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A Targeted Approach to Increasing the African American Blood Donor Pool

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy at Virginia Commonwealth University

By

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List of Abbreviations

ARC	American Red Cross
ATT	Attitude
CHOP	Children's Hospital of Philadelphia
DHTR	Delayed Hemolytic Transfusion Reaction
FDA	Food and Drug Administration
GED	General Education Diploma
Hem/Onc	Hematology/Oncology
HIV	Human Immunodeficiency Virus
IRB	Institutional Review Board
PBC	Perceived Behavioral Control
SN	Subjective Norm
SPSS	Statistical Package for the Social Sciences
TPB	Theory of Planned Behavior
VA	Virginia
VBS	Virginia Blood Services
VCU	Virginia Commonwealth University

Abstract

A TARGETED APPROACH TO INCREASING THE AFRICAN AMERICAN BLOOD DONOR POOL

By Arnethea L. Sutton

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2017

Advisor: William Korzun, Ph.D., DABCC, MT(ASCP), Associate Professor, Department of Clinical Laboratory Sciences

A continuous need for blood products, specifically for those who require frequent transfusions, such as individuals with sickle cell disease, warrants the need for targeted interventions to increase blood donations from underrepresented populations. One population in particular, African Americans, only account for 1% of blood donors in the United States. Literature indicates numerous reasons why this population is underrepresented amongst donors, including fear, lack of knowledge about the blood donation, and specific to this population, lack of trust in the medical community. This study involves the development, implementation, and assessment of a targeted educational approach, incorporating the Theory of Planned Behavior and various teaching methods, to motivate African Americans non-donors to attempt to donate blood.

Participants attended a 1-hour educational session where they completed two surveys, one before the session and one directly after. A third survey was completed 2 months after the session. Of the 155 individuals enrolled in the study, 142 subjects were included in the data analysis. Sixteen percent of the study participants presented to donate as a result of attending the educational session. This resulted in a statistically significantly higher proportion of African Americans presenting to donate than the current proportion in Virginia. Analysis of results from the first two surveys indicated that subjective norm and attitude were significant predictors of one's intent to donate blood, while perceived behavioral control was not a factor. The educational session increased survey scores related to intent to donate in comparison to scores obtained prior to the session. While this study resulted in a significant proportion of new donors, there is still a need for interventions that will focus specifically on changing attitudes toward blood donation and a need for methods to motivate African Americans to educate individuals in the community on the importance of becoming blood donors.

Chapter 1 – Introduction

Overview

The purpose of this study was to increase the African American blood donor pool. A developed recruitment strategy was geared towards educating African Americans about the importance of blood donations and the donation process, altering negative or impartial attitudes towards blood donations, and ultimately motivating non-donors to become donors. The major constructs of the Theory of Planned Behavior provided the foundation and rationale for the information included in the proposed educational strategy. The outcome of this study will add to the knowledge of the attitudes, barriers, and motivators to donating blood reported by African Americans and will provide further knowledge of and insight to mechanisms that may attract this underrepresented population to the United States' blood donor pool.

Chapter One presents both a needs assessment and the implications of this study for the United States' blood donor pool and for the African American population. This chapter will begin with a synopsis of the current blood donor research and the gaps in the literature. An explanation of the significance of this study will follow the background. Next, an introduction of the theoretical framework and the statement of purpose, including the objectives, research questions, and hypothesis will be presented. This chapter will conclude with a brief explanation of the data sources.

Background

Prior to the 1980s, blood shortages were very uncommon (Niza et al., 2013). The blood supply was properly maintained and blood products were readily available for those needing transfusions. A shift occurred in the late 1970s due to a surge in the detection of infectious diseases such as hepatitis and the human immunodeficiency virus (HIV). The presence of these infectious diseases in the blood supply triggered changes to the blood donor center practices. The federal government, specifically the Food and Drug Administration, imposed regulations and guidelines that prohibited the payment of donors by donor centers (Abolghasemi et al., 2010). Following these regulations, donor centers saw a decrease in the number of eligible donors, which prompted the need for more effective recruitment strategies to increase the number of donors in the United States donor pool.

Traditionally, recruiting involved face-to-face interaction between a donor center representative and potential donors; but different recruitment methods were introduced in the 1990s. Methods included the distribution of informational brochures and flyers, the incentivization of non-monetary gifts to donors, and most recently, the utilization of social media and other forms of electronic media to appeal to both current donors and non-donors (Gimble et al., 1995; Reich et al, 2006; Whitfield, 2013). Although these recruitment strategies have had some successes there continues to be a lack of participation by African Americans in the donor pool.

Historically, African Americans are largely underrepresented in the United States' blood donor pool. Of the total United States population, 4.2% of Caucasians are blood donors compared to only 2.4% of African Americans (James, Demmons, Schreiber, Hillyer, & Shaz, 2011). Overall, African Americans make up less than 1% of the blood donor pool. The most

prevalent reasons for African Americans' disengagement in the blood donation process are fear, lack of knowledge about the blood donation process, mistrust in the healthcare system, and donor deferrals (Shaz et al., 2009).

Donor deferrals are the highest amongst African Americans, and serve as a significant contributor to the lack of African American donors (Shaz, James, Hillyer, K., Schreiber, & Hillyer, C., 2010). A donor deferral can be defined as either a temporary or permanent period of time in which an individual cannot donate blood. Deferrals are determined by one's medical and social histories or current state of health. The most common reason for donor deferrals for all donors is low hemoglobin levels (United States Department of Health and Human Services [HHS], 2012).

Despite the current literature regarding the importance of African American blood and the importance of this population to the donor pool, there are still gaps in the literature when considering interventions that will motivate African Americans to donate. Whitfield (2013) suggests the use of "local recruitment drives, scheduled mobilization of authorities and venues, and face-to-face methods" to attract new donors, while Riech et al. (2006) propose including a sympathetic message when attempted to recruit donors. This study incorporated such methods in the development of a new recruitment strategy.

When embarking on research that includes African Americans, it is vital to recognize and address history's role in the lack of participation by this population. African Americans are typically underrepresented in, and apprehensive of research studies, particularly those of a medical nature. The Tuskegee Syphilis experiment is credited with being the most influential historical event that deters African Americans from participating in medical research. This apprehension may contribute to the drastically low number of African American blood donors.

Significance

Efforts to increase the African American donor pool include paper-based media, websites dedicated to informing African Americans of the importance of donating blood, and the use of religious leaders as motivators. Although the literature regarding this topic is robust regarding attempts to increase African American representation, no interventions have resulted in a sustained increase (Price, Boyd, Watkins, Fleming, & Debaun, 2006). Current recruitment methods attempt to increase general blood donation knowledge. While this is necessary, they lack the cultural sensitivity needed to appeal to African Americans (Price, et al., 2006).

Maintenance of the United States' (U.S.) blood supply is dependent upon blood donations from volunteers. A rise in transfusion associated infectious diseases in the 1970s triggered federal regulations that required blood donation centers to label all voluntary and paid blood units. Eventually, blood donor centers relied solely on voluntary donations. The absence of the monetary incentive for blood donation caused a decrease in donations in the 1990s resulting in a demand for more blood donors (Abolghasemi, Hosseini-Divkalayi, & Seighali, 2010).

Blood shortages are a national problem that typically occur during the summer months and in times of crisis such as natural disasters. Even with the recent development of successful blood management programs, a shortage of blood donors continues to pose a threat to the blood supply. In 2012, the American Red Cross reported one of the most critical shortages in history (2014). Although a difficult task, increasing the blood donor pool is a simple solution that would reduce the number and severity of shortages.

The African American contribution to the blood donor pool is vital for the maintenance of the national blood supply. The national blood supply relies on donations from type O individuals, and African Americans have a higher prevalence of that blood type than other ethnic

groups. Approximately 44% of the U.S. population is type O, hence the high demand for type O blood in the blood inventory of the nation's hospitals (Harmening, D., 2012). According to the American Red Cross (2014), seasonal shortages of types O and B frequently occur due to a high demand for those blood types. African Americans and Hispanics have a higher prevalence of types O and B blood than Caucasians (American Red Cross, 2014).

There is a constant need for African American blood, specifically for individuals living with sickle cell disease. Sickle cell disease is a hereditary anomaly that mostly affects African Americans. The American Red Cross reports that approximately 98% of sickle cell patients are African American (2014). Sickle cell disease is marked by the presence of abnormal hemoglobin, hemoglobin S. In 2009 approximately 72,000 African Americans were living with sickle cell disease and 1 in 396 African American babies were born with the disease (Price, et al., 2009). According to the Centers for Disease Control and Prevention (2011), the number of African Americans living with the disease in the United States has increased to an estimated 100,000.

Sickle cell patients require prophylactic and, at times, acute transfusions to treat symptoms associated with sickle cell disease. A majority of African Americans lack the C, E, and Kell antigens on their red cells. Several studies suggest that transfusing sickle cell patients with phenotypically matched red cells lacking the C, E, and Kell antigens can reduce the rate of alloimmunization by as much as 83% (Price et al., 2009; Vichinsky et al., 2001). Alloimmunization results in complications for patients including, but not limited to hemolytic transfusion reactions and difficulty finding compatible blood units for future transfusions. Some antigens, such as Kell and E, although less frequently found on the red cells of African Americans, do not exhibit significant differences between racial populations.

Conversely, 32% of Caucasians lack the C antigen while 73% of African Americans lack the same antigen (Dean, 2005). Therefore, to ensure that there is an adequate supply of blood for sickle cell patients with specific antigen requirements, it is vital that there is a robust supply of African American blood.

While the need for blood specifically from African Americans is justified, recruitment methods have failed to consistently increase the number of African American blood donors. These efforts generally lacked the information needed to convince African American to donate (Price, Boyd, Watkins, Fleming, & Debaun, 2006). Prior attempts include passive methods such as sending mailers to African Americans educating them on sickle cell disease and blood donations, posting blood donor flyers in neighborhoods inhabited predominantly by African Americans, and more active methods such as holding informational sessions led by church leaders expressing the importance of blood donations. Each of these methods has resulted in small but temporary increases in donations from African Americans.

The low success rates of efforts to motivate African Americans to donate blood suggest there is a need for a tailored approach for this population. Whitfield (2013) asserts the need for more face-to face interventions to attract new donors. Furthermore, Price et al. (2006) suggest including a sympathetic message when looking to motivate non-donors. The recommended methods addressed in the cited literature were incorporated into the approach for this study.

Introduction to Theoretical Framework

The Theory of Planned Behavior (TPB) served as the foundation for the educational strategy. The TPB, derived from the Theory of Reasoned Action, was developed in the 1985 by Icek Ajzen. This theory, widely used and accepted in behavioral sciences, asserts that there are four major constructs or concepts that contribute to a change in behavior – subjective norms,

attitude, intent, and behavioral control (Ajzen, 2011). Specifically, subjective norms, attitude, and behavioral control contribute to one's intent to make a behavior change which ultimately results in an actual change in behavior. Through the TPB Ajzen (2011) also postulates:

People should be able to act on their intentions to the extent that they have the information, intelligence, skills, abilities, and other internal factors required to perform the behavior and to the extent that they can overcome any external obstacles that may interfere with behavioral performance (p. 446).

The TPB is commonly cited in blood donor research. There have been positive outcomes of predicting intent to donate by assessing the TPB's major constructs. Prior studies have shown that 70% of the variance in intent to donate can be attributed to attitudes related to blood donation, the influence of subjective norms, and perceived behavioral control (Robinson, Masser, White, Hyde, & Terry, 2008). The constructs of the TPB guided the information included in the proposed educational strategy. The strategy included previously cited barriers to blood donation, knowledge of the donation process, and specific reasons why African American blood is needed, with the expectation of improving attitudes toward, and increasing intent to donate.

Purpose

The purpose of this study was to develop and implement a culturally sensitive educational strategy using the constructs of the Theory of Planned Behavior as its foundation. The goal of the study was to motivate African Americans in the Richmond and Hampton Roads areas to become blood donors. The goal manifested through four objectives. The objectives of this study were:

Objective 1. To develop a novel educational strategy using the TPB as the framework for motivating African American to donate blood. The Theory of Planned Behavior served as the foundation for this new educational strategy. This strategy addressed previously cited barriers to blood donation, information regarding the blood donation process, and specific reasons why African American blood is needed, with the expectation of improving attitudes toward blood donation and increasing intent to donate. The following research question and hypothesis are associated with this objective:

Question 1: Will the proposed education result in a higher proportion of donors than the current proportion of African American donors in Virginia?

Hypothesis 1: Greater than 9% of the study participants will donate blood following the intervention.

Objective 2. To develop, pilot, and distribute a survey instrument that will assess the constructs of the TPB and their contribution to African Americans' decision to donate blood. The following three research questions and their related hypotheses are associated with this objective:

Question 2: Do attitude, subjective norms, and perceived behavioral control, as indicated by survey responses for questions in those particular categories; predict one's intent to donate blood, as indicated by survey responses to specific questions related to intent?

Hypothesis 2: Survey responses will indicate that attitude and subjective norm will be the best predictors of one's intent to donate blood.

Question 3: Do attitude, subjective norm, perceived behavioral control, and behavioral intent predict an actual change in behavior?

Hypothesis 3: The constructs of the TPB – attitude, subjective norm, perceived behavioral control, and behavioral intent- will significantly predict one’s decision to donate blood.

Question 4: Are there differences between the participants’ intent to donate before and after the proposed educational session?

Hypothesis 4: There are differences in participants’ intent to donate before and after the proposed educational session.

Objective 3. To inspire and equip the study participants with information to motivate other African Americans to join the blood donor pool. The research question and hypothesis associated with this objective are:

Question 5: Will the study participants motivate other African Americans to donate blood?

Hypothesis 5: Study participants will motivate other African Americans to donate blood.

Objective 4. To assess the demographic differences between those participants who motivate other African Americans to donate and those who do not.

Question 6: Will recruitment success rates vary between participants who donate blood and those who do not?

Hypothesis 6: Participants who donate will recruit more individuals to donate than participants who do not donate.

Data Sources

Participants completed three surveys during the study. The first survey was completed prior to listening to the educational session, followed by the second survey immediately after the educational session. The third survey was completed two months after the educational

session. The same questions appeared on each of the three surveys; surveys 2 and 3 also assessed the African Americans' feelings about the educational session. Each of these surveys were piloted prior to distribution to participants in order to assure face validity and construct validity.

Study participants were assessed both qualitatively and quantitatively with the surveys. Several questions asked participants to choose a response using a Likert scale. Participants were also given the opportunity to answer open ended-questions about their intent to donate. They were given a chance to record which components of the educational session motivated them to donate blood or deterred them from donating.

The proposed research plan included collecting blood donation data from the local blood donor centers and via the self-report method. Each blood donor center received a lockbox or envelopes which were used to collect study cards from participants who actually attempted to donate blood. Each card contained the participant's unique study number. African Americans who were motivated to donate blood by a study participant received a "referral card" which they could also place in the lockbox or envelope upon attempting to donate blood.

Chapter Summary

This chapter provided a summary of the history and importance of blood donations in the United States. There has been ongoing research for methods to attract new donors to the donor pool; but there is still a need to motivate underrepresented populations to donate blood. In particular, African Americans are vital to the donor pool as their blood is needed to treat patients with sickle cell disease. Increasing the African American donor pool would also contribute to a reduction in the number of blood shortages that occur in the U.S.

The Theory of Planned Behavior was introduced and served as the foundation for the proposed educational strategy. Next, the purpose of the study was stated, along with the research questions and hypotheses that guided this study. Lastly, the data sources were presented. Each of the data sources provide the evidentiary information needed to test the research hypotheses.

Chapter two will provide a review of the literature relevant to this study. Topics include the history of blood donation in the United States, methods to recruit blood donors, the history of African Americans and medical research and how that relates to blood donation, and the relationship between sickle cell disease and blood transfusions.

Chapter 2 – Literature Review

Overview

Chapter 2 offers a review of the literature on various topics that will justify the proposed research study. The beginning of this chapter presents a brief history of strategies used to motivate and incentivize individuals to become blood donors. Next, this chapter will delve into the immunologic processes that occur when individuals receive blood donations, particularly individuals with sickle cell disease. Chapter two will also include references that support the notion that African Americans are vital for maintenance of the blood donor pool. The next section of the chapter focuses on African Americans and their participation in both research studies and the donor pool. This literature will address reasons why African Americans are historically underrepresented in research and discuss both successful and unsuccessful strategies to encourage African American participation. Chapter two will also lay the foundation for the developed educational session by discussing the current literature regarding previous and current methods of motivating donors, specifically African Americans.

Immunology and Transfusions

Blood donations and transfusions in the United States. The national blood inventory was typically optimal in the United States prior to the 1980s. Blood donor centers were fully equipped and stocked with enough products to meet the demand of hospitals that were the primary users of blood products. Blood shortages were an infrequent occurrence due to the incentives offered by the blood donor centers to motivate donors (Niza et al., 2013). Although

other forms of incentivizing would emerge in the following decades, financial gifts were typically given to donors as a sign of appreciation for the blood donation and even more as a means to motivate donors to continue to donate.

Although the Nation's inventory was sustained by paying donors, the literature refers to the negative impact and ethical implications related to this form of incentivizing. Studies suggest that paying individuals may have exploited those of lower socioeconomic classes (James et al., 2012; Pozo, 1994). An individual's need of money may have provided enough motivation to donate out of necessity rather than for any other reason. African American donors were more likely than their White American counterparts to donate in order to receive an item and/or gift, to be tested for an infectious agent, and to receive a free health screen (James et al., 2012). In the United States African Americans are more likely to belong to the lowest socioeconomic classes than White Americans. Donating blood provided a means for gaining income and receiving healthcare for those who were disadvantaged.

The literature also describes a positive correlation between the payment of donors, specifically those of lower economic classes, and the presence of infectious agents detected in donor units. A study conducted in Lithuania explored the relationship between paying first time blood donors and detecting infectious agents in their donations. The researchers reported a higher incidence in the detection of antibodies for hepatitis C, hepatitis B surface antigens, and syphilis in first time donors who were paid, in comparison to non-paid donors (Kalibatas, 2008). The study suggests a direct correlation between the payment of donors and the presence of infectious disease. Similarly, Van, Siefried, and Schaasberg (2002) reported that paid donors had a higher prevalence of donating blood during the window period of a disease when a virus

may not be detectable upon screening. This type of behavior poses a risk to the blood inventory and ultimately to blood recipients.

Paying donors may have sustained the blood inventory, but it posed other challenges to the blood donor centers and the organizations to which they distributed their blood products. Niza et al. (2013) suggest that paying donors resulted in the perception of a lower quality of blood and proved to be economically inefficient. Blood collection costs include paying phlebotomists, recruiters, and other personnel, and the process of testing and preparing the blood product for transfusion. Any blood that tests positive for an infectious disease is ineligible for transfusion and must be discarded. Consequently, costs associated with those units are not recouped. The Cost of Blood Consensus Conference provided a platform for directors to discuss cost issues and offer insight on how to rectify the issues. Upon their assessment of numerous blood centers around the world it was found that the costs associated with collecting and processing one unit of blood ranged from \$191 to as high as \$510 (“The Cost of Blood”, 2005). A rise in the presence of and the ability to detect infectious diseases, namely hepatitis and the Human Immunodeficiency Virus (HIV), resulted in the introduction of reoccurring blood shortages in the U.S. A recent rise in the detection of Chagas disease, West Nile virus, Dengue, and other blood-borne infectious agents along with deferrals related to donor history also pose challenges to sustaining the U.S. blood inventory (Allain, et al., 2009).

The federal government became interested in blood donor centers following a surge of infectious diseases in the 1980s. The Food and Drug Administration (FDA) imposed federal guidelines and regulations that put stipulations on donor centers that paid donors for blood used for transfusions (Poza, 1994). Any blood used for transfusions that was collected from paid donors had to be marked as such. Source plasma, a plasma product used to manufacture

therapies including albumin, immunoglobulin injections (IVIg), is one exception to this guideline, as it does not require such labeling (“Revisions of labeling,” 2012). Donors may also receive monetary payment for donating source plasma, Following the implementation of the federal guidelines, blood centers and blood recipients reported negative perceptions of blood donated by paid donors (Niza et al., 2013).

The United States Department of Health and Human Services is responsible for publishing the National Blood Collection and Utilization Survey Report every two years since 1998. This survey tallies the number of blood components that are collected and transfused in the United States, and provides statistical data comparing the current report to previous reports. According to the most recent AABB Blood Collection, Utilization, and Patient Blood Management Survey Report, approximately 6.1 million units of whole blood and red blood cells were transfused in 2013 (AABB, 2015). Most of these units were dispensed to treat anemia and hematological/oncological disorders and to replace blood lost during traumas and surgeries. General medicine, at 28.5%, is responsible for transfusing the highest percentage of red blood cell units when compared to other medical areas/specialties (AABB, 2015). Although not defined in the AABB report, general medicine is described in the New England Journal of Medicine as the branch of medicine that is responsible for diagnosing medical and surgical conditions, treatment of a majority of medical conditions (excluding conditions requiring major surgery), obstetrics, pediatrics, and psychiatry (Clark, 1954). Following general medicine, the services that transfused the highest number of units of blood and blood components in 2013 were surgery and the hematology/oncology service.

Hematology/oncology (hem/onc) practices provide services to patients with disorders such as solid organ and blood cancers including leukemias, myelomas, and lymphomas and other

blood disorders including thalassemia and sickle cell disease. Transfusions are often times required for treating these diseases, and to prevent further complications for hem/onc patients. Hem/onc patients are one of the most frequently transfused patient populations in the country (Chou, Liem, & Thompson, 2012). Medical protocols recommend chronically transfusing some patients in the hem/onc population. This suggestion depends on the diagnosis and prognosis of the patient. Chronic transfusions involve transfusing one to many red blood cell and/or component units as frequently as every month to every 4 months (Natakunda, 2012). Chronic transfusions are vital for the treatment of patients with numerous hem/onc conditions but particularly for those with sickle cell disease.

Sickle cell disease. Dr. James B. Herrick first described sickle cell disease in 1910. While treating a 20-year-old African American student who presented with severe anemia, Dr. Herrick noticed “peculiar elongated and sickle-shaped red blood corpuscles” upon microscopy (Herrick, 2001). Sickle cell anemia has a deleterious effect on the health of all who inherit the disease.

Sickle cell disease is a hereditary anomaly that affects approximately 100,000 individuals in the United States (Hassell, 2010). Sickle cell disease, although more common in people of African descent also affects Hispanic Americans, and people of Middle Eastern and Asian descent. The American Red Cross reports that approximately 98% of sickle cell patients are African American (2014). One in 396 African American babies are born with the disease each year (Price, et al., 2009). Sickle cell disease is the most common inherited disease amongst African Americans (Okam, et al., 2014).

There are distinct differences in both the physical structure and the molecular structure of the red blood cells of normal healthy individuals and those with sickle cell disease. Normal

red blood cells assume a biconcave discoid shape, but sickle cells are abnormally shaped.

Normal healthy individuals are born with hemoglobin F, A, and A2, but individuals with sickle cell disease possess hemoglobin A2, F and S. Homozygous expression of hemoglobin S, the abnormal hemoglobin, is indicative of sickle cell anemia and the presence of sickle cells.

Sickling occurs in the presence of hypoxic conditions which triggers the polymerization of the hemoglobin S (Lei and Karniadakis, 2013). Polymerization of hemoglobin in the red cell causes an alteration in the membrane to form the abnormal sickle shape. The presence of these abnormally shaped red cells may cause numerous complications including, but not limited to, tissue hypoxia, multiple organ failure, occluded vessels, and in many cases an early death. The mortality of patients with sickle cell disease is a well-researched subject. In more developed countries like the United States, the median age of individuals with sickle cell disease at death is approximately 45 years (Rice & Teruya, 2014). This figure has improved significantly over the last few decades in the wake of more effective treatments and maintenance protocols as well as the emergence of sickle cell specialty practices staffed by experienced practitioners who are devoted to the care of individuals with sickle cell disease.

Pain crisis is one of the most common and hallmark complications experienced by individuals with sickle cell disease. Individuals with the disease may begin experiencing pain episodes as early as 2 months of age. According to Shapiro et al. (1997), pain is the most common reason for emergency department visits and hospital admissions for patients with sickle cell disease. Sickle cells occlude the vessels of individuals suffering from the disease thus causing sickle cell pain crisis (Rees, Williams, Gladwin, 2010). Initially sickle cell patients complain of localized pain, but if not treated immediately the pain will affect other areas of the body (Jacob et al., 2005). There are two types of pain typically associated with sickle cell

disease – acute and chronic. Acute pain, the most common type experienced by sickle cell patients, generally lasts for hours to weeks in the most extreme cases, while the duration of chronic pain can be three to six months (The Management, 2002). This type of pain is episodic in nature; an individual suffering with sickle cell disease may experience day-to-day pain or may not experience pain for an extended period of time (Smith, et al., 2005). The decreased oxygen carrying capacity of sickle cells prevents oxygen from reaching the tissues and other areas of the body. Jacob et al. (2005) also report that 81% of sickle cell patients involved in their study reported the following symptoms occurred concurrently with pain – nausea, vomiting, fatigue, and dizziness.

Acute chest syndrome, recurrent strokes, splenic sequestration, hemolytic crisis, and multi-organ failure are frequently experienced by sickle cell patients (Noizat-Pirenne, 2012; O’Suoji et al., 2013). Acute chest syndrome can be defined as a “new pulmonary infiltrate and some combination of fever, chest pain, and signs and symptoms of pulmonary disease such as tachypnea, cough, and dyspnea” (Paul, et al., 2011). It is the second leading cause of hospitalization of patients with sickle cell disease and is the most common cause of death in this population (Paul et al., 2011).

Strokes, especially in the pediatric population, are a serious complication of sickle cell disease. Overt strokes are the most common neurological symptoms of sickle cell disease (DeBaun, 2011). An overt stroke can be precipitated when the abnormally shaped red blood cells occlude the vessels that lead to the brain therefore preventing blood from getting to the brain. Clinically, overt strokes are recognized by a deficit in neurologic activity in a focal area that lasts for roughly 24 hours (DeBaun, 2011). A study performed by Miller et al. (2001) demonstrated an increased risk of overt strokes in pediatric sickle cell patients who have

experienced a silent infarct. Patients who experience a silent infarct exhibit no outward signs or symptoms of a stroke. The Transcranial Doppler has become useful method for screening this patient population in order to minimize the risk overt strokes (Josephson, Su, Hillyer, K.L., & Hillyer, C.D., 2007).

Bacterial infection is the most common cause of death in pediatric patients with sickle cell disease (The Management, 2002). This complication rarely affects adults due to immunizations against the bacteria during childhood. *Streptococcus pneumonia* and *Haemophilus influenza* were the most reported pathogens that caused significant morbidity in children with sickle cell disease with the latter no longer causing a significant risk due to the presence of effective vaccines (The Management, 2002). Specifically, prophylactic penicillin has been extremely effective in preventing bacterial infections in children with sickle cell disease (Josephson, Su, Hillyer, K.L., & Hillyer, C.D., 2007).

Although it is still very difficult to treat complications such as acute chest syndrome and strokes, medical interventions including hydroxyurea have been administered to help relieve patients' symptoms. While there is still much to learn about the efficacy and mechanism of action for hydroxyurea in sickle cell disease, it has become increasingly more common as a therapeutic agent. Produced in 1869, hydroxyurea's primary purpose was to serve as a treatment for solid tumors (The Management, 2012). It was not until 1998 that hydroxyurea was recognized as an effective therapy for preventing sickle cell complications (Hydroxyurea for the Treatment, 2008). Although still misunderstood, the efficacy of hydroxyurea in patients with sickle cell disease is attributed to its ability to increase the amount of hemoglobin F, which lowers the concentration of hemoglobin S (Hydroxyurea for the Treatment, 2008). Hydroxyurea has been shown to improve outcomes in some patients with sickle cell disease, but red blood cell

transfusion remains the gold-standard and most common practice for the maintenance of sickle cell patients and reduction of the mortality associated with the disease (La-Salle et al., 2011).

Despite the increased use of hydroxyurea as a therapeutic agent the number of sickle cell disease patients who are transfused has increased. In the PROACTIVE study of 2010, Miller et al. (2013) indicate an increase from 50% in the 1980s to 75.8% in 2010 of the number of enrolled subjects who had a history of transfusions at the start of the study. This study is an example of the increased presence and necessity of transfusions in sickle cell treatment protocols. There are two transfusion regimens related to sickle cell disease maintenance – acute and chronic. Acute transfusions, also referred to as episodic transfusions, are used to treat pain crisis and increase oxygen carrying capacity (Natakunda, 2012). These transfusions typically consist of 1-2 red blood cell units and serve as a means of introducing normal red cells into circulation.

Chronic transfusions involve the infusion of multiple red cell units periodically over time. The type of chronic transfusion that is related to the treatment of sickle cell patients is the exchange transfusion. Exchange transfusion are typically considered to when patients do not respond to acute transfusions, following a stroke, to prevent strokes, and/or to treat recurrent diagnosis of acute chest syndrome (Smith-Whitley and Thompson, 2012). Exchange transfusions temporarily remove as many sickle cells from the circulation as possible and replace them with normal red blood cells (Wahl & Quirolo, 2009). Patients who undergo exchange transfusions receive on average ten mL/kg of packed red cells every 3-4 weeks. The goal of this therapeutic intervention is to decrease hemoglobin S levels to less than 30%, while increasing the amount of hemoglobin A. Attaining the aforementioned goal of less than 30% of sickle cells

contributes to an increased oxygen carrying capacity and promotes adequate blood flow through the vessels (Aliyu, Tumblin, & Kato, 2006).

Chronic transfusions are ultimately a proactive form of treatment or a preventative measure while episodic transfusions are reactive. Complications that warrant the need for chronic transfusions include acute chest syndrome, splenic sequestration and other vaso-occlusive complications (O'Suouji, et al., 2013). A study of Kuwaiti Arab patients with sickle cell disease concluded that 44.2% of patients received transfusions for preoperative reasons, while 40.3% were transfused for hemolytic crisis (Ameen, Al Shemmari, & Al-Bashir, 2009). The remaining patients received transfusions for acute chest syndrome and to prevent recurrent stroke and/or pain crisis (Ameen, Al Shemmari, & Al-Bashir, 2009). There is evidence that chronic transfusions may decrease the risk of strokes. A study conducted by Aliyu, Tumblin, and Kato (2006) suggested that 70% of sickle cell patients who have had one ischemic stroke event will have another within 3 years in the absence of transfusions. Although red cell transfusions are necessary and effective, there are complications associated with receiving such a large number of red cells.

Transfusion related complications. Alloimmunization is one of the most common and well researched complications associated with red blood cell transfusions. Alloimmunization refers to the development of antibodies following exposure to foreign red cell antigens (Schonewille, 2007). Foreign red cell antigens are those that are not naturally occurring on one's own red blood cells. Foreign antigens are introduced to the body during pregnancy, transplants, and transfusions. There are several factors that play a role in the production of antibodies to foreign antigens. Those factors include the dose, route of administration, age of the patient at

their first transfusion, and immunogenicity of the antigen (Schonewille, 2007). Immunogenicity describes an antigens ability to stimulate an immune response in the body.

Antibody production may occur within as little as days, primary response, to months, secondary or anamnestic response, following a blood transfusion. Antibodies to some antigens are more likely to develop following a transfusion, as a result of the increased immunogenicity of those antigens. The most commonly identified red blood cell antibodies include those against the Rh, Kell, and Kidd blood group systems. The ABO and Rh antigens are the most highly immunogenic, while Kell antigens are the third most common cause of transfusion related antibody production (Dean, 2005).

Antibody production has negative implications for those who are chronically transfused. The occurrence of antibodies following a single transfusion is 0.5-1.5%, while the alloimmunization rate is 18-76% in sickle cell patients (O'Suoji et al., 2013; Natakunda, 2012; Yazdanbakhsh, Ware, & Noizat-Pirenne, 2012). Other chronically transfused patients, excluding sickle cell patients, have alloimmunization rates of 5% to 20% (Natakunda, 2012). Sickle cell patients demonstrate an increased propensity to develop red cell antibodies even compared to other patients who are chronically transfused.

As previously mentioned, sickle cell patients who are chronically transfused receive transfusions once every 3-4 weeks. The more red cell units these patients receive, the more likely they are to develop antibodies. The likelihood of receiving red blood cell units possessing antigens unlike those of the recipient increases as the recipient receives more red cell units. One complication associated with antibody development is the difficulty of finding compatible units for these patients.

In order for a unit to be compatible with a patient with blood group antibodies, there must be an absence of the corresponding blood group antigens on the donor cells. As the number of blood group antibodies increases it becomes increasingly more difficult to find red cells that lack every corresponding antigen. The process to find these units can delay transfusions for hours to weeks (Vichinsky, 2001). Delayed transfusions may have a deleterious effect on the condition of the sickle cell patient such as prolonged and intensified pain crisis, life-threatening anemia, and multiple organ failure.

Alloimmunization also causes medical problems for sickle cell patients. The development of antibodies can also trigger a delayed hemolytic transfusion reaction (DHTR). A DHTR is a process by which hemolysis of red blood cells causes severe anemia in sickle cell patients. Patients with DHTR may present with or without an aplastic crisis, hemolysis, and reticulocytopenia (Scheunemann & Ataga, 2009). Approximately 4%-11% of sickle cell patients who receive transfusions develop DHTRs, and they usually occur within 4-10 days following a transfusion (Chou et al., 2013; Noizat-Pirenne, 2012; Scheunemann & Ataga, 2009). Another study assessing delayed hemolytic transfusion reactions suggested that 40% of patients with sickle cell disease who are alloimmunized will experience a DHTR (Knowles, 2001).

Another complication that may develop concurrently with DHTR is hyperhemolysis. Hyperhemolysis occurs when the hemoglobin level decreases following a transfusion, which is the opposite of the desired effect. The complete mechanism is still unknown, but studies suggest the presence of activated macrophages and their ability to lyse red cell as a possible cause (Win, New, Lee, De Le Fuente, 2008; Noizat-Pirenne, 2012). Some patients with sickle cell disease experience the destruction of both their red cells and the donor cells. The hallmark of hyperhemolysis is lower post-transfusion hemoglobin than pre-transfusion hemoglobin (Noizat-

Pirenne, 2012). The incidence of hyperhemolysis in sickle cell patients is approximately 11% (Tajano, Hillery, Gottschall, Baylerian, & Scott, 2003). Unfortunately, recognizing hyperhemolysis is very difficult, as many patients have negative direct antiglobulin tests and antibody screens. Although no definitive intervention to date has remedied these complications, advances in therapeutic transfusions have reduced the incidence. Win et al. (2008) assert that intravenous immunoglobulin (IVIG) and steroids have the mechanism to suppress macrophages and ultimately decrease the amount of hemolysis.

Alloimmunization and antigen matched red blood cells. Approximately 99% of individuals with sickle cell disease are of African descent, but the majority of blood donors in the United States are Caucasian. While the U.S. blood donor pool is comprised of 9.2 million donors, less than 1% of those donors are African American (American Red Cross, 2014). Ethnicity plays an important role in transfusion related alloimmunization because blood group antigen frequencies can be significantly different among different ethnic groups. In a landmark study comparing the difference between alloimmunization rates of individuals with sickle cell anemia and individuals with other forms of anemia, Vichinsky et al. (1990) attributed higher rates of alloimmunization in patients with sickle cell disease to the racial differences between donors and recipients. If a patient belongs to an ethnic group with a low frequency of a specific antigen and receives a transfusion from a donor belonging to an ethnic group with a high frequency of that antigen, the patient is more likely to develop an alloantibody to that antigen than if they received a transfusion from a donor of the same ethnic group with similar antigenic expression.

The Rh antigens are among the most immunogenic of the blood group antigens. The most common Rh phenotype among patients with sickle cell disease is D+C-E-c+e+; this

phenotype occurs in less than 2% of Caucasians (Chou et al., 2013). According to Chou et al. (2013) the C-, E-, K-, Fya-, and Jkb- phenotype occurs in 26% of African Americans and only 2% of Caucasians. Furthermore, several studies suggest that transfusing sickle cell patients with phenotypically matched red cells lacking antigens such as C, E, and Kell can reduce the rate of alloimmunization by as much as 83% (Price et al., 2009; Vichinsky et al., 2001). Although there is no standardized protocol for antigen matching blood for sickle cell patients, Afenyi-Annan and Brecher (2004) found the most common approach involves selective phenotyping for C, E, and Kell.

Transfusion medicine protocols are transitioning to extended phenotyping on patients with sickle cell disease. Extended phenotyping involves determining the antigenic makeup of the red cells of an individual in order to provide the best matched donor blood for transfusion. Providing donor blood with a similar antigenic makeup as the recipient has been shown to decrease the rate of alloimmunization. Vichinsky et al. (2001) demonstrated a 2.5% decrease in the alloimmunization rate among sickle cell patients after being transfused with phenotypically matched blood.

Fully phenotyping donor blood and recipients appears to be a promising route for decreasing alloimmunization, but this protocol creates a high demand for blood from individuals of African descent. Natukunda (2012) and Olujohungbe et al. (2001) demonstrated the importance of blood from individuals of African descent for patients with sickle cell disease. One study compares the rates of alloimmunization between sickle cell disease patients in the United Kingdom where donors are predominately Caucasian, and Jamaica where donors are predominately of African origin. The alloimmunization rate in the United Kingdom was 76% while the Jamaican cohort revealed a 2.6% rate (Olujohungbe et al., 2001). Natakunde (2001)

compares rates in Uganda to the published rates in United States and Europe. The results of this study were very similar to the Olujohungbe et al. study. The alloimmunization rate in Uganda was 6-10% while the published rate in the United States and the United Kingdom was 18%-76% (Natakunda, 2001). In both studies, only the ABO and Rh groups were used for crossmatching; neither country's protocol requires the use of antibody screens or indirect antiglobulin techniques that are used in both the United States and European countries. The differences in these rates may be attributed to the ethnic similarities between the recipients and the donors. Studies such as these prove that even with the emergence of molecular techniques and full phenotyping, prevention of alloimmunization and delayed hemolytic transfusion reactions will always be limited if donations by individuals of African descent do not increase.

Historical Context of African Americans and Research Studies

African Americans are underrepresented in the blood donor pool; and this may have ties to the lack of participation of this population in medical research, in general. The literature suggests that there are multiple factors that contribute to the lack of African American participation in medical research studies. The most frequently cited reasons include the failure of researchers to recruit African Americans, the recruiters' lack of knowledge regarding minority populations, African Americans' misconceptions of research, and more notably, African Americans' feelings of mistrust towards the medical establishment.

The mistrust in the medical establishment may be attributed to heinous experiments involving African Americans that began during the United States' antebellum period. One such experiment was conducted in Georgia by a man named Thomas Hamilton. Mr. Hamilton supposedly sought out to test remedies for heat strokes. Hamilton's procedure involved subjecting slaves to pits held at high temperatures, giving them experimental medication, and

observing the side effects of the medication (Boney via Gamble). The goal of this study involved pinpointing a medicinal intervention that would make it possible for slave owners to force slaves to work longer hours during the hottest days of the year. Another antebellum era experiment involves Dr. J. Martin Simms, who is known as the father of modern gynecology. Between the years of 1845-1849, Dr. Simms used three slave women as subjects to develop a method to repair vaginal fistulas. Thirty operations were performed on these women without the use of anesthesia (Simms via Gamble). Only after the technique was perfected on the slave women did Dr. Simms attempt the procedure on white women volunteers with the use of anesthetics (Simms via Gamble). Although not well known, these incidents may have resonated in the African American community during that period and established feelings of mistrust that permeated through generations. The prior examples are only two situations that describe the mistreatment of African Americans for the sake of science and presumably maybe one of the earliest contributors to the mistrust in the medical establishment experienced by African Americans today.

The most frequently cited event that undoubtedly plays a major role in the lack of trust felt by African Americans is the Study of Untreated Syphilis in the Negro Male, more commonly referred to as the Tuskegee Syphilis Study. Gamble (1997) refers to this study as the “singular reason behind African American distrust in the institutions of medicine and public health.” Conducted from 1932-1972 in Alabama, this study was funded and approved by the United States government, specifically the Public Health Service (Gamble, 1997). The goal of this study was to observe and learn more about the natural progression of syphilis. This goal was achieved by comparing a test group of 399 infected African American males to a control group of 201 uninfected males (Armstrong, Crum, Rieger, Bennett, & Edwards, 1999). The test group

was given misinformation regarding the nature of the study, and was led to believe that they were receiving treatment for their illness. The researchers withheld treatment from that group while observing the effects of syphilis on the subjects' bodies. Observations of the subjects ranged from physical examinations to more invasive procedures such as spinal taps. Even after the discovery of penicillin, an effective treatment for syphilis, became available, study participants were denied access to and information about the new medication. Gamble (1997) asserts that some subjects travelled outside of their small town in Alabama to seek treatment, yet were turned away when medical personnel realized that they were involved in the government study.

The 40-year duration of the study resulted in more than 100 syphilis related deaths (Baker, Brawley, & Marks, 2005). Because the participants were unaware of their diagnosis and the sexually transmissible nature of the disease, syphilis spread throughout the community over the life of the study. An article by journalist Jean Heller prompted the demise of the Tuskegee study (Brawley, 1998). Following the article, the remaining study participants and the estates of those who died received \$16,000 to \$37,500, while any participants and family members who were infected with syphilis received free medical care for life (Brawley, 1998). In 1997, President Bill Clinton issued an apology to all individuals affected by the study (Gamble, 1997). Surprisingly, none of the researchers involved in the study were reprimanded or punished for their egregious actions.

African Americans' Perceptions of Research

The ramifications of the Tuskegee Study, many of which have influenced the lack of participation of African Americans in medical research, are well documented and discussed in the literature. The absence of informed consent and full disclosure are examples of the

negligence and the unethical behavior of the researchers. During this time in history there was no mandate or law requiring researchers to obtain informed consent from participants before embarking on a research study. It was not until 1963 that the Kefauver-Harris amendments were introduced which required informed consent of all research participants (National Institutes of Health, 2014). Subsequently, the National Research Act of 1974 was passed by Congress. This act was responsible for protecting human subjects of federally funded studies by requiring the use of institutional review boards (Gamble, 1997). Unfortunately, the men involved in the Tuskegee Study did not consent to nor were they informed of the nature of the study. Interestingly, the men were not even aware that they were infected with syphilis, but believed that they were suffering from 'bad blood', a common phrase used around the community (Gamble, 1997). Some African Americans today express concerns with the process of informed consent which ultimately deters them from participating in research. Freimuth et al. (2001) conducted a round table discussion with a group of African Americans to gain a better understanding of their perceptions of medical research. The researchers found that their participants had apprehension towards the informed consent process, with some participants expressing their lack of knowledge about the nature of informed consent. Some participants believed informed consents to be legal documents that protected the researchers from liability or documents that waived the rights of the study participant (Freimuth et al., 2001). A more common issue regarding informed consent that was shared by African Americans both in the Freimuth et al. study and others dealt with the language of consenting documents. Participants indicated difficulty in understanding the technical jargon; they believed it was a way to hide the real risks related to the study (Mason, 2005). These concerns may be justifiable to many other African Americans. In order to increase the African American presence in medical research,

consent documents must be readable and easy to comprehend. The study participants must also feel a sense of trust in the researchers, a concept that is most certainly easier to discuss than to achieve.

Some studies suggest that the race of the researcher may play a role in African Americans' perception of trustworthy research. Shavers-Hornaday, Lynch, Burmeister, and Torner (1997) assert that the lack of African American participation in research may involve the small number of minority investigators conducting research studies. A study assessing the indicators of effective recruitment of African American college students showed that younger African Americans are more willing to participate in and trust research studies conducted at a Historically Black College and University (HBCU) or by an African American investigator (Diaz, Mainous, McCall, & Geesey, 2008). Similarly, Armstrong, Crum, Rieger, Bennett, and Edwards (1999) reported that African Americans were significantly more likely than their Caucasian counterparts to participate in a research study if the researcher was African American. Researchers have been aware of the increased amount of trust felt by African Americans of individuals of the same race. This was even evident in the Tuskegee Syphilis Study. The principal investigators, two Caucasian physicians sought the aid of an African American nurse, Eunice Rivers, to help with the study, and more importantly, to recruit and gain the trust of the study participants. In return, it was not uncommon to hear study participants bragging about being a part of 'Nurse River's Study' (Brawley, 1998). Although misused in the Tuskegee study, African American researchers may have the ability to recruit more African Americans to participate in research studies.

Gamble (1997) asserts that the Tuskegee study participants were treated more like animals than as humans. This mistreatment offers another explanation as to why African

Americans refrain from participating in research. Studies suggest that African Americans fear being treated like “guinea pigs” during research studies (Roberson, 1994 & Bonner & Chiles, 1997). This specific fear can be related to the lack of trust that was previously discussed. African Americans are fearful of not receiving full disclosure of what may happen to them. They have expressed concerns with not receiving treatment during a clinical trial solely because of the color of their skin color (Shavers, Lynch, & Burmeister, 2002).

There are economic factors impacting African American’s reluctance to participate in research; and income is reported as a predictor of research participation (Ashing, Rosales, & Fernandez, 2014). According to the United States’ census (2007-2011), African Americans are the second most impoverished race. This could contribute to why African Americans are underrepresented in research studies. Lack of transportation and an inability to afford public transportation options prevent this population from participating in research studies. Distance to and location of the study site are key factors that affect willingness to participate in research studies (Ashing, Rosales, & Fernandez, 2014). According to Mason (2005) transportation, child care, travel expenses, and the amount of travel to the research sites are considerations that are often overlooked by researchers. The placement of research sites must be considered in efforts to improve the participation of African Americans in research studies.

Conspiracy theories amongst the African American population regarding research are typically traced back to the pre-antebellum period, yet continue to have a profound effect on research participation. Conspiracy theories range from the belief that the government placed crack-cocaine in the African American community as a way to dismantle families, to the medical establishment unleashing HIV into the African American community as a form of genocide (Gamble, 1997 & Armstrong et al., 1999). A survey conducted in 1990 found that 35% of 1056

African American church members believed that HIV was a form of genocide (Thomas & Quinn, 1991). Conspiracy theories such as these have perpetuated a feeling of fear in African Americans of both the government and the medical establishment – two key players in the facilitation of research studies in the United States.

The Investigator’s Role in the Underrepresentation of African Americans in Research

Although studies typically focus on the characteristics of research participants and non-participants, that past 20 years has resulted in a plethora of studies examining the roles that researchers play in contributing to the underrepresentation of African Americans in research. Armstrong, Crum, Reiger, Bennett, and Edwards (1999) attribute the disproportionately low representation of African Americans to two reasons – African Americans’ lack of interest in participating in research studies and the researchers’ inability to or apprehension about including the population in research. Historically, minorities have been excluded from certain types of research studies, namely those that require tremendous funding. Freimuth et al. (2001) argue that researchers limit minority recruitment because “utilizing funds on minorities may be wasteful”. Caucasian men were viewed as ideal research participants because of the preconceived notion that they were most generalizable to other populations (Armstrong et al., 1999). A study examining clinical trial participation reported that only one-half of the minority cancer survivors surveyed reported having been asked to participate in an ongoing clinical trial (Roberson, 1994). By excluding minority races, researchers were unknowingly contradicting the purpose of gathering and disseminating information.

Researchers have expressed trepidation over recruiting African Americans for research studies. African Americans tend to have higher attrition rates, and more difficulty maintaining compliance with study protocols (Freimuth et al., 2001; Shavers-Hornday, et al., 1997; Shavers

et al., 1997). Conversely, there are some studies that indicate no significant difference between races in attrition and compliance (Pacy, Dodson, Kubicki, Fletcher, & Taylor, 1993; Garrett, Ashford, & Savage, 1986). Although these issues do not occur in all studies, they are concerning to researchers who need a certain number of participants to obtain good power for a study, or for those who are conducting clinical trials or other forms of research with strict protocols. In such studies, noncompliance issues may be cause for termination of the study.

Under the NIH Revitalization Act of 1993, the NIH and the Alcohol, Drug, and Mental Health Administration require all NIH grant recipients to include minorities in their research protocols. This policy seeks to “ensure more equitable racial representation in medical research (Shavers-Hornday et al., 1997). Durant et al. (2007) conducted a national survey that focused on investigators’ recruitment strategies and feelings regarding recruitment of minorities. Although the NIH suggests, and at times mandates, setting goals for recruitment of minority participants, Durant et al. (2007) found that many of those who completed the surveys neglected to set goals. Additionally, of those who set goals for African American participants, 51% did not meet their goals. Setting goals provides a foundation for proper planning for recruitment of minority participants, and meeting those goals increases the generalizability of studies. Durant et al. (2007) attribute the failure to meet minority recruitment goals to a lack of investigator confidence in explaining clinical trials in culturally appropriate terms, and the minimal number of recruitment sites that are accessible to minorities.

Researchers from outside of the community must invest time and effort to gain the trust of African Americans. The African American community possesses a dynamic unlike that of other communities. The community-at-large has to feel a sense of trust in a person or process in order to participate or buy in to what’s being proposed. The lack of African American

participation in research can be attributed to the researchers' failure to establish working relationships within the African American community prior to commencing a research study (Shaver-Hornday et al., 1997). Fostering the relationships needed to successfully conduct research studies in these communities requires proper planning. Swanson and Ward (1995) assert that researchers underestimate the amount of time it takes to prepare for recruitment of study participants, specifically minority participants. A lack of preparation can result in overlooking methods to recruit African Americans efficiently. Outreach efforts specifically targeting African Americans have been insufficient (Huang & Coker, 2010). African Americans are not approached, or given the opportunity to participate in research as frequently as other races.

Recruitment Recommendations for Investigators

Although there continues to be a need to better understand and develop recruitment and retention methods for African Americans, there are plausible recommendations in the literature. Durant et al. (2007) suggest setting minority recruitment goals. Pre-established goals during the conceptual stage of the study provide researchers an opportunity to plan for the inclusion of African Americans. Diversity in research subjects allows for more generalizable results.

After setting recruitment goals, researchers must gain the trust of African American communities. This can be accomplished by establishing relationships and partnerships with influential individuals such as church leaders, business owners, and community program leaders within the community (Huang & Coker, 2010; Shavers, Lynch, & Burmeister, 2002). These relationships must be established prior to embarking on the research study. Establishing a rapport with leaders in the community provides the researcher with an endorsement to seek participants in the community.

Researchers must refrain from technical jargon and use language that is most familiar to the community in which the study will be conducted. Shavers, Lynch, and Burmeister (2002) suggest being honest and frank by discussing possible threats, risks, and benefits to potential participants. Open dialogue gives investigators an opportunity to explain all pertinent study information and the participants an opportunity to ask questions and gain more insight about the study. Anderson (2000) stresses the importance of improving overall communication between health scientists and the general public. Friemuth et al. (2001) proposes that researchers should assess the literacy levels, attitudes, and beliefs of potential participants prior to developing the study protocol. This tailored approach may appeal to study participants and increase their level of understanding of and participation in the study.

Incentivizing participants is a common method of increasing study participation for all races, but especially for underserved and vulnerable populations. Studies generally promote incentivizing as it appears to be an effective means of attracting, motivating, and retaining participants (Armstrong et al., 1999; Freimuth et al., 2001; Huang & Coker, 2010). Incentives refer to both monetary and non-monetary means of rewarding individuals for their participation in a study. Providing transportation to those who need assistance traveling to the study sites or providing childcare so that parents can participate in studies are two examples of non-monetary incentives (Huang & Coker, 2010). Hurdy, Wynn, Huckaby, Lisovicz, and White-Johnson (2005) also suggest public recognition of those voluntary participants who contributed to the body of knowledge at the conclusion of the study. Friemuth et al. (2001) warns of over-incentivizing, as it may appear to be a means of coercing or exploiting underserved individuals.

Some studies suggest regulatory changes may increase African American participation in research. There are currently mechanisms in place to protect vulnerable populations, but

Rencher and Wolf (2013) suggest amending laws to state that investigators must treat any population that has been historically abused as a vulnerable population. They also question the composition and efficacy of current International Review Boards (IRB). According to a study examining African American researchers it was found that while 50% of IRB members are women only 14% of those women belonged to an ethnic minority group and 75% of the IRBs surveyed had no minority representation (Catania et al, 2008). IRBs and the research studies they approve may benefit from a more representative composition.

Lastly, researchers must assume responsibility for learning about the population they plan to study. Specifically, for underserved populations, researchers may want to gain more understanding about racism, classism, social oppression, and sexual identities (Huang and Coker, 2010). Although differences in opinions regarding these issues exist within a community, researchers will benefit by immersing themselves in the community and getting a better understanding of how the individuals think. Huang and Coker (2010) also suggest that researchers consider the socioeconomic and political status of potential participants. Background information about participants may not only help with designing effective studies. Specifically, in regards to improving the health of specific populations, socioeconomic and sociopolitical factors may contribute to individuals' health behaviors (Beatty, Wheeler, & Gaiter, 2004). Learning more about participants could reveal some similarities between researchers and participants. Having the ability to demonstrate similarities between the investigator and potential participants has been shown to gain the trust of African Americans and motivate them to participate in research studies (Sabir and Pillemer, 2014). Sabir and Pillemer (2014) define this method of gaining trust as experiential similarity. The researcher shared her life story with the study participants and as a result, retention remained high throughout the life of eight-week study

(Sabir and Pillemer, 2014). As discussed earlier, one must proceed with caution regarding this suggestion as the primary investigators of the Tuskegee Study used a similar approach.

Blood Donor Recruitment Interventions

The 1990s saw the decline of available blood products and donors stemming from the newly imposed federal regulations that prohibited paying donors for blood donations used for transfusions due to the rise in the detection of infectious agents in the blood supply (Abolghasemi et al., 2010). The new regulations created a need for better recruitment strategies. Traditional recruitment involved face-to-face interaction, but in the early 1990s new methods were introduced and tested. Gimble et al. (1994) utilized brochures as a source of providing blood donation information to both current donors and non-donors. The brochures appeared to encourage current donors to continue donating, but prospective donors were unconvinced. Gimble et al. (1994) also asserted the possibility of increased donations following special appeals for specific patients or patient populations. Researchers implied a need to consider sympathetic messages when considering interventions to motivate prospective donors to become active donors.

More recently, Reich et al. (2006) performed a randomized control trial assessing the effectiveness of the blood donor recruitment strategies in place at the time. The authors developed four arms that represented those recruitment strategies – incentivizing, recruitment scripts with a patient story, telephone recruitment, and email recruitment. The researchers concluded that strategies that include a sympathetic message pertaining to a patient resulted in more donors than all other methods studied. It appears that people are more inclined to donate when they feel that they are directly impacting a person's life.

As electronic media and technology emerged in the early 2000s, blood donor centers began to utilize those methods to recruit prospective donors and to remind current donors of the importance of repeat donations. Although blood donor centers continue to use social media and other forms of technology to recruit, one recent study has indicated a need to reconsider traditional methods of recruitment. Whitfield (2013) suggests the use of “local recruitment drives, scheduled mobilization of local authorities and venues, and face-to-face methods as the most beneficial for attracting new donors.” In order to be effective, new strategies must include both traditional and current methods for motivating individuals to donate.

African Americans’ Participation in the Blood Donor Pool

Although various methods of recruitment have been attempted and implemented, one fact remains – African Americans continue to be underrepresented in the donor pool. No intervention to date has resulted in a sustained increase in African American donations. The literature is robust with reasons why African Americans are underrepresented in the blood donor pool but lacking in efficacious solutions.

Donor deferrals are a major contributor to the lack of African American donors. Deferrals refer to either a temporary or permanent exclusion from the donor pool. Reasons for deferrals range from low hemoglobin levels, which are prevalent in the African American community, to positive infectious disease testing, or traveling to certain areas of the world. Deferrals can range from months to indefinite exclusion from the donor pool. Deferrals are commonly cited in blood donor research as it has become evident that many shortages and lack of donors can be attributed to the fact that most individuals who are temporarily deferred fail to return to donor centers once the deferral period is over (Custer et al., 2011).

There is limited research on the implications of racial disparities in donor deferrals. This deserves attention when assessing the barriers that exist for African Americans to donate. According to a study by Shaz et al. (2010), of the total deferrals observed in the study, 11.1% were white while 17.9% were African American (Shaz et al., 2010). Although this difference may not appear to be significant, donor deferrals may prove to be a barrier to increasing African American blood donors. Shaz and colleagues (2010) also noted that African Americans between the ages of 16 and 50 were more likely to be deferred due to low hemoglobin than any other reasons. African Americans were also more likely, than other race, to be deferred due to the phlebotomists' inability to find/palpate a vein (Shaz et al., 2010). Research also shows that “[minorities] have been associated with lower return rates for eligible donors who have not been deferred and that deferral is an additional impediment that further reduces the likelihood of repeat donations” (Custer et al., 2011). This information may prove to be vital in establishing repeat African American donors. Creating repeat donors and motivating temporarily deferred individuals to return to donate will ultimately increase the numbers of African American donations.

Fear has been associated with reluctance to becoming a blood donor. Grossman et al. (2005) studied reasons why people of all races refrain from donating blood. One of the top reasons for all races was a fear of needles and a fear of the unknown. Although it is highly unlikely for one to possess the ability to reverse a fear of needles, this study is an indication that there is a need for recruitment strategies that inform non-donors of the importance and the process of blood donations. Educating those who fear the unknown may instill a level of comfort that may ultimately result in blood donations.

A study of African American female college students showed that 82% of donors did not regard donation as being painful as compared to 44% of non-donors (Shaz et al., 2009). This study also indicated that donors more often agreed that the blood supply is safe (77% donor, 58% non-donor), less often concerned about receiving a transfusion (61% donor, 73% non-donor), and more often aware of local blood shortages (50% donor, 35% non-donor) (Shaz et al., 2009). These figures identify an issue of misunderstanding even amongst blood donors. Such misconceptions, personal beliefs and a lack of education about the donation process and the benefits of donation may serve as major hindrances for increasing the number of donors in the African American community.

There is also evidence that suggests that historical events prevent African Americans from donating. Brandon et al. (2005) associate African Americans' mistrust in healthcare to reduced "proclivity to donate organs or biological material" amongst other reasons. For African Americans who lack trust in healthcare and equate blood donation centers as being under the umbrella of health care systems, donating blood could be problematic. Studies have also indicated that mistrust in the healthcare system is a major reason why African Americans also refrain from becoming organ donors (Brown, 2012; Russell, Robinson, Thompson, Perryman, & Arriola, 2012). Given their negative perception of the health care system as a whole, they may refrain from donating blood. Shaz et al. (2009) suggest considering African Americans' lack of trust in healthcare when designing methods for recruiting them to the blood donor pool.

Interventions and Sickle Cell Anemia

African Americans respond positively to information material about sickle cell disease and the importance of having African American blood in the donor pool; however, they do not become repeat donors (Price et al., 2006; Price et al. 2009). Although an increase in donors

resulted from these studies, it is possible that the one-time mailer was insufficient to generate repeat donations. Inclusion of sickle cell material in a face-to-face recruitment may address this issue.

The Children's Hospital of Philadelphia (CHOP) teamed up with the American Red Cross to distribute literature about sickle cell disease in children following the death of one of their patients due to a lack of blood for transfusion. Individuals involved in this study noticed a spike in African American donors following the distribution of the literature. This program, initiated in the 1990s, currently experiences a high turnout of African American donors for their pediatric patients. A formal study was not done and no empirical data was collected, but physicians at CHOP report that they have not experienced significant shortages since they began distributing literature. The lead physician for this effort suggests that their results may be due to the fact that they requested donations specifically for children and people may feel more sympathetic for that population (K. Smith-Whitley, personal communication, May 21, 2013).

Theory of Planned Behavior

The blood donor educational intervention developed for this study incorporates the major constructs of the Theory of Planned Behavior (TPB). While there are numerous behavioral theories cited in blood donor research, the TPB provides key constructs to explain behavioral changes, and has resulted in positive donor outcomes. The TPB was developed from the Theory of Reasoned Action and states that attitude, behavioral control, and subjective norms all contribute to intent to change a behavior, which ultimately results in an actual change in behavior (Ajzen, 1991). According to the TPB, the three constructs are major predictors of behavior changes. Figure 1 illustrates the constructs of the TBP and shows how all three constructs contribute to a behavioral change.

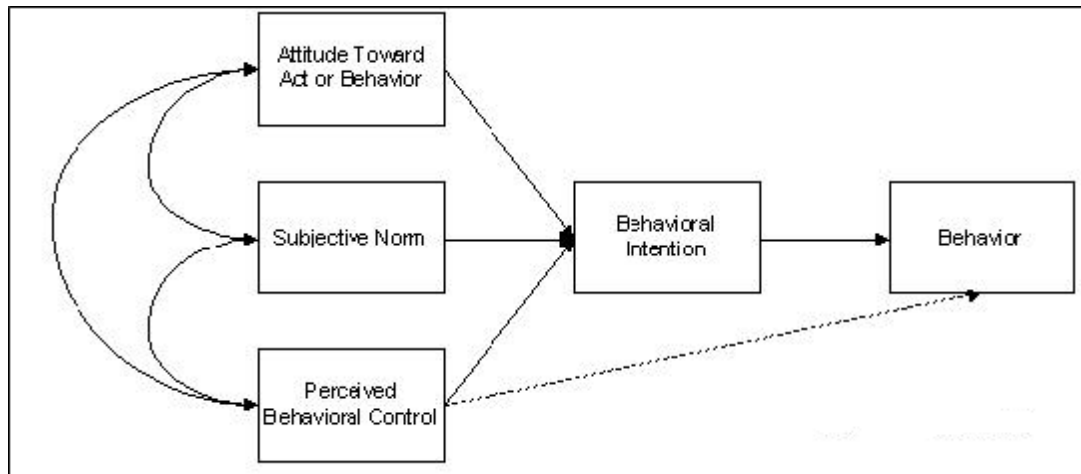


Figure 1: Theory of Planned Behavior Model (Ajzen, 2007)

The TPB posits that human beings take into account available information and couple that with the implication of their actions when considering a behavior change (Ajzen, 2007). The proposed study will provide information regarding blood donation to the study participants with the goal of triggering a behavior change. In order to result in a change, the TPB suggests that each of the three constructs must be addressed.

TPB constructs. The attitude construct is defined differently for the sake of the TPB than in other health behavior theories. Ajzen states that the attitude construct can be defined as a positive or negative feeling about the behavior in question (2007). This study assessed the participants' attitudes about blood donation and the educational session was designed to promote positive attitudes toward blood donation by stressing the importance of African American blood to help others.

A subjective norm refers to social pressures that persuade individuals to engage in or refrain from a behavior (Glanz, Rimer, & Viswanath, 2008). The TPB literature typically suggests the pressure of family, friends, and respected individuals when referring to subjective norms; however, it can also refer to what is deemed as a more acceptable behavior in a particular

group. This educational session addressed the importance of African American blood for sickle cell patients. It was anticipated that study participants would perceive it to be socially acceptable for them to help individuals who may reside in their communities. Including sickle cell patients and current African American blood donors may reinforce the social expectation to donate blood.

Perceived behavioral control describes an individual's "perception of their ability to perform a behavior" (Hamid, Basiruddin, & Hassan, 2013). Study participants received information about convenient locations and times to donate blood. They also learned of the process to make appointments to donate. This portion of the session addressed the last construct of the TPB, perceived behavioral control. Ajzen asserts that people are more willing to change a behavior if they feel that opportunities and resources required to make the change are available (2007).

The TPB literature supports the notion that attitude, subject norms, and behavioral control are significant predictors of the intent to change a behavior and the act of changing a behavior. Studies have indicated a multiple correlation of .68 when assessing the prediction power of the three constructs on intentions (Ajzen, 2007). This study incorporated components of each of the constructs into the educational session, which should ultimately lead to a more significant behavior change in session attendees.

The TPB is commonly cited in blood donor research. There have been positive outcomes of predicting intent to donate by assessing the TPB's major constructs. Prior studies have shown that 70% of the variance in intent to donate can be attributed to attitudes related to blood donation, the influence of subjective norms, and perceived behavioral control (Robinson, Masser, White, Hyde, & Terry, 2008). The TPB was useful theory by which to develop the educational session and to assess the participants' intent to donate throughout the study. Each of

the constructs were addressed in a component of the educational session and each were measured using the assessment tool. The assessment tool helped to determine if the proposed education session truly addressed the constructs of the TPB.

Similar studies have used the TPB to develop surveys that assess participants' blood donation knowledge, attitudes about blood donation, and intent to donate. One study in particular used a survey to measure the above attributes in young people (Lemmens et al., 2005). This survey, with the developers' permission, was modified to fit the proposed study population. Hulley et al. (2007) warn of altering existing instruments but state that it may be appropriate when addressing a different cultural group or environment than the original study. Cronbach's alpha for the survey used in the Lemmens study was $\alpha=0.65$. Polit and Beck suggest revising or adding items to surveys with a Cronbach's alpha less than .80 (2012).

Chapter 3 – Methodology

Overview

This chapter will describe the research design chosen for this study and the rationale for each element of the design. There is also discussion of the sampling and data collection processes and survey and educational session designs. Both the educational session and the surveys are grounded in the TPB; Chapter 2 provided information about the relationships of the constructs of the theory to the proposed strategy. As human subjects were required for this study, IRB considerations are also presented in this chapter. A brief explanation of the plan for data analysis is discussed prior to the chapter summary.

As previously discussed, the goal of this study was to increase the African American blood donor pool using a newly developed educational session that targets African American non-donors. In an effort to ensure a clear understanding of the methodology for this study, Table 1 displays the objectives, research questions and hypotheses, and statistical tests needed to conduct this study. Figure 2 illustrates each step taken to complete this study. Table 2 displays a timeline for completing this project.

Research Design

This study utilized a prospective cohort design. The experimental design involved the delivery of the educational session to the study participants in order to determine if there was intent to donate and/or a change in behavior following the intervention. This study is prospective

Table 1. *Summary of Study Objectives, Research Questions, and Hypotheses*

Objectives	Research Questions	Hypothesis	Statistical Tests
To develop a novel educational strategy using the TPB as the framework for targeting African American non-blood donors.	Will the proposed strategy result in a higher proportion of donors than the current proportion of African American donors in Virginia?	Greater than 9% of the study participants will attempt to donate blood.	Two-Proportion Z-Test
To develop, pilot, and distribute a survey instrument that will assess the constructs of the TPB and their contribution to the participants' decision to donate blood.	Do attitude, subjective norm, and perceived behavioral control predict one's intent to donate blood?	Attitude and subjective norm will be the best predictors of one's intent to donate blood	Multiple Regression Analysis
	Do attitude, subjective norm, perceived behavioral control, and behavioral intent predict an actual change in behavior?	The constructs of the TPB – attitude, subjective norm, perceived behavioral control, and behavioral intent- will significantly predict one's decision to donate blood.	Binary Logistic Regression Analysis
To inspire and equip the study participants with the necessary information to motivate other African Americans to join the blood donor pool.	Are there differences between the participants' intent to donate before and after the proposed educational session?	There are differences between participants' intent to donate before and after the proposed recruitment session.	Paired T-Test
	Will the study participants motivate other African Americans to donate blood?	Study participants will motivate other African Americans to donate blood.	N/A (measured by number of referral cards presented at donor centers)
To assess the demographic differences of those who motivated other African Americans to donate and those who did not.	Will recruitment success rates vary between participants who donate blood and those who do not?	Participants who donate will recruit more individuals to donate than participants who do not.	Independent Sample T-Test

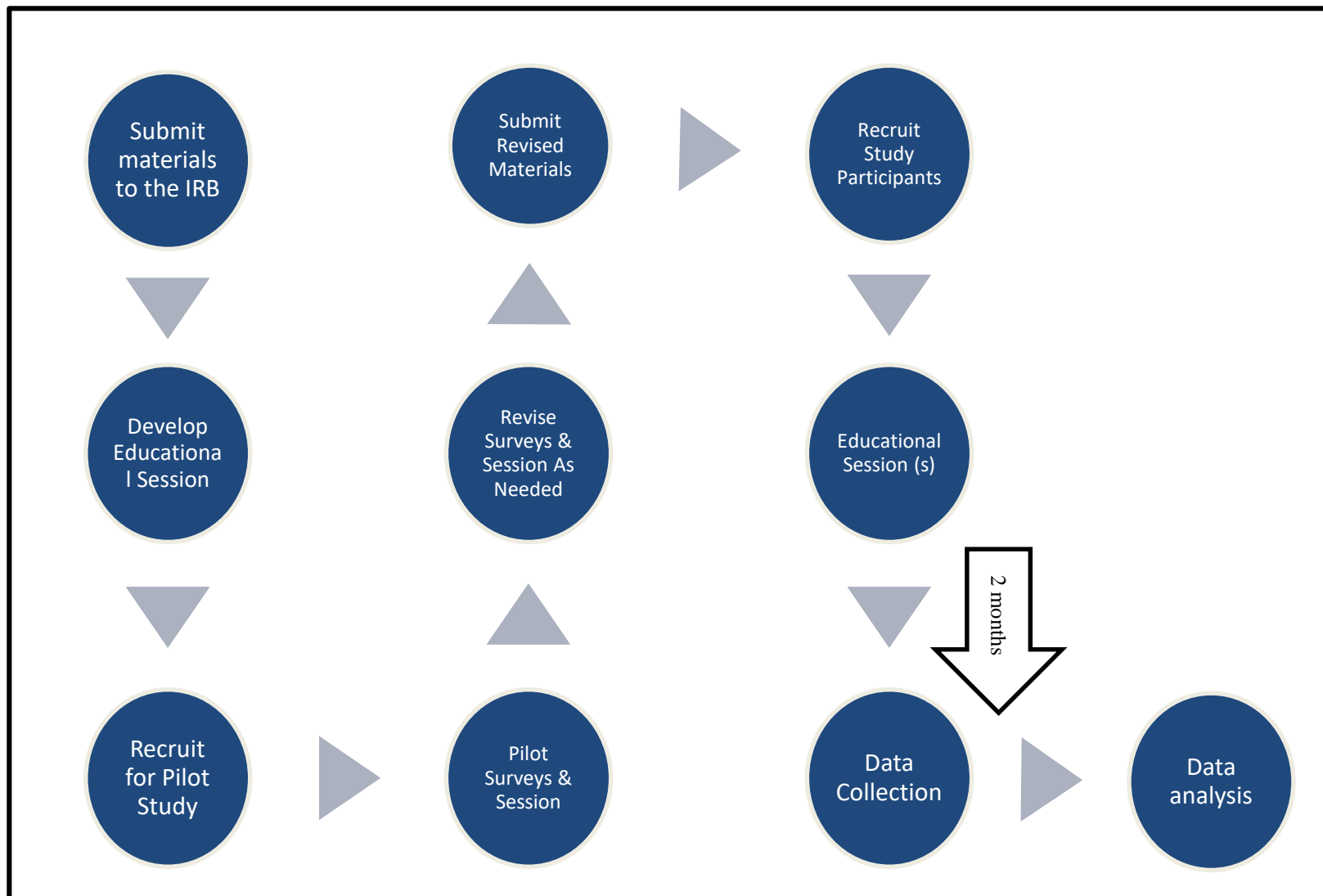


Figure 2. The Research Study Process

Table 2. *Project Completion Timeline*

	1	2	3	4	5	6	7	8-17	18	19
Prepare & submit IRB application	X	X								
Educational Session Development	X	X	X	X						
Pilot Strategy & Surveys				X	X					
Data Analysis					X					
Strategy & Instrument Revisions					X	X	X			
Sample Recruitment				X	X			X		
Educational Sessions								X		
Follow-up period (Data Collection)								X	X	
Final Survey Distribution								X	X	
Data Analysis									X	
Manuscript Preparation									X	X

Note: Each column is representative of one month with the exception of one column representing months 8-17.

in that all data collection began once the study commenced. No pre-existing data was collected from the study subjects.

Collection of the prospective data occurred for a 2-month period, with the educational session marking the first data collection point, and a final survey sent 2 months following the educational session, representing the last data collection point. Other components of the design include a pretest-prottest model and a mixed methods design. The surveys were composed of both Likert –scale items and open-ended questions.

Study participants. The population of interest for this study was African American who have never donated blood. For the sake of this study, an African American was defined as a person who identified him/herself as such. A non-donor, in this study, was defined as an individual who has never tried to donate blood. The state of Virginia permits individuals who are 16 years of age to donate blood, but for this study, the age requirement was least 18 years of age (Virginia Blood Services, 2014). The only exclusion criteria for this study involved permanent deferrals. Once the study commenced, it was evident that this criterion was unnecessary; participants who are non-donors, as defined by this study, would not have a deferral status because they would have never made an attempt to donate. However, all distributed flyers and recruitment material listed both inclusion and exclusion criteria. Participants were asked to consider these criteria prior to enrolling in the study. Participants were asked to exclude themselves from this study if they did not meet the criteria. Table 3 displays inclusion and external criteria.

Table 3. *Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • African American • Never attempted to donate blood • ≥ 18 years of age • Resident of Greater Richmond or Hampton Roads areas 	<ul style="list-style-type: none"> • Permanently deferred from blood donation

The convenience sampling method was used to acquire the sample. All individuals participating in this study were sampled from the Richmond and Hampton Roads, VA areas. The original study plan identified Richmond, VA as the target recruitment area; however, the study was expanded to include the Hampton Roads area of Virginia. Richmond served as a prime location as 50.6% of its population is African American; yet nationally and locally, as previously discussed, African Americans are the minority in the donor pool. Also, in Virginia,

there are an estimated 2500-4500 individuals living with sickle cell disease, which is 8% higher than the national average (Virginia Department of Health, 2012). Twenty-three percent of these individuals are treated at Virginia Commonwealth University Medical Center in Richmond, VA (Royster & Radcliffe-Shipman, 2012). Similarly, Hampton Roads, specifically the Norfolk, VA area, proved to be a productive recruitment location as African Americans account for 42.4% of its population and approximately 49% of the state's sickle cell patients are treated in this area (Royster & Radcliffe-Shipman, 2012).

Recruitment

A majority of study participants were recruited from predominantly African American churches while the other participants were recruited from three universities. The church is commonly used as a recruitment site for studies whose target population is African Americans. Historically, the church is an effective environment in which to study the African American population. Throughout history, “the black church has been integral to the development of not only the black community but to the progress of American society in general” (Calhoun-Brown, 1996). Study participants were recruited from three churches in the Richmond area and three churches in the Hampton Roads area. Information about the study was included in the Sunday bulletins at all churches. The researcher visited each church and was given an opportunity to speak to the congregations about the purpose of the study and how individuals could enroll. Interested individuals were able to enroll for at least two weeks after the researcher made an appeal. In most cases, the researcher worked with the health ministries at each of these churches. A brief description of each church is provided in Appendix A.

Richmond is home to three four-year universities – the University of Richmond, Virginia Commonwealth University, and Virginia Union University. Virginia Union University is an

ideal location for recruitment as it is a Historically Black College/University where African American students are in the majority; however, a majority of college students who participated in this study were current students at Virginia Commonwealth University. Flyers were circulated around Virginia Union's campus and emails sent to students by a representative of the student activities department. An example of a recruitment flyer is displayed in Appendix B.

Recruitment at Virginia Commonwealth University included announcements in the TelegRAM, a daily email sent to all students, staff, and faculty. The Black Graduate Association and the African Student Union also sent emails to all of their members regarding the study and ways to enroll. Lastly, students were recruited at two Student Organization and Volunteer Opportunities fairs.

Efforts to recruit participants from the Richmond area at-large resulted in very minimal responses. Information pertaining to the research study was published in the Richmond Times Dispatch and the Richmond Free Press. Information was also sent to representatives of the Richmond Redevelopment and Housing Authority (RRHA). RRHA oversees and manages many communities that are mostly inhabited by African Americans. Correspondence was also sent to the Baptist General Convention of Virginia, an organization that works with African American Baptist churches in the state of Virginia. An email was sent to all pastors of churches involved with the convention, however this recruitment method did not result in any requests to participate in the study.

The study protocol was submitted and approved by the Institutional Review Board, IRB, at Virginia Commonwealth University prior to conducting the pilot study and the research study. This behavioral study presented no more than a minimal risk to participants; therefore, it was approved for expedited review (Protection of human subjects, 1998).

Pilot Study

A pilot study was performed prior to implementing the protocol. Twenty participants were recruited to participate in the pilot study. Demographics of the study sample are presented in Table 4 and the age distribution shown in Figure 3. These participants were all African Americans at least 18 years of age who have never donated blood. These individuals were recruited from a church in Richmond and a church in Norfolk. Participants completed the surveys and participated in a focus group where the researcher presented the educational intervention. While participants were given an opportunity to offer suggestions and voice concerns about the survey and the educational session, all participants felt that both were adequate. None of the pilot study participants participated in the actual research study.

Table 4: *Pilot Study - Participant Demographics*

N=20	Percent (%)
Gender	
Female	70.0
Male	30.0
Marital Status	
Single, Never Married	45.0
Married or Domestic Partner	50.0
Divorced	5.0
Separated	0.0
Widowed	0.0
Education	
Some High School or less	0.0
High School/GED	20.0
Some College or Associate degree	35.0
Bachelors	30.0
Graduate Degree or Higher	15.0
Know Someone With Sickle Cell Disease	
Yes	55.0
No	45.0



Figure 3: Age Distribution of Pilot Study Participants

Power Analysis

An a priori power analysis was performed to determine the minimum number of subjects necessary to identify a significant effect. The level of significance was set at $\alpha=.05$, meaning that the “null hypothesis is rejected no more than 5% of the time when it is true” (Tabachnick and Fidell, 2013). Beta was set at .20 resulting in a power of $1-\beta =.80$ or 80%. Beta indicates the probability of correctly rejecting the null hypothesis if the actual effect in the population is greater than or equal to the effect size of 0.15. Using these criteria, the minimum sample size required for this study is 76. Post hoc analysis, using 3 predictors, observed $R^2=0.31$ (obtained from multiple regression analysis), $\alpha=.05$, and a sample size of 147 results in an observed power of 0.999.

Survey

Three surveys were created for this research study. Surveys for this study were developed by altering pre-existing instruments to fit the study sample. Dr. Andrew Schnaubelt

developed a survey to assess intent to donate blood using the TPB (Schnaubelt, 2010). His survey was developed to test on the military population.

The surveys for this study incorporated both quantitative and qualitative measures [Appendices C-E]. In order to assess the reliability each measure, the surveys were piloted by 20 individuals prior to the start of the research study. The pilot study participants were African American non-donors over the age of 18. Pilot study participants' surveys were anonymized. Along with answering the questions that would appear on the final surveys, pilot study participants were also asked to assess the survey by responding to the following questions:

- 1) Were the survey directions easy to understand? Yes or No
 - a. If no, please explain.
- 2) Were the questions/statements clear and concise? Yes or No
 - a. If no, which questions were difficult to understand?
- 3) Was the format easy to follow? i.e. were you able to easily determine where to mark your responses? Yes or No
 - a. If no, please explain.
- 4) Are there any suggestions that you would like to offer that may improve this survey?

Participants unanimously stated that all questions were clear and concise and the format, easy to follow. No suggestions for improvement were offered. IBM SPSS was used to assess the reliability of the entire survey and the internal consistency of each construct. Specifically, Cronbach's alpha was calculated to measure the internal consistency of the survey items. Cronbach's alpha was used to assess the reliability of the individual items of each construct represented in the survey. Initial analysis resulted in less than ideal reliability within

the subjective norm measure, leading to the removal of one survey item. Table 5 shows the final Cronbach's alpha results for the entire survey and each of the constructs.

Table 5: *Pilot Survey Analysis*

Item Measured	Cronbach's Alpha
Entire Survey	0.839
Attitude Construct	0.431
Subjective Norm Construct	0.735
Perceived Behavioral Control Construct	0.652
Behavioral Intent Construct	0.911

According to Tabachnick and Fidell (2013), a Cronbach's alpha of 0.70 is ideal for survey reliability. Two constructs, attitude and perceived behavioral control, fell below the ideal value. Further analysis, including factor analysis with a varimax rotation, revealed a subscale within the attitude construct. Each of these scales explains 44.295% and 24.043% of the variance, while, after removing one item representative of the PBC construct, the remaining two items explained 53.091% of the variance. The overall high reliability scores for the survey and two constructs, along with the factor analysis results allowed for use of the final version of the survey.

The first survey included questions to ascertain demographic information from the participants. All three surveys contained the same fifteen, 5-point Likert scale items. These items were representative of the quantitative measures of the surveys. Surveys that contain Likert scales are a suitable way to quantify "attitudes, behaviors, and domains of health-related quality of life" (Hulley, S., Cummings, S. Browner, W., Grady, D., & Newman, T., 2007). The

primary purpose of the surveys was to assess the participants' intent to donate and likelihood of becoming a blood donor, therefore each Likert scale item represented a construct of the TPB. The next section will list each of the four constructs of the TBP and their corresponding survey items.

Survey and TPB Constructs

Similar studies have used the TPB to develop surveys that assess participants' blood donation knowledge, attitudes about blood donation, and intent to donate. One study in particular used a survey to measure these attributes in the military population (Schnaubelt, 2010). Dr. Andrew Schnaubelt, the developer of the aforementioned survey, has given permission for his survey to be modified and used in this study (personal communication, March 16, 2015). Modifications were necessary to accommodate the study population as the original survey was not developed exclusively for African Americans. Hulley et al. (2007) warn of altering existing instruments but state that it may be appropriate when addressing a different cultural group or environment than the original study.

Behavioral intention. Four items measured the participants' intent to donate. Each item required the participants to choose one response on a 5-point Likert scale. The following items addressed this construct:

1. I intend to try to donate blood at least once in the next 2 months.
2. I want to donate blood at least once in the next 2 months.
3. I do not intend to donate in the next month.
4. I intend to try to donate blood at least once in my lifetime.

Attitude. Five items measured the participants' attitude toward blood donation with a focus on the relationship between attitude and historical events:

1. Historical events such as the Tuskegee experiment make me nervous about donating blood.
2. The medical establishment cannot be trusted.
3. Trust plays a major part in my decision to become a blood donor.
4. My prior knowledge about blood donation motivates me to donate blood.
5. My prior knowledge of blood donation motivates me to donate blood.

Subjective norms. Four items measured the participants' subjective norms beliefs:

1. Members of my community need me to donate blood.
2. Donating blood will help individuals in my community.
3. Knowing blood donors in my community would motivate me to become a blood donor.
4. Knowing that someone close to me needs frequent transfusions would motivate me to become a blood donor.

Perceived behavioral control. Two items assessed the participants' perceived behavioral control:

1. Whether I decide to donate blood is entirely up to me.
2. The decision to become a blood donor is completely beyond my control.

Surveys two and three included qualitative items; open-ended questions were asked to elicit further information about the participants' intent to donate and their feelings about the material presented during the education session. The third survey asked participants to explain in detail why they chose to donate blood or why they decided not to donate blood, if they shared the information learned from the education session with others, and if they distributed the referral cards.

Blood donation knowledge. Six true/false items were included on the surveys to assess the participants' blood donation knowledge. This measurement is not related to the TPB but was necessary to determine if participants' blood donor knowledge increased as a result of the intervention. Blood donation knowledge was assessed on all three surveys. The knowledge assessment items included:

1. I have to pay in order to be a blood donor.
2. I can donate blood once every month.
3. I will get paid for my blood donation.
4. My blood donation can only be used for an African American.
5. African Americans donate blood just as frequently as White Americans.
6. Donating blood is a safe process.

Survey Administration

Surveys one and two were distributed to participants upon entering the educational session. In order to ensure compliance with completing the surveys at the correct time, survey two was placed in a sealed envelope and participants were instructed not to open the envelope until they were told to do so. Consideration was given to those with vision impairments and those with varying reading abilities; participants were given the choice to complete the surveys without assistance or with the assistance of a research assistant. Participants were given approximately 7-10 minutes to complete each survey. Survey one was collected immediately after completion, eliminating the possibility of duplicating answers on the second survey.

Educational Session - Components

A script for the educational session was prepared by the researcher and approved by the IRB prior to the first educational session [Appendix F]. Upon entering the study sites,

participants were given a packet containing the following items – a consent form, a demographic sheet, survey one, and a closed envelop that contained survey two, donor cards, and referral cards. Participants were instructed not to open the envelop until told to do so. They were also invited to read over the consent. The educational sessions began with stating the purpose and rationale of the research study. Participants were also reminded of the eligibility criteria and asked to exclude themselves from the study if they did not meet the criteria. The researcher read the consent form to the participants and gave them an opportunity to ask questions. After participants signed the forms, they completed the demographic form and the first survey. Once the forms were completed and collected, the researcher proceeded with the educational material.

In order to maintain consistency, the researcher facilitated all sessions. Educational sessions consisted of 4 components – researcher-led lecture, sickle cell video, question and answer period, and social media. The fourth component, social media, involved the development of a Facebook page used to inform participants and their referrals of upcoming blood donation opportunities. Each of these components was necessary to appeal to different learning styles. Each component of the educational session incorporated at least one of the constructs of the TPB. Table 6 displays each component of the educational session it their associated TPB constructs.

Table 6: *Components of Educational Session and TPB Constructs*

Educational Session Component	TPB Construct(s)
Researcher-Led Lecture	Attitude Perceived Behavioral Control
Video (Sickle Cell Disease)	Attitude Subjective Norm
Question & Answer (Q&A)	Attitude Subjective Norm
Social Media	Perceived Behavioral Control Subjective Norm

Researcher-led lecture. A 10-minute PowerPoint presentation was prepared for this section of the educational session. During this part of the intervention, the study participants received information specifically pertaining to the what, why, and how of blood donations. The goal of the session was to increase the number of first time African American blood donors by informing the participants of the simplicity of the blood donation process and the uses for donated blood, addressing issues commonly cited in the literature that may have a negative impact on the attitudes of study participants in regards to blood donation, and educating them on the importance and uses of blood donated by African Americans. As the literature indicates, some African Americans refrain from donating blood because of a lack of knowledge about the process, a fear of needles, and a lack of trust in the healthcare system (Shaz et al., 2009). Although the literature is lacking in methods to cure the fear of needles, emphasizing how safe the blood donation process is for the blood donor may motivate more participants to donate.

The presentation began with true/false questions, pertaining to the blood donation process, that gave participants an opportunity to engage with the researcher and with one another. These questions were similar, in nature, to the true/false questions on each of the surveys.

Next, the researcher taught research participants about the blood donation process. Steps that were covered included the various ways to make an appointment, what to expect when you arrive for your appointment, procedures and precautions used to ensure a safe donation process, and what to expect following the donation.

Mistrust in healthcare has a historical context that dates back as far as the Tuskegee experiment; therefore, the researcher emphasized the confidentiality involved in the process,

specifically with respect to the donor medical questionnaire and its content and purpose. All blood donors are required to complete a questionnaire that asks questions pertaining to ones' medical, sexual, and travel histories, which determine whether a potential donor is considered high risk for infectious diseases. Although the questionnaire is linked to the donor, all responses remain confidential. All blood products are labeled with a donor number in order to maintain the anonymity of the blood donor. Participants were informed of these important aspects of the blood donation process in order to establish a sense of trust in the process.

After addressing general blood donor facts, the researcher shared information specifically pertaining to the African American community. Participants were informed of the low percentage of African American donors in the United States. The PowerPoint included reasons, as cited in the literature, why African Americans refrain from donating blood. Participants were also given a brief introduction to blood group antigens and antibodies and their importance to blood transfusions, specifically for those who receive frequent transfusions, such as sickle cell patients.

Lastly, the researcher discussed sickle cell disease and the need for blood from African Americans to treat those with the disease. Topics included a brief explanation of the pathophysiology of sickle cell disease, the genetics of the disease, and symptoms and complications associated with the disease. This section of the session concluded with a discussion about treatments for sickle cell disease, including hydroxyurea and red blood cell transfusion. The antigen/antibody information was reintroduced and emphasized in regards to sickle cell transfusion protocols.

Sickle cell video. An important aspect of this educational session was sickle cell disease. Although the PowerPoint presentation provided general information about sickle cell disease and

African Americans, there was still a need to emphasize the importance of becoming blood donors to supply the need of sickle cell patients. The goal of the video was to create a bond between study participants and individuals with sickle cell disease. Physicians at the Children's Hospital of Philadelphia reported that African Americans have responded positively after learning the importance of their blood donations to help children with sickle cell disease (K. Smith-Whitley, personal communication, May 21, 2013).

The sickle cell video was produced and recorded by Metro Productions in Richmond, VA. The video features three individuals with sickle cell disease, the mother of one of the featured sickle cell patients, and a widower whose husband passed away due complications of sickle cell disease. Video contributors were recruited from Virginia Commonwealth University Health, and all contributors signed a waiver prior to recording. Prior to appearing in the video, contributors were given four questions and scenarios that may be posed during the recording. On recording day, contributors were interviewed, on camera, by one of Metro Productions' producers.

The video conveyed multiple messages but concentrated on the struggles endured by those with sickle cell and their experiences with receiving transfusions. Contributors also shared stories about their experiences with blood donor shortages and delays in treatment. The final message in the video focused on the importance of African American blood donors. Each contributor shared their feelings about why they felt it was important for African Americans to donate blood and how the donations would positively impact their lives.

Question and answer (Q&A). During this time of the session, participants posed questions to the researcher. This is a deviation from the original proposal. Originally, the researcher planned to have a sickle cell patient attend every educational session to answer

questions posed by the participants; however, with varying schedules and lengthy unscheduled hospital stays, there was no way to assure that a patient could attend every session. Therefore, in order to achieve consistency in all sessions, the researcher decided not to include patients. The goal of this section of the session was to clarify any concepts that were misunderstood during the session.

Social media campaign. Although the researcher did not communicate with or contact the participants after the session, there still existed a need to inform them of blood donation opportunities and information. A Facebook page was created for each city – one for Richmond and one for Hampton Roads. The social media platform also displayed information about blood drives that occurred throughout the cities, where to find them, and how to make appointments. Lastly, the pages displayed current blood needs as reported by the blood donor centers. Individuals were encouraged to “like” the page and submit their own blood donation photos.

Educational Session – Theory of Planned Behavior

The previous section described the educational session and its four components. This section of the chapter will explain the relationship between the educational session and each construct of the TPB.

Attitude toward the behavior (ATT). The participants’ must typically experience a change in attitude in order for a change in behavior to occur. As discussed in the Chapter 2, many African Americans view donating blood with negative and/or indifferent attitudes which in many cases are caused by a lack of knowledge about the subject. The educational session informed participants of the blood donation process, the reasons why blood donations are needed, and where to donate blood. Educating the participants about the facts of blood donation should ultimately alter their attitudes about donating blood.

Subjective norm. An individual is more likely to change a behavior if a family member, friend, religious leader, or community member promote the behavior change. For those participants living in the Richmond area, it was emphasized that all of the patients featured in the video have been or are currently being treated in Richmond area hospitals. All participants were reminded that their blood donations could be used to help not only individuals in the video but individuals in their own communities as well. Some of the patients featured in the video are ambassadors for sickle cell foundations and the local blood centers, both in the Richmond and Hampton Roads areas. This information was shared with participants, especially in Hampton Roads, in order to stress the notion that individuals in their communities rely on them making a behavior change and becoming blood donors.

Although not required or requested, the pastors of each congregation that participated in the study attended the research study. As pastors are generally recognized as church and community leaders, the presence of these pastors must be addressed and considered when discussing subjective norms.

Perceived behavioral control (PBC). Perceived behavioral control infers that a behavior change is likely to occur if the necessary resources and opportunities are readily available. Some large and small companies, churches, hospitals, and universities, such as Virginia Commonwealth University and its affiliated medical center, host blood donation drives multiples times per week. Study participants received information, via the Facebook page, pertaining to donor center locations and bloodmobile sites. Along with locations, donor center hours of operation and bloodmobile hours were posted on the Facebook page. Providing this information will, according to the TPB, contribute to the goal of motivating the participants to

change their behavior and become blood donors by giving options and allowing them to control when they will change the behavior.

Procedures for Data Collection

All study participants were assigned a unique study number once they consented to participate in the study. The study number appeared on the demographic form and all surveys. The demographic form contained the participants' identifying information - name, address, email, and study number. As a result, after demographic information was entered into a password protected spreadsheet; the demographic forms, along with the consent forms, were locked in a file cabinet within a locked room in VCU's Department of Clinical Laboratory Sciences. The researcher and the researcher's advisor were the only individuals with key access to the file cabinet. Subsequent documents, including all surveys, only contained the participants study number. No other identifiers were displayed on the surveys.

Data was collected using three methods: a self-report paper-based survey, a self-report electronic survey, and donor card submissions.

Survey data. Each study participant received three surveys that were identical in content. All surveys presented questions and statements related to subject's feelings about blood donation and their intent to donate. Survey 1 also captured demographic data for descriptive statistics and to determine if there were any relationships between the demographics and decisions to donate. The demographic data includes age range, gender, marital status, highest level of education completed, and relationship to an individual with sickle cell disease, if applicable. Surveys 1 and 2, which were paper-based, were given before and immediately following the educational session. Survey 3 was completed after the 2-month study period. Survey 3 was administered to assess the participants' attitudes and feelings 2 months after the

session and to determine if the participants made an attempt to donate blood. Figure 4 provides a flowchart of survey administration.

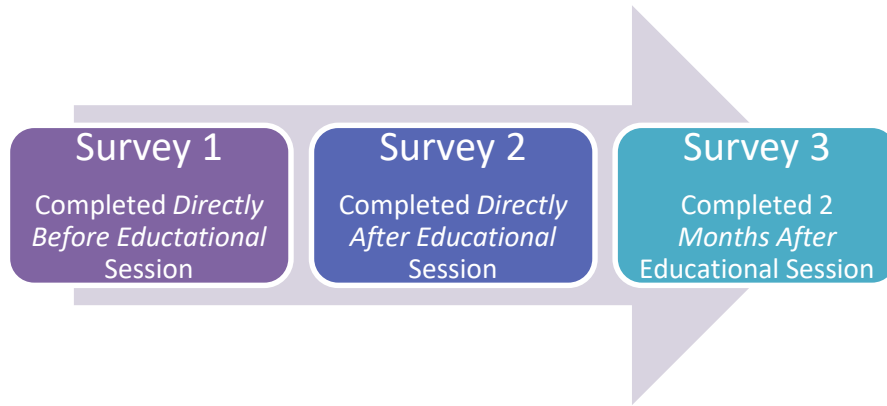


Figure 4. Survey Distribution Timeline

Two format options were available for survey 3 – paper-based hard copy or electronic. Those participants who requested the paper-based survey received a hardcopy via U.S. mail. Individuals who received mailed surveys also received addressed and pre-stamped envelopes in which to return their completed surveys.

Electronic surveys were administered through Red Cap, a secure web application for developing and administering surveys. Only the researcher and the advisor had access to the surveys and survey data on Red Cap. Each survey contained the participant’s unique study number. Red Cap generated a unique URL for each participant. The study participants received their link to the survey via email. Once a participant completed a survey, the results were stored in Red Cap until manually transferred into IBM SPSS for data analysis.

Blood donor cards. At the conclusion of the educational sessions, study participants received two sets of cards – participant donor cards and referral cards. Participants received three donor cards which they were to keep for themselves. Along with their donor cards, the participants received 10 referral cards. The researcher requested that all participants educate ten individuals about the importance of donating blood and give each person a referral card. Both

the participants and their referrals were to give their cards to the blood donor center or bloodmobile staff.

The researcher proposed and implemented a data collection procedure with the local blood donor centers. There are two major blood donation centers in Richmond, VA – American Red Cross (ARC) and Virginia Blood Services (VBS). The American Red Cross is the sole blood donor center in the Hampton Roads area. The researcher met with individuals from each donor center and devised a plan to collect the donor and referral cards. The American Red Cross in Richmond, VA is a relatively new operation and has yet to establish a donor center; therefore, their sole method of collecting blood is through donor drives and bloodmobiles. ARC of Richmond was given envelopes that were used to collect the donor and referral cards at all of their donor drives. Unlike ARC of Richmond, VBS and ARC of Hampton Roads both have established donor centers; these centers received drop boxes to store donor and referral cards. ARC of Hampton Roads housed their drop box at the central and most active location in Norfolk, Virginia. VBS received four drop boxes which were placed in their four busiest Richmond area donor centers – Richmond, Chesterfield County, Innsbrook, and Chester. Due to logistics and the numerous donor drives held by each organization, ARC of Hampton Roads and VBS did not carry envelopes in the field like ARC of Richmond. Staff at all centers were trained to collect all cards from study participants who appeared to donate, regardless of donor eligibility status.

Participants were instructed to drop their cards in the drop box or in the posted envelopes at donor drives whenever they attempt to donate blood. Those participants who referred other African Americans to donate blood were to instruct those individuals to drop their referral cards in the same boxes or envelopes.

Figure 5 shows images of both the participant and referral donor cards that were given to the study participants. The participant’s unique three-digit study number was embedded in a nine-digit letter and number combination; this number was located on the bottom right corner of the donor and referral cards. Each participant’s cards contained the same numbers, however participant cards ended with “111” while referral cards ended in “999.” This method allowed the researcher to connect a non-participant or referral to a study participant. Also, participant cards displayed the statement “I Donated Blood” while referral cards requested non-participants to “Donate Blood Today.”

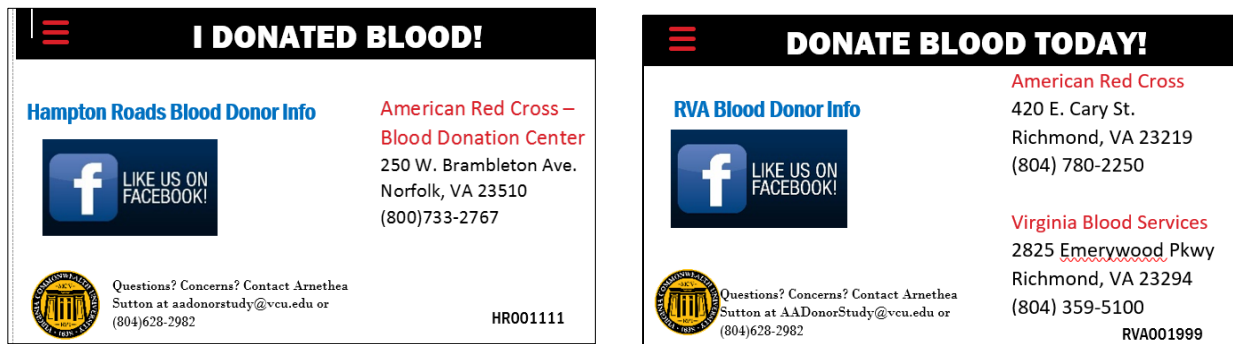


Figure 5. Blood Donor Cards

Data Analysis

All study data was entered into a password protected Excel spreadsheet prior to data analysis. At the conclusion of the study period, the data was analyzed using the most recent version of IBM Statistical Package for Social Sciences (SPSS) software. Descriptive statistics were analyzed to gain an understanding of the demographics of all study participants. The following demographic data contributed to the descriptive analysis - age, gender, highest level of education completed, and relationship status with an individual with sickle cell disease. Exploratory analysis was used to assess any demographic similarities between those who donated and those who did not.

Research question 1. Will the proposed strategy result in a higher proportion of donors than the current proportion of African American donors in the Richmond area?

Hypothesis 1 was tested using a 2-proportion z-test. This statistical test will determine if there is a statistical difference between the current proportion of African American donors in Richmond, 0.09, and the actual proportion during the study. This test is appropriate for this hypothesis given that samples used to determine the two proportions are independent.

The variables and the research and null hypotheses are shown in Table 7.

Table 7: 2-Proportion Z-Test

Research Question	Variables	Research Hypothesis	Null Hypothesis
RQ1	P ₁ : Expected Proportion (>0.09) P ₂ : Known Proportion (0.09)	$P_1 - P_2 > 0$	$P_1 - P_2 \leq 0$

Note: RQ = Research Question; P = Proportion

Research question 2. Do attitude, subjective norm, and perceived behavioral control predict one's intent to donate blood, as indicated by survey responses?

Multiple regression analysis determined if the constructs of the TPB, as represented in the survey, predicted one's intent to donate, as represented by the responses to questions specifically pertaining to intent. This statistical method is appropriate since both the predictors (IV) are continuous and the outcome (DV) is discrete. All survey items related to the independent variables were averaged. Those values were compared to the mean of the responses related to intent to donate. Research hypothesis 2 was tested using this form of regression analysis. The variables are shown in Table 8.

Research question 3. Do attitude, subjective norm, perceived behavioral control, and behavioral intent predict one's actual donation decision?

Table 8: *Multiple Regression Analysis*

Research Question	Variables	Variable Name
RQ2	IV	ATT
		SN
	DV	PBC
		BI

Note: RQ = Research Question; IV =Independent Variable; DV =Dependent Variable; ATT =Attitude; SN =Subjective Norm; PBC =Perceived Behavioral Control; BI =Behavioral Intent

Binary logistic regression analysis determined the relationship between the constructs of the TPB and the actual donation decision. This method is appropriate when the dependent variable is dichotomous and the independent, or predictor variables, are continuous, discrete, and/or categorical (Tabachnick and Fidell, 2013). This statistical test was used to test research hypothesis 3. The three independent variables represented in research question 3 are all continuous in nature. Likert-scale responses were coded and reverse-coded when necessary and a mean score for each construct was calculated for each study participant.

The variables for research question 3 are shown in Table 9.

Table 9: *Binary Logistic Regression Analysis*

Research Question	Variable Type	Variable Name
RQ3	IV	ATT
		SN
		PBC
	DV	BI
		Donation Decision

Note: RQ= Research Question; IV= Independent Variable; DV= Dependent Variable; ATT= Attitude; SN= Subjective Norm; PBC= Perceived Behavioral Control; BI= Behavioral Intent

Research question 4. Are there differences between the participants' intent to donate before and after the proposed educational session?

The paired t-test determined if differences existed in a participant's intent to donate before and immediately after the educational session. The mean of all of the participants' survey responses on Survey 1 were compared to the means of all responses on survey 2.

Research hypothesis 4 was tested using this statistical test. The variables and research and null hypotheses for research question 4 are displayed in Table 10.

Table 10: *Paired T-Test*

Research Question	Variables	Research Hypothesis	Null Hypothesis
RQ4	μ_1 : mean of survey 1 responses μ_2 : mean of survey 2 responses	$\mu_1 - \mu_2 \neq 0$	$\mu_1 - \mu_2 = 0$

Note: RQ =Research Question

Research question 5. The original research design included a method to analyze a fifth research question:

- Research Question 5: Will recruitment success rates vary between participants who donate blood and those who do not?

An independent sample t-test determined the difference in success in recruiting new donors between those participants who donated and those who did not. Hypothesis 5 was tested using this statistical method.

Research questions 6 and 7. A lack of data resulted in the removal of this research question. Neither donor nor referral cards were returned, resulting in an inability to assess Research Questions 6 and 7. Chapter 5 will provide further discussion and explanation.

Study Incentives

All study participants received up to two incentives during the study period. Participants who attended an educational session and complete surveys 1 and 2 received a Target Gift Card. Upon completing survey 3, participants received another Target Gift Card. Incentives were not contingent upon successful blood donations; only completing the surveys. Gift cards received at the educational session were physical cards, while participants were able to choose between physical cards and electronic cards for completing survey 3.

Chapter 4 – Results

Overview

This chapter presents the results and data analysis of this study. The beginning of this chapter will offer an explanation of the data preparation and variables involved in the data analysis. While demographic information was not required to test the research hypotheses, it was collected and analyzed to describe the study sample. Attrition of study participants and incomplete surveys warrant a missing data analysis. Next, the data analysis required to test each hypothesis will be presented.

Data Preparation and Variables

All demographic and variable data were collected via 3 surveys. Table 11 displays all analyzed variables.

A total of 155 individuals enrolled in the study. Data cleaning was necessary to determine if cases and/or variables should be excluded from analysis. Two cases were excluded due to the number of missing items on surveys 1 and 2. Missing Variable Analysis (MVA), performed in IBM SPSS, determined that there were no variables with 5% or more missing values on any of the three surveys. The missing variables for surveys 1 and 3 were missing completely at random or MCAR. Survey 2 analysis displayed a missing values effect; however, since there were fewer than 5% missing variables, the data from the survey was included in the rest of the analyses. The missing values were substituted with item means, an acceptable method

Table 11: *Study Variables*

VARIABLES	ABBREVIATIONS	COMPOSITION/MEASURE
Theory Constructs		
Attitude	ATT	5 Survey Items / Mean Score
Subjective Norm	SN	4 Survey Items / Mean Score
Perceived Behavioral Control	PBC	2 Survey Items / Mean Score
Behavioral Intent	BI	4 Survey Items / Mean Score
Behavior Change		1 Survey Item / Dichotomous Variable (yes or no)
Demographics		
Age		Fill in the blank
Gender		Female; Male; Transgender; Fill in the blank; Prefer not to disclose
Marital Status		Single Never Married; Married or Domestic Partner; Widowed; Divorced; Separated
Education		Some of High School or less; High School/GED; Some of college/Associate degree; Bachelors; Graduate degree or higher
Know Someone with Sickle Cell		Yes; No
Blood Donation Knowledge		6 Survey Items; Composite Score

estimating items with a low proportion of missing values. Six additional cases were identified through Mahalanobis distance as multivariate outliers and were excluded from analysis.

To reduce kurtosis and skewness, transformations were performed. Even following transformations, PBC on the first and second surveys was still significantly skewed. From the frequency distributions for PBC on both surveys, it was evident that too many cases were weighted on one end. To correct this, the PBC variable data for the first and second surveys were transformed into two groups. Two dummy variables were created for data analysis. For the first PBC dummy variable, noted by “3”, all mean scores that were less 4 but greater than or equal to 3 were coded with a “1.” All other mean scores were coded with a “0.” For the second PBC dummy variable, noted by “4”, all mean scores that were less than “5”, but greater than or equal to “4” were coded with a “1” and the remainder mean scores were coded with a “0.” Cell sizes for all groups were within 10% of each other which, according to Tabachnick & Fidell (2013), is acceptable when transforming data into groups. Both dummy variables were entered into all equations to represent the PBC variable. To note, all survey variables consist of a prefix representing one of the three surveys: -pre is representative of Survey 1, -post represents Survey 2, and post2 represents Survey 3. Table 12 shows survey variables, corresponding transformations, and the new variable names, where the addition of “T” indicates a transformation.

Data were examined for multivariate outliers and normality. Scatterplots and residuals statistics indicated multivariate normality of all data; therefore, no additional cases were excluded, leaving 147 participants for hypothesis testing pertaining to surveys one and two. One hundred twenty-four of the 147 participants completed all study activities.

Table 12: *Data Transformations*

Variable	Transformation	New Variable Name
Survey 1		
PBC	Inverse	TPrePBC3 & TPrePBC4
SN	Square root	TPreSN
Survey 2		
PBC	Inverse	TPostPBC3 & TPostPBC4
SN	Logarithmic	TPostSN
BI	Square root	TPostBI
Survey 3	None	

Demographic Data

Table 13 depicts demographic data of the study participants and Figure 6 shows a histogram of the age distribution of the participants. While participants were not required to disclose information, only one participant failed to answer all demographic questions.

Table 13: *Demographic Data*

N=147	Percent (%)
Gender	
Female	79.4
Male	20.0
Prefer Not to Disclose	0.6
Marital Status	
Single, Never Married	45.2
Married or Domestic Partner	31.0
Divorced	17.4
Separated	1.3
Widowed	4.5
Missing	0.6
Education	
Some High School or less	1.9
High School/GED	20.0
Some College or Associate degree	44.5
Bachelors	21.9
Graduate Degree or Higher	11.6
Know Someone With Sickle Cell Disease	
Yes	47.1
No	52.3
Missing	0.6

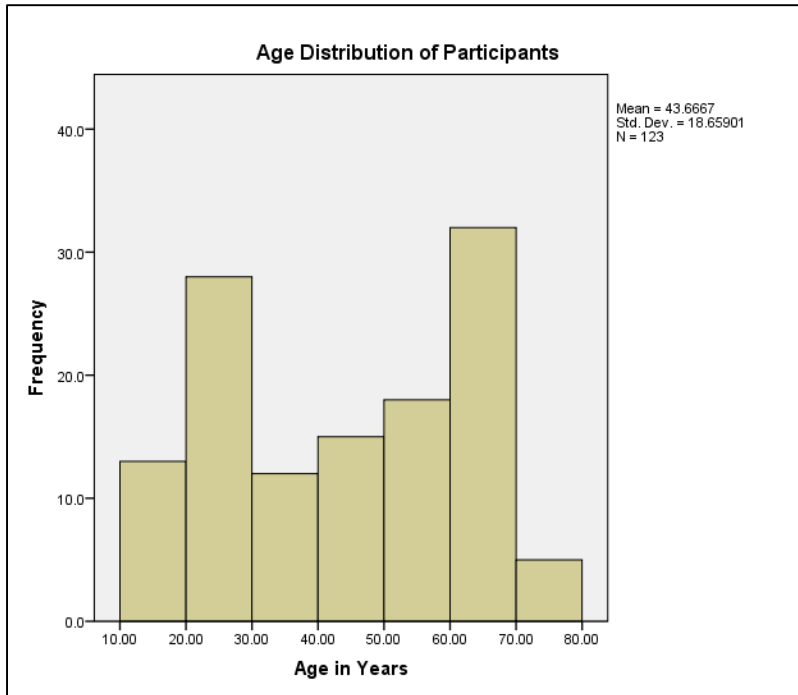


Figure 6: Age Distribution of Study Participants

Objective 1: Proportion of New Blood Donors

The first objective of the educational session was to motivate African American non-donors to attempt to donate blood. The following research question and hypothesis are associated with this objective

Question 1: Will the proposed education result in a higher proportion of donors than the current proportion of African American donors in Virginia?

Hypothesis 1: Greater than 9% of the study participants will donate blood following the intervention.

A 2-proportion z-test was conducted to compare the known proportion of African Americans who attempt to donate to the observed proportion of study participants who attempted to donate during the study period. The proportion of African Americans who present to donate blood in the Richmond area is approx. 0.09. The proportion is very similar in the Norfolk, VA area. As a result of the educational session, 20 individuals attempted to donate blood out of the

124 participants who completed the third survey. This results in a proportion of 0.16. Analysis indicates a significance in the difference between the two proportions ($z = 3.039, p < .001$), supporting the first hypothesis. Open-ended questions accompanied responses regarding donation decision- further discussion will be provided in Chapter 5.

Objective 2 – Testing the Theory of Planned Behavior

The second objective was to develop, pilot, and distribute a survey instrument to assess the construct of the TPB and its contribution to African Americans' decision to donate. Table 14 displays the mean scores and standard deviations for all variables that were analyzed to address the second objective.

Table 14: *Descriptive Statistics*

Variable	Mean Score	Standard Deviation
Survey 1		
PreATT	3.1406	0.78248
TPreSN	1.4104	0.22207
PrePBC	4.5918	0.66985
PreBI	3.4467	0.85546
Survey 2		
PostATT	3.2115	0.81289
TPostSN	0.1670	0.14883
PostPBC	4.5674	0.68621
TPostBI	1.3661	0.29537
Survey 3		
Post2ATT	3.6300	0.95647
Post2SN	4.6125	0.52862
Post2PBC	4.6500	0.65091
Post2BI	4.0750	1.03587

Three research questions and related hypotheses are associated with this objective. The first research question and hypothesis associated with this objective are as follows:

Question 2: Do attitude, subjective norms, and perceived behavioral control, as indicated by survey responses for questions in those particular categories, predict one's intent to donate blood, as indicated by survey responses to specific questions related to intent?

Hypothesis 2: Survey responses will indicate that attitude and subjective norm will be the best predictors of one's intent to donate blood.

To test this hypothesis, a standard multiple regression analysis was performed with the following variables – mean values for attitude, subjective norm, and perceived behavioral control representing the independent variables, and mean values for behavioral intent representing the dependent variable. The results from surveys 1 and 2 are shown in Tables 15 and 16, respectively.

Table 15: *Multiple Regression Analysis - Survey 1*

	β	Correlations		R^2
		Zero-Order (<i>r</i>)	Partial (<i>pr</i>)	
Model 1				.26***
TpreSN	-1.946	-.505	-.505	
Model 2				.31***
TpreSN	-1.827	-.505	-.492	
Pre_Att	0.256	.297	.269	
Model 3 – Excluded Variables				
TprePBC3	-.021		-.026	
TprePBC4	.014		.016	

*** $p < .001$

Table 16: *Multiple Regression Analysis - Survey 2*

	β	Correlations		R^2
		Zero-Order (<i>r</i>)	partial (<i>pr</i>)	
Model 1				.32***
Tpost_SN	-.281	-.568	-.568	
Model 2				.36***
Tpost_SN	-.274	-.568	-.565	
Post_Att	-.066	.229	-.220	
Model 3 – Excluded Variables				
TpostPBC3	.051		.064	
TpostPBC4	.011		.137	

*** $p < .001$

In Tables 15 and 16, β indicates a negative correlation between subjective norm and behavior intent and a positive correlation between attitude and behavioral intent. This negative correlation is due the transformation of the subjective norm variable. Ultimately, there is a positive correlation between the original subjective norm variables, as measured by the survey data, and behavioral intent. There is virtually no relationship between perceived behavioral control and behavioral intent. Along with representing the direction of the correlation relationship between dependent and independent variables, β also represents the strength of the relationship. Table 15 shows that subjective norm is the most important predictor in the model. The zero-order and part correlations in Table 15 are very similar to the standardized coefficients for both subjective norm and attitude; therefore, both attitude and subjective norm are reasonably independent measures of behavioral intent.

Stepwise regression analysis was performed to determine if attitude, subjective norm, and perceived behavioral control contributed to ones' intent to donate blood. In a stepwise multiple regression, variables are only entered in the model if they meet the statistical criteria for

entry (PIN .05) and will remain in the equation unless they meet the statistical criteria for exclusion (POUT .10) (Tabachnick & Fidell, 2013). Survey 1 results suggests that 31% of the variance in behavioral intent was predicted by subjective norm and attitude. Perceived behavioral control was excluded from the model as it does not significantly contribute to the variance in behavioral intent. The overall model for Survey 1 was significant, $R^2 = .32$, $F(1,144) = 11.20$, $p < .001$. Survey 2 results suggests that 36% of the variance in behavioral intent was predicted by subjective norm and attitude. Once more, perceived behavioral control did not contribute to the model. The overall model for Survey 2 was significant, $R^2 = .36$, $F(1,144) = 7.33$, $p < .001$. A comparison of both models shows that subjective norm in survey 2, completed after the intervention, was stronger than in survey 1, completed before the intervention. These results support the hypothesis that attitude and subjective norm would be the best predictors of one's intent to donate blood.

An open-ended question asked participants to explain why they did or did not intend to donate. The following percentages describes the response: 58.5% intended to donate following session, 8.8% did not intend to donate, and 32% were unsure. Chapter 5 provides further discussion of the participants' responses. Table 17 states some of the written responses.

The survey data were also analyzed to answer the following question:

Question 3: Do attitude, subjective norm, perceived behavioral control, and behavioral intent predict an actual change in behavior?

Hypothesis 3: The constructs of the TPB – attitude, subjective norm, perceived behavioral control, and behavioral intent- will significantly predict one's decision to donate blood.

Table 17: *Open-Ended Responses – Reasons Given for Intent to Donate*

<i>Responses</i>	
<i>Yes</i>	<ul style="list-style-type: none"> • Want to help the community • The sickle cell video • I have a family member with sickle cell • The high demand for African American blood • Learning that less than 1% of donors are African American • Information received in the session
<i>No</i>	<ul style="list-style-type: none"> • I'm very uncomfortable with the process • I have health issues • Age factor • I don't want to bother the lifeline • Medication
<i>Maybe</i>	<ul style="list-style-type: none"> • I will if my doctor says I can • Would like to help those with sickle cell disease • The video was very compelling • Information learned in the session • Want to help people in my community

A stepwise logistic regression was performed on donation decision as outcome and four predictors: attitude, subjective norm, behavioral control, and behavioral intent. Data for this analysis was obtained from Survey 3. The test of the full model only included attitude as a predictor. All other predictors were removed from the equation, as they were not significant predictors of actual donation decision. The results were unimpressive. Only 3.5-6.0% of the variation in actual donation decision can be explained by the model, which only included attitude. Table 18 shows the regression coefficients, Wald statistic, odds ratio, and 95% confidence interval for the odds ratio for attitude, the only predictor in the model. Attitude significantly predicted actual donation decision, Chi-Squared (1, N = 124) = 4.215, $p < .05$. There is no evidence to support the hypothesis that attitude, subjective norm, perceived behavioral control, and behavioral intent significantly predicts one's decision to donate blood.

Since attitude was the only variable included in the logistic regression model, further analyses were warranted. Though attitude results were slightly higher after the session, a paired

Table 18: *Logistic Regression Analysis of Donation Decision as a Function of Attitude*

Variable	β	Wald Chi-Square	Odds Ratio	95% Confidence Interval for Odds Ratio	
				Lower	Upper
Attitude	.633	4.215	1.884	1.029	3.448
(Constant)	-3.813	11.501			

T-test showed that there was no statistically significant difference in attitude before and after the session $t_{(146)} = -1.455$, $p = 0.148$. An independent samples t-test was also performed to determine if donors and non-donors were associated with statistically significant different mean subjective norms, perceived behavioral control, behavioral intent, and attitudes. The data for this analysis were obtained from results from the third survey. Table 19 shows the results of this test. The assumption of homogeneity of variances, not shown in the table, was tested and satisfied by Levene's F test for each variable. The independent samples t-test was associated with a statistically significant effect for attitude only, $t(122) = 2.118$, $p = .036$. There was a statistically significant mean difference for attitude between donors and non-donors; donors were associated with better attitudes about blood donation than non-donors. All other variables showed no significant difference between donors and non-donors in relation to subjective norm, perceived behavioral control, and behavioral intent.

Table 19: *Independent Samples T-Test of Donation Decision and TPB Constructs*

Variable	Donation Decision	N	Mean	Std. Deviation	t	df	Sig (2-tailed)
Subjective Norm	Yes	20	4.6125	.52862	1.518	122	.132
	No	104	4.3960	.59380			
Attitude	Yes	20	3.6300	.95647	2.118	122	.036
	No	104	3.2060	.79217			
Perceived Behavioral Control	Yes	20	4.6500	.65091	-.340	122	.734
	No	104	4.6971	.55046			
Behavioral Intent	Yes	20	4.0750	1.03587	.834	122	.406
	No	104	3.8949	.85402			

While no hypothesis is associated with the following analysis, a logistic regression analysis was performed to determine if age was a significant predictor for attempt to donate blood. The results indicate that age was not a statistically significant predictor of donation decision $p=.122$. Table 20 shows the results of this analysis.

Table 20: *Logistic Regression Analysis - Age and Donation Decision*

Variable	β	Wald Chi-Square	Odds Ratio	95% Confidence Interval for Odds Ratio	
				Lower	Upper
Age (in years)	.021	2.396	1.021	-.007	.057
(Constant)	.771	1.750			

The final question for and hypothesis for Objective 2 were:

Question 4: Are there differences between the participants' intent to donate before and after the proposed educational session?

Hypothesis 4: There are differences in participants' intent to donate before and after the proposed educational session.

Hypothesis 4 was tested using the paired t-test. Results indicated a statistically significant difference in the means of the participants' intent to donate directly before and directly after the intervention ($t_{146} = -11.907$; $p < 0.001$). This test also showed a relatively strong positive correlation between the participants' intent to donate before and directly after the session ($r = 0.741$; $p < 0.001$) with scores after the intervention averaging 0.65 points higher than before the session. These results support the hypothesis that there would be statistically

significant difference in the participants' intent to donate before and after the educational session.

Objectives 3 & 4 – Recruiting New Donors

Study participants were asked to share the information they learned in the session with family members and individuals in their communities who were not blood donors. They were also asked to give those individuals referral cards to turn in to the blood donor center if they attempted to donate. These cards were needed to test the third and fourth hypotheses.

Unfortunately, no cards were turned in to the blood donor centers. Some participants included feedback on the third survey regarding both the donor and referral cards. This feedback is discussed in Chapter 5.

Chapter 5 – Discussion

Overview

Interpretation of the data and a summary of the research findings will be presented in this chapter. The surveys offered additional information about the study participants, including questions assessing their knowledge before and after the educational sessions and open –ended questions pertaining to their donation decisions. Although not necessary for data analysis, this information will be discussed as it may offer suggestions for future developments of a targeted approach for motivating African Americans to donate. Also presented in this chapter will be a summary of discussions that occurred during the sessions in which participants offered insight about their feelings about blood donation and medical research in general. Lastly, chapter 5 will cover limitations of the study.

Blood Donation Decisions

The second survey explicitly asked participants if they intended to donate blood following the session. Among those who stated that they intended to donate blood and those who were undecided, common motivators that appeared on multiple surveys were the information shared during the session and the appeal made by the individuals featured in the video. Participants expressed their concern and shock upon learning how underrepresented African American are in the donor pool and how dire the need for African American blood is. It appears that the participants responded positively to the face-to-face approach of learning new

information and viewing the video that reinforced the importance of helping those in need.

Research by Pentecost, Robin, and Thiele (2017) supports that notion that “one way to motivate more people to become donors is to place greater focus on the positive emotional feelings they derive from the act.”

As with the second survey, the third survey also asked participants to offer explanations why they did or did not make an attempt to donate. While not as many individuals replied to this open-ended question, there were some common themes. Individuals who attempted to donate primarily did so as a way to help individuals who need frequent transfusions, specifically individuals with sickle cell disease. Reasons why participants did not make an attempt to donate blood include concerns with donating blood while dealing with health/medical issues, not enough time to donate blood/busy work schedules, and a fear of needles. The most common response was “I forgot about it.” The purpose of the Facebook page was to remind study participants to donate blood and to inform them of times and places to donate. Even in the age of social media, one study found that African Americans preferred to be contacted about donating blood via email and mailed letters (James, Schreiber, Hillyer, & Shaz, 2012). As a majority of participants did not engage in the page, it is evident that other reminder sources need to be considered when motivating African Americans to become blood donors.

Surveys – Theory of Planned Behavior

Pilot data indicated reliability issues with the survey, specifically the attitude construct. Resolving this issue would involve rewriting survey items and piloting the survey until ideal reliability is achieved. The original survey, from which this study’s survey was derived, was developed for military personnel. Since the original survey was not intended for African

American civilians, it may have been more beneficial and effective to develop a new survey for this study or revise a survey that was developed for a similar demographic.

Prior studies have found attitude and perceived behavioral control to be the strongest predictors of intention when applying the Theory of Planned Behavior (Ajzen, 1991; Masser, Bednall, White, & Terry, 2012). Attitude also contributed to the participants' intent to donate in this study. Individuals that had a positive attitude towards blood donation were more likely to donate blood. Survey questions related to attitude focused on trust. As discussed in Chapter 2, studies have found that mistrust in medical community has been a deterrent to African Americans becoming blood donors. An examination of survey items related to attitude –pre and –post intervention revealed that participants had relatively positive attitudes before and after the educational session.

Expanding the number and type of items related to attitude may have revealed more of a change in attitude. The survey items focused on trust, but may not have adequately involved other aspects attitudes about blood donation. Prior studies using the TPB and surveys to assess an intervention included affect terms such as stressful, pleasant, painful, and rewarding (Schnaubelt, 2010). While one goal of the session was to alter attitudes about blood donation, including questions with affect terms may have offered more insight into the participants' attitudes about blood donation before and after the session.

Perceived behavioral control is typically a significant predictor of intent (Ajzen, 1991). However, in this study, PBC was not included in any of the final models as it was not a significant contributor to the regression models. PBC did not contribute to the participants' intent to donate. Like attitude, the participants PBC was not altered by the educational session. A paired t-test revealed no statistically significant difference between the participants' scores on

PBC before and after the session. A majority of participants scored a “5” (the highest score) on the PBC items prior to the session; therefore, it would be expected that they would score high following the session. The participants already felt a strong sense of control prior to the session.

The Facebook pages were developed to give participants a senses of control over their donation decision. The pages contained blood donor drive information so that participants would be aware of when and where they could donate. Since participants in this study already felt a strong sense of control, they may have felt that there was no need to access the Facebook pages. This was indicated by a lack of participation or “likes” on the Facebook pages. No participants accessed the Hampton Roads page and six participants accessed the Richmond page.

Unlike other studies examining the TPB (Booth, Stewart, Curran, Cheney, & Borders, 2014; Masser, Bednall, White, & Terry, 2012), subjective norm was the strongest predictor of intent in this study. The session focused on educating the participants about the importance and need for blood donations for individuals in their own communities. A paired t-test revealed a statistically significant difference between the participants’ scores on SN before and after the session. Not only was subjective norm the strongest predictor, but the session also altered participants’ feelings regarding normative pressures.

Responses to open-ended questions as displayed in Table 17 align with the subjective norm results. The video, featuring African Americans, had a positive effect on the participants. It appears that study participants were more likely to donate after learning of the need for blood specifically for sickle cell patients. While normative pressures are insignificant contributors in regards to other populations, it must be considered when developing interventions for African Americans.

Yazer and colleagues (2017) found that individuals less than 20 years of age were more likely to be first time donors than any other age group. Furthermore, individuals who are 60 years of age and older are more likely to be repeat donors when compared to donors of other ages (Yazer et al., 2017). While statistical analysis did not prove that this was the case in this study, of the 20 individuals who attempted to donate blood, eight participants were 20 years of age or younger. Figure 7 shows a comparison of the ages of donors and non-donors.

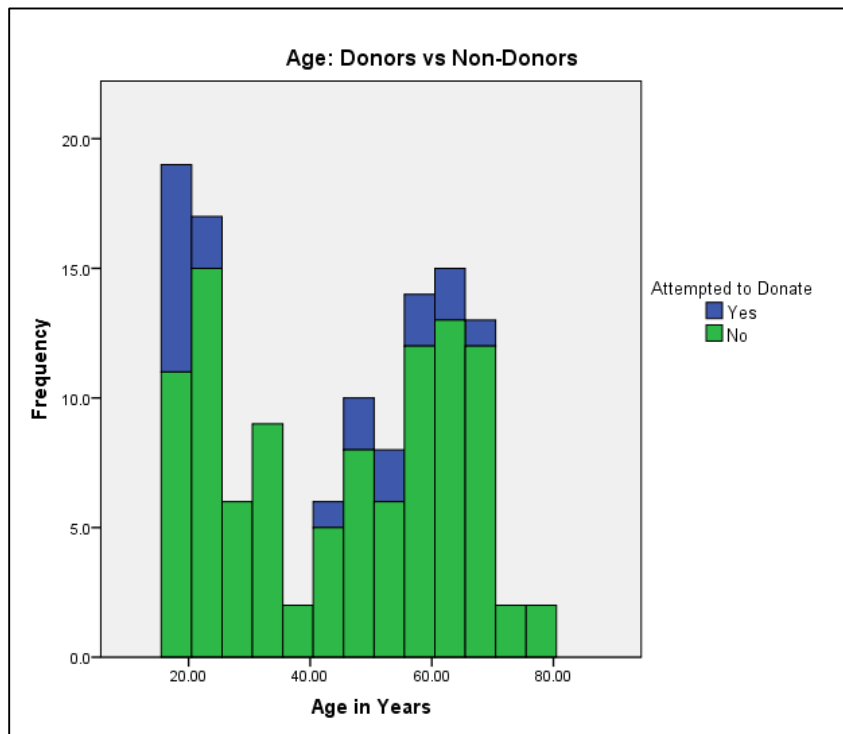


Figure 7: Age: Donors vs. Non-Donors

It is evident that a larger proportion of participants 20 years of age and younger attempted to donate when compared to older participants. Educational strategies targeting high school and college students may result in an increased number of first-time donors. .

African American women are more likely to donate blood than African American men. In one study that observed the donation behavior of a large group of individuals comprised of many races and genders, Price et al. (2009) observed that first-time donors were predominately

African American women. Likewise, 18 of the 20 individuals who attempted to donate in this study were African American women. While there are no explanations as to why African American men are underrepresented among African American donors, there is a need to develop strategies that will motivate this group to participate in interventions and to ultimately attempt to donate blood.

Blood Donation Knowledge

Participants were asked a series of six true/false questions to assess their knowledge of the blood donation process and donor requirements. The same six questions appeared on the three surveys. Each question was addressed during the educational session. As lack of knowledge about the blood donation process is commonly cited as a reason why African Americans refrain from donating blood, it was vital to assess the educational sessions ability to increase the knowledge of the participants. The mean scores on surveys 1 and 2 were 4.73 and 5.52, respectively. The mean score on the third survey, administered two months after the educational session, was 4.76. Scores increased directly after the educational session but decreased after two months of attending the session. It is possible that participants may have forgotten some information learned during the educational session. Survey 3 knowledge scores were still slightly higher than survey 1 knowledge scores. This may have occurred because the participants retained information from the educational session. Since participants were not monitored while completing the third survey, it is possible that some participants sought assistance, such as the Internet, to answer the questions.

Educational Session Discussions

Participants were given an opportunity to ask the researcher questions during the educational sessions. While questions were posed, participants were more eager to share

personal experiences and feelings about blood donation and medical research in general. Many of their feelings not only aligned with cited reasons why African Americans refrain from participating in research studies and are underrepresented in the blood donor pool.

Older adults expressed concerns with trust and past wrongdoings to African Americans. In Richmond, older participants told stories of their parents and grandparents warning them of participating in research being performed by certain local institutions of higher education. Some were told to avoid these institutions all together. Participants also shared their feelings about the Tuskegee Syphilis Study, but on a local level, participants shared about the African American human remains found on a local campus. Although these remains were inhumanly dumped in the mid-19th century, stories and feelings of mistrust still resonate throughout the community (Owsley & Bruwelheide, 2012).

Similarly, participants in the Hampton Roads area also noted the Tuskegee Syphilis Study as a deterrent to participating in research and/or becoming a blood donor. These participants shared their own stories of mistrust in the medical establishment. One participant sparked a conversation regarding one local medical center's disregard and disinterest in treating individuals with sickle cell disease. A conversation with Judith Anderson, Chief Executive Officer (CEO) of the Sickle Cell Foundation in Norfolk, VA, confirmed the stories shared by the participants (J. Anderson, personal communication, August 2, 2016).

Limitations

External validity, specifically generalizability, represents one limitation of this study. While the study was conducted in two areas of Virginia, an ideal study would have tested the effectiveness of the intervention in numerous geographic areas. Duplication of this study in

other geographical areas is required to enhance its generalizability to African Americans in other parts of Virginia and the United States.

Response bias may have affected the results from the second survey. While participants were not given access to the second survey while completing survey one, the time lapse between the first two surveys was only about 1-hour. Given the short amount of time between the two surveys and the similar questions, some participants may have unconsciously provided similar answers on both surveys. A more ideal approach would involve the use of only two surveys – one before the intervention and one at the end of the data collection period, or changing the questions on the second survey if it is given soon after the first survey.

Reliability analysis of the entire survey yielded an acceptable Cronbach's alpha coefficient, however some survey items representative of the attitude and perceived behavioral control constructs of the TBP, resulted in less than ideal reliability. Preferably, this survey would have been rewritten and piloted until all items resulted in Cronbach's alpha greater than 0.70 without any additional analysis. Hulley et.al (2007) warn of altering existing instruments except when addressing a different cultural group than for whom the instrument was originally intended. It could be that in this case, a newly developed instrument may have provided more reliable measures.

Two methods for collecting donor data were proposed and implemented, however the primary method, collecting the donor and referral cards, failed to produce any data. Participants reported losing the cards, or simply forgetting to use them. Ultimately, data analysis relied on the participants' survey responses. Respondent bias is a limitation in this method of data collection. Participants may have responded positively to the question regarding donation decisions, knowing that it was the researcher's preferred outcome.

Lastly, a modification to the grant award resulted in a change in incentive toward the end of the project. A majority of participants received a total of \$40 in gift cards, but individuals who enrolled in the study after the modification could only receive a total of \$20. Recruitment of participants, specifically in Norfolk, occurred at churches within close proximity of one another; during recruitment, questions arose regarding the change in incentive. The decrease in incentive may have contributed to decreased enrollment.

Conclusion

Conversations related trust of the medical establishment, such as the discussions held in the educational sessions, are going to be necessary to effectively design interventions to motivate African Americans to donate blood. Individuals who develop such interventions and methods must be mindful of past wrongdoings in the healthcare system involving the African American population, empathetically address those wrongdoings, and consider them when approaching and working with the sample population.

There continues to be a need for more African American blood donors. There is a need for more concentrated efforts to inform this community of the blood donation process and the importance of African American donors. Efforts must be tailored to the audience, as many of the participants in this study intended to donate or actually presented to donate once they realized the need for blood for individuals with sickle cell disease. One must not focus solely on the need, however. It is important to focus on increasing knowledge about donor eligibility and the blood donation process. Some participants were amazed to learn that donating blood was not an all-day process. Many participants thought they could not donate blood because they have diabetes and/or hypertension. Participants were also excited to learn that there are ways to increase

hemoglobin. Addressing the basics of the blood donation process to increase knowledge about blood donation allows individuals to feel empowered to make a sound decision.

Researchers interested in designing future studies to motivate African Americans to donate blood must consider community engagement as an approach to design an effective study. In order to make an operative change, researchers need to invite individuals in the community to assist with designing and implementing the study (Huang & Coker, 2010; Shavers, Lynch, & Burmeister, 2002). This is especially necessary if the researcher lacks strong ties in the community. Involving community leaders and inhabitants will enhance the likelihood that the rest of the community will participate and will give the community a sense of ownership over the intervention. As SN was the strongest predictor of intent to donate blood, there is evidence that African Americans are more likely to donate blood if they know that it will benefit their community and if the efforts are endorsed by community leaders and other community members.

Researchers must also address feelings of mistrust that reside in African American communities. While attitude was not a significant predictor in an actual decision to donate, it was a significant predictor in one's intent to donate. As all survey items related to attitude in this study revolved around trust/mistrust, it is evident that improving the attitudes may aid in motivating more individuals to donate blood. It is also important to note the increase in attitude scores after the intervention. This may be attributed the participants' ability to openly discuss feelings of mistrust in healthcare and the researcher's ability to facilitate such discussions.

Results of new techniques to treat and cure sickle cell patients are emerging. New efforts must focus on educating this population about the importance of registering. Molecular techniques are becoming more commonly used to fully genotype donor units and recipients. This shift may alter transfusion protocols for sickle cell patients, but with the wide array of red

cell antigen phenotypes that are present amongst the population as a whole, there will still be a need to increase the donor base, which includes increasing the number of African American donors. Bone marrow transplant is surfacing as a cure for sickle cell disease (Nickel et al., 2016). As with blood donations, African Americans are also underrepresented on the bone marrow registry. Motivation will require a similar approach as demonstrated by this study – face-to-face communication that links needs of the community to the actions that the community can take to fill those needs.

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Appendix A

Description of Participating Churches

Antioch Baptist Church

- *A missionary Baptist church with a predominantly African American congregation*
- *Located in the rural community of Varina, a district of Henrico County*
- *Founded in 1922*

Bethlehem Baptist Church

- *A Baptist church with a predominantly African American congregation*
- *Located in the Church Hill area in the City of Richmond*
- *Founded in 1893*

Mount Gilead Missionary Baptist Church

- *A Missionary Baptist Church with a predominantly African American congregation*
- *Located in the Norview area in the City of Norfolk*
- *Founded in 1894*

Mount Lebanon Baptist Church

- *A Baptist church with a predominantly African American congregation*
- *Located in the South Norfolk area in the City of Norfolk*
- *Founded in 1906*

Shiloh Baptist Church

- *A Baptist church with a predominantly African American congregation*
- *Located in the Park Place area in the City of Norfolk; across the street from Norfolk State University, a Historically Black College/University*
- *Founded in 1880*

Sixth Mount Zion Baptist Church

- *A Baptist Apostolic church with a predominantly African American congregation*
- *Located in the Jackson Ward area in the City of Richmond*
- *Founded in 1865*

Appendix B

Sample Recruitment Flyer

WHY DON'T YOU DONATE BLOOD?

RESEARCH STUDY

Virginia Commonwealth University

School of Allied Health Professions

We are conducting research to test a new strategy to increase the African American blood donor pool in RVA & to learn more about African American's feelings about donating blood.

We are looking for African Americans who have NEVER donated blood. Participants will:

- Attend a 1 hour educational session
- Complete 3 surveys &
- Receive compensation for your time

To Be a Participant You Must:

- Be an African American/ Black
- Live in the Greater Richmond Area
- 18 years of age or older
- Not be permanently deferred from



If you would like to participate, please contact Arnethea Sutton at (804)628-2982 or aadonorstudy@vcu.edu

Appendix C

Study Participant Questionnaire 1

The purpose of this questionnaire is to find out how you feel about the topic of blood donation.

This survey will take about 10 minutes to complete. Answer the questions by filling in the blanks, circling a response, or placing a check mark or an “x” in the box. If you have any questions about the questionnaire, please see the individual who gave it to you.

Questions D1-D5 are demographic questions. You are not required to answer the questions, but your answers will help the researchers gain a better understanding the participants in this study.

D1. How old are you? _____ years

D2. What is your gender?

- a. Female
- b. Male
- c. Transgender
- d. _____ {fill in the blank}
- e. Prefer not to disclose

D3. What is the highest level of education you have completed?

- a. Some of High School or less
- b. High School/GED
- c. Some of college/Associate degree
- d. Bachelors
- e. Graduate degree or higher

D4. What is your marital status?

- a. Single, never married
- b. Married or domestic partner
- c. Widowed
- d. Divorced
- e. Separated

- D5. Have you ever tried to donate blood?
a. Yes
b. No

- D6. Do you know someone with sickle cell disease?
a. Yes
b. No

Questions K1-K6 will assess your blood donation knowledge. Circle 1 answer for each question.

K1. I have to pay in order to donate blood.

True False

K2. I can donate blood once every month.

True False

K3. I will get paid for my blood donation.

True False

K4. My blood donation can only be used for an African American.

True False

K5. African Americans donate just as frequently as White Americans.

True False

K6. Donating blood is a safe process.

True False

Questions Q1-Q17 will ask about your attitude and feelings about blood donation. Place an "x" or "check mark" in one box for each statement.

Ex. *I am enjoying this session.*

<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Strongly Agree</i>	<i>Somewhat Agree</i>	<i>Neither Agree nor Disagree</i>	<i>Somewhat Disagree</i>	<i>Strongly Disagree</i>

Q1. The medical establishment cannot be trusted.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q2. Members of my community need me to donate blood.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q3. Knowing that someone close to me needs frequent transfusions would motivate me to become a blood donor.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q4. I intend to try to donate blood at least once in the next 2 months.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q5. Historical events, such as the Tuskegee experiment, make me nervous about donating blood.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q6. Whether I decide to donate blood is entirely up to me.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
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Q7. I want to try to donate blood at least once in the next 2 months.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
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Q8. Trust plays a major part in my decision to become a blood donor.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
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Q9. I do not intend to donate in the next month.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
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Q10. The decision to become a blood donor is completely beyond my control.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
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Q11. I intend to try to donate blood at least once in my lifetime.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
----------------	----------------	----------------------------	-------------------	-------------------

Q12. Donating blood will help individuals in my community.

Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
----------------	----------------	----------------------------	-------------------	-------------------

Q13. My prior knowledge about blood donation motivates me to donate blood.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q14. Knowing blood donors in my community would motivate me to become a blood donor.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Q15. Knowledge of prior mistreatment of African Americans affects my decision to donate blood.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

Appendix D

Additional Question for Survey 2

Q1. Do you intend to donate blood after this recruitment session?

- Yes
- No
- Maybe

If you responded “Yes” or “Maybe” to the previous question please tell us what, if anything, from this recruitment session motivated you to want to become a blood donor.

If you responded “No” to the previous question, please tell us why you do not intend to become a blood donor.

Appendix E

Additional Questions for Survey 3

Q1. Did you donate blood at least once during the past 2 months?

- Yes
 No

Please tell us why you did or did not donate during the past 2 months in the box provided. In your answer please include anything that may have motivators and/or barriers that affected your blood donation decision.

Q2. Did you share the information you learned in the educational session with anyone?

- Yes
 No

If you responded yes, what part of what you learned in the educational session did you share? If you responded no, why didn't you share any information?

Q3. Did you hand-out your referral cards?

Yes

No

If you responded yes, do you think those individuals made an attempt to donate blood? If you responded no, why didn't you hand out your referral cards?

Appendix F

IRB Consent Form

TITLE: A Targeted Educational Intervention: Motivating African Americans to Donate Blood

VCU IRB PROTOCOL NUMBER: HM20005247

SPONSOR: Virginia Blood Foundation

If any information presented in this consent documentation is unclear to you please do not hesitate to ask the study staff to explain it to you. A copy of this consent form can be taken home to think about or discuss with family or friends before you sign and make your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to test a new recruitment strategy aimed at increasing the number of African American blood donors. Your participation in this study is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which that you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. Please notify the study coordinator if, during the study, you decide you no longer want to participate.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to participate in this research study, you will be asked to sign this consent form after you have had all of your questions answered and understand what will take place during the study.

In this study you will be asked to attend a recruitment session that will last approximately 1 hour. In this session you will be in a large group with other study participants. During this hour, information will be shared about the importance of blood donations and how you can become a blood donor. You will watch a video about blood donation. You will be given an opportunity to ask questions about blood donations at the end of the session.

During the 1-hour session, you will be asked to complete two surveys. You will be given a unique study number that you will include on your survey. You will not be required to use your name, and all responses will be confidential. The first survey will ask you questions about yourself i.e. gender, marital status, age, etc. To complete the surveys, you will also answer questions about your feelings and attitude about blood donation. They will test your knowledge about blood donation. None of the surveys are graded. You are not required to answer any questions that make you uncomfortable, but any answers you provide will be greatly appreciated.

During the educational session, you will also view a video that features sickle cell patients and family members of sickle cell patients. This video will educate you about sickle cell disease and its relevance to African American blood donors.

The study coordinator will ask you to consider being a blood donor. She will also give you blood donor information to pass along to your friends and family. After 2 months you will be asked to complete one final survey. It will be very similar to the first 2 surveys. On the demographic form that you complete at the beginning of this study you will be asked to choose

how you would like to receive the final survey. You can either receive a paper copy in the mail which will include a stamped envelope for returning the survey, or you can complete the survey on the Internet. If you choose the internet-based survey, you will receive a link that will direct you to the survey.

ALTERNATIVE

If you decide that you are not interested in enrolling in this study, you may still attend this educational session. You are not required or expected to sign and return this form if you are choosing not to enroll in the study.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but the information we learn from people in this study may help us increase the blood supply. It may also help us design better strategies to motivate more African Americans to donate blood.

RISKS ASSOCIATED WITH STUDY

There are very minimal risks associated with this study. While viewing the video, you may find some of the information about the sickle cell patients' lives and experience with the disease to be upsetting. This is unlikely to occur, but it is possible. At any time during the showing of the video, you are more than welcome to leave the viewing area.

Breach in confidentiality is always a potential risk. The coding process is the safeguard in place to minimize this risk

COSTS

There are no costs for participating in this study other than the time you will spend in the groups and filling out the surveys.

PAYMENT FOR PARTICPATION

You will receive a \$10.00 gift card to a retail establishment after you complete the first 2 surveys at the session. You will receive the first gift cards before you leave the educational session. You will receive another \$10.00 gift card after completing the third survey at the end of the study. You can choose to receive the second gift card either by email, postal mail, or in person. You may receive a total of \$20.00 if you complete all 3 surveys. Your name and the amount you received will be submitted to VCU's Business Administration office as a gift card recipient. This office will not receive any other identifier information.

CONFIDENTIALITY

Data is being collected for research purposes only. Your consent form that will also include your unique study number will be stored separately from research data. Your data will be identified with your unique study number only, not names, and locked in a research area. Only the study coordinator will have access to this information. All personal identifying information will be kept in password protected files and these files will be deleted upon completion of the research study.

We will not tell anyone the answers you give us; however, information from the study and information from the consent form signed by you may be looked at or copied for research or

legal purposes by the sponsor of the research, or by Virginia Commonwealth University. Personal information about you might be shared with or copied by authorized officials of the Department of Health and Human Services or other federal regulatory bodies

QUESTIONS

If you have any questions or concerns about your participation in this research, please contact Arnethea Sutton and/or Dr. William Korzun at (804)628-2982 or aadonorstudy@vcu.edu.

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research
Virginia Commonwealth University
800 East Leigh Street, Suite 3000
P.O. Box 980568
Richmond, VA 23298
Telephone: (804)827-2157

Contact this number to ask general questions, to get information or offer input, and to express concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk to someone else.

CONSENT

I had a chance to read this consent form. I understand the information in this study. I was able to ask questions and they were answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name printed	Participant Signature	Date
--------------------------	-----------------------	------

Name of Person Conducting Informed Consent Discussion/Witness (Printed)

Person Conducting Informed Consent Discussion/Witness (Signature)	Date
---	------

Principal Investigator Signature (if different from above)	Date
--	------

Appendix G

Educational Session PowerPoint Presentation

Why Should I Become a Blood Donor?

The Importance of African American Blood Donations

Do These Look Familiar?



What do YOU Know?

- True or False
 - Donating blood is a SAFE process.
 - TRUE
 - If I donate blood, my body will not be able to make more blood.
 - FALSE
 - I can get a disease.
 - FALSE

The FACTS

Donating blood is a **SAFE** process

You **CANNOT** catch any diseases by donating blood

The FACTS

Minimum age to donate:
16 years old

The FACTS

You can donate Red Cells
1x/56 days

The FACTS

All donors are screened for infectious diseases (HIV, HBV, HCV, etc.)

The FACTS

You CANNOT get paid to donate blood for transfusions



Blood Donation Process

- Donor Screen Questionnaire
- Hemoglobin Check
- Collect blood tubes
- Actual Donation
 - Takes approx. 35-40 mins.
- Goodies & Gifts



What Happens Next?

- You will receive a donor card
- Follow-up calls



Your blood will be used to **save someone's life!**

Why African American Blood?

- African Americans only make up _____% of donors in the U.S.
 - 40%
 - 20%
 - 5%
 - 1%

Why Only 1%?



Why African American Blood?

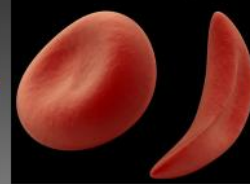
- General Blood Inventory
 - Shortages -> Natural Disasters and Seasonal shortages
- And?

SICKLE CELL DISEASE

Let's Talk about Sickle Cell Disease

- 99% of people with sickle cell disease are of African descent
- Hereditary disorder (recessive)
- Body makes abnormal red blood cells

Normal Red Blood Cell

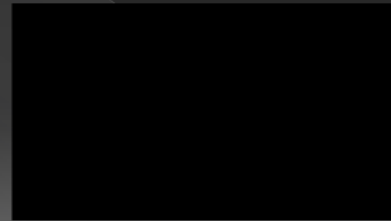


Sickle Cell

Sickle Cell Disease (continued)

- Complications
 - Pain
 - Strokes
 - Crisis
 - Organ Failure
 - Death

Normal Red Cells vs. Sickle Cells

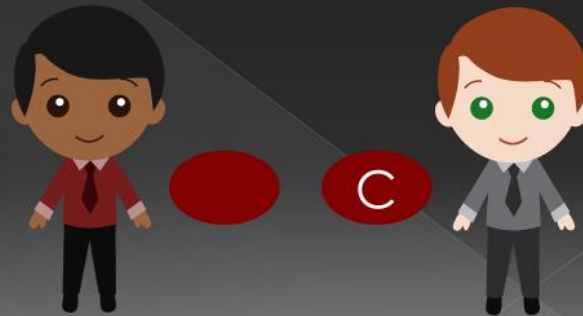


Monroe Carell Jr. Children's Hospital at Vanderbilt
<https://youtu.be/KMpyLau4YF4>

TREATMENTS

- Hydroxyurea – Drug
- * RED BLOOD CELL TRANSFUSION *
 - Require blood from **African American** donors
 - Why?

Red Blood Cells and Race



Sickle Cell Patients and Transfusions

- Blood Needs
 - Sickle Negative – Blood from donors who do not have sickle cell disease or trait
 - C, E, K NEGATIVE
 - **AFRICAN AMERICAN DONORS**
 - Repeat Donors!

Will YOU Donate?

Check out this Video



So What Now?

- Facebook Page
- Donor Cards
- Surveys 2 and 3
- Gift Cards

**SAVE LIVES!
Become a
Blood Donor!**

Vita

Arnethea La'Shaun Sutton was born May 8, 1983, in Portsmouth, Virginia, the daughter Lolethea Abraham. After graduating from Granby High School in 2001, she entered Virginia Commonwealth University (VCU), receiving the degrees Bachelor of Science in Clinical Laboratory Science and Master of Science in Clinical Laboratory Science in 2006. She worked as an adjunct in the Medical Laboratory Technology program at J. Sargeant Reynolds Community College for 3 years. She is currently the Referrals Supervisor in the Department of Pathology at Virginia Commonwealth University Health System where she has worked since 2005.