2. Sub-questions were introduced to gain more understanding of how the factors identified in the Phase I influenced the participants in Phase 2.

The fourth question asked participants to describe their experiences with carrier testing. This question was asked to explore the participant's attitude toward carrier testing and the process involved in the testing. This question was derived from the participants' responses on the open ended items on the survey in Phase 1. The participants suggested that accessibility and ease of carrier testing was a factor in their decision to participate.

The fifth question addressed the participants' thoughts about testing positive or negative for SCT. In Phase I the responses of the participants indicated that many felt that they were at a higher risk for SCT and few participants viewed SCT as being a severe or serious condition. This question was asked as a way of exploring their perceived susceptibility to and severity of being identified as a SCD carrier or noncarrier in Phase 2.

The sixth question asked the participant to describe or define genetic testing. This was asked as a way of assessing the participants' familiarity with the term *genetic testing* and their thoughts in general about genetic testing. This question was derived from

literature that suggest that African Americans have limited knowledge of genetic testing (Laskey et al.,2003; Kalfoglou et al., 2004).

The seventh question asked the participants to give their thoughts on how genetic testing is perceived among African Americans. This question was asked to understand both the participant's current perspective about genetic testing and the factors that might contribute to this perspective. Also, the question was asked as a way of further exploring the support indicated in Phase 1 for SCD carrier testing among African Americans, particularly as this finding contradicts past studies that suggest African Americans have negative attitudes about genetic testing (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Harris, Gorelick, Samuels, & Bempong, 1996;Laskey et al.,2003).

The eighth question asked the participants to explain, on the basis of what they knew about SCT, what advice they would give to a young woman who was found to be an SCD carrier, given what they knew about the SCT. This was asked to explore whether they expressed the relationship between carrier testing and reproductive decision making for young adults. Also, the researcher hoped to ascertain the depth of the support for carrier testing among young adults and partners that the participants had indicated in Phase 1.

The tenth question asked the participants about their views on the value of providing SCD carrier testing to individuals of reproductive age or to young adults. This question was asked as a way of assessing whether or not the participants found any value in preconception testing in comparison to prenatal testing. In addition, the researcher wished to gain more understanding about the study population's view on this issue in

comparison to other literature (Markel, 1997, IOM, 1994<sup>a</sup>) that presents an argument between the value of preconception and prenatal testing.

#### *Pilot Testing of Interview Protocol*

An individual tested at a college health fair was selected to pilot test the interview protocol. The participant was provided a code number (PT0) to maintain anonymity. The participant was given two copies of the consent form, and I instructed her to read and sign the form, if she agreed to participate and had no further questions. A second copy was provided to the participant to keep for her records. The researcher reiterated that the interview would be audiotaped and that the data transcribed would be coded with a false name to maintain her anonymity. PT0 was an African American female student who was 23 years of age, single, and without children. She had a family history of SCT and SCD, but was not found to be a carrier. The interview lasted approximately 35 min. PT0 was given a \$35.00 incentive for participating in the interview. As a result of the pilot interview with this participant, four additional questions were added to the interview protocol to further probe the participants' concerns regarding reproductive issues, specifically regarding the future possibility of passing on SCD or SCT to their child or children. The questions added to the interview protocol were as follows:

“Did participating in SCD carrier testing make you think any differently about genetic testing in general, for yourself or your partner” (Question 11)?

“Did participating in SCD carrier testing make you think any differently about prenatal testing for yourself or your partner” (Question 12)?

“What are your thoughts about couples with SCD or SCT having children” (Question 13)?

“What are your views on having a child with SCD or SCT” (Question 14)?

Question 11 was asked because the researcher wished to explore the participants’ interest in genetic testing for themselves or their partner. Question 12 was asked as a way of discovering the participants’ understanding of the difference between prenatal testing and preconception testing such as SCD carrier testing. Questions 13 and 14 were asked to explore the participants’ views on the possible risk involved with having a child with SCD or SCT. The questions were asked because their responses to the HOS item E in Phase 1. Eighty-three of the responses indicated between unfavorable and ambivalent attitudes toward carrier couples having children.

All of the questions asked on the interview protocol are presented in Appendix E.

An example of how the protocol questions were developed is presented in Figure 3.

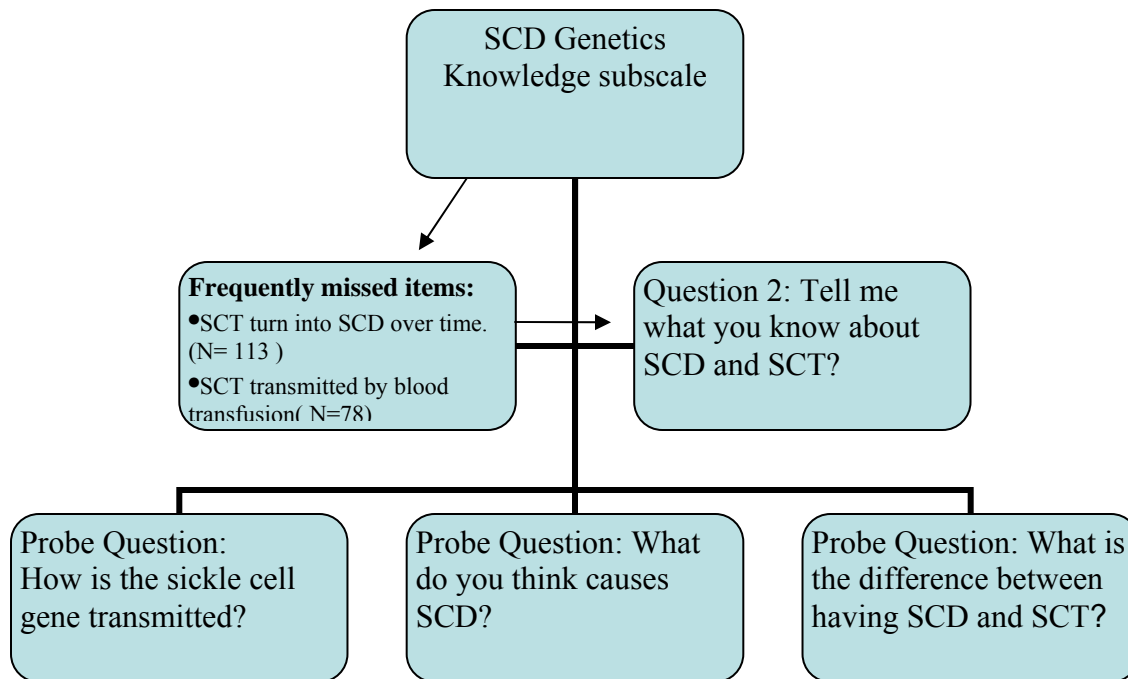


Figure 3. Example of interview protocol development

## Phase 2: Qualitative Research

The purpose of Phase 2 was to address the central research question that framed the qualitative arm of the study. The research question was, “Why do African American college students participate in SCD carrier testing?”

### *Target Population*

Eighty-one individuals participated in carrier testing and were eligible for participation in Phase 2 of the study; however, only 10 individuals agreed to participate, and only 8 of those 10 individuals completed interviews.

Eighty-one individuals who completed the SCT test were invited by letter to participate in Phase 2 of the study. Regardless of whether their test results were positive or negative, the results did not exclude them from eligibility. The recruitment letter included a brief description of the study; the purpose of the second phase; the incentive provided; and my contact information, including name and cell phone number. Once the participant contacted me, a time and date were scheduled for the face to face interview.

Nearly half of the individuals who participated in testing came from the SSU site. SSU is approximately 4 driving hours from the SCDF of GA office; therefore, conducting face to face interviews with individuals from that site was improbable. A total of 81 letters were sent to participants in July 2006 that requested their participation in follow-up interviews. Of the 81 letters mailed, 46 letters were sent to participants from the SSU site to invite them to participate in a scheduled telephone interview. After 2 weeks, none of the participants from the SSU site had contacted the researcher. The researcher

discussed the lack of participation with participating staff at the SCDF of GA. The agency administrative assistant agreed to conduct follow-up calls on behalf of the researcher to potential participants. For the next week the administrative assistant and the researcher conducted follow-up calls to the potential participants. The administrative assistant was responsible for contacting 23 participants and the researcher was to contact 23 participants. Twenty of the participants were left voice messages, 8 of the participants had telephone numbers that were disconnected or not operational and 10 of the participants agreed to call the researcher to schedule an interview. Two of the participants contacted the administrative assistant stating that they were not willing to conduct the hour interview on their mobile phones and had no land line. Six of the participants did not leave contact telephone numbers on their information card. By approximately 3 weeks after the mailing, none of the participants had scheduled a phone interview. Because of unforeseeable time and financial constraints, including the cost of long distance telephone calls, the researcher decided not to continue with the recruitment of participants from the SSU site. The decision was made to focus on recruiting participants from the other five sites. Along with other study limitations, the implications of excluding the SSU participants from the study are discussed in chapter 5.

Simultaneously, 35 recruitment letters were sent out to participants from the other five sites. This recruitment effort yielded responses from 5 individuals. During the first week of September, a second attempt was made to recruit more participants. Staff from SCDF of GA and the researcher made telephone calls to individuals with positive test results only. Simultaneously, a second group of flyers were mailed to the same participants. This process produced 5 additional participants. Interviews were scheduled with these 5

individuals; however, 2 of the potential participants failed to appear for their scheduled interview. The recruitment process for this phase lasted from mid-July through late September 2006. In total, eight interviews were completed in Phase 2.

### *Data Collection*

#### *Procedure*

In March 2006, the UAB IRB and the President and CEO of the SCDF of GA granted approval for the study. The process of determining results from the SCD carrier testing takes approximately 5-15 days. After the participants were sent letters indicating their results, recruitment letters were sent inviting those individuals to participate in follow-up interviews. The face-to-face interviews lasted approximately 45-60 min. and were held at the SCDF of GA offices. On the day of the interview, the participants received two copies of the informed consent letter before beginning the session. One copy was read, signed, and returned to me; the other copy remained with the participant for his or her records. The signed letter of informed consent gave the researcher permission to interview the participant, audiotape the interview, and use the participant's words in the final study report. Upon completion of the interview, each participant received a \$35.00 cash incentive. After being transcribed the data were sent back to the participants via e-mail to verify what was transcribed and to further clarify any responses.



## *Data Analysis*

### *Data Reduction*

The data analysis procedure began with each audiotaped interviews being transcribed using word-processing software. A 2-inch margin was left on each side of the transcribed document. The left side of the transcribed document was used for coding and the right side for any notes or pertinent comments. The transcripts were transcribed verbatim and then checked for accuracy. The transcripts contained the date of the interview and the participant's code. A copy of the transcribed interviews was printed and reviewed by the researcher. The data were read repeatedly for understanding, clarity, and familiarity. Then the transcripts were compared with the audiotaped interviews. Five copies of the transcripts were made. A master copy of each transcript was kept in a locked metal file cabinet in my office. For review, the second and third sets of transcripts were given to an outside coder (Dr. Lesa N. Hope) from Georgia State University who was selected because of her extensive training in qualitative research methodology. The fourth set of the transcripts was used throughout the data analysis process, and the fifth set was used for cutting and pasting during the coding process.

### *Typological Analysis*

In the current study, the typological groupings were derived from the interview protocol questions, which were generated from the HBM and the TRA, from the literature, and from the results of Phase 1 of the study. The typological analysis was guided by the nine-step method described by Hatch (2002) and explained in Table 4. The

steps included analyzing and identifying typologies from the data, reading and marking entries of interest, recording the main idea of relevant entries, identifying patterns and relationships within entries, coding entries according to patterns and identify and recognizing relationships among patterns.

Table 4

*Typological Analysis Procedure*

Typological analysis steps	Person responsible	Product
Typologies to be analyzed were identified.	Researcher	Typologies identified for further examination
The data were read and marked if related to the typologies of interest.	Researcher, outside coder	Entries grouped by typology
The entries were read by typology, and the main ideas in entries were recorded.	Researcher	The summary sheet included a brief statement of the main idea of the data excerpt.
Patterns, relationships and themes were identified within typologies.	Researcher	Record produced that outlined patterns, relationships and themes
The entries were coded according to patterns identified.	Researcher, outside coder	Record produced that indicated what entries went with which elements of patterns
The researcher identified patterns that were supported by the data and the data that did not exemplify of the patterns.	Researcher	Confirmatory and disconfirming examples Identified
Relationships among patterns were reviewed.	Researcher	Relationships among patterns were identified
Patterns were identified as one-sentence generalizations.	Researcher	One sentence generalizations Categorized
Data excerpts that supported generalizations were identified.	Researcher	Data excerpts that supported generalizations were grouped and recorded

The researcher elicited the assistance of the same outside coder, who was asked to review five of the transcripts and to analyze them on the basis of the nine-step typological analysis method (Hatch, 2002). The coder was given 4 weeks to analyze the transcripts, and we met at the end of the 4 weeks to discuss the codes and themes identified. The results of this procedure are discussed in the section related to inter-coder agreement.

### *Credibility in Qualitative Phase*

Credibility for the qualitative data was established during Phase 2. Validity or legitimation is the considered strength of qualitative research because the purpose of such research is to determine whether the findings are accurate from the perspective of the researcher, the participant, or the readers of an account (Creswell, 2003). In qualitative research, the idea of trustworthiness refers to the overall idea of reliability and validity (Meyers & Sylvester, 2006). Credibility, another facet of trustworthiness, refers to the appropriateness and accuracy of data sources and interpretations. The strategies most appropriate for this study were (a) member checking, (b) peer debriefing and (c) inter-coding agreement.

*Member checking.* To increase the validity of qualitative research methodology, the member checking technique was used. Member checking consisted of taking the data and interpretations back to the participants in the study so that they could confirm the credibility of the information and narrative account (Creswell & Miller, 2000). With member checking, the validity/credibility procedure shifted from me to the participants.

All 8 participants were sent copies of their transcripts and summaries of their themes via e-mail. The participants were asked to review the transcripts to ensure that

their thoughts and views were interpreted correctly and to record on the Transcription Feedback Form any additional thoughts that the participants may have about the topics discussed during the interviews (see Appendix G for Transcription Feedback Form). None of the participants gave further explanations of their responses. Two of the participants made comments about typing errors, and 2 the participants did not complete the form.

*Peer debriefing.* Peer debriefing is a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of revealing aspects of the inquiry that might otherwise remain implicit within the inquirers' mind (Tashakkori & Teddlie, 1998). Lincoln and Guba (1985) contended that the ultimate purpose of peer debriefing is to enhance the credibility or truth-value of a qualitative study by providing an "external check on the inquiry process" (p. 301). Spillett (2003) suggested that peer debriefing is particularly advisable because of a distinctive characteristic of qualitative research in which the researcher is seen as being an instrument.

In qualitative research, individual researchers are the primary means of data collection and analysis. Each investigator brings a different combination of subjective knowledge, skills, and values to the research environment. Peer debriefers can be beneficial in assisting the researchers to become aware of what value system they bring to the research study (Spillett, 2003). A researcher from the University of Pennsylvania acted as the peer debriefer for this study. She completed her doctoral program in social work two years ago and is currently a postdoctoral researcher with experience in qualitative and quantitative mental health research.

The researcher felt that this colleague could contribute to the study by providing me with an unbiased perspective. She has little knowledge of SCD or carrier testing. Spillett (2003) posited that an “outsider as a debriefer may notice more readily the researcher’s taken for granted beliefs and thus stimulate the researcher’s self-examination”.

The researcher discussed with the peer debriefer the difficulties encountered in recruiting individuals for Phase 2 of the study. The peer debriefer suggested that researcher send out reminder letters to potential participants and conduct follow-up telephone calls. The researcher also expressed concern with the limited number of men participating in this phase of the study.

The peer debriefer and the researcher explored the questions that guided the interview protocol. She understood the questions posed in the interview protocol but understood neither the questions addressing genetic testing and prenatal testing, nor the relevance of the questions to the current study. The researcher discussed with the debriefer the challenges involved in reducing the large amount of text into smaller segments.

After reviewing two of the transcriptions, the peer debriefer had two comments: (a) the researcher appeared to have difficulty maintaining the role of researcher and not educator and (b) the researcher appeared to be leading the participant to answer some questions in certain ways.

*Inter-coding Agreement.* Also, the verification mechanism of inter-coder agreement was used. The inter-coder agreement check was used because it has been determined to be a strong verification procedure in qualitative research (Miles &

Huberman, 1984). The outside coder (Dr. Hope) and the researcher independently coded the transcripts for categories and themes by using the approach described by Hatch (2002). The codes and themes were compared, and the percentage of inter-coder agreement was determined.

Miles and Huberman (1984) suggested a procedure for verifying inter-coder agreement. The researcher used the procedure in the following manner:

1. The outside coder and the researcher separately coded 5-10 pages of each of the transcribed interviews.
2. Then collectively the coder and researcher reviewed the same 5-10 pages of the transcripts to compare the codes reviewed that each had assigned to the text segment.
3. The researcher kept a codebook listing the number of agreed upon codes and the number of codes upon which we differed

The themes found were then compared across all of the transcripts. Records were kept on the number of themes on which we agreed and on the number of themes on which we differed. After the transcripts were reviewed, the process was divided into two stages, which included, (a) comparing codes and (b) identifying themes. The first stage consisted of coding the transcripts and then comparing them for similarities and differences.

The researcher generated 43 codes, whereas the outside coder generated 40 codes; we agreed on 40 codes. The second stage was composed of identifying themes that were found under the typologies. The researcher identified 14 major themes, and the outside coder identified 12 themes; as a result we agreed upon 12 themes. The inter-coder agreement was calculated on the basis of the following equation:

Reliability = No. of agreements/total No. of agreements + disagreements.

Based on the equation, the percentages of agreement on codes and themes were 93% and 86%, respectively. Based on this equation it was concluded that the data was credible.

### *Integration*

#### *Purpose of Integration*

The purpose of the integration or mixing in mixed methods research is to illustrate how the outcomes of quantitative and qualitative analyses may be related to each other in a meaningful way (Erzberger & Kelle, 2003). As previously mentioned, Phases 1 and 2 were connected in the intermediate stage of the study. This connection was made through the selection of participants for the follow-up interviews and through the development of the interview protocol. The integration of Phases 1 and 2 is discussed in chapter 5; in which the quantitative and quantitative research questions are discussed with relevance to the results and the ways in which the follow-up interviews and existing literature support or contradict the findings.

### *Legitimation*

#### *Legitimation of Mixed Methods Research*

Mixed methods research is faced with many challenges, with the greatest challenge being legitimation. Legitimation refers to the difficulty in obtaining findings and/or making inferences that are credible, trustworthy, dependable, transferable and/or confirmable. The complexities of combining qualitative and quantitative approaches

often give rise to the problem of integration. The underlying theme of this problem is the extent to which merging quantitative and qualitative approaches address the five purposes of mixed methodological studies (Onwuegbuzie & Johnson, 2006).

The problem of legitimation is a barrier to mixed methods research being accepted among the majority of researchers. The objective of mixed methodological research studies is to combine the strengths of both approaches and reduce the weakness of them. Tashakkori & Teddlie (2003) indicated that the problem of integration in mixed methods research suggests the need to identify legitimation issues that are not associated with monomethod designs. Onwuegbuzie and Johnson (2006) presented a typology of nine legitimation types, including: (a) sample integration, (b) inside-outside, (c) weakness minimization, (d) sequential, (e) conversion, (f) paradigmatic mixing, (g) commensurability, (h) multiple validities, and (i) political. The types of legitimation addressed in this study included sample integration legitimation, and inside-outside legitimation.

Sample integration legitimation refers to the extent to which the relationship between quantitative and qualitative sampling designs yields quality results. This type of legitimation applies to situations in which the researcher wants to make statistical generalizations from the sample participants to a larger target population. This issue was addressed by selecting participants from Phase 1 of the study for inclusion in Phase 2. Specifically, individuals who participated in SCD carrier testing in Phase 1 were invited to participate in Phase 2 for follow-up interviews.



Inside-outside legitimation refers to extent to which the researcher accurately presents and appropriately utilizes the insiders' view and the observers' views for purposes such as description and explanation. The ability to present these views can be compromised when a researcher is ethnocentric or is so entrenched in the group that he or she is biased. The member checking strategy addressed this legitimation issue in the present study. The participants were sent their transcribed interviews and asked to review them and clarify any misinterpretations.

### *Ethical Considerations*

In the initial stages of the study the researcher sent a letter to the President/CEO of the SCDF of GA requesting permission to participate in the activities of the mobile testing unit. The letter gave a brief description of the study and included a discussion of the study's purpose and proposed methodology. In January 2006, the President/CEO of the SCDF of GA granted me permission to conduct the study (see Appendix B) contingent on approval from the IRB.

The UAB IRB granted approval for both Phases 1 and 2 of the study in March 2006 (see Appendix A) and documentation of IRB approval was forwarded to the SCDF of GA for final approval. After final permission was granted, the researcher contacted the foundation's Outreach Coordinator regarding the testing schedule for the mobile unit.

For Phases 1 and 2, a separate consent form was developed. The consent form for Phase 1 gave a brief description of the first phase of the study and contained a discussion of the individuals' rights as voluntary participants' in the study. The first phase consisted of the participants completing a cross-sectional survey during the SCDF of GA screening

event. The individuals were instructed that the consent form was for completing the survey and not for being tested. The consent form gave permission to use the responses provided on the survey for research purposes. Thus, participants who were not tested could still complete the survey.

On the day of the event, the participants were instructed to read and sign the consent form only if they were going to complete a survey. Once the consent form was signed the researcher gave the participant a survey and an additional copy of the consent form for his or her records. The surveys from this phase were labeled with an alphanumeric coding system to protect the confidentiality of the participants.

The consent form for Phase 2 gave a brief description of the purpose of this phase and included a description of the individuals' rights as voluntary participants in the study. The second phase consisted of semi-structured personal interviews held at the SCDF of GA office. The individuals were instructed that the consent form was for being interviewed and not for being tested. The consent form gave permission to use the recorded and transcribed responses for research purposes.

On the day of the interview, the participants were instructed to read and sign the consent form before the interview. The participant was given a copy of the consent form for his or her records. The individuals who participated in the interviews were referred to only by a code so that identity would remain anonymous. The participants were made aware that their words and thoughts would be represented in a report. All surveys, audiotapes, and transcribed interviews have been kept in a locked metal file cabinet to protect privacy and confidentiality and the materials will be destroyed after 3 years.

### *Role of Researcher*

The researcher has worked in the public health field for over 12 years. Currently, she is the Director of Clinical and Social Services for the Atlanta Alliance on Developmental Disabilities, which is located in Atlanta, GA. The researcher develops and implements health programs for youth and adults with developmental disabilities. These programs are designed to reduce the incidence of the secondary conditions associated with having a developmental disability; such conditions include: physical and sexual assault, obesity, and substance abuse. Because of the nature of the profession, the researcher is familiar with primary and secondary conditions that are caused by disabling conditions. Whether the condition results in a physical disability or a cognitive disability, some of the psychosocial factors that arise with SCD are similar and generate many of the same concerns. The researcher did not participate in the testing process but does have a family history of SCD and SCT.

In the current study, the researcher served in two different roles. In Phase 1, the researcher was responsible for administering the cross-sectional survey to the participants and for collecting the data. The participants' interaction with the researcher was very limited because she wished to reduce the opportunity for bias. In Phase 2, the researcher was responsible for conducting personal interviews with participants. This exchange was more intensive because the researcher's interaction with participants was more intimate. Also, Phase 2 required the researcher to shift from the role of observer to that of an active participant.

## Chapter Summary

The purpose of this chapter was to discuss the fundamentals and rationale for using the mixed methods approach and the sequential explanatory design in the study. The population used in the study was described as were the sampling strategies utilized in the selection of participants for each phase. Additionally, the specific steps used in the development of instruments and collection of data for Phase 1 and Phase 2 of the study were presented. Moreover, this section provided a description of the procedures for treatment and analysis of data collected in Phase 1 and Phase 2. The next chapter provides the results of the data analysis and details the findings of the study.

## CHAPTER 4

### QUANTITATIVE AND QUALITATIVE RESULTS

This chapter describes and summarizes the quantitative and qualitative analyses used to evaluate the research questions presented in the previous chapters. The chapter is divided into two sections: Phase 1 (quantitative results) and Phase 2 (qualitative findings). In the Phase 1 section, the following items are discussed: sample characteristics and the results of analysis based on the quantitative research questions. In the Phase 2 section the following items are discussed: identification of themes and the analysis of themes across interviews.

#### Phase 1: Quantitative Findings

##### *Sample Characteristics*

The demographic variables included in the study were age, gender, years of education, marital status, and parental status and family history of SCD and SCT.

The mean age of participants was 21.9 years and the majority of the participants were female (67%). More than half (64.9%) of the participants reported that they did not have a family history of SCD or SCT. With respect to carrier status, 46.6% indicated that they were not carriers of the trait, and 46.1% reported that they were unsure of their status. A description of the demographic variables is presented in Table 5.

Table 5

*Description of Demographic Variables*

Variable	F	%
<b>Site</b>		
Clayton State University	44	21.8%
Savannah State University	96	47.5%
100 Black Men Conference	23	11.4%
Georgia State University	15	7.4%
Clark Atlanta University	11	5.4%
Emory University	13	6.4%
<b>Age (years)</b>		
19-24	150	78.5%
25-30	41	21.5%
<b>Gender</b>		
Male	65	32.2%
Female	137	67.8%
<b>Years of education</b>		
16 years or less	168	88.0%
17 years or more	23	12.0%
<b>Marital Status</b>		
Married	16	7.9%
Single	185	91.6%
Divorced	1	0.05%
<b>Parental Status</b>		
No children	185	84.7%
One child	19	9.4%
Two or more children	12	5.9%
<b>Family History of Sickle Cell Disease/Sickle Cell Trait</b>		
Yes	27	13.4%
No	133	65.8%
Don't know	42	20.8%

*Note.* N=191. F=frequency

*Results of Analysis**Research Question 1*

**What is African American college students' level of knowledge about SCD, attitude regarding SCT and SCD carrier testing, level of perceived susceptibility to SCT, and perceived severity of SCT?**

*SCD/SCT genetics knowledge.* The average score obtained by the participants on the SCD/SCT Genetics Knowledge subscale was 58.2%. This score indicated that more than half of the participants answered at least 6 of 10 questions correctly.

In this sample, female participants scored slightly higher (60.1%) than male (54.4%) participants did on the subscale. Based on a one way ANOVA test there was a statistically significant difference ( $p=.02$ ) found between the level of knowledge of female participants and that of male participants.

The variable age, was, recoded into two groups, 19 to 24 years and 25 to 30 years, at the midpoint. Participants who were between the ages of 19 and 24 were labeled the younger group, and participants who were between the ages of 25 and 30 were labeled the older group. The knowledge scores were slightly higher for the younger group ( $M=59.07$ ,  $SD=15.59$ ) than for the older group ( $M=55.37$ ,  $SD=17.90$ ). .

There was little variation between the scores of those with children and the scores of those without children. The mean score of participants with one child was 61.4%, that of participants with two or more children was 51.3%, and that of those without children was 58.2%. There was little variation between the level of knowledge of individuals with a family history of SCD or SCT and that of individuals who did not have a family history of SCD or SCT or were unaware of any family history.

*Attitudes toward SCD carrier testing.* Overall, the majority 85.3%, ( $n =116$ ) of participants had very favorable attitudes or feelings toward SCD carrier testing (a

composite score of 6). The possible score range for the FCT subscale was 1 to 6, with 1 indicating very unfavorable attitudes and 6 indicating very favorable attitudes.

The mean score of the participants aged 19 to 24 years was 5.47, and the mean score of participants 25 years of age and older was 5.80. There was a statistically significant difference ( $p = .03$ ) between the younger and older participants in their attitude toward carrier testing. However, it is important to mention that only 9.0% (17) of the sample considered carrier testing for young adults to be bad and that, of those 17 participants, 88% (15) were between ages 19 and 24.

Participants with one child scored slightly higher on the subscale ( $M = 5.90$ ,  $SD = .436$ ) than those participants with no children did ( $M = 5.50$ ,  $SD = 1.22$ ) and than participants with two or more children did ( $M = 5.50$ ,  $SD = 1.22$ ). Parental status had no influence on the participants' attitudes toward carrier testing.

*Perceived susceptibility.* Overall, the participants believed that they were at higher risk or “perceived susceptibility” for testing positive for SCT. The mean perceived susceptibility score was, 3.75 and  $SD = 2.75$ . The possible composite scores for the two items ranged from 1 to 10, with a score of 1 indicating a very high perceived susceptibility and a score of 10 indicating a very low perceived susceptibility.

Gender did not appear to have a significant influence on the participants' level of perceived susceptibility; however, of the 13 (9%) participants reporting their perceived level of risk for testing positive for SCT to be very high; however, 12 of the participants were female.



Age did not appear to contribute to the participants' level of perceived susceptibility. Marital status did contribute to the participants' level of perceived susceptibility. The mean score of the single participants was 3.62, and that of the non single participants was 5.13. A one way ANOVA revealed that there was a statistically significant difference ( $p = .04$ ) found between the groups.

There was no statistically significant difference in the perceived susceptibility scores of the participants with children and those without children.

However, a one way ANOVA revealed that there was a statistically significant difference found between participants with a family history and those without ( $p = .00$ ) such a history. The mean score for participants who reported a family history of SCD or SCT was higher (2 points) than those for participants without such a family history and for participants with an unknown family history were found to be (4.14 and 4.96, respectively).

*Perceived severity.* The mean perceived severity score was , 7.05 (SD = 2.18), indicating a feelings of less severity or seriousness. The possible composite scores for the two items ranged from 1 to 10, with a score of 1 indicating a very high-perceived severity and a score of 10 indicating a very low perceived severity.

Female participants were found to have only slightly higher perceived severity scores ( $M = 7.38$ ,  $SD=2.07$ ) than male participants had ( $M = 7.00$ ,  $SD=2.24$ ).

Also, there was no significant difference between parents' and nonparents' perceived severity.

However, a one way ANOVA revealed that there was a statistically significant ( $p = .00$ ) difference found among participants with family history, participants without family history, and participants who were not knowledgeable of their family history. Participants with no family history had a 77% likelihood of having a high or very high concern for testing positive for SCT; this likelihood was greater than that found for participants with a family history (66.6%) and for participants unaware of family history (62.5%). More than half (51.6%) of participants with no family history, 50% of those unaware of family history responded that it was likely or very likely that they would feel less healthy than others if they were to test positive for SCT. Moreover, individuals with a family history of SCD or SCT perceived the conditions to be less serious than those did who had no family history or who were not aware of their family history.

*Attitude toward SCD and SCT.* The HOS was a 4-item scale used to assess the attitudes of the participants toward SCD and SCT. The mean score on the HOS was, 28.20 (SD = 12.84), a score indicating that the majority of participants had ambivalent, neither favorable nor unfavorable attitudes toward SCD and SCT. The scores represented the following categories: very unfavorable (0-12), unfavorable (13-24), ambivalent (25-36), favorable (37-48), and very favorable (49-60). In the literature reviewed related to genetic disorders such as SCD, gender plays an important role in the perception of the disorder.

Gender had no significant influence on the participants' attitudes toward SCD and SCT. Nonetheless, there was a statically significant ( $p = .01$ ) difference found between the younger and older age groups' attitudes toward SCD and SCT based on a one way ANOVA.

Both of the groups were ambivalent toward SCD and SCT. However, younger participants were more likely to have ambivalent attitudes toward discussing SCT carrier status with others in a casual setting than older participants.

A one way ANOVA revealed that there was a statistically significant ( $p = .00$ ) difference found between the participants with a family history ( $M=35.67$ ) and those without a family history ( $M=26.97$ ). Participants with a family history of SCD or SCT were more likely to have favorable attitudes toward discussing SCT carrier status with others in a casual setting than those without family history. Participants with family history were more likely to report favorable attitudes in response to the possibility of being diagnosed with SCT or SCD. The attitudes of participants with no family history were neither favorable nor unfavorable. The descriptive statistics for the SCD Genetics Knowledge, FCT, Perceived Susceptibility, Perceived Severity, and HOS subscales are presented in Table 6.

Table 6

*Descriptive Statistics for Sickle Cell Disease (SCD) and Sickle Cell Trait (SCT) Genetics Knowledge, Feelings About Carrier Testing (FCT), Perceived Susceptibility and Perceived Severity subscales and for Health Orientation Scale (HOS)*

Variable	SCD Genetics Knowledge		FCT		Perceived Susceptibility		Perceived Severity		HOS	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
<b>Gender</b>										
Male	60.16*	16.69	5.38	1.37	3.68	2.53	7.00	2.24	13.61	1.71
Female	54.44*	14.23	5.63	1.05	3.79	2.87	7.38	2.07	12.4	1.09
<b>Age (yrs)</b>										
19- 24	59.07	15.59	5.49*	1.23	3.89	2.80	7.30	2.11	27.50*	13.08
25-30	55.37	17.90	5.91*	.417	2.78	2.21	6.96	2.30	33.30*	9.66
<b>Education (yrs.)</b>										
13-16	59.07	15.55	5.40*	1.20	3.80	2.75	7.35	2.10	26.96*	11.92
17 or more	55.37	17.90	5.80*	.74	3.59	2.81	6.90	2.21	32.73*	15.08
<b>Marital status</b>										
Married	56.00	14.04	5.60	1.12	5.13	2.94	7.33	1.87	33.67	16.77
Single	58.51	16.33	5.54	1.18	3.62	2.72	7.26	2.16	27.88	12.28
<b>Parental status</b>										
No children	58.21	16.52	5.50	1.22	3.69	2.74	7.36	2.11	27.65	11.78
1 child	61.43	13.88	5.90	.436	3.81	2.97	6.52	2.22	32.95	15.59
2 or more	51.25	11.26	5.50	1.41	4.88	2.64	7.00	2.13	26.88	22.62
<b>Family History</b>										
Yes	62.96	19.17	5.63	1.11	5.19	3.27	6.15*	2.23	35.67*	14.32
No	55.48	14.61	5.57	1.12	3.57	2.51	7.51*	2.04	26.86*	12.52
Don't know	63.75	11.26	5.40	1.37	3.35	2.86	7.23*	2.14	27.20*	11.27

Note. N=191. \* Indicates statistical significance

The results for Question 1 can be summarized as follows:

The average SCD Genetics Knowledge score was 58.2%. The SCD Genetics Knowledge scores of female participants were slightly higher than those of male participants were found to be; this difference was statistically significant ( $p = .02$ ).

The majority of the participants (85.3%) had favorable attitudes toward SCD carrier testing. The attitudes of participants with 13-16 years of education were less favorable than those of participants with 17 years or more of education were found to be; the difference was statistically significant ( $p = .00$ ). The attitudes of older participants were slightly more favorable toward carrier testing than those of younger participants were found to be; the difference was statistically significant ( $p = .03$ ).

Overall, the participants believed they were at a higher risk for testing positive for SCT. The perceived susceptibility of participants with a family history of SCD or SCT was higher than that of participants without such a family history was found to be; this difference was statistically significant ( $p = .00$ )

Moreover, the participants believed that testing for positive for SCT was less serious or severe. The perceived severity was lower among participants with a family history of SCD or SCT than among those without such a family history; the difference was statistically significant ( $p = .00$ ). The majority of the participants' attitudes toward SCD and SCT were neither favorable nor unfavorable. Both older and younger participants were ambivalent in their attitudes towards SCD and SCT, but the difference in their mean scores was statistically significant ( $p = .01$ ). Participants with a family history of SCD or SCT, as well as those without a family history were ambivalent in their attitudes toward

SCD and SCT; however the difference in their mean scores was statistically significant ( $p = .00$ ).

### *Research Question 2*

**Is there a relationship between African American college students' level of knowledge about SCD, attitude regarding SCT and SCD carrier testing, level of perceived susceptibility to SCT, or level of perceived severity of SCT and their intention to participate in SCD carrier screening?**

To test the null hypothesis that there is no relationship between the dependent variable intention to participate in carrier testing [intent score] and the independent variables attitude toward carrier testing (FCT score), and perceived susceptibility, perceived severity, and attitude toward SCD and SCT (HOS score), zero correlation coefficients and a stepwise MRA were computed. The zero correlations were calculated with the independent variables attitude toward SCD carrier testing, attitude toward SCD and SCT, perceived susceptibility, and perceived severity and with the dependent variable intention to participate in SCD carrier testing. The correlation coefficients for the MRA are presented in Table 7.

As illustrated in Table 7, only one of the independent variables, attitude toward carrier testing, was significant at the .05 level ( $r^2 = .15$ ). This statistic indicates that 15.2% of the variance in intention to participate in SCD carrier testing was explained by attitude toward carrier testing. In the analysis, attitude toward carrier testing was entered into the analysis on Step 1 of the procedure because it had the strongest correlation with

the dependent variable. The  $F$  value of the variable attitude toward carrier testing exceeded the  $F$  criteria set at 3.84 to enter the equation and at 2.71 to remain in the equation. The results of the computation (including the variable attitude toward carrier testing) were  $F(1,190)=4.48, p=.05$ .

Table 7

*Correlation Matrix and Descriptive Statistics for Independent Variables and Intention to Participate in Sickle Cell Disease Carrier Testing*

Variables	Intention to participate in testing	Attitude towards SCD carrier testing	Perceived Susceptibility	Perceived Severity	Attitude toward SCD and SCT
Intention to participate in testing	1.00				
Attitude toward SCD carrier testing	.152*	1.00			
Perceived Susceptibility	-.050	-.038	1.00		
Perceived Severity	-.003	.068	-.110	1.00	
Attitude toward SCD and SCT	-.001	.052	.014	-.226	1.00
Mean	3.50	5.54	3.75	7.26	28.20
Standard deviation	1.89	1.17	2.75	2.13	12.84

*Note.* Significant at  $p < .05$  level. SCD= sickle cell disease; SCT=sickle cell trait

The  $F$  values of the other independent variables entered on Steps 2, 3, and 4 (attitude toward SCD and SCT, perceived severity, and perceived susceptibility, respectively) were insufficient and were deleted from the computer computations for the regression model because they did not meet the  $F$  criteria to either enter (3.84) or remain (2.71) in the equation. In this model,  $R^2 = .023$  indicates that, after controlling for the

demographic variables, only 2.30% of the variance in intention to participate in SCD carrier testing was explained by the four- variable model.

The *F* test included in the ANOVA was used to compute the significance of each added variable to the explanation reflected in R-square. However, no other variables were added to the model. Thus, the *F* statistic for the complete regression model was  $F(1, 190) = 4.48$  with a *p* value that was statistically significant at the .05 level. The summary of results from the stepwise regression analysis is presented in Table 8.

Table 8

*Summary of Regression of the Independent Variables on Intention to Participate in Sickle Cell Disease (SCD) Carrier Testing*

Independent variable	B	Beta	<i>T</i>	<i>P</i>
Constant	2.13		3.24	<.001
Attitude toward carrier testing	.246	.152	2.11	<.05
Excluded from model				
Perceived susceptibility		-.044	-.614	>.05
Perceived severity		-.014	-.187	>.05
Attitude toward SCD and Sickle cell trait		-.009	-.118	>.05

The beta coefficients presented in Table 8 reflect the unique contribution of each of the independent variables in the model. As mentioned previously, the variable, attitude toward carrier testing, contributed 15.2% to explaining the variance in the dependent variable; this result was supported by value of  $t = 2.11$  that was statistically significant at the .05 level. The other variables that were excluded from the model contributed less than 1% to explaining the variance, and the *t* values were not statistically significant.

The complete regression model that resulted from the analysis was as follows:



$Y$  (intention to participate in carrier testing) = 2.134 + 0.246(attitude towards carrier testing). Therefore, when attitude toward carrier testing scores increase by one point, intention to participate in carrier testing increase by 2.380 points.

The null hypothesis that there was no relationship between the independent variables and the dependent variable was rejected. Additionally, the regression model was evaluated for the violation of assumptions and outliers. The regression model was examined for violations of normality, linearity, and homoscedasticity. Regression plots were graphed to test the assumptions. An examination of the histogram and plots for standardized residuals indicated that the assumptions of normality, linearity, and homoscedasticity were met. A Mahalanobis ( $D^2$ ) statistic was computed to identify outliers within the regression model. On the basis of the calculated  $D^2$  statistic there was only one case that was considered an outlier. The case was included in the analysis to maintain the sample size.

In summary, the four-variable model failed to explain a meaningful percentage of variance in the dependent variable. The only variable that explained any of the variance was attitude toward carrier testing.

### *Research Question 3*

Research Question 3 asked, Research Question 3: Do African American college students with certain levels of (a) perceived risk for SCT and (b) concern for receiving a positive SCT result have greater intention to participate in SCD carrier testing? An ANOVA was conducted to test the null hypothesis that there was no difference between students with levels of perceived risk for SCT and their intention to participate in SCD

carrier testing. The results of the ANOVA are presented in Table 9 and indicate that there were no significant differences between the participants' level of perceived risk and their intention to participate in carrier testing,  $F(5, 185) = 1.87, p = .10$ . The null hypothesis was not rejected, which means that there was no difference between the groups.

Table 9

*ANOVA Summary Table for Level of Perceived Risk for Sickle Cell Trait and Intention to Participate in Sickle Cell Disease Carrier Testing*

Comparison	<i>df</i>	<i>SS</i>	<i>MSE</i>	<i>F</i>	<i>p</i>
Model	5	24.38	4.87	1.37	.10
Error	185	657.36	3.55		
Total	190	681.74			

*Note.*  $F(5, 185) = 1.87, p = .10$

An ANOVA was conducted to test the null hypothesis that there was no difference between students' level of concern for a positive SCT result and their intention to participate in SCD carrier testing. The results of the ANOVA are presented in Table 10 and indicate that there were no statistically significant differences found between the participants' level of concern for testing positive for SCT and their intention to participate in carrier testing,  $F(5, 185) = .745, p = .59$ . The null hypothesis was not rejected.

Table 10

*ANOVA Summary Table for Level of Concern for Positive for Sickle Cell Trait Result and Intention to Participate in SCD Carrier Testing*

Comparison	<i>df</i>	<i>SS</i>	<i>MSE</i>	<i>F</i>	<i>P</i>
Model	5	5.14	1.029	.745	.59
Error	185	255.55	1.381		
Total	190	260.69			

*Note.*  $F(5,185) = .745, p = .59$ .

In summary there was no statistically significant difference found between participants' varying levels of perceived risk for SCT and their intention to participate in carrier testing. Similarly, there was no statistically significant difference found between participants' varying levels of concern for testing positive for SCT and their intention to participate in carrier testing. So we may conclude that participants' perceived risk for SCT and concern for testing positive for SCT do not affect their intention to participate in carrier testing.

*Research Question 4*

**Is there a relationship between African American college students' support of SCD carrier testing and their intention to participate in SCD carrier testing?**

A chi-square analysis was conducted to test the null hypothesis that there was no significant relationship between the participants who responded that they agreed with SCD carrier testing in young adults (supporters) and those that responded that they

disagreed with SCD carrier testing in young adults (nonsupporters). The dependent variable intention to participate in carrier testing was recoded into two groups, (a) scores of 0-3 (low intention) and (b) scores of 4-6 (high intention). The results of the cross-tabulation are presented in Table 11 indicate that, in the low intention group, there were 4 (3.96%) nonsupporters of testing in young adults and that, in the high intention group, there were, 2 (2.22%) nonsupporters and 88 (97.7%) supporters.

Table 11

*Cross-Tabulation of Support and Non-support of Sickle Cell Disease (SCD) Carrier Testing of Young Adults and Intention to Participate in SCD Carrier Testing*

Testing among young adults	Intention to participate in SCD carrier testing	
	Low intention	High intention
Disagree	4	2
Agree	97	88
Total	101	90

The results of the chi-square analysis are presented in Table 12. These results indicate that there were no statistically significant differences between the participants' support or nonsupport of young adult carrier testing and the participants' intention to participate in carrier testing,  $\chi^2 (5, N=191) = 3.75, p=.05$ .

Table 12

*Chi-Square Analysis of Support and Non-supporter of Sickle Cell Disease (SCD) Carrier Testing Among of Young Adults and Intention to Participate in SCD Carrier Testing*

Statistic	<i>df</i>	<i>Value</i>	<i>P</i>
Chi-square	5	3.75	>.05
Likelihood ratio	5	5.74	>.05
Linear-by-linear association	1	1.71	>.05

*Note.*  $\chi^2 (5, N=191) = 3.75, p = .05$ .

A chi square analysis was conducted to test the null hypothesis that there was no significant relationship between the participants who responded that they agreed with SCD carrier testing in young adults (supporters) and those who responded that they disagreed with SCD carrier testing in the African American community (nonsupporters). The dependent variable intention to participate in carrier testing was recoded into two groups: (a) scores of 0-3 (low intention) and (b) scores of 4-6 (high intention). The results of the cross-tabulation are presented in Table 14 and indicate that, in the low intention group there were 6 (5.94%) nonsupporters and 95 (94.0%) supporters of carrier testing in the African American community and that, in the high intention group there were, 4(4.44 %) nonsupporters were in the high intention group and 86 (95.5%) were in the high intention group.

Table 13

*Cross-tabulation of Support and Non-support of Sickle Cell Disease(SCD) Carrier Testing of African Americans and Intention to Participate in SCD Carrier Testing*

Testing among African Americans	Intention to participate in SCD carrier testing	
	Low intention	High intention
Disagree	6	4
Agree	95	86
Total	101	90

The results of the chi-square analysis are presented in Table 14. and these results indicate that there were no statistically significant differences between the participants' support or nonsupport of carrier testing in African Americans and the participants' intention to participate in carrier testing,  $\chi^2 (5, N=191) = 4.78, p = .05$ .

Table 14

*Chi Square Analysis of Support and Non-support of Sickle Cell Disease ( SCD) Carrier Testing of African Americans and Intention to Participate in SCD Carrier Testing*

Statistic	df	Value	P
Chi square	5	4.78	>.05
Likelihood ratio	5	4.52	>.05
Linear-by-linear Association	1	1.05	>.05

Note.  $\chi^2 (5, N=191) = 4.78, p = .05$ .

A chi-square analysis was conducted to test the null hypothesis that there was no significant relationship between the participants who responded that they agreed with SCD carrier testing in partners (supporters) and those who responded that they disagreed with SCD carrier testing in partners (nonsupporters). The dependent variable intention to

participate in carrier testing was recoded into two groups: (a) scores of 0-3 (low intention) and (b) scores of 4-6 (high intention). The results of the chi-square analysis presented in Table 15 and indicate that, in the low intention group there were 6 (5.94 %) nonsupporters and 95 (94.0%) supporters of testing in partners and that in the high intention group, there were 4 (4.44 %) nonsupporters and 90 (95.5%) supporters.

Table 15

*Cross-tabulation of Support and Non- support of Sickle Cell Disease (SCD) Carrier Testing in Partners and Intention to Participate in SCD Carrier Testing*

Testing among African Americans	Intention to participate in SCD Carrier Testing	
	Low intention	High intention
Disagree	4	2
Agree	97	88
Total	101	90

The results of the chi-square analysis are presented in Table 16, these results indicate that there were no statistically significant differences between the participants' support or nonsupport of carrier testing in partners and the participants' intention to participate in carrier testing,  $\chi^2 (5, N=191) = 1.78, p=.05$ .

Table 16

*Chi- Square Analysis of Support and Non- Support of Sickle Cell Disease (SCD) Carrier Testing in Partners and Intention to Participate in SCD Carrier Testing*

Statistic	df	Value	P
Chi-square	5	1.78	>.05
Likelihood ratio	5	2.26	>.05
Linear-by-linear association	1	.427	>.05

*Note.*  $\chi^2 (5, N=191) = 1.78, p=.05$ .

In summary, there was no statistically significant difference found between participants who indicated that they agreed (supporters) or did not agree (nonsupporters) with SCD carrier testing for young adults, African Americans, and partners and the participants' intention to participate in SCD carrier testing.

## Phase 2: Qualitative Findings

### *Sample Characteristics*

The sample for Phase 2 of the study was selected from a subgroup of individuals who had participated in Phase 1 of the study. For Phase 2 of the study, participation in SCD carrier testing was added to the inclusion criteria for selecting participants. Because of low response rates, a convenience sample of 8 participants completed semi-structured interviews. All of the participants were African American. The participants' ages ranged from 19 to 30 years. There were seven female participants and 1 male participant. All of the participants were single, with the exception of one married participant. Four of the participants had a minimum of 1 to 3 years of college, 3 of the participants had completed baccalaureate degrees, and one had completed a master's degree. Two of the participants were parents. Three of the participants were identified as SCD carriers. Three of the participants had a family history of SCD or SCT. Participants' demographic information is presented in Table 17.



Table 17

*Summary of Participants Demographic Data*

Participant	Age	Gender	Level of Education	Marital Status	Children	Family History	Test Results
1	24	Male	Some college	Single	1 or more	Yes	Negative
2	19	Female	Some college	Single	None	No	Negative
3	25	Female	Master's	Single	None	No	Negative
4	29	Female	Bachelors	Single	None	No	Negative
5	23	Female	Bachelors	Single	None	Yes	Positive
6	26	Female	Some College	Single	None	No	Positive
7	22	Female	Bachelors	Single	None	No	Negative
8	30	Female	Some College	Married	1 or more	Yes	Positive

*Themes*

The results of the analysis of the knowledge, beliefs and attitudes of African American men and women who participated in SCD carrier testing are described in this section. The findings were derived from my analysis and interpretation of the participants' accounts of their experiences with SCD carrier testing. The following themes were identified from the typological analysis: (a) lack of knowledge, (b) perceptions of genetic testing, (c) reproductive choice, and (d) factors for participation in SCD carrier testing. The themes are discussed in the order in which they are listed in Table 18.

Table 18

*Themes and Categories*

Themes	Categories
Lack of Knowledge	<ul style="list-style-type: none"> <li>• Biology of SCD and SCT</li> <li>• SCD and SCT and African Americans</li> <li>• SCD community education</li> <li>• Availability of testing</li> </ul>
Perceptions of Genetic Testing	<ul style="list-style-type: none"> <li>• Limited understanding of genetic testing</li> <li>• Value and importance of genetic testing</li> <li>• Beliefs about African Americans and genetic testing</li> </ul>
Reproductive Choice	<ul style="list-style-type: none"> <li>• Importance of carrier identification</li> <li>• Having a child with SCD or SCT</li> <li>• Carrier couples having children</li> <li>• Perceptions of prenatal testing</li> <li>• Testing of current and future partners</li> </ul>
Factors about Carrier Testing	<ul style="list-style-type: none"> <li>• Social influence</li> <li>• Family history</li> <li>• Carrier testing process</li> </ul>

*Note.* SCD=sickle cell disease; SCT=sickle cell trait

*Lack of Knowledge*

Lack of knowledge appeared to be a common theme throughout the interviews with all participants. The participants indicated that they lacked knowledge about SCD and that they lacked an understanding or awareness of issues related to SCD or SCD carrier testing. Four categories were identified under the lack- of- knowledge theme: (a)

biology of SCD and SCT, (b) SCD and SCT in African Americans, (c) SCD community education, and (d) availability of SCD carrier testing

*Biology of SCD and SCT.* The participants were asked what they knew about SCD and SCT. Comments made by the respondents indicated that participants shared general knowledge of SCD and SCT but were unable to provide specific knowledge of the biology of the disease. The responses varied in detail as the participants provided descriptions of the disease. Some participants reported that they saw pictures of sickled cells and knew that the disease was related to blood cell:

It attacks the red blood cells and makes them a crescent shape, I don't know if it has to do with the immune system, but I know it makes the blood cells a crescent shape. Because I've seen the pictures and that's pretty much it. (PT5)

Other participants expressed that they knew that SCD was an inherited blood disorder: "I don't know too much. I know that it's an inherited blood disorder and it affects the red blood cells" (PT3). The descriptions of the biology of the disease varied. However, none of the participants illustrated a clear understanding of SCD.

Some explained what they knew about SCD through recalled personal experiences with friends or family; one participant responded, "when I grew up, my brothers' babysitter, her grand-daughter had SCD and I knew she was always sick and at the doctor's, I know it makes you tired all the time, she was always tired" (PT8). There did not appear to be confusion in the participants understanding of SCT; all of the participants' understood that there was a difference between having SCD and having SCT. Several of the participants recognized that SCT did not cause the health complications typically associated with SCD. However, there was a lack of

understanding of how SCT was expressed in inheritance patterns. Participants who were found to be carriers were unsure of the risk of transmitting the sickle cell gene to their offspring if they were to produce children with another carrier. This comment was made by one participant: “So if I have the trait and I get pregnant by someone with SCD or SCT, all of our children will have SCD, is that how that works?” (PT5). Noncarriers were unsure of their risk of transmitting the gene if they were to have children with a carrier. One noncarrier stated, “if my future husband has SCT and I know I don’t, I mean, if we have one child, it’s possible they might not have it, right?” (PT2). There was little evidence that carriers or noncarriers were knowledgeable of SCD inheritance patterns.

*SCD, SCT and African Americans.* The participants were generally unaware of the connection between SCD and being African American. It was not uncommon for the participants to share that they were unaware of the prevalence of SCD and SCT among African Americans. Several of the participants indicated that their first real education about SCD and SCT occurred while attending a health fair. One student revealed, “I decided to get tested after I read information about SCD at the SCDF of GA booth. It was not until then that I was informed that SCD and SCT primarily affected African Americans (PT1). One respondent reported, “As an African American, I was embarrassed that I knew so little about SCD” (PT2). The perception of these participants was that few young adult African Americans were familiar with SCD. Many of the participants reported that they discussed their SCD carrier testing experience with friends and family members and that there was an apparent lack of knowledge among these individuals, as well. Some of these individuals were familiar with SCD, but few of them were aware of how it was transmitted or of the fact that it largely affected African

Americans. A young woman just completing her first year of college recalled her experience: “After I got tested, I was discussing it with my boyfriend and sisters, and they didn’t know much either, like how you get it or that Black people get it a lot” (PT2). The participants admitted that, after being informed of the connection between SCD and the African American community, they decided to participate in carrier testing. Only 2 of the participants acknowledged that being African American was a major factor in their decision to participate in SCD carrier testing: “ I knew the disease affected the Black community, so I felt it was important to do” (PT4).

*SCD community education.* There was a consensus that there needs to be more community education related to SCD. There was little evidence that these participants were educated about SCD or SCT by formal or informal means, parents, school, health provider, or SCD agency. One participant explained, “I don’t recall hearing anything about SCD when I was growing up, really not until I got to high school biology, and that wasn’t much” (PT7). The participants indicated that they were unfamiliar with any health promotion activities related to SCD or SCT. I inquired about the SCD stamp sponsored by the United States Postal Service. The stamp was nationally available for purchase in 2004 to raise money for SCD research and to increase awareness about the disease and about SCD carrier testing. None of the participants indicated that they were cognizant of the stamp or of the campaign for awareness; “I didn’t know there was a sickle cell stamp, I have to ask about it the next time I get stamps” (PT8).

At a local level, the SCDF of GA launched during the study period a radio campaign encouraging participation in SCD carrier testing. The public service

announcement was played on two urban radio stations with target populations that were similar to the participants. When probed, none of the participants indicated that they were aware of the public service announcement. One participant asked, “I have not heard the commercial, on what station is it being played?” (PT2). It was suggested that, if the visibility of health promotion activities related to SCD and SCT was enhanced, awareness might be increased among African Americans; “I think there should be more commercials about SCD, like we hear about diabetes and high blood pressure. That’s the only way to get people to talk about it” (PT8).

Overall, the participants believed that, within the African American community, SCD was not being promoted as well as other health conditions were being promoted. The participants discussed the need for more information about SCD and SCT. On the basis of participants’ responses, it was inferred that the SCD health promotion activities that have been implemented have not reached target audiences.

*Availability of SCD carrier testing.* Many of the participants conveyed that the college health fairs provided a convenient opportunity for SCD carrier testing for them. Several of the participants revealed that, if they were seeking SCD carrier testing, they would be unsure of where to obtain the test. The participants had little knowledge of the SCDF of GA or of any of the services offered regarding SCD carrier testing or genetic counseling. One participant who lived near the building occupied by the SCDF of GA, a testing site, stated, “I did not know that this place was even here, I was reading the pamphlets they had outside, and I didn’t know I could get tested here” (PT1). The participants also perceived SCD carrier testing to be very expensive and therefore

inaccessible. The participants were unclear about when SCD carrier testing could be obtained. Moreover, the participants held the belief that SCD carrier testing was routinely offered through a physician or ob/gyn or through blood testing for a marriage license and did not need to be requested. One misconception was that SCD carrier testing (i.e., blood test) was a required measure before a couple obtained a marriage license and that, therefore, carrier status would be identified, upon a person's entering into marriage; one participant stated, "I guess that's why we get tested before we get married" (PT8). Another misconception was that SCD carrier testing was routinely conducted during ob/gyn examinations once a woman became pregnant. One participant who did not have a child believed that, "when you have a baby, the doctor checks for diseases like sickle cell disease and diabetes and other things" (PT6).

Overall, the participants were unaware of SCD inheritance patterns and how the disease and trait were transmitted, but they expressed a desire to learn more about SCD and SCT. The participants believed that there was not enough community education about SCD and SCT. As a solution to the lack of community education, the participants suggested that health education campaigns about SCD be increased.

### *Perceptions of Genetic Testing*

Perception of genetic testing refers to the participants' beliefs about genetic testing in general. Participants in the study revealed their thoughts about genetic testing and three categories emerged: (a) limited understanding of genetic testing, (b) the value and importance of genetic testing, and (c) participants beliefs about African Americans and genetic testing.

*Limited understanding of genetic testing.* Most of the participants were vaguely familiar with the term *genetic testing*. The participants were often unable to give a description or definition of genetic testing. This inability was reflected in one description: “I am not sure, not really sure what it is. Maybe a group of people who are trying to find out something about their genes, they have a hypothesis about something and they are trying to figure it out” (PT8). It appeared that the participants did not make the connection that SCD carrier testing or carrier testing was simply another form of genetic testing; one participant stated, “Honestly, SCD testing doesn’t come to my mind, if at all, when I think about it [genetic testing]”(PT2). One of the responses given indicated that genetic testing was being confused with testing for sexually transmitted diseases: “ I can’t say, I am not going to get tested for disease, or that I have not had unprotected sex, because people did before all these diseases were known about” (PT1). Although a few the participants were unable to accurately define or describe genetic testing, they appeared to understand the general concept during discussion.

*Value and importance of genetic testing* .The majority of participants believed that the information that could be ascertained from genetic testing was valuable. In general, the belief was that genetic testing was important for disease identification and treatment purposes. A participant recalled her experience with genetic testing: “My mom, about 13 years ago was diagnosed with thyroid tumors. So me and my sisters took the test and we can get it, so I really think it’s important” (PT2). One participant made the distinction between genetic testing’s being used for the identification of genes



associated with disease versus the testing being used for the identification of genes for altering the characteristics of offspring, such as eye or hair color;

I don't necessarily know that I would choose genetic testing for a cosmetic type thing. Oh, I want my kid to be tall, or that kind of thing. But, I think it is important to offer it for genetic diseases like breast cancer, and health consequences such as that, where you know, things that can be passed through generations. (PT5)

Most stated that genetic testing was not something to which they would give any thought without provocation from a health provider; "I don't think about genetic testing. If my doctor would present it to me I would, but on my own I wouldn't" (PT2).

*Participants' beliefs about African Americans and genetic testing.* The responses of these participants suggested that African Americans were not interested in genetic testing and that the testing was not frequently discussed within the African American community. It was inferred that there was a lack of interest because there was little awareness of genetic testing among African Americans. One participant explained, "I'm not sure that African Americans have been very interested in that topic at all. Or, have been, or that it's a subject that's been talked about in our community for any extended purpose" (PT6). The participants believed that genetic testing practices of African Americans would be dependent upon level of knowledge and upon experiences with testing. They concurred that some individuals are very open to the advances made by genetic testing; the participants also agreed that others may fear genetic testing because the end product is disease identification, and those persons they might be wary of knowing this information. One participant stated, "Based on your background, some areas yes there is lack of knowledge, but in some areas they do have knowledge but they

are afraid to know about certain diseases, some do have the knowledge and want to know” (PT8). Similar to participants’ responses about SCD carrier testing, their responses about genetic testing of African Americans indicate that they were unsure about how to access genetic testing information. They did not feel that their health providers would offer this type of information, and they would not have a clear understanding of what to ask about. A participant stated, “I don’t think we know about it and then when we do know, we don’t know where to get it done, it’s knowledge and an access issue” (PT6).

There were two major ideas that were expressed as rationales for the lack of interest in genetic testing: the lack of insurance/money and the mistrust of the medical community. First, it was suggested that, for individuals without insurance or the financial means to pay for genetic testing, there were limited options. The underlying notion was that, if an individual is uninsured or is unable to pay for health care or a service, preventative care was not a priority;

I think that in the African American community there is probably still is a tendency not to seek health care treatment, there is the financial part of it. You know if you don’t have great insurance you try to stay away from the doctor. (PT6)

Second, it was proposed that many individuals still mistrust and or fear the medical system. One participant referred to the racism and discrimination experienced by African Americans in the past, which she believed has impacted current attitudes towards genetic testing:

For people who probably grew up in the times like my father, where you couldn't get treated by white doctors. Or if you did, they treated you so horribly when you went there you were scarred by the experience. Some people never get over that, and never realize that times can change, and things are not the same as they used to be. (PT 5)

Overall, the participants were unable to clearly define or describe genetic testing. Upon further discussion, it was apparent that the participants understood the basic concept of genetic testing. They found genetic testing, like any other preventative test, to be valuable and important. However, the participants' perception was that most African Americans were uninformed about and disinterested in genetic testing. These perceptions were supported by their beliefs that most African Americans were unable to pay for genetic testing and mistrust the medical community.

### *Reproductive Choice*

The premise of preconception carrier testing is that it provides individuals with an opportunity to make informed decisions about their reproductive health. Within the reproductive choice theme, there were five categories that emerged: (a) carrier identification, (b) having a child with SCD or SCT, (c) perceptions of carrier couples having children, (d) perceptions of prenatal testing, and (e) partner testing.

*Carrier identification.* The participants believed that carrier testing and knowing carrier status were very important and valuable for making informed decisions about childbearing. The participants' responses indicated that SCD carrier testing was important for identifying carrier status before pregnancy. Nonetheless, it was implied that knowledge of carrier status would not hold any value until a family was being planned .

One participant stated, “The value for me personally, and for anybody who is interested in having children at some point in their lives, is to know basically what you are facing” (PT4).

*Having a child with SCD or SCT.* Both female carriers and female noncarriers revealed that rearing a child with SCD would be difficult but that, because they would be the mother of the child, it would have to be done. One participant identified as a carrier replied, “If God has given me that child, then I should take care of that child. I guess I would kind of feel really blessed, or maybe even privileged, that God would give me a child like that” (PT5). The only male participant in the study held a different view. He indicated that he would be distraught if learned that his child had SCD:

I guess it not something I ever really thought of before, if my son had it, I would be going crazy. I might be a little mad, I would ask God why my son. I would be scared of when or if he was going to die (PT1).

Carriers and noncarriers implied that there would be feelings of guilt or sadness for passing the sickle cell gene to their offspring. One participant shared this thought: “I would just feel, guilty in a sense, I would feel bad that I had done this to my child, but for the life that, that child would not have” (PT3).

*Perceptions of carrier couples having children.* The participants expressed some indifference in their discussions about carrier couples having children. The participants, mostly noncarriers, appeared to be less supportive of individuals who were carriers and at greater risk for producing a child with SCD. They felt that the carrier parents should be very cognizant of the challenges involved with rearing a child with SCD. It was believed

that carrier couples who produced offspring were not acting in the best interest of the child. One noncarrier participant expressed this thought:

If they decide to have children, I don't know what to think about that. On the one hand, I think it could be a selfish decision, because they are not going to be the ones to suffer the consequences, the child is going to be the one to suffer the consequences. (PT4)

It was implied that this child would be the burden of those individuals and not of society. Carriers were aware of the possibilities and felt that, if parents were well informed and if the child was loved, the situation would be managed. One young woman who was diagnosed as a carrier said,

I feel that its God's work if God did not want the child to be born it would not have happened, if God did not feel like I could not have handled it, he wouldn't have given it to me, so if my child has SCD or trait I would make sure I was knowledgeable of the disease and treatments (PT6).

*Perceptions of Prenatal Testing.* To obtain a clear understanding of the participants' views on carrier testing I asked them about prenatal testing (i.e., testing of the fetus during pregnancy). They implied that prenatal testing in theory was important and that the benefits of the procedure were understood. However, the participants generally felt that prenatal testing was not an option for them. One participant said, "I think you should know about [SCT] prior to pregnancy so there are no surprises, I mean it's not like finding out that your child has Down's syndrome"( PT 7 ). The assumption behind prenatal testing is that, if the fetus is determined to have genes that may lead to a chronic condition, birth defect, or disability (e.g., SCD, CF, or Down's Syndrome), the parents have information about their child and can make an informed decision about the maintenance or termination of the pregnancy. The responses provided indicated that the

participants would prefer to have a child tested after delivery. One carrier replied, “I would definitely have my child tested, to know if my child had the trait, but I don’t necessarily want it to be done prenatally” (PT6). Therefore, using prenatal testing as a method by which to avoid having an affected child did not appear to be a consideration for these participants. All of the participants conveyed that prenatal testing was a benefit for others. One participant had these thoughts about prenatal testing:

For a person that is in an older age range, I guess, but I would not necessarily encourage them but I would understand why they would do it, they would like to know and they are high risk, I guess it is good to know so you can be prepared for whatever when the baby comes. (PT8)

*Partner testing.* Another aspect of SCD carrier testing and reproductive choice is partner testing. Identification of potential partners’ carrier status and support for partner testing was a consistent theme in the interviews. One participant remarked,

Since I am childbearing age, and I am not opposed to having kids, I’m not sure if I will at any point. I would just like to know whether or not I am carrying the trait, so that I will know to be careful to have my partner tested for the trait if we decide to have kids. (PT 4)

Theoretically, the participants appeared to support partner testing; however, most were reluctant to indicate that they would avoid or reject a potential partner who was identified as a carrier. Carriers expressed being cognizant of the risk involved with having children with another carrier, but they did not feel that it was realistic to end a relationship because of health status. Several of the participants also stated that they would advise young women diagnosed with SCT to have their partner tested to be aware of the partner’s family history. For women, the other challenge of carrier testing of partner testing is convincing males to participate. One carrier participant discussed her attempt to convince her partner to get tested:

I did talk to my boyfriend about getting tested and he said, if we were to get married and have a child, regardless of whether that child has SCD or SCT, you know, we are going to love him. So that's [getting tested] not something that I would be willing to do. (PT 6)

In general, there was a positive attitude toward partner testing; however, using carrier identification in partner selection was not the desired outcome. One participant, a carrier and mother of a child with SCT, stated, "If you're in love with this person and you want to have kids with this person you take that risk" (PT 8).

Overall, the participants believed that SCD carrier testing was valuable and important. On the basis of their responses, it appears that preconception carrier testing was preferred over prenatal testing. Generally, the participants were not opposed to having children with SCD or SCT. Noncarriers seemed to be less enthusiastic about carrier couples having children. Although all of the participants (carriers and noncarriers) believed that current and future partners should be tested, they were less eager to suggest that carrier status should be a determining factor in partner selection.

#### *Factors Contributing to Decision to Participate in Carrier Testing*

The participants reported the following factors as reasons for their participation in SCD carrier testing. Those factors are: (a) social influence, (b) family history, and (c) carrier testing process.

*Social influence.* Many participants indicated that they participated in SCD carrier testing because they had a friend or personal experience with someone with SCD or SCT. Their comments suggested that they felt that, by getting tested, they were contributing to

the efforts to control the effects of SCD. Participants who had a friend with SCD specifically conveyed greater empathy for individuals with SCD. One participant recalled, “I remember my friend had to go to the hospital a couple of times, so I know the medical consequences to be very severe and painful and since the opportunity presented itself, I decided to get tested” (PT3). Also, celebrities with SCD and spokespersons for SCD organizations had some influence on individuals’ participation in testing. The 12-year-old spokesperson for the SCDF of GA was a guest speaker at a few of the health fair events. During his presentations, the young man discussed the impact of SCD on his life, and on the lives of those around him and the importance of testing. For some participants, this presentation was a motivation to test:

I heard a little boy speak while I was there and he had sickle cell and he was inspiring, I was like wow. Because I never knew anyone who had and just to hear him speak about it, I knew I had to do it. (PT4)

On several occasions, participants associated SCD with Tionne Watkins (T-Boz), the national spokesperson for the Sickle Cell Disease Association of America. Ms. Watkins, nationally recognized for her membership in a popular music group, has for many years discussed in the media her having SCD. Respondents indicated that persons connected or associated with SCD influenced them to test, as well. One participant commented, “After reading about T-Boz and her trouble with SCD, I really wanted to know more about the disease and I really wanted to get tested” (PT7).

*Carrier Testing Process.* The participants described issues related to the carrier testing process as being justifications for their participation in testing. Accessibility, one reason given, by the participants for their decision to be tested, related to their having



financial constraints or time or transportation limitations. Several of the participants mentioned that they were tested because it was “free” and “convenient.” Many of the participants indicated that participation in health fair events provided an opportunity to test or get screened for various conditions simultaneously and at no cost. Some respondents implied that testing for SCT was done as a matter of convenience and opportunity and not out of necessity. One participant responded,

At the same venue I got tested for HIV and whatever other testing they were offering. I just I like the fact that everything was there, it was free, I didn't have to go out of my way to get it done, and I think that's important for folks who are busy. (PT4)

This justification was most evident for individuals who did not perceive themselves to be at great risk for being carriers. Participants agreed that, if the SCD carrier testing were not available through an event such as a health fair, they would not purposely seek this information from their regular health provider. Additionally, because as the sample was predominantly female, I inferred that SCD carrier status would typically not have been considered until a pregnancy was being planned. One participant with a family history of SCT revealed, “I probably would not have gotten tested now; I would have later when I got ready to have children, yeah just to make sure” (PT5).

Overall, the participants liked the fact that they could be tested very quickly, with a simple blood test. However, the method of testing was a concern for some; the preference was not to give blood or “be pricked” for the test. “A lot of people are scared of needles, if there was another way like hair sample or saliva more people might do it” (PT1). Although the testing method was a concern, it was not seen as being a major barrier to participation. The results were mailed to the participants 5 to 15 days after the

date of testing; the waiting time for the results was not reported as being a concern. The participants did not express any apprehension about being testing in a health fair setting versus being test in a private physician's office. Several of the participants mentioned that testing through a private physician would be much more costly; for those without insurance, this method was not an option. One participant who had a family history of SCT, responded,

I do not have insurance, I take advantage of the free things, so that's why when the opportunity came as far as getting it done [SCD carrier testing] for free, I took it, it would have taken a lot more time if I had to have a physician, with no insurance. (PT8)

There did not appear to be any concern or stigma associated with SCD carrier testing. Some participants felt that in comparison with being tested for more complex diseases being tested for SCD was of no real concern: "I don't think SCD, finding out if you have trait or not is anything that is quote unquote that personal, its not like HIV or AIDS or anything in that boat"( PT7). They reported that, when they were being tested in a health fair environment, privacy was not an expectation.

*Family History.* Genetic disposition, or family history, is typically the most common factor in individuals' decisions to participate in carrier testing for any genetic disorder. However, there were two aspects that were revealed from these data: (a) individuals were interested in getting testing because they were aware of their family history and felt that they were susceptible, or (b) they were unaware of their family history and did not know whether they were at risk. Individuals who were aware of their family history of the disease appeared to be less anxious about the test results. One

participant who had several family members with SCD and SCT replied, “Because of all of my cousins with SCD and SCT, I was not really surprised by the results, I mean its no big deal to me, I mean not now” (PT5). Others who were not aware of their family history indicated that they were somewhat apprehensive about the results of the test. One participant was shocked when she tested positive for SCT. To her knowledge, she had no family members with the trait or disease, “I immediately called my mom after counseling and said I have this and you get it from your parents so it’s either you or him” (PT 6). More often, individuals participated in testing because they were unaware of their paternal family history. It was implied that knowing their maternal history was only one part of the picture; “I knew my mother did not have SCD or SCT, but I was not sure about my father’s side, so I got tested to see what I got from him” (PT2).

Overall, it appeared that the respondents participated in SCD carrier testing because it was available and accessible. Additionally, hearing or reading about the life stories of individuals living with SCD was an inspiration for some to get tested. Further discussion revealed that participants with a family history of SCD or SCT participated in SCD carrier testing to determine whether they were carriers. This information was most relevant for individuals who were not familiar with the medical histories of either of their parents. For others without a known family history of SCD or SCT, carrier testing was simply viewed as being a mechanism with which to gain additional health information such as screening for health conditions like high blood pressure or diabetes.

### *Summary*

In general, the participants did not convey a vast knowledge of SCD, SCT, and prenatal and genetic testing. It was apparent that many were not aware of or had not given much thought to issues surrounding carrier testing. The participants expressed an interest in knowing their carrier status and potential partners' carrier status. They were interested in understanding inheritance patterns, because of the possibility of their becoming involved with a carrier. Those participants who had personal experience with someone with the disease appeared to be more aware of the course of the disease. There was a lack of knowledge about genetic testing in general. Participants indicated that they would not know what questions to ask health providers offering this genetic information.

The participants suggested that all genetic testing is important and specifically noted SCD carrier testing, genetic testing for other conditions, and prenatal testing. However, they appeared to be more supportive of carrier testing conducted before pregnancy than of prenatal testing conducted during pregnancy. The participants tended to believe that other African Americans were unacquainted with genetic testing and were not likely to participate in genetic testing. Also, the participants perceived that, because of an inability to pay for testing (i.e., lack of insurance) and because of a mistrust of doctors, other African Americans were less likely to participate in genetic testing. It was evident that SCD carrier testing was seen more as being preventative testing for chronic conditions like diabetes or cholesterol than as being a form of genetic testing.

Although the participants found SCD carrier identification to be useful information, they related that it truly does not become valuable information until preparations for pregnancy are being made. The participants felt that partner testing was

very important but should not be a determining factor in partner selection. There were varying opinions about the risk that carrier couples undertake when choosing to have children. Some felt that this choice was personal but that such couples should be aware of the consequences. Some respondents held the belief that knowingly having a child with SCD would be selfish; in contrast, others believed that, if they were to have a child with SCD, the child would be considered a gift from God. None of the participants stated that knowing the disease or trait status of their child would cause them to avoid having the child.

### Chapter Summary

This chapter presented the quantitative and qualitative results of the study. The Phase 1 section presented the findings from the SCDAS. Phase 2 illustrated the method by which the findings were from Phase 1 were clarified in follow-up interviews with 8 participants. The next chapter provides a discussion of the way in which Phase 1 and Phase 2 of the study integrate to present a comprehensive picture of the participants' beliefs about SCD and SCT and about SCD carrier testing. Also included are the implications that these findings have for public health practice, policy, education, and research.

## CHAPTER 5

### DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS

The aim of this study was to examine the relationship among African Americans college students' current level of knowledge and attitudes about SCD and SCT, their attitudes toward SCD carrier testing, and their intention to participate in carrier testing at various SCD sites. Additionally, qualitative interviews of men and women who were tested were used to explore in detail the participants' experiences, thoughts and feelings about SCD and SCT and about SCD carrier testing. This chapter presents the discussion and interpretation of the findings, limitations of the study, implications for practice, and recommendations for further research.

#### Overview of Integration

Erzberger and Kelle (2003) suggested that, in principle quantitative and qualitative methods are combined to answer a specific research question. The complementary model was applied to this study because the quantitative method alone was not sufficient in the collection of data to support the initial theoretical assumptions; the cross-sectional surveys used during the quantitative phase of the study conveyed only a small part of the theoretical framework. Integrating the results from both quantitative

and qualitative methods was found to highlight various aspects of the phenomenon; thus, the different methods supplemented each other by providing a more complete picture of the phenomenon (Erzeberger & Kelle) . The integrated findings of Phase 1 and 2 are presented in the following sections.

*Knowledge and Attitudes toward Sickle Cell Disease, Sickle Cell Trait and Sickle Cell Disease Carrier Testing*

*Level of knowledge about SCD*

In Phase 1, the average score on the SCD Genetics Knowledge subscale was 58.5%; this score indicates that a majority of participants answered more than half of the true/false statements correctly. A majority of the participants knew that there was a difference between being diagnosed with SCD and being diagnosed with SCT. Generally, the participants correctly answered questions about inheritance patterns. However, it was unclear whether the participants were simply more knowledgeable about genetic inheritance patterns. The questions that addressed characteristics of SCD or SCT were more frequently missed. For example, a number of the participants believed that SCD was more prevalent than SCT. Moreover, 40% of participants thought that SCT developed into SCD over time. Additionally, 40% of participants thought that SCD was transmitted via blood transfusions. These percentages were significantly higher than the results Treadwell and colleagues (2006) found in their study about the SCD knowledge and awareness of African American women and men; these authors reported that 17% of

their participants thought that SCD was transmitted via blood transfusion and that 31% believed that SCT could develop into SCD over time.

In the current study, the mean scores on the SCD Genetics Knowledge subscale were 54.3% for male participants and 60.5% for female participants. In terms of level of knowledge there was a statistically significant difference between the mean scores of the men and women. Ogamdi (1994) investigated the knowledge level of male and female African American college students in Texas regarding SCD and SCT. Ogamdi concluded that this population had limited knowledge of SCD genetics and inheritance patterns as well.

In Phase 2 of the present study, the predominately female sample illustrated a lack of knowledge regarding SCD and SCT. One of the participants believed that SCD was an infectious disease that was transmitted from one person to another. Overall, the participants knew that the disease was hereditary and could be passed to offspring. Several of the participants discussed the biological aspects of SCD and SCT. They were generally aware that the SCD involved blood and sickle shaped cells. Typically, the participants understood that there were minimum health consequences involved with having SCT in comparison to having SCD.

Boyd et al. (2005), who published one of the few studies of African American women's knowledge of SCD, concluded that African American women have not been equipped with adequate information about the incidence and inheritance patterns of SCD and SCT to make informed reproductive decisions. A limitation of the study by Boyd et al. was the target population of only African American women. In addition, the current



study yielded results indicating that being equipped with adequate information about SCD and SCT was only one factor involved in women's reproductive decision making.

#### *Attitudes toward SCD and SCT*

Attitude toward behavior is a major construct of TRA and is associated greatly with intention to perform a behavior. The majority of the participants in Phase 1 had neither favorable nor unfavorable attitudes toward SCD and SCT. In Phase 2, the participants represented very similar views. The participants were asked what their thoughts were about testing positive for SCT. One young woman indicated that, because she was unaware of any family history she was shocked to obtain positive results. Another participant stated that because of her strong family history she had been certain that she was at least a carrier; therefore, the positive results were not alarming. All of the individuals who were found to be carriers during the study period stated they preferred not to be carriers; however, they did not consider their carrier status devastating. These findings were different from prior research that indicated that women tend to exhibit anxiety when they or their spouse are identified as being carriers (L.Andrews, 1996). It was also suggested that in some cases, learning genetic information about oneself might have an impact on an individual's emotional well-being and self-concept. Additionally, carriers typically have more negative feelings about their future health than members of the general population do (L. Andrews). None of these characteristics appear to be issues for the women who were diagnosed as carriers in the sample for the present study.

#### *Attitudes toward Carrier Testing*

Overall, the participants had very favorable attitudes toward carrier testing. Findings from MRA revealed that such attitudes constituted a significant factor in the

participants' intention to participate in carrier testing. Attitude is a major component of the TRA and is strongly associated with intention. The items asked the participants their thoughts about carrier testing among African Americans, including young adults and their partners. The results of the survey indicated that the participants were in support of SCD carrier testing; however, less than half (46.2%) of the individuals actually underwent testing. The participants revealed in their interviews (Phase 2) that they believed that carrier testing was very valuable. However, if it were not offered to them or very accessible they would not seek this information.

### *Perceived Susceptibility*

Generally, participants in Phase 1 believed that they were at higher risk, or “perceived susceptibility”, for testing positive for SCT. It was anticipated that this variable would have been a significant factor in the participants' carrier testing decision-making process. Perceived susceptibility is a major construct of the HBM and the conceptual model used in this study. As mentioned chapter 1, the model posits that individuals' participation in a health behavior (in this case, participation in carrier testing), is often dependent on their belief that they are at risk for a disease or condition. In terms of inheritable diseases, two of the factors that are associated with individuals' perception of disease risk are (a) membership in a certain racial/ethnic group (e.g., identifying oneself as being African American), and (b) family history.

The mean perceived susceptibility mean score 3.75 indicated that the students believed that they were at higher risk for testing positive for SCT. In contrast, the Phase 1 participants were asked to identify factors that would contribute to their decision to

participate in carrier testing, less than 5% of participants considered being African American to be a factor. To date, there has been no published literature found that addresses patterns in SCD carrier testing and the relationship of the testing to race/ethnicity. Additionally, only 12% of participants identified family history as being a factor in their intention to participate in carrier testing. Thus, this study yielded little data that explained the participants' high perceived susceptibility scores. In Phase 2, participants did not convey that they felt they were in higher risk of testing positive for SCT. Intuitively those individuals that had a family history of SCD or SCT believed that it was possible for them to test positive for SCT. But, those that had no family history did not reveal any indication that they felt at an increased risk for SCT. However, the Phase 2 participants were on average 4 years older than the participants in Phase 1, which may affect their perception of risk.

#### *Perceived Severity.*

On average, there was a lower level ( $M=7.05$ ) of perceived severity among the participants about testing positive for SCT. Andrews (1996) found that carriers typically have more negative feelings about their future health than members of the general population do. In contrast, most of the 16 participants in the current study, who were self-identified carriers and did not undergo carrier testing, indicated that it was either unlikely or very unlikely that they felt less healthy because of having SCT. Perceived susceptibility and perceived severity are both major constructs of the HBM and are typically strongly associated with each other. However, neither perceived susceptibility nor perceived severity was found to be significant factors in this study. The participants in Phase 2, of the study conveyed similar feelings. Neither carriers nor non-carriers

perceived testing positive for SCT as a severe or serious condition. Some non carriers stated in comparison to testing positive for other conditions such as HIV, SCT was of little concern or anxiety. Carriers believed that have SCT was only a concern when making reproductive decisions.

Several groups of investigations have applied the HBM as a theoretical framework for the prediction of African American men and women's participation in health screening programs (James, Campbell, & Hudson, 2002; Reese & Smith, 1997, Rowley et al., 1991). However, Hill (1994) stated that the HBM model alone was not successful in predicting reproductive decisions among women with SCT in the African American community. Other researchers have also implied that the HBM includes neither a construct that addresses intention to participate in behavior nor on that addresses the cultural beliefs of the individuals participating in the screening program. As suggested by Poss (2001) and others, models combining constructs from HBM and TRA have been proven successful in predicting participation in screening programs in minority populations.

The model for the current study included constructs both HBM and TRA: attitudes toward SCD and SCT, attitudes toward SCD carrier testing, and perceived susceptibility and severity of SCT. The variable, knowledge level, was not included in the regression analysis because of the weak reliability of the assessment instrument. An MRA was used to examine the relationship between the independent variables and the dependent variable. The variable, attitudes toward carrier testing, had the strongest correlation with the dependent variable, intention to participate in carrier testing. A

higher FCT score indicated that the respondent was more likely to participate in carrier testing. The correlations between perceived severity, perceived susceptibility, and attitudes toward SCD and SCT and the dependent variable were very weak and negative this result demonstrates that, as perceived severity of SCT, perceived susceptibility to SCT, and attitude toward SCD and SCT scores decreased, the participants were more likely to participate in testing.

The regression model suggested that the variable, attitude toward carrier testing was most significant in explaining the students' participation in carrier testing. The variable, attitude towards carrier testing, accounted for 15.2% of the variance in the dependent variable, intention to participate in carrier testing. However, the model, which consisted of four variables (attitude toward SCD and SCT, attitude toward SCD carrier testing, level of perceived susceptibility to SCT, and perceived severity of SCT), accounted for only 2.30% of the variance in the dependent variable. The model was not successful in explaining the remaining 98% of the variance in the dependent variable. Based on the follow-up interviews is believed that a combination of external factors, including but not limited to cost, convenience, or opportunity, and internal factors, including knowledge, attitude toward health providers, and timing might have contributed to the variance in the dependent variable however, these factors were not included in the model.

The Phase 2, participants had limited knowledge of SCD and SCT. Many of them were unaware of health promotion campaigns developed to increase African Americans awareness of SCD and SCD carrier testing. Also, it was conveyed that feelings of

mistrust toward health providers remain a barrier for obtaining health care and health information. Also, factors such as timing were also, revealed in the follow-up interviews. Many of the participants believed that SCD carrier testing is most useful when an individual is preparing for pregnancy.

An ANOVA revealed that there was no statistically significant difference between the participants' level of perceived risk for SCT or level of concern for positive SCT results and their intention to participate in carrier testing. It was anticipated that there would be a significant difference between the categories of the perceived risks for SCT (i.e., very high, high, moderate, low, and very low) and the intention scores. The test failed to reject the null hypothesis that there was no statistically significant difference among the groups. This result may be explained by the lack of variance among the groups. As was mentioned previously, the participants' overall level of perceived susceptibility was high or very high. However, such levels did not appear to have an influence on the participants' decision to participate in testing. The follow-up interviews in Phase 2 did not provide any additional information about this result. Similarly, it was anticipated that there would be a significant difference between the level of concern for positive test results categories (i.e. very high, high, moderate, low, and very low) and the intention scores. The test failed to reject the null hypothesis that there was no statistically significant difference among the groups. This result may be explained by the lack of variance among the groups. As was discussed earlier, the participants' overall level of perceived severity was lower. The follow-up interviews in Phase 2 did not provide any additional information about this result.

*Participants Support for Carrier Testing and Intention to Participate in Carrier Testing*

A chi-square analysis was conducted to determine whether there was a relationship between the participants' support for carrier testing among young adults, African Americans, and their partners and their intention to participate in carrier testing. The test failed to reject the null hypothesis that there was no relationship between support for carrier testing and intention to participate in carrier testing. The participants had very favorable attitudes toward carrier testing for young adults. Additionally, the participants expressed very favorable attitudes toward carrier testing within the African American community.

Duster and Beeson (1998) suggested that, although the participants in their study of African American families affected by SCD and SCT supported carrier testing, there was little enthusiasm to participate in this process. This perspective may explain the low testing rates among the sample in the present study. The participants also conveyed support for encouraging their partners to be tested for SCT. This support implied that the participants were interested in knowing the carrier status of their partners because this information could be useful in future childbearing decisions. However, only a small number of individuals identified family planning as being a factor that would contribute their decision to participate in carrier testing. The follow-interviews in Phase 2 of the current study revealed that participants are in support of carrier testing for young adults. The participants agreed that it is important to have information about SCD and SCT prior to having children. The participants also conveyed that this information becomes more relevant and valuable as one prepares for pregnancy. The participants also expressed that

they supported partner testing, although the carrier status of an individual would have no bearing on their mate selection. The carriers who are at increased risk for having a child with SCD or SCT, indicated that they would have some concern with having a partner that was a carrier, but felt that whatever the outcome it could be managed.

#### *Contributing Factors to Participation in Carrier Testing*

The reasons that were discussed most frequently as contributing to participation in carrier testing were family history and accessibility. The participants were generally tested if they were aware of a family history or if they were unaware of family history. Most of the participants reported that they knew the carrier status of their mothers but not of their fathers and were interested in knowing their own carrier status. Also, several participants knew of their family history and wanted to identify their own status. As was mentioned previously, many of the participants who decided to be tested did so because the testing was convenient.

In general, this sample of participants was interested in participating in carrier testing. Many of the participants did suggest that, if testing were not available or accessible through a health fair or community event, they would be less likely to get tested. The majority of the participants were single and without children. Several suggested that they underwent testing because of the convenience of the health fair but that they would not have sought this information until they were approaching marriage or child-bearing decisions. Community health fairs appear to be a major factor in enabling participation in carrier testing. Also, personal experience with an affected person such as a friend or family member was a significant factor in several participants' decision to get tested.



The results of this study indicated that many African Americans would like to know more about SCD and SCT and about carrier testing. Generally, participants who had a personal connection with SCD or SCT, such as a family member or friend, offered a multifaceted view of SCD carrier testing. Those who did not have that connection typically had not given much thought to SCD or SCT or to carrier testing. Overall, there was no sense of responsibility to get tested because the disease primarily affects African Americans. There also appeared to be a disconnection between SCD and the participants. In general, the participants felt that they knew little about SCD, and their perception was that few African Americans were knowledgeable about the disease. This conclusion is supported by findings in recent studies conducted in the other regions in the United States (Boyd et al., 2005; Treadwell et al., 2006).

Overall, the participants believed that, in general genetics testing was beneficial. However, few of the participants could define genetic testing or explain what they thought it entailed. Several of the participants were confused between preventative screenings (e.g., mammograms) and genetic tests (e.g., SCD carrier testing). Several of the participants perceived that African Americans are generally not interested in genetic testing and do not find it accessible. Moreover, the participants implied that some African Americans are fearful and distrustful of the medical community; therefore, a lack of enthusiasm for medical advances exists within the African American community.

Several of the participants were in agreement that SCD carrier testing should be offered to young adults before pregnancy. They indicated that knowing one's carrier

status would be beneficial for partner selection. However, the participants also insinuated that carrier status should not be the basis for avoiding a relationship that may produce children. The participants also felt very strongly about having children with SCT or SCD. In general, the participants believed that caring for a child with SCD would be fraught with difficulties but a blessing from God. However, they also appeared to be more critical of carrier couples, which were at a higher risk of having a child with SCD.

*The Combined Health Belief Model and Theory of Reasoned Action Model*

The MRA revealed only one statistically significant factor that contributed to the students' intention to participate in carrier testing. The relevance of the quantitative variable, attitude toward carrier testing, was supported in the qualitative findings of this study. Although this construct was derived from the TRA, the combination of the HBM and TRA models has been found to be successful in explaining the health behaviors of individuals participating in other preventative tests or screenings as well (Doukas et al., 2004; Ham, 2006; Poss, 2001; Rubel & Garro, 1994). However, the four-variable model that was applied to this study failed to explain the participants' intention to participate in carrier testing. It is believed that a combination of other external and internal factors that were not included in the model, but were revealed in the interviews, such as accessibility, knowledge, and attitude toward health providers may better explain the participants' decision-making process.

The central concern of health promotion and health education is health behavior. Health behavior refers to those "personal attributes such as beliefs, expectations, motives"

values, perceptions and other cognitive elements; personality characteristics, including affective and emotional states and traits; overt behavioral patterns, actions, and habits that relate to health maintenance, to health restoration and to health improvement” (Glanz, Lewis, & Rimer, 2002, p.3 ). In the case of SCD carrier testing, the specific health behaviors and beliefs that might impact the genetic testing process had not been explored. The premise of the present study was to gain an understanding of the health and cultural beliefs that color African American college student’s interpretation of SCD carrier testing and their decision process leading to testing. The goal of the study was to provide a preliminary exploration of the individual factors that influence SCD carrier testing decisions; it was hoped the results of the exploration would lead to the development of more effective adult carrier testing protocols.

#### *Perceptions of Test Results*

Overall, the participants in this study demonstrated little concern for testing positive or negative for SCT. Those participants who tested negative for SCT were relieved to be non carriers; however, none of the participants believed that testing positive would have been life changing. Although it was not the preference of the participants who were diagnosed as carriers to have the trait or to transmit the trait or disease to a child, health status was not considered a deterrent from having a child. This perception might result from the strong value placed on motherhood and childbearing among many African Americans. Studies by Hill (1994) and Duster & Beeson (1998) mirrored this perspective. Hill found that the reproductive decisions of women diagnosed with SCD or SCT were not influenced by their disease status. Hill reported that the

women were cognizant of the risk involved with having children but that motherhood was a greater priority. In the present study, this perception was also evident in discussions about prenatal testing. Although the participants were generally supportive of the idea of prenatal testing, they expressed no enthusiasm for being tested prenatally themselves. It is my opinion that these participants had no real aversion to undergoing carrier testing or to knowing carrier status but that having this information would not significantly impact their reproductive choices. In conjunction with the idea of family is partner selection; again, the participants generally were in support of partner testing. However, the idea of selecting a mate on the basis of his or her carrier status was not realistic for these participants. It was apparent that the idea of romantic love and family superseded any potential health risk. Duster and Beeson's findings support this conclusion. The participants in their study supported carrier testing but did not feel obligated to use this information in partner selection.

## Study Limitations

### *Limitations of the Quantitative and Qualitative Phases*

The sample sample of participants from Phase 1 was lacked representativeness. Most of the participants resided in the same geographic area. Participants residing in different geographic areas (i.e., urban vs. rural) were included in the study, their varying or complementary views on SCD and SCD carrier testing would have made the results more generalizable.

The second limitation identified was the low reliability score for the SCD Genetics Knowledge subscale. The level of knowledge of the participants was an integral

factor in assessing the participants' beliefs about SCD and SCD carrier testing. However, the low reliability of the scale suggests that the results from the scale be viewed with caution. The low reliability score was also a factor in the removal of the knowledge variable from the MRA.

There were two external factors that were identified as limitations in this phase of the study. First, the health fairs were often held in locations where there was limited seating for those who completed the survey. Participation in the study may have been influenced by lack of seating or the associated discomfort. Second, budget and time constraints significantly impacted this study. The small budget for this study did not allow for travel to health fairs in other locations within the state. Had such travel been feasible, the sample size of the study would have been larger and more representative of African American college students outside the metropolitan Atlanta area and Savannah, GA.

The limitations identified in Phase 2 of the study were reflective of those identified in Phase 1. The sample size for this phase lacked representativeness as well. The participants in Phase 2 were only eligible to participate if they participated in carrier testing. The researcher did not explore the perspectives of individuals that elected not to participate in carrier testing. Thus the factors that would contribute to an individual's decision not to participate in carrier testing were not examined. Over half of the eligible participants for Phase 2 of the study were eliminated because of low response rates, thus a convenience sample of 8 individuals instead of a purposefully sampled 15 was used. Because a convenience sample was used, the participants in Phase 2 were on average 4

years older than those in Phase 1. It is believed that the age of the participants had a significant impact on their knowledge, beliefs, and attitudes about carrier testing. Additionally, the sample was predominately female, and there was only one male participant. Thus, the perspectives of male participants were not represented adequately. As was previously mentioned, the time and budget constraints of this study did not allow for interviews with participants from health fair testing sites across the state. Therefore, the perceptions of college students residing outside the metropolitan Atlanta area were not represented in this phase of the study. Consequently, the reported beliefs and attitudes toward SCD and SCD carrier testing can only be discussed within the experiences of this sample.

### Implications for Public Health Practice, Policy and Education

#### *Public Health Practice*

One of the purposes of the study was to contribute to the public health knowledge base about adult SCD carrier testing. It was desired that this study would further discussions about appropriate and effective strategies to increase knowledge about SCD and SCD carrier testing within the African American community.

In an evaluation of the future of public health in the United States, IOM defined the core functions of public health agencies as assessment, policy development, and assurance (Khoury, 1996). For the purposes of this study, the relationship of these core functions to carrier testing is discussed. One of the core functions of public health in relation to genetics is assurance. Assurance includes informing populations about

relevant health and social services, and about cultural, educational, and other issues, as well as ensuring that patients, families, and communities have access to appropriate, cost-effective, and timely services that enhance family and community relationships (Kaye, Laxova, Livingston, Lloyd-Puryear, & Mann, 2001). Assurance can be viewed in the context of the three overlapping strategies for disease prevention: behavior prevention, environmental prevention, and clinical prevention. The strategy that is most applicable to SCD carrier testing among African Americans is behavior prevention.

The behavior prevention strategy requires the ability to educate individuals regarding the risks for diseases in them, their offspring, and their relatives on the basis of the unique combination of their genetic background and their lifetime experiences. In genetics, the basic premise is that education and behavior modification can be targeted toward individuals with differential genetic susceptibilities (Khoury, 1996). This premise has specific implications for prevention education and future public health practitioners. Three issues related to disseminating SCD carrier information should be addressed in the preparation of public health practitioners.

First, it is desired that the results of the current study will assist in training public health practitioners to discuss issues related to SCD carrier testing that affect the communities of color. It must be understood that genetic diseases such as SCD differ from infectious diseases such as HIV and TB in two ways: (a) infectious diseases can put society at large at risk by rapidly spreading to a number of people in a limited period, whereas genetic diseases do not pose an immediate threat to society. (b) The transmission of a genetic disorder to an offspring does not have an immediate impact on society but

does create an increased risk for future generations; this increased risk is important to comprehend because parents or family members responsible for transmitting the affected gene might have feelings of guilt or anxiety about their health status.

Second, the results of this study should assist in the preparation of public health practitioners to address the cultural and health beliefs that influence individuals' SCD knowledge and carrier testing practices. Cultural values give an individual a sense of direction, as well as giving meaning to life. These values are held on an unconscious level. As was revealed in this study and many others, there is a direct relationship between culture and health practices. In fact, of the many factors that are known to determine health beliefs and behaviors, culture is the most influential (Harwood, 1981). Although the benefits of genetic technology and its application to disease prevention are widely known, there are some barriers to its utilization in some communities. Many African Americans continue to distrust healthcare providers because of prior and continuing unequal health care experiences. This distrust significantly impacts SCD carrier testing, as well as other genetic screening efforts targeting African Americans. The overarching theme for public health practitioners is to understand culture and maintain the ability to provide services that are culturally relevant to their population through identifying innovative ways to reach the community.

Third, it is desired that use of a mixed method design in this study will encourage public health practitioners to use multi-methodologies to assess (by monitoring, analyzing, and evaluating) SCD interventions . As was discussed previously, literature related to SCD carrier testing among African Americans is limited, as is literature on



other forms of genetic testing. Thus, the assessment of data in four areas is necessary:

(a) health, well-being, social-cultural, and educational status of individuals and populations; (b) community concerns; (c) resources available and/or need; and (d) access to, availability of, utilization of, affordability of, and satisfaction with services.

Quantitative or qualitative methods independently may not provide the most complete or accurate of these issues as it relates to SCD carrier testing.

### *Public Health Policy*

Policy development, also considered a core function of public health practice, has for decades been deeply rooted in issues related to SCD carrier testing. As was previously discussed, the National Sickle Cell Anemia Control Act of 1972 (Hill, 1994) made federal funding available for community screening and education; however, several unintended outcomes were produced by this legislation.

An IOM report cited by Botto and Mastroiacovo (2000), summarizes the lessons learned from the early SCD screening programs as follows:

The experience with SCD screening programs in the 1970's illustrates the difficulties that can arise when the goals of screening programs are not clearly specified. Particularly when there is no treatment that improves health outcomes, and when intervention is not acceptable to the target population because stigma and discrimination. The change in approach to SCD screening over time, as new facts and treatment opportunities emerge, illustrates that programs must have the flexibility to change over time as situations change.

In the 1980s, the prophylactic regimen of penicillin in infants was recognized as being an effective mechanism in reducing the morbidity and mortality of SCD. In 1987,

the NIH recommended that newborn screening for SCD be universal instead of being targeted to African Americans only. Currently, 48 states and the District of Columbia have adopted universal newborn screening programs for SCD. SCD carrier testing for adults is still conducted on a voluntary basis.

The 1997 Final Report of the Task Force on Genetic Testing, an organization established by the NIH, provided extensive recommendations on the safety and effectiveness of genetic tests, as well as guiding principles for future policy. Policy makers for SCD carrier testing should follow these suggestions. Public health policies should provide guidance in the following areas: (a) provision of care for individuals identified by genetic screening, including guidance for diagnosis, treatment, and prevention programs; (b) prevention of misuse of genetic information; (c) prevention of discrimination based on an individual's carrier status; and (d) consumer involvement in policy development.

On the basis of the results of this study it is paramount that providers of health care respect individual's/couple's beliefs and values about tests taken to assist with reproductive decisions. One way to ensure that an unbiased stance is maintained and that parents' decisions are autonomous is to require informed consent.

Both the misuse of genetic information and discrimination are often linked to confidentiality issues. Protecting the confidentiality of information is essential for SCD carrier testing. Test results should be released only to those individuals for whom the test recipient has given permission. Health providers have an obligation not to inform other family members of test results without first receiving the permission of the tested person.

It is imperative that policy makers continuously assist in the development of comprehensive federal and state legislation that supports this notion.

Discrimination is a significant issue among the African American community. Policy makers should champion legislation that ensures that individuals are not subjected to unfair practices by a third party such as employers, insurers, or other institutions on the basis of having had a carrier test or receiving an abnormal genetic test result.

It has been recommended that inequities often faced by consumers of health care be addressed by involving consumers in the policy making process. Although stakeholders are concerned about protecting consumers, they cannot always provide the perspective brought by consumers themselves, the end users of carrier testing. Policy making groups should consist of diverse individuals and organizations, all of whom participate in decision making about the importance of health, social, educational, and other issues related to genetic testing or screening (Gaare-Bernheim, Bonnie, & Nieburg, 2003).

#### *Public Health Education*

It is believed that SCD carrier rates among African Americans would increase if more public health practitioners were providing education and testing to communities. The most effective way to increase the participation of public health practitioners in SCD related health promotion is to prepare a well-trained workforce. The lack of health care providers and public health practitioners with genetic experience makes it crucial to implement strategies that will increase this workforce and the financial resources necessary to support it. The following strategies have been suggested to be effective ways

in which to develop a qualified workforce: (a) incorporating genetics training into curricula at schools of public health and (b) offering joint graduate degrees in public health and genetic counseling.

The training of minorities in genetics education and public health is essential. It is proposed that intense recruitment efforts targeting African Americans interested in public health and genetic education would produce a new generation of culturally competent providers. These individuals possessing skills from both disciplines would be capable of communicating the benefits, risks, limitations, and implications of carrier testing and accurately interpreting and appropriately utilizing genetic information in clinical and public health practice.

#### Recommendations for Further Research

SCD-related health education and health promotion research efforts need to be increased within the African American community. It is apparent that African American men and women are interested in participating in carrier testing when it is accessible. Many of the participants indicated that, if the opportunity to test through outreach events were not available, information concerning their carrier status would not have been ascertained. Therefore, community outreach efforts are a vital component to maintaining and increasing carrier testing uptake rates. Hence, empirical studies that evaluate the effectiveness of strategies used to educate African American women and men about SCD or SCD carrier testing is of the essence.

A limitation of the current study was the exclusion of individuals that did not participate in carrier testing from follow-up interviews. In continuing this line of

investigation, qualitative research should be conducted to gain insight into the thoughts of individuals that do not support or would not participate in SCD carrier testing.

The study participants characterized accessible carrier testing as being low cost or free, and convenient, and offered in conjunction with other testing opportunities. On the basis of this idea, there exists a need for feasibility research to identify the characteristics of supportive environments that facilitate SCD carrier testing (i.e., testing via health fairs at community venues, work sites, and churches).

In this study, as well as in other recent studies pertaining to SCD (Asgharian & Anie, 2001; Boyd et al., 2005; Hill, 1994; Treadwell et al., 2006), the majority of participants were women. Several of the respondents indicated that they participated in testing because they were unaware of their father's genetic history. If men are uninformed about their carrier status and SCD genetics, reproductive decision making for couples can be a challenge; therefore, those providing genetic information or carrier testing should understand the role of men in the testing process. Research studies that investigate the perspectives of African American males with regard to SCD and SCD carrier testing would be beneficial.

Genetic testing in various forms such as carrier testing, prenatal testing, and pre-implantation genetic diagnosis offers the individual or couples the opportunity to prevent or terminate pregnancy on the basis of genetic makeup or risk of disease. Although carrier testing is considered to be among the least controversial types of genetic testing, it sets the stage for dilemmas centered on partner selection and childbearing (Duster & Beeson, 1998). In general, the participants of the study believed that, if their child were to be born with SCD or SCT, the child would be considered a blessing and

that God would provide for the child. Consequently, researchers need to further explore the connection between cultural beliefs, religious beliefs, and reproductive genetic testing.

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APPENDIX A

UAB INSTITUTIONAL REVIEW BOARD FOR HUMAN USE  
APPROVAL LETTER



Institutional Review Board for Human Use

Form 4: IRB Approval Form  
Identification and Certification of Research  
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines. The Assurance became effective on November 24, 2003 and expires on February 14, 2009. The Assurance number is FWA00005960.

Principal Investigator: STEWART, KAI

Co-Investigator(s):

Protocol Number: **X060301009**

Protocol Title: *An Examination of African American College Students Knowledge and Attitudes Regarding Sickle Cell Trait and Sickle Cell Disease Carrier Testing: A Mixed Method Study*

The IRB reviewed and approved the above named project on 03/28/06. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 3/28/06

Date IRB Approval Issued: 03/28/06

HIPAA Waiver Approved?: N/A

Marilyn Doss, M.A.  
Vice Chair of the Institutional Review  
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

APPENDIX B

SCDF of GA APPROVAL LETTER

**SICKLE CELL  
FOUNDATION  
OF GEORGIA, INC.**

January 18, 2006

• A LEGACY TO SERVE •

**D. Jean Brannan**  
*President and Chief Operating Officer*

**Brian D. Poe, Esq.**  
*General Counsel*

**Otis S. Powell, Jr., M.D.**  
*Laboratory Director*

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Otis Smith, *M.D.*

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Clinton E. Warner, *M.D.*

**Ms. Kia Stewart, MPH**  
3940 Balleycastle Lane  
Duluth, Georgia 30097

Dear Ms. Stewart:

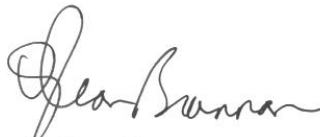
The purpose of this letter is to approve your request to work in conjunction with the Sickle Cell Foundation of Georgia, Inc. in conducting research for your dissertation study. It is the Foundation's belief that your study "An Examination of African American College Students Knowledge and Attitudes Regarding Sickle Cell Disease Carrier Testing" parallels the goals and objectives of this agency.

It is the mission of the Foundation to provide education, screening and counseling programs for sickle cell and other abnormal hemoglobins. The Foundation also has a deep-rooted commitment to making strides in monitoring the occurrence of sickle cell, improving the quality of life for those with the disease and cooperating with individuals and institutions conducting research.

In this effort you will be working with Harold Dobbs, the Foundation's Outreach Coordinator. Through this partnership, we hope to explore the perspectives of young African-Americans regarding sickle cell disease, sickle cell trait and their experiences related to sickle cell disease carrier testing.

We look forward to the results of this effort.

Sincerely,



**D. Jean Brannan**  
President and Chief Operating Officer



The United Way



Member of the  
Sickle Cell Disease  
Association of America, Inc.

APPENDIX C  
RECRUITMENT MATERIAL

Sickle Cell Disease Foundation of Georgia, Inc  
2391 Benjamin E. Mays Dr.  
Atlanta, GA 30311

Dear President/CEO:

My name is Kai Stewart and I am a doctoral student at The University of Alabama-Birmingham, School of Public Health, and Department of Health Behavior. I am currently conducting a study for my dissertation about views and attitudes of African American college students regarding Sickle Cell Disease (SCD), Sickle Cell trait (SCT) and SCD carrier testing. The goal of my study is to identify the knowledge level, characteristics and salient beliefs of individuals participating in SCD carrier testing. A great amount of literature discusses the benefits SCD newborn. However, there has been little literature published on adult SCD carrier testing. With this being the case, I believe it is important to learn more about the current perceptions of men and women of childbearing age with regard to sickle cell disease, sickle cell trait and their reasons for or against participating in carrier testing.

I am writing to request your permission to recruit participants and distribute my surveys to students being tested through your screening program with the Mobile Testing Unit. If you grant me permission, I will contact you or the appropriate person to discuss the best way to distribute the surveys to the participants. In my cover letter to potential participants, I will explain the purpose of the study that participation is strictly voluntary and all responses to the surveys will be confidential, anonymity will be maintained and an incentive will be provided.

At this time there are no harmful effects anticipated from participation and potential benefits may occur on an individual basis. One of the purposes of this study is to open a dialogue in the area of reproductive health, sickle cell disease and genetic testing and contribute to the knowledge base for an area that is often considered sensitive.

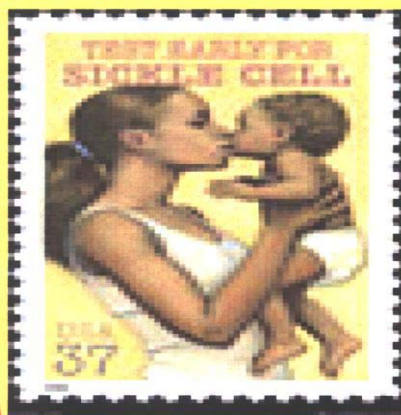
It is anticipated that this study will benefit your agency by: having an instrument that can be used to track trends in your testing program, being able to identify the need for SCD information among population tested and not tested, identify the population's beliefs and attitudes about testing and identify current perceptions about testing positive for SCT.

Please review the enclosed proposal summary if you have any questions, please do not hesitate to contact me, Kai Stewart, MPH at 404.881.9777 ext. 202, mobile number 678.641.0445 or [kai@aadd.org](mailto:kai@aadd.org).

Respectfully,

Kai Stewart, MPH

**“What are your thoughts about Sickle Cell Disease  
and Sickle Cell Disease Carrier Testing”**



**If you are African  
American, between the  
ages of 19 and 30, and  
a student you are  
eligible to participate  
in this study.**

**Where:**

**When:**

**Time:**

**A \$10.00 cash incentive will given for participation in the  
study.**

**Sponsored by the SCDF of Georgia and University of  
Alabama-Birmingham**

Participant Recruitment Letter  
Phase 2

Dear Potential Participant:

My name is Kai Stewart and I am a doctoral student at The University of Alabama-Birmingham, School of Public Health, and Department of Health Behavior. I am currently conducting a study for my dissertation about views and attitudes of African American college students regarding Sickle Cell Disease (SCD), Sickle Cell Trait (SCT) and SCD carrier testing.

The goal of my study is to examine characteristics and salient beliefs of individuals participating in SCD carrier testing. A great amount of literature discusses the benefits SCD newborn. However, there has been little literature published on adult SCD carrier testing. With this being the case, I believe it is important to learn more about the current perceptions of men and women of childbearing age with regard to sickle cell disease, sickle cell trait and their reasons for or against participating in carrier testing.

If you are receiving this letter chances are you completed one of my surveys when you were tested through the Mobile Testing Unit. At this time I would like to request your participation in the second phase of my study. This phase requires personal interviews to be held at the Sickle Cell Disease Foundation of Georgia office. The interviews will last approximately 45-50 minutes. Participation is strictly voluntary and all taped interviews will be confidential and anonymity will be maintained.


**If you are interested in participating in this phase of the study please call 404.275.0520 and leave a message, including your name and a contact number. An incentive of \$35.00 will be provided for your time and cooperation.**

Respectfully,

Kai Stewart, MPH



## Follow-Up Contact Card



*We Want to Know What You Think!*

Potential Participant,

We would like to know what you think about sickle cell trait and sickle cell disease carrier testing. There is still an opportunity to participate in face to face interviews. The interviews will last approximately 45-60 minutes. The incentive for participation is \$35.00. The interviews will be held at the **Sickle Cell Foundation of GA, 2391 Benjamin E. Mays Dr. Atlanta, GA.** If you are interested please contact **Kai Stewart, at 404.275.0520.**

## APPENDIX D

### SCDAS

# SICKLE CELL DISEASE ASSESSMENT SURVEY



**Instructions:** We will be asking you some questions about your understanding of sickle cell disease, sickle cell trait and sickle cell disease carrier testing. Again, your answers will be kept confidential and used for research purposes only. Please follow the instructions provided for each section of the survey. The survey packet contains two surveys: The Sickle Cell Disease Assessment Survey (SCDAS) and the Health Orientation Scale.

**When you have completed the survey please, place in the box marked “SURVEYS”.**

Thank you for your time and cooperation.

**Kai Stewart, MPH  
University of Alabama-Birmingham  
School of Public Health**

**SICKLE CELL DISEASE ASSESSMENT SURVEY**

ID NUMBER ( \_ \_ \_ \_ \_ ) SITE \_\_\_\_\_

**Please tell us about yourself by answering the following questions. Your answers will be kept confidential and used for research purposes only. Your individual responses will not be identified. Please follow the instructions provided for each section of the survey.**

1). Please **circle** the highest level in school you completed.

COLLEGE/ \_\_\_\_\_ Graduate/Professional

13 14 15 16

17 18 19 20 21+

2). What is your age? \_\_\_\_\_

3). What is your gender?  MALE  FEMALE

4). Which best describes your marital status:

MARRIED  WIDOWED  SINGLE  SEPARATED

DIVORCED

5) How many children do you have? :  NONE  ONE

TWO OR MORE

6) Do you have a family history of Sickle Cell Disease or Sickle Cell Trait?  YES  NO  DON'T KNOW

**PLEASE GO TO THE NEXT PAGE**

**SICKLE CELL DISEASE ASSESSMENT SURVEY**

**Below are statements about sickle cell disease (SCD) and sickle cell trait (SCT).** Please check (X) the box that represents whether you think the statement is true or false.

*SICKLE CELL DISEASE and SICKLE TRAIT  
Genetics Knowledge*

<b>Statements</b>	<b>True</b>	<b>False</b>
1. There is no difference between people with SCD or SCT	<input type="checkbox"/>	<input type="checkbox"/>
2. If one parent has SCD and the other is normal, all of the children will have SCT.	<input type="checkbox"/>	<input type="checkbox"/>
3. If one parent has SCD and the other has SCT, there is a 50% chance of having a baby w/ either SCD or SCT.	<input type="checkbox"/>	<input type="checkbox"/>
4. When both parents have SCT, they have a 25% chance (1 of 4) of having a baby with SCD.	<input type="checkbox"/>	<input type="checkbox"/>
5. The mother transmits the sickle cell gene only.	<input type="checkbox"/>	<input type="checkbox"/>
6. Sickle trait can turn into sickle cell disease over time.	<input type="checkbox"/>	<input type="checkbox"/>
7. There are several different types of sickle cell disease.	<input type="checkbox"/>	<input type="checkbox"/>
8. Sickle cell disease occurs in 1 out of 12 African Americans.	<input type="checkbox"/>	<input type="checkbox"/>
9. Sickle cell trait can be transmitted through blood transfusions	<input type="checkbox"/>	<input type="checkbox"/>
10. One out of 600 African Americans is born with SCT.	<input type="checkbox"/>	<input type="checkbox"/>

**SICKLE CELL DISEASE ASSESSMENT SURVEY**

**Instructions:** We will be asking you some questions about your thoughts regarding sickle cell trait and SCD carrier testing. Please check (X) the answer that best describes how you feel.

**FEELINGS ABOUT CARRIER TESTING**

	<b>Agree</b>	<b>Disagree</b>
11. Do you support SCD carrier testing in young adults?	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you support SCD carrier testing in the African American community?	<input type="checkbox"/>	<input type="checkbox"/>
13. If you were found to be a SCD carrier would you encourage your partner to get tested?	<input type="checkbox"/>	<input type="checkbox"/>
	<b>Good</b>	<b>Bad</b>
14. Do you think that SCD carrier testing in young adults is..	<input type="checkbox"/>	<input type="checkbox"/>
15. Do you think that encouraging your partner to be tested is..	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you think that SCD carrier testing in the African American community is..	<input type="checkbox"/>	<input type="checkbox"/>

CARRIER AND TESTING STATUS

17. What is your carrier status? HAVE SCT  DO NOT HAVE SCT  DON'T KNOW

18. How likely are you to participate in SCD carrier testing today? VERY LIKELY  LIKELY  NOT LIKELY OR UNLIKELY  UNLIKELY  VERY UNLIKELY

19. Did you participate in SCD carrier testing today? YES  NO

20. What factors would contribute to your decision to be tested?

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21. What factors would contribute to your decision not to be tested?

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## SICKLE CELL DISEASE ASSESSMENT SURVEY

**Instructions:** We will be asking you some questions about your thoughts regarding sickle cell trait and SCD carrier testing. Again, your answers will be kept confidential and used for research purposes only. **Please check (X) the box that best represents what you think.**

22. How likely is it that you are at risk for SCT

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very likely	Likely	Not likely or unlikely	Unlikely	Very Unlikely	Don't know	

23. What is your level of risk?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very high	High	Moderate	Low	Very low	Don't know	

24. What would be your level of concern if you tested positive for SCT?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very high	High	Moderate	Low	Very low	Don't know	

25. Would you feel less healthy than others if you learned that you had SCT?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very likely	Likely	Not likely or unlikely	Unlikely	Very Unlikely	Don't know	

**PLEASE GO TO THE NEXT PAGE**

<b>Instructions:</b> Below is a list of items that get at your feelings about SCD and some other health concerns. <b>Please make a selection for all of the items.</b> Give your first response. <b>Indicate your feelings by CIRCLING an “X”</b> closest to the word which best describe what you think.						
<b>SITUATION A: I AM IN CHARGE OF 50 PEOPLE WHO DO DIFFERENT KINDS OF JOBS. I LEARN THAT SEVERAL OF MY EMPLOYEES HAVE SCT. I FEEL</b>						
	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY
<b>SITUATION B: AS THE BOSS I IMAGINE THAT THE SCT CARRIER MIGHT FEEL:</b>						
	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY
<b>SITUATION C :MY DOCTOR HAS JUST TOLD ME THAT I HAVE SCT, I FEEL:</b>						
	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOTGUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY

<b>Instructions:</b> Below is a list of items that get at your feelings about SCD and some other health concerns. <b>Please make a selection for all of the items.</b> Give your first response. <b>Indicate your feelings by CIRCLING an “X”</b> closest to the word which best describe what you think.						
<b>SITUATION D: I HAVE SCT. OVER A GAME OF CARDS THERE IS A CONVERSATION ABOUT SICKLE CELL. AS I CONSIDER WHETHER OR NOT TO MENTION I HAVE SCT, I FEEL:</b>						
	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY
<b>SITUATION E: MY SPOUSE AND I HAVE BEEN DIAGNOSED AS SCT CARRIERS. THIS MEANS THAT WE MIGHT HAVE CHILDREN WITH SCD, CONSIDERING THE RISK WE TAKE IF WE HAVE CHILDREN, I FEEL:</b>						
	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY
<b>SITUATION F: MY DOCTOR HAS JUST TOLD ME I HAVE SCD, I FEEL:</b>						
	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY

**Instructions:** Below is a list of items that get at your feelings about SCD and some other health concerns. **Please make a selection for all of the items.** Give your first response. **Indicate your feelings by CIRCLING an “X”** closest to the word which best describe what you think.

**SITUATION G: MY DOCTOR HAS JUST TOLD ME I HAVE CANCER, I FEEL:**

	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY

**SITUATION H: MY DOCTOR HAS JUST TOLD ME I HAVE HIGH BLOOD PRESSURE, I FEEL:**

	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY

**SITUATION I: THE FOLLOWING TERMS BEST DESCRIBE ME:**

	Ratings					
BAD	X	X	X	X	X	GOOD
AFRAID	X	X	X	X	X	UNAFRAID
NOT GUILTY	X	X	X	X	X	GUILTY
ASHAMED	X	X	X	X	X	UNASHAMED
STRONG	X	X	X	X	X	WEAK
SHOCKED	X	X	X	X	X	RELIEVED
SAD	X	X	X	X	X	HAPPY
UNMARKED	X	X	X	X	X	MARKED
UNABLE	X	X	X	X	X	ABLE
NOT PLEASED	X	X	X	X	X	HAPPY
INACTIVE	X	X	X	X	X	ACTIVE
SICK	X	X	X	X	X	HEALTHY

**THANK YOU FOR YOUR TIME AND COOPERATION  
KAI STEWART, MPH**

APPENDIX E  
INTERVIEW PROTOCOL

WHY DO AFRICAN AMERICAN COLLEGE STUDENTS PARTICIPATE  
IN SCD CARRIER TESTING?  
INTERVIEW PROTOCOL

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

LOCATION: \_\_\_\_\_

*Introduction*

I want to thank you for taking time to talk to me today. I will be recording and transcribing what we say today. I will be asking you to review the transcription with some of the notes I make regarding my interpretations of what you say. It is important that I reflect in my writing what you mean. Therefore, I want you to review it to make sure I am representing your views. The transcription will be a verbatim one, so be prepared to see any “uhs” or “ahs” that you say. If I use any quotes in the final written paper, those will not be there. It is important that the transcription be verbatim so that I do not paraphrase something you’ve said with an incorrect interpretation.

What I am interested in finding out in this study is why you would participate in SCD carrier testing. You have had a chance to review the questions that I am going to ask you today and give them some thought. I really want to know your perspective so feel free to discuss your views. I may ask you some additional questions that you have not reviewed as we go along in order to clarify what you mean. Are you ready to start?

- 
1. Tell me a little about yourself? Age, occupation, single/married, student etc.
  2. Share with me what you know about SCD? SCT

*Probe 1: How is the sickle cell gene transmitted?*

*Probe 2: What do you think causes SCD?*

*Probe 3: What is the difference between having SCD and SCT?*

3. Why did you decide to participate in carrier testing?

*Probe 1: Do you think testing is accessible?*

*Probe 2: Are you Aware of anyone in your family with SCD  
or SCD?*

*Probe 3: Do you Have any friends or know anyone with SCD  
or SCT?*

4. What was the carrier testing process like for you?

*Probe 1: Is there anything about the carrier testing process that you  
would change?*

5. What does testing positive for SCT mean for you?

*Probe 1: When you got your test results in the mail what was your  
initial feeling?*

*Probe 2: Does testing positive change your life in anyway?*

6. What does testing negative for SCT mean for you?

*Probe 1: When you got your test results in the mail what was your  
initial feeling?*

*Probe 2: Does testing positive change your life in anyway?*

7. What is genetic testing?

*Probe 1: When I say genetic testing what comes to mind?*

*Probe 2: How do think genetic testing is used?*

*Probe 3: Do you think genetic testing is valuable?*

8. Tell me when you think about genetic testing and African Americans what comes to mind?

*Probe 1: Do you think African Americans support genetic testing?*

9. You are a genetic counselor and an 18 year-old woman has just tested positive for SCT, what do you say to her?

*Probe 1: What would you say to her about having children in the future?*

*Probe 2: As a carrier what advice would you give to this young woman?*

10. After participating in SCD carrier testing do you think any differently about genetic testing in general either for yourself or your partner?

*Probe 1: How would you convince you partner to participate in genetic testing?*

11. After participating in SCD carrier testing do you think any differently about prenatal testing for yourself or your partner?

*Probe 1: Do you know what prenatal testing is?*

*Probe 2: How is prenatal testing different from carrier testing?*

12. What is the value of SCD carrier testing?

*Probe 1: Was there value in SCD carrier testing for you?*

13. What are your thoughts about carrier couples having children?

14. What are your thoughts about having a child with SCD? What are your thoughts about having a child with SCT?

*Probe 1: Would you feel guilty for having a child with SCD?*



APPENDIX F  
CONSENT FORM PHASE 1 AND PHASE 2

**Title: An Examination of African American College Students Knowledge and Attitudes Regarding Sickle Cell Trait and Sickle Cell Disease Carrier Testing: A Mixed Method Study( Phase I)**

**SPONSOR:** The University of Alabama at Birmingham (UAB), School of Public Health, Department of Health Behavior

**INVESTIGATOR:** Kai Stewart, MPH

**PURPOSE OF THE STUDY**

In the present study quantitative and qualitative methods are used to examine the relationships between African American college student’s knowledge and attitudes toward sickle cell trait and sickle cell disease carrier testing. The objective of the mixed method study is to identify internal factors that may contribute to college student’s decision to participate in carrier testing. Very little research exists to document the perspectives African American men and women of child-bearing age as it relates to sickle cell trait and genetic testing. Research indicates that genetic disorders are an aspect of care that is often overlooked by providers treating young adult men and women.

**DESCRIPTION OF THE STUDY**

The goal of Phase I of the study is to identify the health beliefs of African American men and women of child-bearing age with regard to sickle cell disease and their perspectives on sickle cell disease carrier testing. The target population for this study is African American college students, between the ages of 19-30, attending schools that host the Sickle Cell Disease Foundation of Georgia, Mobile Testing Unit.

**PROCEDURES**

The study is divided into two parts, Phase I and Phase II. Phase I consists of completing the Sickle Cell Disease Assessment Survey and the Health Orientation Scale. The surveys will be administered either at various colleges/and or universities hosting the Sickle Cell Disease Foundation of Georgia, Mobile Testing Unit. The surveys should take 10-15 minutes to complete.

**RISKS AND DISCOMFORTS**

Answering our questions should not cause much risk or discomfort. Some people may feel uneasy about answering some of the questions. You have the right not to answer any questions deemed uncomfortable or inappropriate.

**Participant’s Initials** \_\_\_\_\_

Page 1 of 3

Revision 3/27/2006

UAB – IRB  
Consent Form Approval 03-28-06  
Expiration Date 03-28-07

**BENEFITS**

You may not benefit directly by being apart of the study. However, the information we get from you will help us better to understand the perspectives of young persons participating in sickle cell disease carrier testing.

**ALTERNATIVES**

The alternative is not to participate in the study.

**COSTS**

There will be no costs to you.

**PAYMENT FOR PARTICIPATION**

If you take part in Phase I of the study, we will give you \$10.00 cash for completing the questionnaire

**COMPENSATION FOR INJURY**

UAB has made no provision for monetary compensation in the event of injury resulting from the research. In the event of such injury, treatment is provided but is not free.

**LEGAL RIGHTS**

You are not waiving any legal rights by signing this consent form

**WITHDRAWAL WITH PREJUDICE**

You are free to withdraw your consent and get out of the study at any time without prejudice.

**QUESTIONS**

If you have any questions about your rights as a research participant you may call , **Kai Stewart at 678-641-0445 or Dr. Monica Baskin at 205-975-5704.** If you have questions regarding your rights as a research participant, you may call Ms. Sheila Moore, Director of the Office of the UAB Institutional Review Board for Human Use (IRB). Ms. Moore may be reached at (205) 934-3789 or 1-800-822-8816, press the option for operator/attendant and ask for extension 4-3789 between the hours of 8:00 a.m. and 5:00 p.m. CT, Monday through Friday.

**Participant's Initials \_\_\_\_\_**

**Page 2 of 3**

**SIGNATURES**

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions. If you agree to participate in this study, you will receive a signed and dated copy of this consent form for your records.

\_\_\_\_\_  
Participant Name

**CONSENT SIGNATURE:**

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Person Conducting Informed  
Consent Discussion

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

**An Examination of African American College Students Knowledge and Attitudes Regarding Sickle Cell Trait and Sickle Cell Disease Carrier Testing: A Mixed Method Study ( Phase II)**

**SPONSOR:** The University of Alabama at Birmingham (UAB), School of Public Health, Department of Health Behavior

**INVESTIGATOR:** Kai Stewart, MPH

**PURPOSE OF THE STUDY**

In the present study quantitative and qualitative methods are used to examine the relationships between African American college student’s knowledge and attitudes toward sickle cell trait and sickle cell disease carrier testing. The objective of the mixed method study is to identify internal factors that may contribute to college student’s decision to participate in carrier testing. Very little research exists to document the perspectives African American men and women of child-bearing age as it relates to sickle cell trait and genetic testing. Research indicates that genetic disorders are an aspect of care that is often overlooked by providers treating young adult men and women.

**DESCRIPTION OF THE STUDY**

The goal of Phase II of the study is to identify the characteristics of African American men and women of child-bearing age that participate in sickle cell disease carrier testing and their perspectives on carrier testing. The target population for this study is African American college students, between the ages of 19-30, that participated in carrier testing through the Sickle Cell Disease Foundation of Georgia, Mobile Testing Unit.

**PROCEDURES**

The study is divided into two parts, Phase I and Phase II. Phase II of the study consists of personal interviews to be conducted at the office of the Sickle Cell Disease Foundation of Georgia. Eligible participants will be invited to participate in in-depth interviews. The interviews should take approximately 45-60 minutes to complete. By signing this consent form you are agreeing to be interviewed and recorded by the researcher. Also, this gives the researcher permission to use your words or ideas in the final report. The tapes will be transcribed and you will be given an opportunity to review the transcription of our interview. Transcripts and audio-recordings will be destroyed no sooner than 5 years after the end of the study. This information will be kept in the event that there is an error in the transcript and the original recordings need to be reviewed.

**RISKS AND DISCOMFORTS**

Answering our questions should not cause much risk or discomfort. Some people may feel uneasy about answering some of the questions. You have the right not to answer any questions deemed uncomfortable or inappropriate.

**Participant’s Initials** \_\_\_\_\_

Page 1 of 3

Revision 3/27/2006

UAB – IRB  
Consent Form Approval 03-28-06  
Expiration Date 03-28-07

**BENEFITS**

You may not benefit directly by being apart of the study. However, the information we get from you will help us better to understand the perspectives of young persons participating in sickle cell disease carrier testing.

**ALTERNATIVES**

The alternative is not to participate in the study.

**COSTS**

There will be no costs to you.

**PAYMENT FOR PARTICIPATION**

If you take part in Phase II of the study, you will be given \$25.00 cash for participating in the personal interviews.

**COMPENSATION FOR INJURY**

UAB has made no provision for monetary compensation in the event of injury resulting from the research. In the event of such injury, treatment is provided but is not free.

**LEGAL RIGHTS**

You are not waiving any legal rights by signing this consent form

**WITHDRAWAL WITH PREJUDICE**

You are free to withdraw your consent and get out of the study at any time without prejudice.

**QUESTIONS**

If you have any questions about your rights as a research participant you may call , **Kai Stewart at 678-641-0445 or Dr. Monica Baskin at 205-975-5704.** If you have questions regarding your rights as a research participant, you may call Ms. Sheila Moore, Director of the Office of the UAB Institutional Review Board for Human Use (IRB). Ms. Moore may be reached at (205) 934-3789 or 1-800-822-8816, press the option for operator/attendant and ask for extension 4-3789 between the hours of 8:00 a.m. and 5:00 p.m. CT, Monday through Friday.

Participant's Initials \_\_\_\_\_

Page 2 of 3

**SIGNATURES**

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions. If you agree to participate in this study, you will receive a signed and dated copy of this consent form for your records.

\_\_\_\_\_  
Participant Name

**CONSENT SIGNATURE:**

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Person Conducting Informed  
Consent Discussion

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

APPENDIX G  
TRANSCRIPT FEEDBACK FORM



## TRANSCRIPT FEEDBACK FORM

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

**INSTRUCTIONS:** Please read and review your transcripts. Below are the questions asked during the interview. If you feel your answers were interpreted correctly please “ X” the box indicating yes or no. If your thoughts were not interpreted correctly and you wish to clarify, please use the space below to express your thoughts or beliefs.

### 1. SHARE WITH ME WHAT YOU KNOW ABOUT SCD? WHAT YOU KNOW ABOUT SCT?

YES

NO

EXPLAIN:

### 2. WHY DID YOU DECIDE TO PARTICIPATE IN CARRIER TESTING?

YES

NO

EXPLAIN:

### 3. WHAT WAS THE CARRIER TESTING PROCESS LIKE FOR YOU?

YES

NO

EXPLAIN:

**5. WHAT DOES TESTING POSITIVE FOR SCT MEAN TO YOU?**

YES

NO

EXPLAIN:

**6. WHAT DOES TESTING NEGATIVE FOR SCT MEAN TO YOU?**

YES

NO

EXPLAIN:

**7. WHAT IS GENETIC TESTING?**

YES

NO

EXPLAIN:

**8. TELL ME WHEN YOU THINK ABOUT GENETIC TESTING AND AFRICAN AMERICANS  
WHAT COMES TO MIND?**

YES

NO

EXPLAIN:

**9. YOU ARE A GENETIC COUNSELOR AND AN 18-YEAR OLD WOMAN HAS JUST  
TESTED POSITIVE FOR SCT, WHAT TO YOU SAY TO HER?**

YES

NO

EXPLAIN:

**10. AFTER PARTICIPATING IN SCD CARRIER TESTING DO YOU THINK ANY DIFFERENTLY ABOUT GENETIC TESTING IN GENERAL EITHER FOR YOURSELF OR YOUR PARTNER?**

YES

NO

EXPLAIN:

**11. AFTER PARTICIPATING IN SCD CARRIER TESTING DO YOU THINK ANY DIFFERENTLY ABOUT GENETIC TESTING IN GENERAL EITHER FOR YOURSELF OR YOUR PARTNER?**

YES

NO

EXPLAIN:

**12. WHAT IS THE VALUE OF SCD CARRIER TESTING?**

YES

NO

EXPLAIN:

**13. WHAT ARE YOUR THOUGHTS ABOUT COUPLES WITH SCD HAVING CHILDREN? WHAT ARE YOUR THOUGHTS ABOUT CARRIER COUPLES HAVING CHILDREN?**

YES

NO

EXPLAIN:

**14. WHAT ARE YOUR THOUGHTS ABOUT HAVING A CHILD WITH SCD? WHAT ARE YOUR THOUGHTS ABOUT HAVING A CHILD WITH SCT?**

YES

NO

EXPLAIN: