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Awareness and Attitudes of Young Nigerian Immigrants in the United States to Sickle Cell Screening and Premarital Genetic Testing

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Abstract

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by

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MS, Johns Hopkins University, 2001

MSc, University of Ibadan, 1987

BSc, University of Ibadan, 1985

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

The carrier frequency for sickle cell anemia among Nigerians, who account for a high percentage of African immigrants in the United States, is high, according to the World Health Organization. Even though sickle cell disease contributes $2.4 billion annually to U.S. health care expenditures, ascertaining the number of affected individuals in the U.S. is difficult because sickle cell is not a reportable genetic disease. However, according to the Census Bureau, the number of African immigrants continues to grow at a steady pace among the foreign-born immigrant population in the U.S. There is a lack of research on the contribution of the immigrant population to the sickle cell incidence and mortality rates in the U.S. The purpose of this study was to examine the level of awareness and attitude of young Nigerian immigrants in the United States to sickle cell screening and premarital genetic testing. The health belief model constituted the study's theoretical foundation. It was assumed that the level of awareness of sickle cell disease and the romantic choices among young Nigerian college and graduate students in the United States would have a direct relationship. A sample of undergraduate and graduate students of Nigerian origin completed an online survey developed for the study. The results from SPSS analyses indicated that even though this population sample has a high knowledge and awareness of sickle cell disease, they are non-committal about adapting and implementing such knowledge when making romantic choices. In order to continue to reduce the burden of sickle cell disease on healthcare delivery in the United States, public health education programs that address the adaptation and implementation of knowledge about sickle cell disease are needed.

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Dedication

This is work is dedicated to God for His amazing love for me, and to my wife Lidia, my son Ayomide and my daughter Ayodeji. I could not have done this without your support.

Acknowledgments

I have been enabled to see beyond the forest by standing on the shoulder of giants. Dr. Paige Wermuth, my dissertation chairperson, has been that giant along my dissertation journey. Her encouragement and guidance propelled me through many challenging stages. Thank you.

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Chapter 1: Introduction to the Study

Sickle cell disease exerts a high economic and psychosocial burden on the individual, the family, caregivers, and public health systems. According to Lanzkron, Carroll, and Haywood (2010), sickle cell disease contributes $2.4 billion annually to U.S. health care expenditures. However, because sickle cell is a non-reportable genetic disease, ascertaining the number of affected individuals in the United States is difficult (Hassell, 2010). Every year there are 3,000 children born with sickle cell disease in the United States, and one in 12 African American children is born with the sickle cell trait (Chakravorty, 2015). In reviewing the literature, I found no data on the number of U.S. immigrants who have sickle cell disease. Immigration from countries with high incidences of sickle cell to the United States will continue to add to the disease burden (Piel et. al. 2014). According to Grieco et al. (2012), a large percentage of immigrants, especially African immigrants, from high sickle cell incidence countries arrived in the United States after 1990. This suggests that the contribution from those carrying the sickle cell gene among these populations to the sickle cell incidence in the United States may increase in the future.

Background

Nigeria, India, and the Democratic Republic of Congo account for 57% of the 305,800 global annual newborns with sickle cell anemia (SCA; Piel et al. 2013). As a result of global migration, SCA has become a disease occuring in human populations in Africa, Asia, Europe, and the Americas (Ware, 2013). In the United States, a large proportion of sickle cell research has focused on clinical diagnosis and management of

sickle cell disease, without giving equal attention to the steady contribution of immigrants to the incidence of sickle cell anemia (Prabhakar, Haywood & Molokie, 2010). Premarital screening and genetic counseling for diseases such as thalassemia, cystic fibrosis, sickle cell, and Tay Sachs is based on the assumption that genetic screening provides useful information about potential offspring between two individuals planning to marry (Verma & Puri, 2015). Furthermore, if both individuals are carriers of the defective gene, they could avoid marrying each other in other to prevent the 25% chance of having a child with a severe genetic disease (Verma & Puri, 2015). If only one or neither of the individuals is a carrier, their marriage will not produce a child affected by the genetic disorder. Kaback (2001) successfully applied this rationale to screening for Tay Sachs disease among over a million married couples in Jewish communities in the United States thereby preventing the births of 90% of potentially affected children.

Problem Statement

Nigerians account for 15% of African immigrants in the United States, and the World Health Organization (WHO) has estimated that the carrier frequency for SCA among Nigerians is about 20% (WHO, 2006). The carrier frequency of SCA indicates that Nigerian immigrants in the United States may be an important population for sickle cell awareness and education programs, especially because these immigrants are mostly of child-bearing age (WHO, 2006) and may start their families in the United States. Even though African immigrants constitute only about 4% of the foreign-born immigrant population in the United States, the number of African immigrants continues to grow at a steady pace (Reed, Andrzejewski, & Strumbos, 2010).

Purpose of the Study

According to the 2010 U.S. Census Bureau, there were 1.6 million African immigrants in the United States in 2012, 35% of whom had arrived in the country in 2000 or later. Every year around the world, 312,000 children with sickle cell disease are born (Chakravorty, 2015). About 3,000 of these births occur in the United States according to Ojodu et. al., (2014), furthermore, one in 12 African American children is born with the sickle cell trait. Piel et al. (2013) predicted a global decrease in SCA mortality by 2050; however, the contribution of U.S. immigrants to this projected decrease is unknown (Lanzkron, Carroll, & Haywood, 2010). The potential contribution of immigrants, especially Nigerian immigrants, to the predicted decrease in sickle cell incidence in the United States could be an important knowledge. Therefore, the purpose of this study was to assess the level of awareness and attitude of young Nigerian immigrants in the United States regarding sickle cell screening and premarital genetic testing.

Research Questions

RQ #1: What is the level of awareness of sickle cell disease among Nigerian college students in the United States?

RQ #2: Does awareness of sickle cell carrier status affect romantic choices among Nigerian college students in the United States?

Theoretical Foundation

The health belief model (HBM) was the theoretical construct for this study. It was developed in the 1950s by a group of U.S. Public Health Service social psychologists to explain why so few people were participating in programs to prevent and detect disease

(Hochbaum et al., 1952). The central principles of HBM are that behavior is mediated by cognitions and knowledge is necessary for, but not sufficient, to produce most behavior changes (Hochbaum et al., 1952). Therefore, perceptions, motivations, skills, and the social environment are key influences on behavior (Glanz & Rimer, 1997). HBM holds that people are ready to act when they believe they are susceptible to a condition that has serious consequences and that taking action would reduce their susceptibility to the condition or its severity (Champion & Skinner, 2008). Another tenet is that people are ready to act when they believe the costs of taking action are outweighed by the benefits and they are exposed to factors that prompt action they are confident they can perform successfully (Champion & Skinner, 2008). Because it is more descriptive than explanatory, Street & Haidet, (2011) suggest that HBM lacks a predictive value for some of its core tenets and may be limited because health beliefs may be greatly influenced by other factors such as cultural factors, socioeconomic status, and previous experiences.

I chose HBM because it enables an understanding of how the attitudes and beliefs of study subjects about a health issue affect their choices of potential future partners. Because health motivation is the central focus of the HBM, it is appropriate for addressing behavioral problems that evoke health concerns (Glanz & Rimer, 1997). Furthermore, it provides an exploration of the theory that individuals at risk for health challenges will consider changing habitual unhealthy behaviors once they understand the severity of the risk and the benefits of making timely behavioral changes. This theoretical model was useful in understanding how an awareness of sickle cell carrier status affects romantic choices among Nigerian college students in the United States.

Nature of the Study

A qualitative method using a non-experimental descriptive design was the primary method of inquiry in this study. This method is appropriate for assessing attitudes, levels of awareness, and individual beliefs (Champion & Skinner, 2008). An online survey was used to gather cross-sectional data from a random stratified sample of college and graduate students of Nigerian origin in the United States who did not have sickle cell disease. I used the HBM to highlight how the attitudes of the study participants are based on knowledge of sickle cell disease and assess the extent to which their behaviors are influenced by perceptions, motivations, and the social environment.

Definitions

Genetic screening: Clinical laboratory analyses to determine the inheritance basis of disease.

Sickle cell: An inherited non-communicable red blood cell abnormality that results in an abnormal change in the structure of the hemoglobin HbA to HbS. while those who inherit the homozygous gene (HbSS) suffer lifelong acute and chronic complications.

Sickle cell disease: The variant gene inherited as an autosomal recessive Mendelian trait in persons who inherit the homozygous hemoglobin gene (HbSS). Such persons are referred to as “sicklers” and generally suffer lifelong acute and chronic complications.

Sickle cell trait: The variant gene inherited as an autosomal recessive Mendelian trait in persons who inherit the heterozygous hemoglobin gene (HbAS). Such persons are referred to as carriers and generally show no symptom of the disease.

Assumptions

I assumed that the participants freely chose to be part of the study without any ulterior motive that may have skewed the findings of the study, and that each participant was truthful about their sickle cell status. I also assumed that the participants in the study would complete the survey truthfully and without any outside influences. Additionally, I presumed that survey instrument would be an appropriate means for assessing the designated variables.

Scope and Delimitations

Rather than being applicable to all U.S. immigrants with sickle cell disease, study findings may only be generalizable to immigrants from Nigeria and others who share similar social, economic, and cultural backgrounds. According to the Institute of Medicine, (2001, p.58), there is a wide diversity among all people in their resilience and coping efforts related to illness and environmental stressors and in overcoming adversity. Participants' responses in this study may have been affected by such stressors thereby altering the findings.

This study was cross-sectional and non-experimental in nature; therefore, causation was not assessed. I revalidated the original survey instrument from Olubiyi et. al. (2013) after it was modified for this study. There was no predetermination of the number of males and females as well as the sickle cell trait status of the survey

participants. This may have led to an imbalance in the influence of either of these variables on the study findings.

Limitations

This was a cross sectional study, therefore, it was not possible to investigate any cause and effect relationships in the study variables. Moreover, it was difficult to ascertain whether the participants were completely truthful in their responses to the survey questions. Also, it is impossible to rule out whether there were any external influences from nonparticipants during the completion of the online survey.

Significance

Out of the nearly 40 million foreign-born persons in the United States reported in the 2008-2012 American Community Survey, 1.6 million are from Africa. Immigrants from Nigeria, the country with the highest sickle cell incidence (WHO, 2006), represent 15% of these African immigrants. Even though African immigrants represent only a small fraction of the total number of U.S. immigrants, their number nearly doubles every decade (U.S. Census Bureau, 2010). According to Piel et al. (2014) "the number of net migrants with the sickle cell gene is increasing faster than the net number of migrants" (p. e84). This increase indicates that sickle cell disease might be an emerging public health problem in the United States.

Furthermore, despite the long history of legislative actions and federal programs designed to increase the knowledge and awareness of sickle cell disease in the United States, the level of awareness and knowledge remains persistently low, especially among minority populations (Long et. al. 2011). The distinction between sickle cell disease and

the trait is unclear to many persons in the general population, which sometimes results in adults incorrectly reporting their sickle cell carrier status (Bean et al., 2014).

The WHO has estimated that the carrier frequency for SCA among Nigerians is about 20% (WHO, 2006) and 15% of African immigrants in the United States are Nigerians.. The carrier frequency of SCA indicates that Nigerian immigrants in the United States are an important population for sickle cell awareness and education programs. Piel et al. (2013) predicted a decrease in sickle cell anemia mortality in the United States by 2050, but the contribution of U.S. immigrants to such decrease is unknown.This knowledge is an important indication of the affect of immigrants, especially Nigerian immigrants, on the predicted decrease in sickle cell incidence in the United States (Piel et al. 2013).

This study is unique because it addressed an important, but little studied area. Knowledge resulting from the study could potentially have a significant effect on the health of some sectors of the U.S. population (Yusuf et al. 2011). The results of this study could inform the public health education strategies targeted to immigrants in the United States, especially those of African origin. An increased awareness of sickle cell disease could affect romantic choices and potentially lead to a decrease in sickle cell incidence among African immigrants in the United States.

Summary

There are public health programs across the United States that address the clinical diagnosis and management of sickle cell disease. However, based on my review of the literature, little is known about the steady contribution of U.S. immigrants to the

incidence of sickle cell disease. Because a large percentage of immigrants from high sickle cell incidence countries arrived in the United States after 1990, the contribution from immigrants carrying the sickle cell gene to the sickle cell incidence in the United States may be yet unseen (Grieco et al., 2012). However, Piel et al. (2013) predicted a decrease in sickle cell anemia mortality in the United States by 2050. This study may provide some evidence concerning the possibility of such a decrease in sickle cell incidence as well as contributing factors for the disease among immigrants especially those from Nigeria.

Chapter 2 provides a review of the current knowledge about sickle cell and the gap that this research study was designed to fill. The chapter will begin with a description of the early history of sickle cell disease in the United States, the burden of the disease, as well as an overview of the contribution of immigrants to the sickle cell incidence in the United States. There will be discussions of the social implications of sickle cell screening and genetic counseling. Chapter 2 will also include a discussion of the current level of sickle cell awareness in the United States especially among minority populations. The chapter will end with a discussion of reproductive health attitudes and behaviors and its implications on sickle cell awareness on romantic choices.

Chapter 2: Literature Review

Introduction

Sickle cell disease is a noncommunicable genetic disease that is caused by an abnormal change in the structure of the hemoglobin HbA to HbS (Ojodu et. al., 2014). The variant gene is inherited as an autosomal recessive Mendelian trait, which means that persons who inherit the heterozygous hemoglobin gene (HbAS) generally show no symptom of the disease while those who inherit the homozygous gene (HbSS) suffer lifelong acute and chronic complications (Lanzkron, Carroll, & Haywood, 2010)). The disease occurs predominantly in people of African, Mediterranean, Middle Eastern, or Indian origin (Ojodu et. al., 2014). Even though much progress has been made in the United States in sickle cell screening and caring for those afflicted by the disease (Hassell, 2010), little is known about the attitude and knowledge of sickle cell screening among U.S. immigrants from these populations.

The HBM (Hochbaum et al., 1952) was the theoretical construct for this study. Use of this psychological model enabled an understanding of how the attitudes and beliefs of the study subjects about a health issue affect their choices of potential future partners. This aligns with the theory that individuals at risk for health challenges will consider changing habitual unhealthy behaviors once they understand the severity of the risk and the benefits of making timely behavioral changes.

The strategies I used in locating articles for the research will be described in order to provide future reference. The remaining contents of this literature review will focus on pivotal research related to sickle cell epidemiology and the potential contribution of U.S.

immigrants to the incidence of sickle cell disease. This content could provide health practitioners with a better understanding of appropriate public health education strategies that may be effective among immigrants in the United States, especially those of African origin. Finally, I will consider how an increased awareness of sickle cell disease could affect romantic choices and potentially lead to a decrease in sickle cell incidence among African immigrants in the United States.

Literature Search Strategy

I conducted the literature research through direct online searches of PubMed, MEDLINE, Science Direct, EMBASE, and other literature databases at Walden University Library. The general search terms *sickle cell*, *awareness*, *attitude*, *immigrants*, *Nigeria*, and *knowledge* were used as the root of all inquiries. A review of articles provided additional literature not located by the general search. Walden University's online library provided many of the needed articles for this review. I found very minimal research literature that directly described the role of U.S. immigrants in the incidence of sickle cell disease. Therefore, the content of this review is limited to sickle cell epidemiology in the United States and projections into future changes in sickle cell incidence in the United States.

Literature Related to Key Variables and/or Concepts

Sickle cell disease exerts a high psychosocial burden on the individual, family members, and caregivers. Even though the level of medical care and survival rates for sickle cell disease patients have greatly increased in the United States, awareness of carrier trait and premarital and genetic counselling are still important strategies in sickle

cell education (Prabhakar et al. 2010). The following literature review provides insight on the epidemiology of sickle cell disease in the United States and projections about future changes in sickle cell incidence in the United States.

The Early History of Sickle Cell Disease in the United States

Early clinical case reports of sickle cell disease by Herrick in 1910, and Pauling's investigations into its molecular basis in 1949, combined with basic and clinical research over the past 100 years, have led to ground-breaking discoveries which yielded great improvements in the care and survival of sickle cell patients (Prabhakar et al. 2010). Even though sickle cell was the first genetic disorder with a known molecular basis, it remained a mostly neglected disease in the U.S., because public health resources were focused on other higher morbidity diseases such as tuberculosis, syphilis, and childhood diseases (Savitt, 1981). Clinical research studies during the 1960s showed that pediatric sickle cell patients were more susceptible to bacterial infections such as streptococcus pneumonia and pneumococcal meningitis resulting in a mortality rate of nearly 37/1,000 in the United States (Ashley-Koch, Yang, Q. & Olney, 2000). Moreover, were wide disparities in sickle cell mortality rates across the United States between 1968 and 1980 primarily due to the availability and access to advanced care sickle cell management centers (Ashley-Koch, Yang, Q. & Olney, 2000).

These reasons, along with other important clinical findings and recommendations, paved the way for the passage of the 1972 Sickle Cell Anemia Control Act which led to the federal allocation of resources in the United States for public health programs focused on sickle cell disease (Davis et. al 1997). As a result of this legislation, in 1972 the

National Institutes of Health organized and funded 10 Comprehensive Sickle Cell Centers across the United States to enhance national awareness and research activities focused on sickle cell anemia (Yusuf et. al, 2011). These activities, laid the foundation for a series of landmark studies that brought improvements in the management of sickle cell disease. These studies included Gaston et. al. (1986) which established penicillin prophylaxis for reducing pneumococcal infection in children younger than 5 years old; the Stroke Prevention Trial in Sickle Cell Anemia (STOP), which demonstrated the benefit of chronic transfusions in stroke reduction (Adams, 2000); and the Multicenter Study of Hydroxyurea in Sickle Cell Anemia study, which demonstrated that hydroxyurea therapy reduces complications of sickle cell disease (Charache, 1990).

After the passage of the Sickle Cell Anemia Control Act in 1972, other federal legislations were passed to benefit sickle cell disease patients in the United States. These include the National Sickle Cell Anemia, Cooley Anemia, Tay Sachs, and Genetic Diseases Act of 1976; the Americans with Disabilities Act of 1990; the Sickle Cell Treatment Act of 2004; and the Genetic Information Nondiscrimination Act of 2008. The benefits of all the legislative attention and public health investments in sickle cell disease began being realized by the mid-1980s when clinical studies demonstrated that the combination of penicillin therapy, parental education, neonatal screening, and hydroxyurea therapy had resulted in improved survival (Ashley-Koch, Yang, Q. & Olney, 2000). According to Davis et al. (1997), mortality rates among young Black children in the United States were reduced from 10.5 deaths per 1,000 person-years during the 1968-1980 period to about 6.8 deaths per 1,000 person-years in 1982. Yanni

et. al. (2009) showed that sickle cell disease mortality rates continued to decrease among children younger than 4 years old, most notably since 2000 when the heptavalent pneumococcal conjugate vaccine became available. However, Lanzkron et. al. (2010) suggested that the U.S. adult mortality rate increased by about 1% from 1979 to 2005. This increase was attributed to adult sickle cell disease patients having less access to comprehensive medical team care compared to people with genetic disorders such as cystic fibrosis and hemophilia (Grosse et. al.2009). According to the National Newborn Screening 10-Year Incidence Report (CDC, 2009), 1.5% of children born in the United States have the sickle cell trait, with varying incidence rates across the country and in every population group. Therefore, as of 2009, the CDC (2011) reported that sickle cell disease affects nearly 100,000 Americans. However, this estimate does not include the contribution of immigrants, especially those from countries with high incidences of sickle cell.

The Burden of Sickle Cell Disease

Genetic diseases have not benefited from the large portions of international resources currently devoted to reducing the worldwide burden of infectious diseases, especially malaria, tuberculosis, and HIV (Ware, 2013). According to Chakravorty (2015), every year around the world 312,000 children with sickle cell disease are born. About 3,000 of these births occur in the United States, and one in 12 African American children is born with the sickle cell trait (Ojodu et. al., 2014). Sickle cell disease exerts a high economic and psychosocial burden on the individual, the family, caregivers and on public health systems. According to the CDC (2009), in the United States nearly $475

million in medical expenditures were spent on about 75,000 hospitalizations for children with sickle cell disease from 1989 to 1993. However, Lanzkron, Carroll, & Haywood (2010) reported that sickle cell disease contributes $2.4 billion annually to the US healthcare costs while Brousseau et. al. (2009) suggested that the sickle cell population in the United States may be larger than 89,000. This is because sickle cell is a non-reportable genetic disease, therefore ascertaining the number of affected individuals in the United States is difficult. Due to the unpredictable episodes of severe recurrent pain and chronic anemia, sickle disease patients, especially school age children and young adults, are often affected by repeated absences from school, increased use of the health care system, reduction in or inability to participate in school and social activities (Jenerette & Brewer 2011). Moreover, others may experience low self-esteem, embarrassment because of small body mass, delayed menarche or may be concerned that their illness is burdensome to their families and siblings (Jenerette & Brewer 2011). Some parents of children with sickle cell disease may become overprotective due to their fear and anxiety about their children being helpless, isolated, having more problems than their peers or even dying (Trzepacz et. al. 2004). Jenerette & Brewer (2011) suggested that these challenges may lead to a health-related stigma which can prevent sickle cell disease patients from seeking care especially as they transition from pediatric to adult care.

Survival rates for sickle cell disease patients have greatly increased in the United States due to the introduction of penicillin prophylaxis, hydroxyurea, transfusion therapy and heptavalent pneumococcal vaccinations (Prabhakar et. al. 2010). Moreover, universal

newborn screening programs have been introduced in the United States thereby ensuring that newborn children with sickle cell disease receive adequate care from birth. Together, these developments have led to a reduction in mortality rates among people living with sickle cell disease in the United States (Piel et. al., 2013). However, recent estimates of sickle cell incidence in the United States are higher than all previous estimates and do not include estimates of whites, Asians and immigrants (Brousseau et. al. 2009). According to Wang et. al. (2013), as of 2008 in the state of New York, the estimated newborn sickle cell incidence among non-Hispanic black mothers was 1in 230 live births, 1in 2,320 births for Hispanic mothers, and 1 in 41,647 births for non-Hispanic white mothers. Moreover, the incidence of sickle cell disease among newborns of foreign born non-Hispanic black mothers was twice as high as in those born to US-born non-Hispanic black mothers.

The Contribution of Immigrants to Sickle Cell Incidence in the United States

Immigration from countries with high incidences of sickle cell to the United States will continue to add to the disease burden (Brousseau et. al. 2009). Out of the nearly 40 million foreign-born persons in the United States reported in the 2008-2012 American Community Survey, 1.6 million are from Africa. Immigrants from Nigeria, the country with the highest sickle cell incidence, represent 14 percent of these African immigrants. Even though African immigrants represent only a small fraction of the total number of United States immigrants, their number nearly doubles every decade (U.S. Census Bureau, 2010). Moreover, about seventy-five percent of these African immigrants arrived in the United States after 1990 (Grieco et. al. 2010) indicating that their

contribution to the sickle cell incidence in the United States from those carrying the sickle cell gene among this population may be yet unseen. The literature is sparse on the number of African immigrants with sickle cell disease arriving in the United States. However, Piel et. al. (2014) have estimated that between 1990 and 2000, the annual number of United States immigrants with sickle cell disease was 26,194. During the same period, about 6409 people with sickle cell disease migrated from Nigeria to the United Kingdom and the United States. Immigrants from Latin America and the Caribbean constitute 53.1 percent of the United States immigrant population (Grieco et. al. 2012). In 2005, out of every 100,000 live births among non-Mexican Hispanic children in the United States, about 90 had sickle cell disease while the rate was about 3 among Mexican immigrant children (Brousseau et. al. 2009). Immigrants from other countries especially India also contribute to the sickle cell incidence in the United States. Such contributions are often in the form of compound sickle cell disease manifestations such as hemoglobin C disease and sickle cell with thalassemia (Yusuf et. al. 2011). However, little is known at the current time about the distribution and prevalence of such compound sickle cell disease manifestations. According to Piel et. al. (2014) "the number of net migrants with the sickle cell gene is increasing faster than the net number of migrants. p. e84". This indicates that sickle cell disease might be an emerging public health problem in the United States.

Sickle Cell Screening, Genetic Counseling, and Social Implications

Genetic screening may be performed for different reasons, and at various stages of life. It is done preoperatively to rule out the risk of some surgical complications, before marriage to inform potential couples about the likelihood of diseases in their offspring, during pregnancy or as part of newborn screening (Siddiqui et. al., 2012). Genetic screening may also be performed among specific groups of people who may be at risk for genetic diseases. Sickle cell disease screening could aid early diagnosis of the disease, as well as enable people to make informed reproductive decisions such as termination of a pregnancy. According to Abioye-Kuteyi et. al. 2009, countries such as Cyprus, Italy, Greece, and Bahrain have seen significant reductions in the prevalence of sickle cell disease as a result of implementation of national programs that combined genetic screening and counseling. In the United States, the early history of screening for sickle cell disease lacked many of the important protective measures of modern public health programs (Berghs, Dyson, & Atkin, 2016).). In response to the National Sickle Cell Control Act of 1972, sickle cell screening was legally required in several states for newborns, preschool children, pregnant women, couples applying for marriage licenses, inmates of state institutions (Farfel & Holtzman, 1984). As a result, many children were screened for sickle cell disease without parental consent and adequate measures to protect confidentiality were lacking. Inadequate public health education about sickle cell disease led to widespread confusion of the carrier status with the disease, as a result of which many African Americans were stigmatized, discriminated against and even suggested to be genetically inferior (Atkin & Ahmad, 1998).

Current public health policies provide better protections for the United States population due to a combination of legislation and reports. The Genetic Information Nondiscrimination Act of 2008 prohibits employment or insurance discrimination based on personal or familial genetic predisposition to a disease or condition. A 1993 National Academy of Sciences report recommended the establishment of ethical guidelines for the use of genetic screening, and in 1995 the Equal Employment Opportunity Commission stated that the use of genetic screening to deny employment could violate the Americans with Disabilities Act.

Currently in the United States, all states including the District of Columbia have mandatory newborn screening (NBS) programs that test all newborns for a panel of disorders including sickle cell disease. According to Gallo et. al. (2010), mandatory newborn screening is done in order to ensure that such babies receive all the appropriate medical care especially immunizations thereby reducing the morbidity and mortality associated with the diseases. However, Ross (2011) maintained that it is popularly held belief that all genetic testing should be performed on a voluntary basis with the informed consent of the person to be tested. Furthermore, "as public health screening merges with clinical practice and medical research in state NBS programs, the practice of seeking parental consent can no longer be viewed as optional" (Ross, 2011, p.320). With the exception of the US National Collegiate Athletic Association (NCAA) which requires mandatory testing of all student athletes competing at a high level, carrier sickle cell testing is no longer mandatory throughout the United States. Zlotogora (2009) proposed another means of identifying sickle cell disease carriers by offering genetic testing to

high school students. However, in many countries including Iran, United Arab Emirates, Jordan, Bahrain, Qatar, the West Bank, the Gaza strip, Tunisia, Turkey and Saudi Arabia, premarital screening for thalassemia and sickle cell is still mandatory.

Sickle Cell Awareness in the United States

Despite the long history of legislative actions and federal programs designed to increase the knowledge and awareness of sickle cell disease in the United States, the level of awareness and knowledge remains persistently low especially among minority populations (Long et. al., 2014). The distinction between sickle cell disease and the trait is unclear to many persons in the general population sometimes resulting in adults incorrectly reporting their sickle cell carrier status (Bean et. al., 2014). According to Long et. al. (2011) a large percentage of African Americans were unaware of not only their personal sickle cell trait status but also of their spouses / partners as well as their children. This was consistent with the reported findings of Acharya et. al. (2009), Gustafson et. al. (2007), Kladny et. al. (2005) and Midence et. al. (1994). Despite similar prevalence of sickle cell, the levels of awareness and knowledge about sickle cell among other minority immigrant groups appear similar or sometimes lower than those of African Americans. Among Dominicans of reproductive age in Northern Manhattan, Siddiqui et. al.,(2012) reported a notable reduction in knowledge about sickle cell disease and sickle cell trait among the Dominicans when compared with the African Americans. This could be partly attributed to the belief that sickle cell is a disease that afflicts only persons of African origin. However, Price, Johnson, Lindsay, Dalton, & DeBaun, (2009) have

shown that the levels of knowledge and awareness among minority populations can be increased through community participatory educational programs in collaboration with religious organizations. Family members and friends could be quite influential in engaging conversations that increase awareness and knowledge of about sickle cell disease and sickle cell trait especially among minority populations (Long et. al. 2014).

Awareness and Attitude of African Americans to Sickle Cell Testing and Genetic Counseling

Although many African-Americans have some understanding of the severity of sickle cell disease and recognize the benefit sickle cell testing plays in avoiding the occurrence of the disease in their offspring, their general attitude to sickle cell testing and genetic counseling remain mostly unchanged (Gustafson et. al., 2007). Even though African-Americans are more likely to express a preference for prenatal testing (Singer et. al., 2004), newborn screening and aborting a fetus affected by sickle cell disease than Caucasians, studies among this population continue to show a lower than expected level of adaptation and implementation of knowledge from sickle cell disease education (Long et. al., 2014). This could be because many African Americans believe that their personal chances of producing offspring with sickle cell disease are low (Long et. al., 2014). However, Singer et. al. (2004) stated that African Americans may not participate in genetic testing because of their concerns about misuse of genetic information. Meanwhile, Gustafson et. al. (2007) discovered that some African American women believe that sickle cell testing is painful and getting their partners to participate will be

challenging. For many people, the knowledge of their sickle cell status may not occur until during prenatal screening or newborn screening thereby eliciting varied reactions including feeling overwhelmed, shock, surprise, worry, depression, indifferent, and accepting (Smith & Aguirre 2012).

Awareness and Attitude of African Immigrants to Sickle Cell Testing and Genetic Counseling

The limited information available in the literature suggest that African immigrants in the United States hold a variety of beliefs and views about past experiences that greatly affect their adoption and participation in healthcare practices. According to Jegede (2009), throughout Africa, there are many cultural practices which may encourage community and social cohesion, but predispose individuals and communities to adopting stances that are unfavorable to the adoption of modern medical practices, especially genetic screening. These include rituals, taboos and beliefs such as predestination, son preference, polygyny, female spouse sharing, patriarchy and widowhood practices (Jegede, 2009). However, Buseh et. al. (2012) suggested that in recent times, the need to authenticate identity for inheritance sharing and the insistence of many families on proof of a negative HIV test before approving a marriage plan may be increasing the acceptance of genetic testing in Africa. In the United States, African immigrants could be hesitant to participate in genetic testing for a variety of reasons including the fear of employment and health insurance discrimination as well as racial profiling (Buseh et. al., 2012). Furthermore, many African immigrants who filed petitions for their relatives with

the United States Center for Immigration Services are required to undergo DNA testing to ascertain their biological relationship (Weiss, 2011). A lack of knowledge about how the government secures the confidentiality and privacy of these genetic information may contribute to the fears and hesitancy of African immigrants to engage in genetic testing.

Sickle cell Awareness and Romantic Choices

There is a large body of evidence in the literature documenting the complexity of reproductive health attitudes, behaviors and decisions among adolescents and adults (Ahluwalia, Johnson, Rogers, & Melvin, 1999; Joyce, Kaestner, & Korenman, 2002). However, even though there are 100,000 Americans with sickle cell disease and more than 3 million Americans of African descent with sickle cell trait, Modell & Darlison, (2008) and Yusuf et. al., (2011) have shown that there is a limited amount of research findings available about the reproductive health knowledge and decisions of Americans with sickle cell disease or sickle cell trait. The implementation rate of knowledge about the genetic inheritance of sickle cell disease or sickle cell trait among at-risk population has been low despite a long history of scientific discoveries about how to limit the spread of the disease. Wilkie et. al. (2013) showed that among people with sickle cell disease or sickle cell trait, making informed reproductive health decisions may be challenging due to their lack of accurate information about the genetic inheritance of sickle cell disease.

The lack of accurate information is fraught with other complications such as a widespread belief that sickle cell disease is limited to African Americans, denial of having sickle cell trait by many people especially men, and the tendency to value a

potentially stable long-term relationship over the risk of having children with sickle cell disease (Gallo et. al., 2010). As a result, pregnancies may occur without adequate preparation and planning. Gustafson (2006) observed that there is a favorable reception of genetic testing for sickle cell trait status when sickle cell disease education is conducted in a prenatal environment. However, Treadwell et. al. (2006) found that people are enabled to make informed reproductive decisions when public health education is provided beginning with grade school through college. The next chapter will provide information on how this study will be performed, how the participants will be identified, the questions that will be asked, and how the information will be organized and analyzed.

Chapter 3: Research Method

Introduction

Sickle cell disease exerts a high psychosocial burden on the individual, family members, and caregivers. Even though the level of medical care and survival rates for sickle cell disease patients have greatly increased in the United States, awareness of carrier trait and premarital and genetic counseling are still important strategies in sickle cell education (Prabhakar et. al. 2010). Based on my review of the literature, there is limited information on the attitude and disposition of young Nigerian immigrants in the United States to sickle cell screening and premarital genic testing. Piel et. al. (2013) predicted a decrease in sickle cell anemia mortality in the United States by 2050, but the contribution of U.S. immigrants to such decrease is unknown.This knowledge is an important indication of the contribution of immigrants, especially Nigerian immigrants, on the predicted decrease in sickle cell incidence in the United States (Piel et. al. 2013). Therefore, the purpose of this study was to assess the level of awareness and attitude of young Nigerian immigrants in the United States to sickle cell screening and premarital genetic testing.

Research Design and Rationale

A qualitative research design was the primary method of inquiry in this study. This method is appropriate for assessing attitudes, levels of awareness, and individual beliefs (Champion & Skinner, 2008). I used the HBM (Hochbaum, Rosenstock, & Kegels, 2016) to highlight how the attitudes of study participants to genetic screening were based on knowledge of sickle cell disease and assess the extent to which their

behaviors were influenced by perceptions, motivations, and the social environment. Using this theory will enable an exploration of how individuals at risk for health challenges consider changing habitual unhealthy behaviors once they understand the severity of the risk and the benefits of making timely behavioral changes. The research questions for this study were the following:

RQ1. What is the level of awareness of sickle cell disease among Nigerian college students in the United States?

RQ2. Does an awareness of sickle cell carrier status affect romantic choices among Nigerian college students in the United States?

Following are definitions of the core concepts of this study:

Genetic screening: Clinical laboratory analyses to determine the inheritance basis of disease.

Sickle cell: An inherited non-communicable red blood cell abnormality that results in an abnormal change in the structure of the hemoglobin HbA to HbS. while those who inherit the homozygous gene (HbSS) suffer lifelong acute and chronic complications.

Sickle cell disease: The variant gene inherited as an autosomal recessive Mendelian trait in persons who inherit the homozygous hemoglobin gene (HbSS). Such persons are referred to as “sicklers” and generally suffer lifelong acute and chronic complications.

Sickle cell trait: The variant gene inherited as an autosomal recessive Mendelian trait in persons who inherit the heterozygous hemoglobin gene (HbAS). Such persons are referred to as carriers and generally show no symptom of the disease.

In this study, I assessed the level of awareness and attitude of young Nigerian immigrants in the United States regarding sickle cell screening and premarital genetic testing. This important, but little studied area, that could potentially exert an effect on the health of a portion of the U.S. population (Yusuf et. al. 2011). Result of this study could inform public health education strategies among immigrants in the United States, especially those of African origin. Health communication messages that are appropriate for target populations can be an effective means of lessening the population effect of a disease (Gallo, Knafl, & Angst, 2009). Because Nigerians make up 15% of African immigrants in the United States (Grieco et. al., 2012) and because 20% of them carry the sickle cell trait (Nnodu, 2014), sickle cell awareness and education programs are needed for this population (Piel et. al. 2013). An increased awareness of sickle cell disease could affect romantic choices and potentially lead to a decrease in sickle cell incidence among African immigrants in the United States.

Role of the Researcher

I met in person with the participants in the two focus groups. Other than these meetings, there was no in-person contact between the participants in the online survey and myself. Study participants who had questions about the study were able to contact me either by telephone or electronic mail. I was responsible for the study design, the design of the survey, the execution of the study, the collection, analyses and interpretation of the

study data. I had neither a personal nor a professional relationship with any of the participants, especially as a supervisor or an instructor.

For the survey phase of the study, questions were administered online using *SurveyMonkey* at www.surveymonkey.com to gather cross-sectional data from a sample of the population. Researcher bias was minimized because of the limited interaction between the participants and me as participants were recruited and surveyed online. The questions were designed so that responses to important study questionnaires could not be skipped, thereby minimizing bias and variability in the study.

Methodology

Participants Selection Logic

I recruited volunteers for two focus groups that informed the creation of an online survey for other study participants. The Walden IRB approval number for the study was 09-16-16-0046564. Participants were male and female undergraduate or graduate students of Nigerian origin who were sickle cell trait carriers or non-carriers in the United States. Sickle cell disease patients were excluded from the study in order to minimize bias in the study. I focused on sickle cell trait carriers and non-carriers in order to assess the extent to which the awareness of sickle cell disease affects the attitude and romantic choices among this population. All participants had at least one parent who was born in Nigeria. They also needed to have some idea about their sickle cell carrier status. The data collected in this study was based on a self report of the participants' sickle cell status and it was not verified by clinical laboratory analyses. Participants were persons

born in the United States or in Nigeria. The sample size for the online survey was dermined based on Faul et. al. (2007) as 134 for a two tail t-test where

Effect size |r| = 0.3, α err probability = 0.05, Power (1-β err probability) = 0.95, Df = 132, and actual power = 0.950922.

I planned to recruit a total of 150 participants for the study: five to eight for each of the two focus groups and 134 for the online survey. I used one focus group to identify and streamline pertinent questions for the study and the other focus group to ba test or validate the survey questions. Participants were recruited through the use of social media, e-mail and telephone contacts for the online survey. An online survey is economical to administer and it provides a rapid turnaround in data collection (Creswell, 2009). 21 to 39 year old, un-married college and graduate students of Nigerian origin across the United States were contacted through multiple forums including churches, and other groups that cater to young Nigerians in the United States.

All participants in the two focus groups were recruited from the greater Baltimore-Washington metropolitan area and m with me in person in a reserved private room at a public location. Light refreshments and a $10.00 gift card were offered to all focus group members. I provided all participants information about the nature of the study and requested their assistance in recruiting participants for the online study. I also gave a sample of the letter describing the proposed study to all potential volunteers. The letter is shown in Appendix A. According to the United States Embassy, as of 2012, there were 6,568 students from Nigeria studying in the United States.

Instrumentation

The survey questions are a modified version of the tool used by Olubiyi et. al. (2013). The survey instrument was used by the authors in a study of the knowledge and attitude of undergraduate students towards premarital genetic screening at Ekiti State University in Nigeria. These questions were adapted to the study population in order to make them effective, sensitive, relevant, clear and culturally appropriate by the first focus group (Gallo et. al, 2010). The study participants were surveyed online using SurveyMonkey, a web-based survey tool (SurveyMonkey.com) that allows researchers to create surveys which can be administered online. The results of the survey can be downloaded into a spreadsheet or database for statistical analyses. The questions for the survey to address are listed in Appendix B.

Ethical protection of participants

The participants in this study were adults (over the age of 18) who volunteered to participate in the research. There was no known harm associated with participating in this study, and no participant reported any harm or difficulty associated with participating in this study. Each volunteer completed a consent form prior to participating in the study. The study files, audio recordings, and transcripts are stored in a locked fireproof cabinet in my home office. Besides me, access to the transcripts was granted only to those assisting in validating the results. All identifying information was removed from the transcripts prior to data validation.

Procedures

The following were the procedures I used to recruit and inform participants, collect and analyze data, and validate findings.

1. Contacted, via telephone, key opinion leaders of Nigerian student organizations in Maryland, New York City, Atlanta, GA, Houston TX, Chicago, IL, and Loma Linda, CA to provide information about the study.
2. Sent informative e-mail detailing the nature of the study to leaders and requested assistance in recruiting participants.
3. Scheduled meetings with identified leaders to present proposed study and provided a copy of letter describing the study.
4. Recruited participants from around the greater Baltimore-Washington metropolitan region for the first focus group.
5. During the first focus group, I gave each participant a copy of the letter describing the proposed study. Each person that agreed to participate in the study then completed the consent form. The first focus group also identified and streamlined pertinent questions for the study.
6. I made an audio recording of the first focus group and transcribed it verbatim before analysis in order to inform the modification of the survey questions.
7. A second focus group met two weeks after the first focus group to validate the survey questions for issues relating to sensitivity, relevancy, clarity and culturally appropriateness.

8. I made an audio recording of the second focus group and transcribed it verbatim before analysis in order to finalize the survey questions.
9. I used the finalized survey questions to create an online survey at SurveyMonkey.com
10. I sent the web link to the online survey by electronic mail, and Facebook to leaders of Nigerian student organizations in Maryland, New York City, Atlanta, GA, Houston TX, Chicago, IL, and Loma Linda, CA.

Data Collection

I collected data from participants in the two focus groups and from a larger group of participants in an online survey. The first focus group identified issues that are relevant to young Nigerians with sickle cell trait as well as sensitive subjects that needed to be included or excluded from the survey questions. I showed an excerpt from the 2014 Nigerian movie "Dazzling Mirage" (downloaded from http://youtu.be/cmsyH8_QAqs) to the first focus group. The video depicted four main scenes which were used to stimulate responses to social issues that resonate with sickle cell carriers and their family members. The four scenes are summarized as follows:

SCENE 1:

The mother of a young man described his sickler girlfriend as a walking time bomb, who will likely die prematurely and leave her only son to care for motherless

children. The son became angry and announced to his mother that he will marry the young woman over his mother's objection.

SCENE 2:

The young woman angrily confronted her parents to know why they brought her into the world knowing that her life will be filled with pain and illness. While her father was trying to assure her that it was because they loved her, the mother tearfully acknowledged that her pregnancy would have been terminated had it not been for the father's insistence.

SCENE 3:

The young woman was at a job performance review meeting with her boss who told her to seek employment in a less stressful environment because she had taken too much time away from work. The young woman insisted that despite her sickle cell disease, she had proven that she can work effectively by securing and maintaining the contract on which she was working.

SCENE 4:

The young man entered a car with the young woman waiting in the driver's seat. He hesitantly told her that their medical incompatibility is a problem in their relationship. She questioned why he had not brought this up during the last six years of their relationship, and when the delivery date was for his child from another woman. She ordered him to get out of the car and stay out of her life.

Each focus group participant signed the consent form, and provided some demographic data. Information gathered during the first focus group provided insight into the formulation of effective questions to assess the attitude to and awareness of sickle cell disease and premarital genetic screening within this population.

The second focus group validated the survey questions for appropriateness and relevancy to the study population. This served to confirm that the survey questions are understood in the same way to readers and the questions elicited responses that accurately reflect the attitude of the study population.

The online surveys were the same questions that the focus group validated. The layout and print size of the online surveys was based on standardized online survey templates available at SurveyMonkey.com. I restricted access to the online survey electronically to study participants located in the United States in order to minimize bias from persons outside the U.S. The online survey featured a hierarchical design which allowed potential participants to proceed through different sections of the survey. Clicking on the survey link opened the section which provided background information about the study. The next section provided the eligibility criteria for the study followed by a section that requested participant consent. Those who did not consent to take the survey were directed to page that said “Thank you for your time” as they exited. Participants who met the eligibility criteria and consented to take the survey were directed to the online survey. I exported the data from the online surveys in a format compatible with SPSS version 23 for further analyses, and secured access to the original

data on the survey site was by a stringent password. I stored all study files and recordings securely in a locked filing cabinet in my home office.

Data Analysis Plan

I imported the data into SPSS (version 23) in order to obtain a systematic evaluation and interpretation of the survey responses. I analyzed the focus group data in order to reveal the general themes emerging from the groups. This was the first step in understanding how the participants' responses described the awareness of sickle cell disease and the attitude to premarital genetic screening among this study population. The second step was to probe the data for specific relationships that are relevant to the study phenomena. In this case, I intended to extract survey data relationships that describe how the knowledge of sickle cell disease affected the attitudes and awareness of genetic screening as well as romantic choices among young Nigerian immigrants.

Issues of Trustworthiness

Verification of Findings

It is important to verify the findings of the proposed research in order maintain the integrity of qualitative inquiry (Creswell, 2009). The process of verifying the findings included some out of the eight steps Creswell (2009) recommended. The eight steps are "persistent observation, triangulation, peer review, negative case analysis, clarifying researcher bias, member checks, rich thick description, and external audits" (pp. 191-192). Of the eight steps mentioned, I verified the findings of this research using external audit, clarifying researcher bias, and rich, thick description. The external audit was conducted by a person experienced in the process of scientific inquiry but not familiar with the proposed research. This step provided an objective assessment of the research.

The interpretation of the research findings needs to be free from the researcher bias. This ensured that reporting the research findings was free from socioeconomic or cultural influences from my background (Creswell, 2009).

The third form of verification was rich, thick description. Ponterotto (2006) posited that "thick description accurately describes observed social actions and assigns purpose and intentionality to these actions, by way of the researcher's understanding and clear description of the context under which the social actions took place." Creswell (2009, pp. 204) suggested that detailed description "allows the readers to transfer information to other settings and to determine whether the findings can be transferred based on shared characteristics". Therefore, by capturing the thoughts and feelings of

participants as well as the often complex web of relationships among them (Ponterotto, 2006) thick description enables the researcher, the participants as well as the audience that reads research report to grasp the meaning of the findings.

Summary

The contribution of United States immigrants from countries with high incidence of sickle cell disease to the sickle cell incidence in the United States is unknown. Even though Piel et. al. (2013) predicted a decrease in sickle cell anemia mortality in the United States by 2050, the attitude and disposition of young immigrants in the United States to sickle cell screening and premarital genetic testing as well as the romantic choices could be important predictors of the outcome. This research study assessed the level of awareness of sickle cell disease among Nigerian college students in the United States and its effect on their romantic choices. The next chapter will provide the data gathered for the study, show how the data was organized and analyzed. This provides the basis for how the data was interpreted and the conclusions drawn from the research study.

Chapter 4: Results

Introduction

Family members and caregivers of individuals with sickle cell disease experience high psychosocial burdens along with the individual. Even though the level of medical care and survival rates for sickle cell disease patients have greatly increased in the United States, Prabhakar et. al., (2010) stated that the awareness of carrier trait and premarital and genetic counseling are still important strategies in sickle cell education. The WHO has estimated that the carrier frequency for sickle cell anemia among Nigerians is about 20%. Nigerians account for 15% of African immigrants in the United States (Gambino, Trevelyan, & Fitzwater, 2014)). My review of the literature found a gap on the attitude and disposition of young Nigerian immigrants in the United States to sickle cell screening and premarital genetic testing. Piel et. al. (2013) predicted a decrease in sickle cell anemia mortality in the United States by 2050, but there is no information in the literature about the contribution of U.S, immigrants to this projected decrease. This study fills the gap in the knowledge about the contribution of African immigrants especially Nigerians to the predicted decrease in sickle cell mortality in the United States (Piel et. al. 2013).

Therefore, the purpose of this study was to assess the level of awareness and attitude of young Nigerian immigrants in the United States to sickle cell screening and premarital genetic testing. In this chapter, I present data gathered for the study via focus groups and an online survey. I also discuss how these data were organized and analyzed. In the chapter, I will also provide the rationale for how these data were interpreted and consider the conclusions that can be drawn from the research study.

I conducted two focus groups for this research. Focus Group 1 was conducted on November 19, 2016, in Bowie, Maryland. Focus Group 2 was conducted on December 21, 2016, in Fulton, Maryland. Each focus group meeting was held in a private access room in a public building which I had reserved. I made audio recordings of the focus group discussions, and provided light refreshments for all the participants during the meetings. At the conclusion of the meetings, each participant received a $10 gift card.

There were 14 participants in Focus Group 1 consisting of eight men and six women between the ages of 18 and 39 whereas Focus Group 2 consisted of three men and two women between the ages of 18 and 39. I facilitated both groups. Focus Group 1 lasted approximately 30 minutes while Focus Group 2 lasted approximately 20 minutes. Each focus group participant received a copy of the letter describing the study before indicating their agreement to participate in the study by completing the consent form.

The purpose of these focus groups was to gain feedback for the online survey questions. I showed an excerpt from the 2014 Nigerian movie *Dazzling Mirage* (downloaded from http://youtu.be/cmsyH8_QAqs) to focus group participants. The video depicted four main scenes which were used to stimulate responses to social issues that resonate with sickle cell carriers and their family members. A sickler refers to an individual who has sickle cell disease due to an inheritance of the homozygous hemoglobin gene (HbSS; Ojodu et. al., 2014). Such persons generally suffer lifelong acute and chronic health complications. The four scenes are summarized as follows:

Scene 1. After his mother described his sickler girlfriend as a walking time bomb, who will likely die prematurely, an angry young man announced to his mother that he will marry the young woman despite his mother's objection.

Scene 2. A sickler young woman angrily confronted her parents to know why they brought her into the world knowing that her life will be filled with pain and illness. While her father was trying to assure her that it was because they loved her, the mother tearfully acknowledged that her pregnancy would have been terminated had it not been for the father's insistence.

Scene 3. A young woman is shown during her job performance review meeting. Her boss tells her to seek employment in a less stressful environment because she has taken too much time away from work. The young woman insisted that, despite her sickle cell disease, she had proven that she can work effectively by securing and maintaining the contract on which she was working.

Scene 4. The sickler young woman was in the driver's seat of a car as the young man entered. He hesitantly told her that their medical incompatibility is a hindrance to the future of their relationship. She questioned why he had not brought this up during the last 6 years of their relationship. Then, she asked him when the delivery date was for his child from another woman. She ordered him to get out of the car and stay out of her life.

Focus Group Responses

The purpose of showing the movie excerpts was to facilitate discussion of the issues faced by sicklers that are relevant to the study. After viewing the excerpts, a male participant in Focus Group 1 stated that the movie excerpt portrayed situations where

sicklers “are not allowed to work as they’d like to or they are terminated before they’re able to prove themselves in the work.” When asked what issues relevant to romantic relationships were raised in the movie excerpt, another male participant said that sicklers “are seen as a risky romantic match because people do not want to risk not having a future with them.” A female participant was in agreement and said “they’re very prone to be sick and usually have a short life expectancy. Because of that, some people are hesitant to engage them in a romantic relationship.” Speaking about the importance of bringing up the subject of sickle cell in a relationship, a female participant in Focus Group 1 said “I think it’s something people really don’t think to ask, but I feel that if you know that you’re a carrier, then you’ll probably bring it up early in a relationship.” Another female participant responded “yes, you should, but I feel that someone who is not a carrier would not have that on their mind, as opposed to someone who is, and may more likely bring it up so that they don’t run the risk of bringing a child with sickle cell into the world.”

Next, I presented Focus Group 1 with a list of 10 questions designed to assess sickle cell awareness and attitudes towards premarital genetic testing (see appendix XX). These questions were the same ones used in the online survey.The researcher probed the participants to identify potentially sensitive issues and concerns such questions could elicit among online survey participants. The focus groups did not propose any major change to the list of questions. While responding to the question “would any of these questions cause you emotional or psychological distress?”, a male participant in Focus Group 1 responded “It’s okay, family genetics, why won’t you disclose it?” A female

Focus Group 1 participant replied “none of these would bother me”. However, another male responded “for some people who have suffered greatly from some diseases in the past, just the thought of it may be traumatic and may be sensitive to such questions, but I think these are exceptions to the general population.” The members of the focus groups were quite vocal about the importance of awareness and disclosure of sickle cell carrier status between romantic partners. A male Focus Group 1 participant stated “I feel like if you’re a carrier, you cannot assume that the other person will be okay with you being a carrier, you should bring it up early in a relationship, especially when things start getting serious.” A female in the same focus group stated, “If you’re a carrier, you have the responsibility to bring it up early in a relationship, I don’t want to waste months into the relationship, then I have to start all over again with someone else.”

The participants in Focus Group 1 however seemed to discount the significance of premarital genetic counseling. A male participant stated “You cannot always choose who you love, right? If the one you love is a carrier, and there are other options to having a family, you would marry them anyhow.” A female participant responded “After investing a long time in a relationship, basing the future of the relationship on premarital genetic screening could be very tough. Not doing it could prevent a lot of heartache.”

Another female participant responded “I feel like it is important to know, but it should not be a make or break determinant in my relationship or my life because there are other options to having a child such as adoption, foster parenting and surrogate mothers.”

When asked what they would do if premarital genetic testing indicated the likelihood of having a sickler child in a romantic relationship, a female participant in

Focus Group 1 stated "since there are other options to having a family, I think a lot of people will continue their relationship without caring about the results of premarital genetic screening."

Two weeks after the Focus Group 1 meeting, Focus Group 2 met to watch the movie excerpt and discuss the list of questions previously presented to Focus Group 1 for appropriateness and relevancy to the study population. Focus Group 2 participants concurred with Focus Group 1 participants that the list of questions appropriately addressed the issues being assessed without eliciting any negative social or emotional reactions. One of the male participants in Focus Group 2 repeatedly used the phrase "it's a fair question" to indicate that the questions would not generate psychological harm to online survey participants. This served to confirm that the survey questions are understood in the same way by the readers and the questions elicit responses that accurately reflect the attitude of the population being studied.

At the end of each group, participants received a copy of the letter describing the proposed study in order to be able to contact me if needed.

Online Survey

I exported the online survey from *SurveyMonkey* into SPSS version 23 for analyses to reveal themes and categories from these data. A password-protected Excel version of the data was downloaded and saved online as well as on a local computer drive. I used the list of questions presented to the focus groups without modification to

generate the online survey which was distributed through *SurveyMonkey* (www.surveymonkey.com).

Online participants were recruited via email. Clicking on the survey link in the recruitment email took potential participants to the online survey introduction page. Each online survey participant completed the survey once without any interaction or contact with the researcher.

The online data collection was from December 26, 2016 to April 30, 2017 (approximately 4 months) during which the researcher made multiple attempts to recruit survey participants from across the United States. I had hoped to complete the online survey collection in within a shorter time duration. I ended the online survey after 107 participants had completed the survey. The original data collection plan proposed a sample size of 134, however, I stopped the data collection with a sample of 107 due to time constraints and low enrollment uptake.

The distribution of the states of residence of the online survey participants is shown in Table 1. The online survey was completed by 107 participants, of which 64% (69) were women and 36% (38) were men. 10% (11) of the online survey participants were married, one was separated and 88% (95) had never been married. 42% (45) of the online survey participants were born in the United States, 7% (seven) in other countries and 50% (54) were born in Nigeria. 45% (48) of the online survey participants were from the Southern region of the United States, 12% (13) were from the West, 19% from the Mid-West and 22% from the Northeast. Table 1 shows the distribution of the states of residence of the online survey participants.

Table 1

Distribution of the States of Residence of Online Survey Participants

	State of residence	Number of online survey participants
Row 1	Alabama	1
Row 2	California	11
Row 3	District of Columbia	12
Row 4	Florida	2
Row 5	Georgia	2
Row 6	Illinois	4
Row 7	Indiana	6
Row 8	Kentucky	1
Row 9	Maryland	17
Row 10	Massachusetts	1
Row 11	Minnesota	1
Row 12	Missouri	2
Row 13	New Jersey	1
Row 14	New Mexico	1
Row 15	New York	22
Row 16	North Carolina	2
Row 17	Ohio	7
Row 18	Texas	9
Row 19	Virginia	2
Row 20	Washington	1

80% of the online survey participants were between the ages of 18 and 29. The proposed age range for this study was 18 to 39 years, however, there were eight online survey participants whose ages were outside of this range. Two participants (1.9 percent) were 17 or younger, and six (5.6 percent) participants were 40 or older. The data from these outliers was not removed from the analyses since together, they represent only 7.5 percent of the total data. The age range distribution of the online survey participants is shown in Table 2.

Table 2

Age Range Distribution of the Online Survey Participants

Age	Frequency	Percent	Valid percent	Cumulative percent
Valid	1	.9	.9	.9
17 or younger	2	1.9	1.9	2.8
18-20	25	23.1	23.1	25.9
21-29	59	54.6	54.6	80.6
30-39	15	13.9	13.9	94.4
40-older	6	5.6	5.6	100.0
Total	108	100.0	100.0	

Awareness of Sickle Cell Disease

In order to assess the level of awareness of sickle cell disease among the survey participants, questions were asked about the definition of sickle cell, who is susceptible to it and how it is acquired. Fifty-nine percent of the survey participants correctly identified that sickle cell is a disease that causes the red blood cell to become sickled.

The responses from the online survey participants are summarized in Table 3.

Table 3

Definition of Sickle Cell

		Frequency	Percent	Valid percent	Cumulative percent
Valid		9	8.3	8.3	8.3
	A disease that causes the red blood cell to become sickled	64	59.3	59.3	67.6
	A hereditary blood disorder that causes the affected individual to fall sick often	35	32.4	32.4	100.0
	Total	108	100.0	100.0	

57% of the survey participants correctly identified that sickle cell disease is not limited to only African Americans but everyone in the United States can be affected. Table 4 shows the summary of the responses from the online survey.

Table 4

People Affected by Sickle Cell Disease in the United States

		Frequency	Percent	Valid percent	Cumulative percent
Valid		9	8.3	8.3	8.3
	Blacks or African-Americans	36	33.3	33.3	41.7
	Everyone	62	57.4	57.4	99.1
	I don't know	1	.9	.9	100.0
	Total	108	100.0	100.0	

About ninety one percent of the survey participants correctly identified how sickle cell disease is acquired. A summary of their responses is shown in Table 5.

Table 5

How Sickle Cell Disease is Acquired

	Frequency	Percent	Valid percent	Cumulative percent
	9	8.3	8.3	8.3
I don't know	1	.9	.9	9.3
It is inherited	98	90.7	90.7	100.0
Total	108	100.0	100.0	

Attitude to and Awareness of Premarital Genetic Screening.

The next set of questions was designed to assess the survey participants' attitude to and awareness of premarital genetic screening. 72% of the participants correctly identified the SS genotype as the genetic cause of sickle cell disease. Table 6 summarizes the participants' understanding of the genetic cause of sickle cell disease.

Table 6

Genetic Cause of Sickle Cell Disease

		Frequency	Percent	Valid percent	Cumulative percent
Valid		9	8.3	8.3	8.3
	AA	1	.9	.9	9.3
	Anyone	1	.9	.9	10.2
	AS	6	5.6	5.6	15.7
	I don't know	13	12.0	12.0	27.8
	SS	78	72.2	72.2	100.0
	Total	108	100.0	100.0	

When asked about their understanding of the purpose of premarital genetic counseling, 79% of the survey participants indicated that premarital genetic counseling is done for intending couples to detect hereditary diseases that could affect their offspring. The responses from the online survey participants are summarized in Table 7.

Table 7

Understanding of the Purpose Premarital Genetic Counseling

		Frequency	Percent	Valid percent	Cumulative percent
Valid		9	8.3	8.3	8.3
	I don't know	4	3.7	3.7	12.0
	It is a means for preventing the transmission of genetically inherited diseases.	8	7.4	7.4	19.4
	It is a means of knowing a person's genotype	2	1.9	1.9	21.3
	It is done for intending couples to detect hereditary diseases that could affect their offspring	85	78.7	78.7	100.0
	Total	108	100.0	100.0	

When asked why they would not undergo premarital genetic screening, 57% of the survey participants responded that they would undergo premarital genetic screening. This is similar to the responses of the focus group participants. The responses from all the online survey participants are summarized in Table 8.

Table 8

Reason for Not Undergoing Premarital Genetic Screening

		Frequency	Percent	Valid percent	Cumulative percent
Valid		9	8.3	8.3	8.3
	Afraid that a positive test will prevent continuation of romantic relationship	19	17.6	17.6	25.9
	Afraid that the test results will not be in favor of my choice	12	11.1	11.1	37.0
	I will undergo premarital genetic screening	61	56.5	56.5	93.5
	Don't want to interfere with God's will	7	6.5	6.5	100.0
	Total	108	100.0	100.0	

When the online survey participants were asked what they would do about their romantic relationship if premarital genetic screening indicated they might have children affected by sickle cell disease, 19% of the survey participants indicated that they would end the relationship. This is in contrast to the almost 54% of participants who indicated that they would continue their relationships for other reasons. Reasons listed for continuing a romantic relationship despite sickle cell issues were "because I believe in God" and emotional reasons.

Table 9 summarizes the online survey participants' responses to the question on what decisions they would make about their romantic relationships if premarital genetic relationship reveals possibility of affected children.

Table 9

Decisions on Romantic Relationships if Premarital Genetic Relationship Reveals Possibility of Affected Children

		Frequency	Percent	Valid percent	Cumulative percent
Valid		9	8.3	8.3	8.3
	Continue relationship due to emotional reasons	11	10.2	10.2	18.5
	Continue relationship due to family pressure	1	.9	.9	19.4
	Continue the relationship because I believe in God	37	34.3	34.3	53.7
	End the relationship	20	18.5	18.5	72.2
	I don't know what to do	30	27.8	27.8	100.0
	Total	108	100.0	100.0	

Evidence of Trustworthiness

I downloaded the online survey data from the *SurveyMonkey* website in Excel format and then imported it directly into the SPSS software without any modification to the data. There were no coded data units employed before the data analyses.

Four major themes emerged from the analyses: *Awareness, Genetics, Premarital Genetic Screening, and Future of Romantic Relationships*. The first theme *Awareness*

indicated that majority of the online survey participants were aware of both sickle cell disease and who could be affected. The second theme *Genetics* indicated that these participants were knowledgeable about the genetic cause of sickle cell disease as well as its inheritance basis. The third theme *Premarital Genetic Screening* indicated that a large percentage of the survey participants understood the purpose of premarital genetic screening and would choose to undergo the screening. The fourth theme, *Future of Romantic Relationship* suggested however that less than 20% of the survey participants would end a romantic relationship if pre-marital genetic screening indicates the likelihood of producing an offspring affected by sickle cell disease. Many of the participants in Focus Group 1 stated that since other options exist for having a family, the future of their romantic relationships would not be dependent on the outcome of pre-marital genetic screening.

I had proposed (chapter 3) that the findings of this research will be verified by using external audit and clarifying researcher bias. In order to provide an objective assessment of the research, the external audit was conducted by a person experienced in the process of scientific inquiry but not familiar with the proposed research or the researcher. Furthermore, in order to ensure that the interpretation of the research findings was free from researcher bias, Creswell, (2009), stated that reporting the research findings needs to be free from socioeconomic or cultural influences from the researcher's background.

The questions used in the online survey were modified from Olubiyi et. al. (2013) a study of the knowledge and attitude of undergraduate students towards

premarital genetic screening conducted in Nigeria. Similar questions were used by Al-Farsi et. al. (2014), and Al-Sulaiman, (2008) in studies conducted in Oman and Saudi Arabia respectively. These questions appropriately and sensitively assessed the attitude as well as the level of awareness and knowledge of sickle cell disease and genetic screening in the online survey participants. According to Ulin et. al., (2005), credible information is characterized by open-ended questions, absence of self-contradiction, and the ability to speak about own one's own beliefs, motivations or experiences. The questions in the online survey were worded to mirror these characteristics.

Results

The first research question was to assess the level of awareness of sickle cell disease among Nigerian college students in the United States. These data from the survey show that 59% of the survey participants correctly identified that sickle cell is a disease that causes the red blood cell to become sickled (see Table 3). 57% of the survey participants correctly identified that sickle cell disease is not limited to only African Americans but everyone in the United States can be affected (see Table 4). About 91% of the survey participants correctly identified how sickle cell disease is acquired (see Table 5). These data suggest that this population of young people of Nigerian origin have a high level of awareness about sickle cell disease.

The second research question was to assess the awareness of sickle cell carrier status affect romantic choices among Nigerian college students in the United States. The data showed that 79% of the participants understood that the purpose of premarital genetic counseling is for intending couples to detect hereditary diseases that could affect their offspring (see Table 7). However, even though 57% of the survey participants indicated that they would undergo premarital genetic screening (see Table 8), only 19% of the survey participants indicated that they would end their romantic relationship if premarital genetic screening that they might have children affected by sickle cell disease (see Table 9).

The proposed research hypothesis was that there will be a direct relationship between the level of awareness of sickle cell disease and the romantic choices among young Nigerian college and graduate students. However, the data from the online survey does

suggest that even though there is a high level of awareness about sickle cell disease among this population, less than 20% of them would end a romantic relationship that could produce children affected by sickle cell disease.

The sample size for the online survey was determined according to Faul et.. al. (2007) as 134 for a two tail t-test where

Effect size |r| = 0.3, α err probability = 0.05, Power (1-β err probability) = 0.95,

Df = 132 and actual power = 0.950922. However, the sample size from which the data was collected was less than 134, therefore there is a limit to transferability of the findings of this study. The findings from this study provide a relevant template for further inquiries into the study subject among similar immigrant populations. The research questions informed the formulation of the online survey questions. This study was designed to be readily reproducible by using online survey questions that had been previously used in similar published studies. Slight modifications were made to the online survey questions before further testing them within two focus groups participants. This was to ensure that the online survey questions were appropriately worded and clearly understood by the study population.

Summary

These data from the online survey suggest that even though the level of awareness about sickle cell disease is high among this population sample, there is also a high reluctance to end romantic relationships that could produce children affected by sickle cell disease. Piel et. al. (2013) predicted a decrease in sickle cell anemia mortality in the United States by 2050. However, the contribution from immigrants carrying the sickle cell gene to the sickle cell incidence in the United States may be yet unseen since a large percentage of immigrants from high sickle cell incidence countries arrived in the United States after 1990 (Grieco et. al. 2010).

The next chapter will include a discussion of the social implications of sickle cell screening and genetic counseling especially among immigrant populations. The discussion will also include reproductive health attitudes and behaviors among African immigrants especially those from Nigeria and the implications of sickle cell awareness on romantic choices. Chapter 5 will end with a discussion of implications of these data from the online survey, as well as, the implication of the extension of the results to the possibility of a decrease in sickle cell incidence in the United States.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Every year around the world, 312,000 children with sickle cell disease are born. About 3,000 of these births occur in the United States, and one in 12 African American children is born with the sickle cell trait (Chakravorty, 2015). As a result of public health improvements such as increased prophylactic penicillin, hydroxyurea, and vaccine administration, Piel et. al. (2013), said sickle cell anemia mortality is expected to decrease globally by 2050.

There is no information in the literature about the contribution of U.S. immigrants from countries with high incidence of sickle cell disease to the sickle cell incidence in the United States. However, Nigerians account for 15 % of African immigrants in the United States (Grieco et. al., 2012), and the WHO has estimated that the carrier frequency for sickle cell anemia among Nigerians is about 20% (Modell & Darlison, 2008). Therefore, the attitude and disposition of young immigrants in the United States to sickle cell screening and premarital genetic testing as well as their romantic choices could be important predictors of the incidence of sickle cell anemia. The goal of this research study was to assess the level of awareness and attitude of Nigerian college students in the United States to sickle cell screening and premarital genetic testing.

The findings of this study indicate that among this population of young people of African ancestry, the level of awareness of sickle cell disease is nearly 60%. Ninety percent of the study participants were knowledgeable about how the disease is acquired. Seventy-two percent of the participants knew the genetic cause of sickle cell disease and

79% correctly understood the purpose of premarital genetic screening. These levels of knowledge and awareness are higher than those reported among other populations of African Americans (Long et. al., 2011). However, participants' attitudes toward genetic screening revealed that only 57% of the study population would undergo premarital genetic screening. The reasons given for not being willing to undergo premarital genetic screening include fear that the test result might not be favorable, thereby leading to an end to their romantic relationship (31%) or an unwillingness to interfere with God's will (7%). Fifty-four percent of the study participants reported they would continue their romantic relationship if premarital genetic screening revealed the possibility of affected children, while only 19 % would end their romantic relationship based on genetic testing results.

Interpretation of the Findings

Brousseau et. al., (2009) stated that recent estimates of sickle cell incidence in the United States do not include estimates of Whites, Asians, and immigrants, and are higher than all previous estimates. The findings of the current study are consistent with those of Gustafson et. al. (2007), who found that many African-Americans have some understanding of the severity of sickle cell disease. However, even though many African-Americans recognize the benefit sickle cell testing plays in avoiding the occurrence of the disease in their offspring, their general attitude to sickle cell testing and genetic counseling remain mostly noncommittal. The findings of the present study are also consistent with those of Long et. al. (2011), who found African Americans have a lower than expected level of adaptation and implementation of knowledge from sickle cell

disease education. Long et. al., (2011), suggested that this might be because many African Americans believe that their personal chances of producing offspring with sickle cell disease are low. Gallo et. al., (2010) suggested that another possible complication could be the tendency to value a potentially stable long-term relationship over the risk of having children with sickle cell disease.

According to the HBM, which was chosen as the conceptual framework for this study, individuals at risk for health challenges will consider changing habitual unhealthy behaviors once they understand the severity of the risk and the benefits of making timely behavioral changes (Hochbaum, G., Rosenstock, I., & Kegels, S. (2016). My study findings, however, suggest that among this study group of young college age Nigerian immigrants, there are other factors which may explain the lower than expected level of adaptation and implementation of knowledge about sickle cell disease. According to the Institute of Medicine. (2001), health beliefs may be greatly influenced by other factors such as culture, socioeconomic status, and previous experiences. Findings from my study show that this population of Nigerian immigrants are young, without children, and generally have limited life experiences. This might explain the tendency to value a potentially stable long-term relationship over the risk of having children with sickle cell disease. Additionally, according to Tachere & Umunna (2017), recent advances in therapies for the management of sickle cell could lead to decreases in the global sickle cell mortality rate. Perhaps, an awareness of these advances could lessen the appreciation of the risk and burden of having children with sickle cell disease among this population.

Limitations of the Study

Findings from this study are not generalizable to the population of Nigerian immigrants in the United States. No cause and effect relationships could be assessed from this study because I used a cross sectional study design. Moreover, it was difficult to ascertain whether the participants were completely truthful in their responses to the survey questions. Also, it was impossible to rule out external influences from nonparticipants during the completion of the online survey. Nonetheless, these data consistently support each of the study findings and are similar to other studies conducted on this topic. The participants in this study were young college age Nigerian men and women, a group which represents only 0.7% of the total immigrant population in the United States (Grieco et. al., 2012)). Another study limitation was that, in the original data collection plan, I proposed a sample size of 134. However, I terminated the data collection with a sample of 107 due to time constraints and low enrollment uptake.

Recommendations

This is the first study to my knowledge, to assess the knowledge and awareness of sickle cell disease and premarital genetic screening in this growing immigrant population in the United States. The findings of this study are important because Nigeria is one of three countries that have the highest sickle cell incidence (Piel et. al., 2013). Even though African immigrants represent a small but growing proportion of the U.S. immigrant population, nearly 20% of African immigrants are from Nigeria (Reed, Andrzejewski, & Strumbos, 2010).

The findings from this study provide an important basis for further studies into sickle cell disease incidence, the contribution of immigrants in the United States to, and potential factors that may elicit behavioral change. Studies among larger and more diverse immigrant populations, especially those with high sickle cell incidence, could provide useful information about changes in sickle cell incidence. Researchers of such studies could assess sociocultural factors that enable immigrant populations to adapt and implement knowledge from premarital genetic screening. Such knowledge may inform the creation of effective public health strategies for increasing the level of adaptation and implementation of knowledge about sickle cell disease and premarital genetic screening.

Implications

The findings from this study indicate the need for public health community education strategies that promote knowledge and increased awareness of sickle cell disease and genetic screening. This is important especially among minority and immigrant populations because of their growing share of the U.S population. The findings of this study also highlight at least two areas of potential effects for positive social change among individuals and families, affected by sickle cell disease.

First, a strong desire for having biological children even in the presence of a high risk of having a child with the disease (Gallo et. al. 2010) might indicate a lack of knowledge of the emotional, financial and social burden sickle cell disease exerts on individuals and families. Secondly, the tendency to value a potentially stable long-term relationship over the risk of having children with sickle cell disease underestimates the potential toll sickle cell disease could place on a romantic relationship. This calls for the

adoption of preconception care, a term defined by the WHO (2013) as "a set of interventions and/or programmes that aims to identify and enable informed decision-making to modify biomedical, behavioral, and psychosocial risks to parental health and the health of their future child, through counseling, prevention and management, emphasizing those factors that must be acted on before conception or early in pregnancy to have maximal affect and/or choice."

However, with the recent FDA approval of a drug that reduces the severe complications of the disease, the growing promise of bone marrow transplantation and gene therapy, having a child with sickle cell disease within a stable long-term relationship might be an informed choice after genetic screening. The findings of this study indicate the need for public health education about sickle cell disease and genetic screening. Such public health education initiatives need to be strategically adapted for minority populations and could also be included in school curricular.

Conclusion

The effect of the growth of the immigrant population in the United States on the sickle cell incidence might be seriously underestimated. In order to continue to reduce the burden of sickle cell disease on healthcare delivery in the United States, public health education programs that address the adaptation and implementation of knowledge about sickle cell disease are needed. The successes of the Dor Yeshorim program, a premarital screening program for Tay-Sachs disease among the Jewish community and the Cyprus premarital screening for thalassemia major could be adapted to sickle cell disease in the United States. Premarital screening for Tay-Sachs disease prevented the births of 90

percent of possibly affected children among over a million people who were screened, and an 80 percent reduction in thalassemia major births (Verma & Puri 2015). An effective adaptation of similar public health initiatives might provide the foundation for a sustainable reduction in sickle cell incidence and mortality in the United States.

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Appendix A: Letter to Potential Study Participants

Date:

Dear (Name),

My name is XXXX XXXX and I am a doctoral candidate at Walden University. I am conducting dissertation research to assess the level of awareness and attitude of young Nigerian immigrants in the United States to sickle cell screening and premarital genet.ic testing.There are many studies detailing progression of sickle cell disease in the United States and some have predicted a decrease in sickle cell anemia occurrence in the United States by 2050. What is not known, however, are the contributions of immigrants especially those of Nigerian origin to such decrease. This research will provide insight into the level of awareness of sickle cell disease among young men and women of Nigerian origin in the United States and also assess the extent to which sickle cell awareness affect their romantic choices.

Your participation in this much needed research is important. All that is required is that you take an online survey. The participants of this study need to be college or graduate school students in the United States who have at least one parent of Nigerian origin. The participants are free to choose whether or not to participate and can discontinue participation at any time. Information provided by the participants will be kept strictly confidential.

I would welcome a telephone call from you to discuss any questions you may have concerning this study and your role in identifying research participants. I can be reached at (XXX) XXX-XXXX or emailed at name@waldenu.edu.

Sincerely,

XXX XXXXXX
Doctoral Candidate
Walden University

Appendix B: Focus Group Demographic Sheet.

Date:_____

1. Where were you born?

2. Where were your parents born?

   Father _____

   Mother _____

3. How old are you?
   - 21-25
   - 26-30
   - 31-35
   - 36-40

4. Gender
   - Male
   - Female

5. Marital Status
   - Single
   - Married
   - Separated
   - Divorced

Online Survey Questions

Family History

What is your genotype?

- SS
- AS
- SC
- AA
- I don't know

Which of your immediate relatives have sickle cell disease?

- Sibling
- Parent
- Uncle
- Aunt
- Grandparent
- I don't know

Knowledge of Sickle Cell

Sickle cell is

- A disease that causes the red blood cell to become sickled
- A hereditary blood disorder that causes the affected individual to fall sick often
- A sexually transmitted disease
- I don't know

Who can sickle cell affect in the United States?

- African Americans
- Hispanics
- Caucasians
- Everyone
- I don't know

Genet.ics of Sickle Cell

Which genotype causes sickle cell disease?

- AA
- AS
- SS
- I don't know

How do people get. sickle cell disease?

- Through an infection
- It is inherited
- It is sexually transmitted
- I don't know

Pre-marital genetic counseling

What do you understand by premarital genetic counseling?

- It is a means of knowing a person's genotype
- It is a means of deciding who to marry
- It is done for intending couples to detect hereditary diseases that could affect their offspring
- It is a means for preventing the transmission of genetically inherited diseases.
- I don't know

Why would you undergo premarital genetic screening?

- To prevent transmission of diseases to my offspring
- To ensure that my partner is healthy
- To ensure fitness for marriage
- To prevent transmission of diseases to me
- I will not undergo premarital genetic screening

Why would you NOT undergo premarital genetic screening?

- Afraid that the test results will not be in favor of my choice
- Don't want to interfere with God's will
- Afraid that a positive test will prevent continuation of romantic relationship
- Family will refuse marriage
- I will undergo premarital genetic screening

Relationships & Sickle Cell

What would you do about your relationship if premarital genetic screening reveals that you might have affected children?

- End the relationship
- Continue relationship due to emotional reasons
- Continue relationship due to family pressure
- Continue the relationship because I believe in God
- I don't know what to do