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Impact of Social Influence on Willingness to Participate in Clinical Trials among African Americans

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Abstract

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MSDD, University of Cincinnati, 2013

MPH, Wright State University, 2012

Dissertation Submitted in Partial Fulfillment
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Abstract

Global rate of participation in clinical trials is especially low among African Americans in the United States due to social factors identified by research, which adversely impact this group's willingness to participate in clinical trials. The purpose of this cross-sectional quantitative study was to evaluate the role of social influence in the decision-making patterns of African Americans as it relates to clinical trial participation. The theory of planned behavior was used as the theoretical framework to understand an individual's interaction with social factors and how it affects their willingness to participate in clinical trials. The participants in the study were 115 African Americans residing in a greater metropolitan area of Ohio. Data were collected using 1-time questionnaire administered by paper instrument. Regression and correlation analyses were conducted for all 115 collected survey responses. Results of the analyses were statistically significant in proving that social influence is a good predictor of willingness to participate in clinical trials where the research involves minimal risk to the participants ($p = 0.047$). The results also showed that attitudes and beliefs about clinical trials are good predictors of willingness to participate in clinical trials among African Americans ($p = 0.000$). The results of this study offer new insight for the development of patient recruitment initiatives within the African American community in the United States and create a path to the development of viable and sustainable intervention.

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Dedication

I dedicate this research to the legacy of my late mother, Obiageli Okere. She was an advocate for public health and taught me what it means to preserve the health of our community through care and research.

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I would like to thank Dr. Raymond Panas and my committee for their unwavering support and encouragement through this process. Their guidance provided much needed assurance, which led to the successful completion of my dissertation.

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Finally, I would like to give special thanks to my father, Augustine Okere. He was the first “Dr. Okere” in the family and created and fostered this vision for success, which has guided me to this milestone. His words of encouragement went a long way and continue to guide my future goals.

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Chapter 1: Introduction to the Study

Introduction

Clinical trials explore the safety and efficacy of novel drugs or devices used in the treatment of new or existing diseases in humans and highlights the best medical treatment that best serves a certain group of people (National Institutes of Health [NIH], 2017). There is a general acceptance by the medical community as well as the public of the importance of advancing medical knowledge (Center for Information & Study on Clinical Research Participation, 2012; Steinke, 2004). Notwithstanding these facts, together with the overall acceptance of the benefits of clinical trials, global rates of clinical trials participation is low in the United States (Lee, Ow, Lie, & Dent, 2016). This issue is of great concern, particularly among African Americans and other ethnic minorities, and little or no improvement has been recorded over the years (Hughes, Varma, Pettigrew, & Albert, 2017; Lang et al., 2013). Clinical trial participation numbers have seen a decrease in the past 30 years, a decline which is expected to continue in the coming years (Galea & Tracy, 2007; Rogers, Murtaugh, Edwards & Slattery, 2004).

The burden of disease data in the United States confirms that African Americans stand a higher risk of morbidity and early mortality than other races (Noonan, Velasco-Mondragon, & Wagner, 2016). Research has shown that race and ethnicity are correlated with the growing health disparities in the United States (Noonan, Velasco-Mondragon, & Wagner, 2016). Nonetheless, there is an increase in the lack of willingness to participate in clinical trials and recruitment of African Americans for participation in these trials continues to be a discouraging task (Anwuri et al., 2013). There is a need for more research into the factors that are specific to the African American population, including the behaviors that promote the lack of willingness to participate in clinical trials in the United States. The inability to develop a viable strategy to overcome this issue raises a concern regarding the future of clinical trials that are generalizable to all races and ethnicities in the United States (Hughes et al., 2017).

The problem of low ethnic minority participation in clinical trials is significant to public health because adequate therapies to cure illnesses result from extensive research in the targeted population. African American representation in clinical trials is needed because they have a greater risk of morbidity and early mortality compared to other races in the United States (Noonan et al., 2016), and race and ethnicity correlates with the rising health inequalities in the United States (Fisher & Kalbaugh, 2011). Research that is considered ethical and scientifically sound must include a sample population that is representative of the population (George, Duran, & Norris, 2014; Hughes et al., 2017).

Willingness represents an individual's inclination or favorable mental disposition towards an action ("Willingness," 2017). African Americans differ from European Americans and other ethnic groups in their willingness to participate in clinical trials, and this issue has been attributed to a host of factors including a low level of trust of medical research (Bruce et al., 2014; Tanner, Kim, Friedman, Foster, & Bergeron, 2015). Previous research studies have provided conclusions that suggest a link between social factors operating within a group and their willingness to participate in clinical trials (Bruce et al., 2014; Tanner et al., 2015). In a literature review conducted by Luebbert and Perez (2016), the authors reported that the barriers to willingness to participate in clinical trials among African Americans included issues related to trust, experimentation, communication, and logistics. Hughes et al. (2015) concluded that fear and lack of trust for research were the most common barriers to participation in clinical trials among African Americans. These barriers were attributed to factors like lack of information related to the research and prevailing knowledge of historical instances of unethical research practices (Hughes et al., 2015). Other social factors like racism (Sherman, Hawkins, & Bonner, 2017; Speights et al., 2017), attitudes towards research (Bruce et al., 2014), fear of being used as guinea pigs (Hughes et al., 2015; Tanner et al., 2015), and socioeconomic status (Chen, Lara, Dang, Paterniti, & Kelly, 2014; Unger et al., 2013) have also been identified.

The younger generation of African Americans who have not directly experienced or have direct evidence of unethical practices against ethnic minorities may rely on inaccurate information as it relates to clinical trials, passed on from parents or older, earlier generations through storytelling (Lee, Fawcett, & DeMarco, 2016; Palacios et al., 2015). The authority influence hypothesis proposed by Schöbel, Rieskamp, and Huber (2016) predicts that

> people’s behavior will also be influenced by the hierarchical status of other decision makers and will make decisions that conform to higher ranked others’ decisions more often, even if other available public information and their own private information suggest doing otherwise (p. 5).

According to Hughes et al. (2015), one of the most commonly identified barriers to participation is the historical occurrences of past unethical research practices. Through an individual’s interaction with these sociocultural factors, these valid historical occurrences could easily be mixed up with urban legends and then passed down through generations in the African American community (Hughes et al., 2015).

Social influence represents the changes in behavior, opinion, or beliefs that individuals initiate, based on interactions with the prevailing social factors (Moussaïd, Kämmer, Analytis, & Neth, 2013). It represents the process through which an individual can adapt their opinions, revise their beliefs, or adjust their behavior, resulting from social interactions with others (Moussaïd, Kämmer, Analytis, & Neth, 2013). The role of social influence in potentially diminishing the willingness of African Americans to participate in clinical trials is not well established. Due to unfavorable health outcomes in the African American community, it is important to identify the process by which the history of unethical practices against this population continues to be at the forefront of all identifiable barriers to research, despite great advances in research participant protections and research ethics in the United States. The answer to this could lie in an African American’s recognition of the activities that apply to them based on their desire to conform to a behavior or norm developed through sociocultural values (Moussaïd et al., 2013).

The barriers to African American participation in clinical trials have been examined by different researchers (e.g., Anwuri et al., 2013; George et al., 2014; Lee et al., 2016). However, these barriers have not been effectively linked to the ever-present impact of social influence. More research is needed to evaluate trends that support the role played by social influence in either encouraging or discouraging the willingness of

African Americans to participate in clinical trials because an individual's social conditions, environmental exposures, and past experiences work together to produce behavior and motivation (see Garza et al., 2017; Moussaïd et al., 2013). Common opinions are created by common cultural beliefs, and according to Moussaïd et al. (2013), opinions are more likely to be reinforced by group discussions conducted by individuals with similar judgement. The results of this study provide much needed insight into this issue that impacts health promotion because failure to increase the participation rates of African Americans in clinical trials will inhibit the progress of clinical trial research into novel and effective methods in drug development (see Frew, Schamel, O'Connell, Randall, & Boggavarapu, 2015).

Background of the Problem

African Americans represent approximately 13.3% of the U.S. population (U.S. Census Bureau, 2016) and continue to experience an unequal burden of disease, limited access to health and health care services, and lower life expectancy when compared to other races (Correa-de-Araujo, 2017; Frist, 2005). When compared to other races, African Americans differ unfavorably in their willingness to participate in clinical trials (Kurt et al., 2016; Shavers, Lynch, & Burmeister, 2002), representing only 5% of all clinical trials participants in the United States (Hughes et al., 2015). This issue has been attributed to a host of factors, including distrust for medical research (Kurt et al., 2016; Shavers et al., 2002; Stuchlik et al., 2015), resulting from a history of unethical practices and harsh treatments that were meted out to the African Americans (e.g., the Tuskegee Study; Durant, Legedza, Marcantonio, Freeman, & Landon, 2011). Several researchers have proposed that the distrust resulting from the Tuskegee Study is the major impediment for the willingness of African Americans to participate in clinical trials (Sacks, 2015). Shavers, Lynch and Burmeister (2000) reported that 81% of the 179 African American adult participants in their study had knowledge of the Tuskegee Study. The researchers also found that this knowledge directly influences their level of trust for medical research (Shavers et al., 2000). Knowledge of historical instances of unethical practices is further compounded by present feelings of comparable mistreatment

Although there is a mandate by federally funded agencies to include racially diverse populations in clinical trials, the enrollment of African Americans in clinical trials remains a discouraging task (Hughes et al., 2015). Data shows that although African Americans make up 12.4% of the entire U.S. population, only 5% of clinical trials participants in the United States are African Americans (Fisher & Kalbaugh, 2011; Hughes et al., 2015). The current gap in research needed to understand this issue and the inadequacy in the development of a practical approach to overcome the issue raises a concern regarding the future of research into treatments for race-specific diseases like sickle cell disease, as well as concern for the ability of researchers to generalize clinical trials results to the entire population (Hughes et al., 2015).

It is important to understand the impact of social influence, an intricate inherent human factor that holds the potential to impact attitudes and behaviors, on the decision-making patterns and the willingness to participate in clinical trials among African Americans. An individual’s partner or family members can influence their willingness to participate in clinical trials, and this was concluded to be greater in clinical trials conducted in developing countries than in developed countries (Lobato et al., 2014). This finding was attributed to the influence of culture identification, which promotes interdependence (Lobato et al., 2014). In a multicenter study of hypertension and genetics by Marshall et al. (2006), 47% of female participants enrolled in Nigeria solicited the guidance of their partners prior to participating in the research compared to the U.S.-enrolled female participants of which none solicited the advice of a partner before participation. Banks-Wallace (2002) reported that storytelling, which is a part of the core of the African American culture, can also affect behavior. When life events or experiences are considered, this process of storytelling could create a communal experience that links the teller to the listener, thereby promoting similar behavior and attitudes (Banks-Wallace, 2002). The mistrust exhibited by African Americans for healthcare services and healthcare providers as well as other institutions has survived many generations.

With this study, I shed light on the existence of the concept that social influence, as an intricate inherent human factor, holds the potential to impact attitudes and behaviors related to willingness to participate in clinical trials. The results of this study provide a better understanding of the positive and/or negative impact of social influence factors (i.e., culture, beliefs, values, attitudes, and learned individual preferences) on clinical trials and contribute to ongoing research into developing methods to maximize ethnic minority participation in clinical trials in the United States (see Branson, Davis, & Butler, 2007). Some research studies aimed at identifying barriers to participation in clinical trials among African Americans have been replicated without specifically capturing and assessing the role played by social influence, a core factor when evaluating behaviors within a culturally unique population, thus making my research the logical next step to assess how social factors may influence willingness. (see Marshall et al., 2006). In this study, I looked at the impact of social influence on an African American's willingness to participate in clinical trials. The findings of the study shed light on how information passed from generation to generation through storytelling affects current behaviors related to research participation decisions and lends significance to a common goal of equity and equality in health care services and delivery.

Problem Statement

There is an unequal burden of disease, limited access to health and health care services, and lower life expectancy among African Americans when compared to other races (Frist, 2005). This issue is worsened by a systemic underrepresentation of African Americans in clinical trials, including clinical trials which target race-specific diseases (e.g., sickle cell disease), culminating in shortfalls in data generated from clinical trials and limiting the ability of researchers to generalize the results to the entire U.S. population (Frist, 2005). Information regarding the impact of newly developed therapies used in the treatment of diseases that affect the African American population is limited, and although there are government regulations aimed at enforcing ethnic minority participation in government-funded research, African Americans as well as other minorities remain underrepresented in important clinical trials (Sanders, 2011). Therefore, the problem I addressed in this study was the inability of researchers to generalize clinical trial results and to develop new therapies targeting diseases that are prevalent in the African American population. I addressed this issue by identifying the role played by social influence and its effectiveness and potential use in the development of viable interventions.

Purpose of the Study

I designed this study to identify how social influence affects the willingness of African Americans to participate in clinical trials as a platform for the development and implementation of interventions to improve clinical trial participation among this population. In this study, I methodically examined and elucidated the potential association between the willingness of African Americans to participate in clinical trials and predisposing variables that included social influence and other demographics (i.e., gender, age, employment status, and family history of research participation; Chen et al., 2014). The theory of planned behavior was used as the framework to guide the research questions.

Study Population

The population for this study included African Americans, aged 18 years and older, who resided in a greater metropolitan area of Ohio. In this study, I defined African Americans as individuals who are Black and are of African descent and who identify as Black, African, or African American. This definition ensured the inclusion of a broader range of individuals for the study.

The racial make-up of the city is 49.3% White, 44.8% Black or African American, 1.8% Asian, 2.8% Hispanic or Latino, and 0.3% American Indian or Native Americans (U.S. Census Bureau, 2017). The population of people 18 years or older in the city is 232,150, of which African Americans make up 41% (U.S. Census Bureau, 2017).

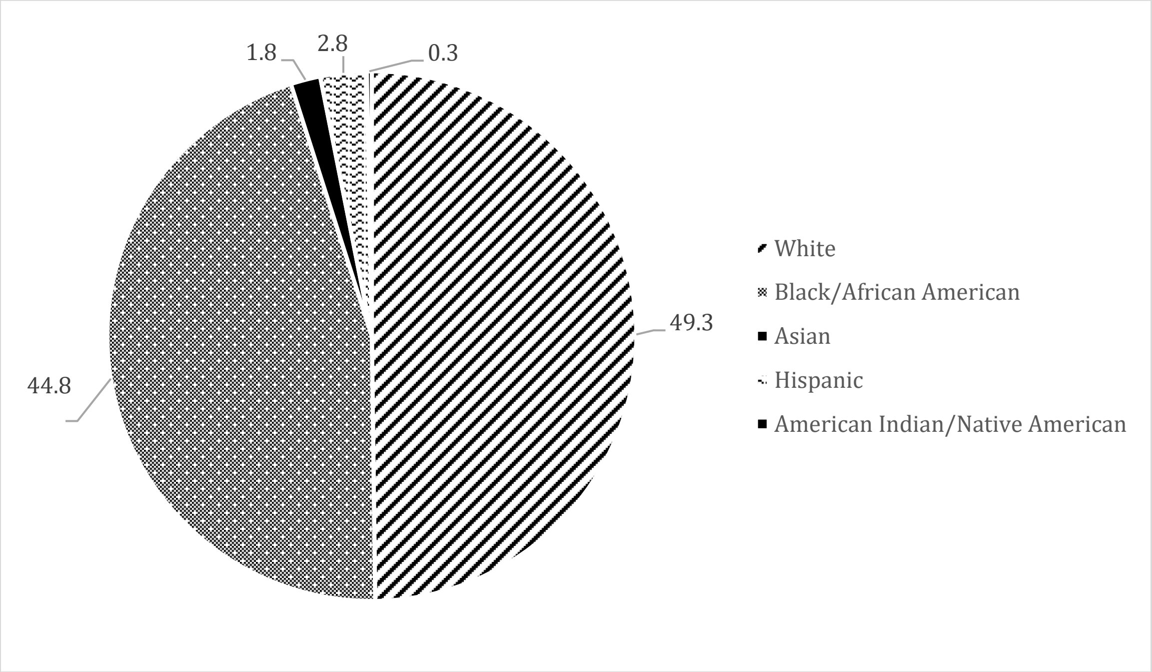

Figure 1. Racial demographics (U.S. Census Bureau, 2017)

Of the 30.5% of the city's population who live below the poverty line, 42.3% are African Americans (U.S. Census Bureau, 2017). There are mixed reports regarding the impact of socioeconomic status on health care trust among African Americans (Hammond, 2010; Rajakumar, Thomas, Musa, Almario, & Garza, 2009; Watkins et al., 2012). However, Guerrero, Mendes de Leon, Evans, and Jacobs (2015), in a study exploring the differences in socio-demographic and psychological correlates of institutional trust in health care among older African Americans and other minorities, concluded that psychological factors played a more prominent role in health disparities among older African Americans. Social interactions and the impact of the environment were identified as major players in the level of trust in health care (Guerrero et al., 2015).

Research Questions and Hypotheses

The research questions I developed for this study were primarily focused on the socio-cultural factors that influence the willingness to participate in clinical trials among African Americans aged 18 years and older. The following research questions and corresponding hypotheses guided this dissertation:

Research Question 1: What is the relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans?

$H_0$1: There is no statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

H_A1: There is a statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

Research Question 2: What is the relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans?

$H_0$2: There is no statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans.

H_A2: There is a statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans

Research Question 3: Does social influence within the African American community affect the willingness of an African American to participate in clinical trials?

$H_0 3$: There is no statistically significant relationship between social influence within the African American community and the willingness of an African American to participate in clinical trials.

$H_A 3$: There is a statistically significant relationship between social influence within the African American community and willingness of an African American to participate in clinical trials.

Assumptions

My first assumption for this study was that the validated survey instrument would be fully completed by all research participants once administered. I also assumed that research participants would have the necessary educational level to read and understand the content of the survey with no difficulty and that they would truthfully answer the questions. Another assumption was that the lack of willingness to participate in clinical trials is a known phenomenon within the African American community and may have limited the participation rates in this study. Finally, I assumed that the results of this research could provide guidance for the development of interventions aimed at improving African Americans participation in clinical trials.

Limitations

I identified some factors that could have limited the findings of this study. These include the potential for incomplete surveys being submitted by participants as well as a possible low level of honesty in the responses. The responses from the participants may have been influenced by my presence, skewing the results. Another limitation laid in the fact that the quality of a quantitative research depends profoundly on the researcher’s efficiencies and is influenced by individual predispositions of the researcher (see Anderson, 2010). Furthermore, due to the planned data collection method, in which only church attendees who agreed to participate in the research were included, the results may not be generalizable to all church attendees in a greater metropolitan area of Ohio. Although a previous study reported that religiously based differences on social issues are less evident among African Americans compared to the overall population, with 53% of African Americans polled reporting attending religious services at least once a week (Sahgal & Smith, 2016), the results of this study may not be generalizable to the entire African American population because of differences in opinions that may exist among church goers vs. non-church goers.

Delimitations

This study included only African Americans residing in a greater metropolitan area of Ohio. Recruitment of other ethnic groups did not fit in the boundaries of the study. The choice of the geographic location for this study was based on ease of conduct and the availability of a higher population of African Americans in the selected area in, Ohio.

Definition of Terms

African American: An American citizen of Black, African descent (“African American,” 2017).

Clinical trial: A process used to evaluate the safety and efficacy of medical strategy, treatment, or device in humans and that highlights the best medical treatment that best serves a certain group of people (NIH, 2017).

Social influence: Changes in behavior, opinion, or beliefs that individuals initiate based on interactions with the prevailing social factors. It represents the process through which an individual can adapt their opinions, revise their beliefs, or adjust their behavior, resulting from social interactions with others (Moussaïd, Kämmer, Analytis, & Neth, 2013).

Willingness: An individual’s inclination or favorable mental disposition towards an action (“Willingness,” 2017).

Implications for Social Change

Failure to increase the participation rates of African Americans in clinical trials will inhibit the progress of clinical trial research into novel and effective methods in drug development (Frew et al., 2015). I designed this study to identify how social influence affects the willingness of African Americans to participate in clinical trials as a platform for the development and implementation of interventions to improve clinical trial participation among this population. This study will serve as a starting point for further research into the interactions stated in the focus of this study.

Summary

Clinical trial participation is an intricate part of advancing medical science and drug development. Notwithstanding the acceptance by most Americans, the overall participation numbers continue to see an uncontrolled decline (Anwuri et al., 2013). Low rates of participation in clinical trials ultimately impact advancements in medical science, the health of the nation, and eventually the economy of our nation. In this chapter, I examined the potential link between the low participation rates among African Americans and social influence, which represents the process through which an individual can adapt their opinions, revise their beliefs, or adjust their behavior, resulting from social interactions with others. An understanding of this interaction will be of benefit to clinical researchers by enabling the identification and elimination of barriers to participation among African Americans. In the next chapter I reviewed some existing literature which highlight results that support the existence of a relationship between social factors and willingness to participate in clinical trials.

Chapter 2: Literature Review

Introduction

In this chapter, I will provide a review of relevant literature related to people's willingness to participate in clinical trials and African Americans' willingness specifically, focusing on the roles of distrust and other barriers created by the historical knowledge of unethical practices against African Americans and other ethnic minorities in the United States. I will also review literature related to the potential effects of normative social influence and sociocultural norms like generational information sharing on knowledge, attitude, and beliefs (KAB) towards participation in clinical trials. Literature related to social norms that impact health behavior will also be reviewed.

The NIH (2017) defined a clinical trial as "A research study in which one or more human subjects are prospectively assigned to one or more interventions" (p. 4). Clinical trials (also known as clinical treatment research) is medical research through which researchers witness the progression of a disease or condition in human beings to assess the effectiveness of a drug or therapy (Brown & Topcu, 2003). Clinical trials serve to explore the efficacy and safety of various medicinal treatment strategies in humans (NIH, 2014). The problem of low ethnic minority participation in clinical trials is significant to public health because there is a greater risk of morbidity and early mortality among African Americans compared to other races in the United States and race correlates with the rising health inequalities in the United States (Fisher & Kalbaugh, 2011). I aimed this systematic literature review at elucidating the interactions between social influence and willingness to participate in clinical trials. Several factors have been identified by researchers that affect willingness to participate in clinical trials including age, race/ethnicity, gender, socioeconomic status, education, health status, knowledge about clinical trials, perceived risk or benefit, compensation, altruism, and trust.

Search Strategy

I located the information presented in this literature review using peer-reviewed journal articles and books found through the EBSCO Research Database, PubMed, and Google Scholar. I focused on literature published within the past 5 years. My search strategy for identifying relevant literature consisted of Boolean combinations of the following terms: *social influence, normative social influence, willingness, African Americans AND clinical trials, African Americans AND clinical research, African Americans AND clinical trials, barriers to research participation, Tuskegee Study and distrust, African American AND research willingness, distrust AND research, cultural distrust, storytelling, historical trauma, social influence, Tuskegee experiment, unethical experiments AND African-Americans, social distrust, fear of research,* and *African American knowledge of research*.

Developing Social Influence Concept

Individuals within a community regularly make decisions in a social environment; they are more likely to adopt the opinion of others while ignoring their own, with little or no regard to the accuracy of the information (Schöbel et al., 2016). Most human decisions are made in a framework of highly multifaceted social interactions, and many of an individual’s decisions are influenced by the behavior of others (Hertz, Romand-Monnier, Kyriakopoulou, & Bahrami, 2016). Social influence represents the changes in behavior, opinion, or beliefs that an individual may initiate based on interactions with the prevailing social factors and the process through which an individual can adapt their opinions, revise their beliefs, or adjust their behavior, resulting from social interactions with others (Moussaïd et al., 2013). There are two types of social influence that are helpful in explaining human conformity: normative social influence and informational social influence (Schöbel et al., 2016). The former, which was the focus of this study, defines behavior motivated by an individual’s desire to achieve an appreciated, clear self-identity, followed by an expression of a defined impression to others (Schöbel et al., 2016). The latter defines behavior that is developed from valuable information provided by another individual’s opinion and used to improve judgement or a decision (Schöbel et al., 2016).

Although the impact of social influence on the willingness of African Americans to participate in clinical trials could be positive or negative, my focus in this study was to understand how social influence serves to deter most African Americans from participating in clinical trials. Research has documented associations between sociocultural factors and health; however, the role of social influence in potentially diminishing the willingness of African Americans to participate in clinical trials is not well established (Berkman & Kawachi, 2000; Marmot & Wilkinson, 2006).

Since common opinions are created by common cultural beliefs, and per Moussaïd et al. (2013), opinions are more likely to be reinforced by group discussions conducted by individuals with similar judgement, it is important to identify the process by which the history of unethical practices against this population continues to be at the forefront of all identifiable barriers to their participation in research, despite great advances in research participant protections and research ethics in the United States. The answer to this could be present in African Americans’ recognition of the activities that apply to them based on their desire to conform to a behavior or norm developed through sociocultural values (Palacios et al., 2015). There are social factors beyond the memories of the Tuskegee Study that play a role in negatively influencing African Americans’ willingness to participate in clinical trials (Saleem et al., 2016).

Some researchers have argued that the history of abuse and unethical practices may not be the direct driver of societal distrust in clinical trials (Durant et al., 2011; Saleem et al., 2016), making it plausible that social factors (i.e., opportunity, income, ethnic minority status, and health conditions), which are antecedents of inequity in the U.S. society, could contribute to African Americans’ lack of willingness to participate in clinical trials (Lang et al., 2013). An individual’s social conditions, environmental exposures, and past experiences work together to produce behavior and motivation (Boulware et al., 2016). Individuals also apply differential weighting to social information based on the authority of other individuals who are decision makers, and this influence of authority is at its highest strength when the decision of an individual with authority contrasts with private information (Schöbel et al., 2016).

Conformity behavior has been shown to be motivated by developing and maintaining acceptance (Schöbel et al, 2016). The results of this study provide insights into the effects of the relationship between social influence and the willingness of African Americans to participate in clinical trials as a benefit to health promotion.

The Concept of Storytelling

Storytelling is an age-old institution that exists among different communities and cultures around the world. Information sharing preserves cultural beliefs and practices from generation to generation, and most people will remember most negative actions towards them to avoid similar actions in the future (Barton & Barton, 2017). Stories have been found to play a vital role in the lives of individuals across various age groups and diverse backgrounds (Barton & Barton, 2017). The impact of storytelling in native communities is well documented for cultural and historical legacy and communication (Barton & Barton, 2017). The younger generation can form and build a strong identity that could potentially affect their ability to develop immediate opinions about well-established issues like racism and distrust for the healthcare community (Barton & Barton, 2017). According to Eder (2010), through storytelling, children are empowered to frame their understanding of multifaceted moral issues within a society.

Nolan et al. (2008) suggested that normative information could be an underdetected source of influence on behavior. The behavior of younger African Americans who are apparent descendants towards clinical trials continues to be affected by the narratives that originated from the Tuskegee Study (Sacks, 2015). Storytelling can affect behavior and when life events or experiences are considered, this process of storytelling could create a communal experience that links the teller to listener, thereby promoting similar behavior and attitudes (Banks-Wallace, 1998; 2002; Larkey et al., 2015; Palacios et al., 2015). The mistrust exhibited by African Americans for healthcare services and healthcare providers as well as other institutions has survived many generations. Evidence of this assumption may be found in the fact that younger African Americans with little or no negative experience exhibit similar levels of mistrust for clinical trials (Sacks, 2015).

An Examination of Willingness Among African Americans

African Americans differ from European Americans and other ethnic groups in their willingness to participate in clinical trials, and this issue has been attributed to a host of factors including a low level of trust of medical research (Meng, McLaughlin, Pariera, & Murphy, 2016; Shavers et al., 2002). Trust has been suggested as an antecedent to willingness (Chu, Kim, Jeong, & Park, 2015), and there is a clear distinction in the level of trust between African Americans and other races in the United States (Meng et al., 2016). African Americans may not be willing to participate in clinical trials due to the influence of family members as well as fears inculcated through cultural beliefs and folklore (Hammond, 2010; Meng et al., 2016). This idea is supported by research, which suggested that a link exists between social factors operating within a group and their willingness to participate in clinical trials (Meng et al., 2016).

Willingness to participate in clinical trials among African Americans includes barrier issues related to trust, experimentation, communication, and logistics (Luebbert and Perez, 2016). Fear and lack of trust for research were the most common barriers to participation in clinical trials among African Americans (Hughes et al. 2015). These barriers have been attributed to factors like lack of information related to the research and prevailing knowledge of historical instances of unethical research practices (Hughes et al., 2015). Other social factors like racism, attitudes towards research, fear of being used as guinea pigs, psychological barriers to recruitment, and socioeconomic status have also been identified (Boulware et al., 2016; George et al., 2014; Tanner et al., 2015). Most African Americans do not have a positive perception of safety and favorable feeling towards clinical trials (Hughes et al., 2015). Research has shown that there is an increase in the likelihood that a person would participate in clinical trials based on their perception of safety, and there is a strong association between perceived wellbeing, advantageous feeling, and willingness to participate in clinical trials (Chu et al., 2015).

Health Disparities Experienced by Black or African Americans

The Centers for Disease Control and Prevention (2017) defined disparities as the existence of differences in the incidence, prevalence, and mortality of a disease, together with its related adverse health outcomes, among specified populations. African Americans represent approximately 13.3% of the U.S. population (U.S. Census Bureau, 2016) and continue to experience an unequal burden of disease, limited access to health and health care services, and lower life expectancy when compared to other races (Correa-de-Araujo, 2017; Frist, 2005). It is not coincidental that the African American population is the least healthy group in the United States. Dublin (1928) stated that “improving the health of African Americans to a state where it compares favorably with that of Caucasians, would easily eliminate the many disabilities which plague the African American population and improve its economic status” (p. 80). There are social factors at work, deeply rooted in the history of African Americans in the United States, which continue to impact the overall health of this population (Noonan et al., 2016). Social determinants of health disparities (i.e., poverty, housing, education, access to healthcare, environmental exposures, and racism) continue to play a vital role in the health and wellbeing of African Americans (Noonan et al., 2016). Racism, which is correlated with deficiencies in education, housing, income, and access to health services, continues to affect the overall health of this population (Noonan et al., 2016). There is evidence that race, as a factor in health disparities, is not moderated by other factors like age, sex, and educational level (Paradies et al., 2015). There is also documented evidence of a relationship between perceptions of racism and mistrust for healthcare providers; the perception of racism has been shown to have a significant negative effect on the trust and satisfaction with care (Bankert, Peters, Clark, & Keeves-Foster, 2006).

African Americans and Participation in Clinical Trials

Although the burden of disease is higher among African Americans when compared to other ethnic minorities, and African Americans are at a greater risk of morbidity and early mortality (Fisher & Kalbaugh, 2011), participation of African Americans in current clinical trials continues to be a difficult task for the drug development industry (Fisher & Kalbaugh, 2011). There is evidence of low participation in clinical trials among all minorities in the United States (Chen et al., 2014; Shavers et al., 2002) with most research identifying distrust for medical research as the main cause of the issue (Hughes et al., 2015; Luebbert & Perez, 2016; Shavers et al., 2002). The global rates of participation in clinical trials is low, particularly among ethnic minorities in the United States, and this issue has not seen an improvement over the years (Hughes, et al., 2017; Lang et al., 2013). African Americans are particularly at a disadvantage from the unintended consequence of this issue (Hughes et al., 2017).

Quantitative and qualitative research examining the barriers and facilitators to clinical trials participation among African Americans has revealed numerous notable barriers. The barriers include lack of awareness regarding clinical trials, mistrust, fear of research, and fear of adverse consequences (Corbie-Smith, Thomas, & George, 2002; George et al., 2014; Owens, Jackson, Thomas, Friedman, & Hébert, 2013). Altruism, the desire to help others or their community, has been identified as a one of the main facilitators for clinical trial participation by African Americans (Shavers, 2001). Others include access to healthcare and healthcare services, perceived risk, and compensation (Brown & Topcu, 2003; Byrne, Tannenbaum, Glück, Hurley, & Antoni, 2014).

In a study conducted by Lang et al. (2013), they aimed at clarifying the factors which impact African American willingness to participate in health-related research, the researchers concluded that the willingness to participate in clinical trials exists among this population. Their results showed that over 70% of the clinical trials naïve participants in the study expressed willingness to participate in clinical trials (Lang et al., 2013). This group consisted mostly of younger adults (<40 years old) who also attained a higher level of education that the other participants. The researchers also pointed out that trust was an impediment to participation and that participants with knowledge of the Tuskegee Syphilis Study were 50% less likely to show willingness to participate in clinical trials (Lang et al., 2013). Although this willingness exists, consideration must be given to the unique sociocultural factors which exist within the African American community through which behaviors are formed and decisions are made based on local and community beliefs (Lee et al., 2016).

African Americans and Distrust of the Medical Community

The various past and present medical atrocities which African Americans have been victims of have led to a lack of trust for the medical community in the United States. Research has shown that African Americans are less likely to participate in research and exhibit more distrust of the medical community than any other ethnic group in the United States (Boulware et al., 2016; Mokwunye & Nneka, 2006). There is also documented evidence that African Americans continue to believe that the medical community, possibly due to poor communication, do not acknowledge their perspective during their interactions (Cuevas, O'Brien, & Saha, 2016). A combination of personal and passed-on experiences and ongoing reiteration of doubts has led to a strong assertion of distrust over the years in African American communities (Cuevas et al., 2016). The legacy of racism and racial discrimination in healthcare is linked to the issue of lack of trust in medical research among African Americans and its perception has become imbedded in the sociocultural behavior of this population towards participation in all things related to health and clinical trials (Boulware et al., 2016).

There are differences in the level of distrust for clinical trials among African Americans based on age (Boulware et al., 2016); thus making it logical to assume that the issue of distrust in medical research should reside mostly among the elderly African Americans, who may have been directly impacted by landmark episodes of unethical research practices, and less with the younger generation, raised in an era where stringent regulations prevent such brash occurrences. This idea is supported by research, which concluded that convincing older African Americans to participate in clinical trials has been and continues to be a difficult task, despite unfavorable health disparities that they experience in the United States (Sabir & Pillemer, 2014). The term distrust, as used in this research encompasses the both cultural mistrust and medical mistrust. Cultural mistrust is defined as an inclination among African Americans to distrust European Americans (Terrell & Terrell, 1981). Research has shown that distrust of the health care system could be an important barrier to individuals' willingness to seek healthcare services, adhere to preventive health care and treatment regimens, as well as participate in clinical trials (Rose, Peters, Shea, & Armstrong, 2004).

Patients who exhibit greater trust in their healthcare providers are more likely to consent to participation in clinical trials (Westergaard, Beach, Saha, & Jacobs, 2014). A widely-accepted assumption is that under-representation of African Americans in clinical trials is a result of less willingness to participate due to mistrust and fear created by a history of unethical practices (Stuchlik et al., 2015). There is a greater distrust for clinical trials within the African American community when compared to the Caucasian community (Durant et al., 2011; Fisher & Kalbaugh, 2011). This distrust among African Americans has been attributed to the history of unethical practices and harsh treatments that were meted out to the African Americans in the past e.g. Tuskegee Airmen Study (Durant et al., 2011). There are many in the African American community for whom the memories of the Tuskegee Study preserved in their thoughts and decisions related to health care services are informed by these memories both on an individual as well as on a group level (Doucet-Battle, 2016).

Although distrust and socio-cultural factors have been identified as the leading cause of the lack of or reduced willingness of African Americans to participate in clinical trials, Anwuri et al. (2013) provided background for other potential factors, which may play a role in the process, which leads to the decision not to participate in clinical trials. These factors include individual-level factors like fear, faith, culture; interpersonal-level factors like healthcare provide-patient relationship and information sharing about research within family boundaries; institutional-level factors like physician training, regulations, and limited minority patient pools; and public policy-level factors like federal mandates (Anwuri et al., 2013).

The impact of knowledge regarding research cannot be diminished. Research conducted using a hypothetical setting showed that an informed consent process which encompasses teaching regarding the clinical trials processes and safeties currently in place to protect subjects, increases the number of patients who are willing to participate in clinical trials. The researchers concluded that there was a significantly lower likelihood of patients receiving pre consent education to refer to factors like mistrust, fear of adverse effects, absence of perceived benefits, and patient privacy as reasons for lack of willingness to participate (Dunlop et al., 2011). Though well recognized and widely researched with over 20 years of a statutory directive to promote actions that increase inclusion of minorities in government-funded clinical trials, low rates of participation of African Americans in clinical trials continues to be an issue (Chen et al., 2014; Chu et al., 2015). This supports the conclusion by researchers of the existence of inherent social factors within this populations that drive low participation in clinical trials (Chen et al., 2014).

Other Barriers to Clinical Trials Participation Among African Americans

There are various barriers that have been identified in research as the leading factors that limit the willingness of African Americans to participate in clinical trials. Various studies have identified the following factors as important barriers to willingness to participate in clinical trials. These include: age, race/ethnicity, gender, socioeconomic status, education, health status, perceived risk or benefit, altruism, distrust, and knowledge of clinical trials (Advani et al., 2003; Boulware et al., 2016; DeFreitas, 2010; Ding, et al., 2007; Dunlop et al., 2011; Dunn et al., 2009; Durant et al., 2011; Holman et al., 2010; Israni et al., 2004; Lee et al., 2005; Mathews et al., 2009; Sabir & Pillemer, 2014; Shavers et al., 2002; Volkmann et al., 2009; White & Hardy, 2010). This study focused on the barriers that are moderated or amplified by the unique sociocultural factors which exist within the African American community. It is important to understand the point at which altruism is overcome by fear, and how social influence lends weight to distrust in the African American community.

Theoretical Foundation

Fishbein and Ajzen's theory of planned behavior (TPB) served as a conceptual framework for this study. As a well-established and recognized social cognitive theory, the TPB has been broadly used to effectively predict and elucidate different health behaviors and intentions to include health service utilization (Sicilia, Sáenz-Alvarez, González-Cutre, & Ferriz, 2015). The TPB model is based on a belief that assumes that the intention of an individual to exhibit a behavior is an important determinant for exhibiting that behavior (Ajzen & Madden, 1986). The extent to which an individual will plan and develop their efforts leading to the expression of a behavior defines intention (Ajzen & Fishbein, 1980). Intention is a motivational construct which is determined by attitudes towards the behavior, subjective norms, and perceived behavioral control (Ajzen, 1991); and defined as the probability that an individual will exhibit a specific behavior in specific conditions, regardless of the outcome. The development of this model was preceded by works of social psychologists who suggested “attitudes could explain human actions” (Ajzen & Fishbein, 1980, p. 13). According to Ajzen and Fishbein (1980), “people consider the implications of their actions prior to a decision to engage or not engage in each behavior” (p. 5). The goal of TPB is to describe the cognitive process of behaviors, focusing on a person’s choice or desire to engage in a specific behavior (Hale, Householder, & Greene, 2002). Intention has been identified as a significant predictor of behavior, leading to the belief that interventions must include models that promote intention-related strategies (Doswell, Braxter, Cha, & Kim, 2011). With consideration to external variables, which constitute the characteristics of a behavior, a person’s trust in the outcome of a behavior determines that person’s attitude towards that behavior (Montano & Kasprzyk, 2015).

The TPB has been utilized in research which evaluated willingness to participate in clinical trials as the theoretical foundation. In a study conducted by Quinn et al. (2011) to explore the application of the theory of planned behavior to patients’ decisions about participating in a clinic trial, the results highlighted potential of the TPB as a useful tool for investigating psychosocial needs as they relate to behavioral intention of clinical trial participation. This theory lends a benefit to my research because provides a perspective that allows the researcher to evaluate individual intentions and attitudes towards participation in clinical trials, as well as consider objective norms that influence this behavior, thus highlighting behavioral intent. My research considered that subjective norms are affected by an individual’s perceptions of his/her family’s and social beliefs, i.e. a consideration of whether these close social networks will approve or disapprove of the planned behavior (Ajzen & Fishbein, 1980). The constructs of social influence, which exerts its impact through different routes, was measured in the framework of attitudes and self-efficacy opportunities, intention, and past behavior (Vries et al., 1995). Social influence was defined as an individual’s conformity, compliance, and obedience to social factors within the community with which the individual identifies (Vries et al., 1995).

Summary

In this section, I discussed the issue of low participation in clinical trials among African Americans in the United States, using literature to show the significance of this issue. Though well documented in various reports, bridging this wide participation gap has been a daunting task for both researchers and pharmaceutical companies. Social factors which border around racism play a major role in promoting distrust of the healthcare community. Research has identified the existence of some level of willingness which may be diminished by the well-established beliefs developed through social influences, storytelling, and personal experiences. Conventional methods, which involve practices like the expansion of recruitment efforts, inclusion activities and information sharing, have not been effective, thus highlighting the need for a creative approach to the identification of the antecedents to the distrust of this population for clinical trials. Interventions to improve participation must be culturally acceptable and consider all aspects of how distrust is learned through social interactions and storytelling. In the next chapter, I will describe the research methods, as well as state the research questions and hypotheses

Chapter 3: Research Method

Introduction

In Chapters 1 and 2, I discussed the historically low rate of participation of African Americans in clinical trials compared to other ethnicities despite multiple efforts made by researchers and federally funded agencies to offset these differences (see Hughes et al., 2015). Research has provided evidence that African Americans are less willing to participate in clinical trials due to a lack of trust of the research community as well as other socially modifiable factors (Boulware et al., 2016; Mokwunye & Nneka, 2006). In this chapter, I will discuss the quantitative research method which was used to determine (a) the relationship between KAB towards clinical trials and African Americans' willingness to participate in clinical trials and (b) whether social influence affects this group's willingness to participate in clinical trials. The dependent variable was willingness to participate in clinical trials, and the independent variables were social influence and KAB towards research.

Research Questions and Hypotheses

The questions I developed for this study were primarily focused on the socio-cultural factors that influence the willingness to participate in clinical trials among African Americans aged 18 and older. The following research questions and corresponding hypotheses guided this dissertation:

> Research Question 1: What is the relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans?

$H_0$1: There is no statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

H_A1: There is a statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

Research Question 2: What is the relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans?

$H_0$2: There is no statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans.

H_A2: There is a statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans.

Research Question 3: Does social influence within the African American community affect the willingness of an African American to participate in clinical trials?

$H_0$3: There is no statistically significant relationship between social influence within the African American community and the willingness of an African American to participate in clinical trials.

H_A3: There is a statistically significant relationship between social influence within the African American community and willingness of an African American to participate in clinical trials.

Study Design

I conducted this study using a cross-sectional design to determine the prevalence of the lack of intended willingness to participate in clinical trials for this population as well as to collect data on individual characteristics, including exposure to social factors, alongside information about the outcome of interest. Quantitative data, in the form of a one-time questionnaire administered by paper instrument, were collected from research participants.

Justification for Study Design

This research design was acceptable for study because it is inexpensive and does not require a lot of time. The cross-sectional design also allows for multiple variables at the time data are collected as well as for outcomes and results to be analyzed to create new theories for future research (Frankfort-Nachmias & Nachmias, 2008). The quantitative research approach supports the research questions and allows for a higher level of objectivity and accuracy, aggregation, quantification of data, and a concise presentation of collective results (Lakshman et al., 2000). In addition, it is easy to design and implement surveys needed for a cross-sectional design, and the use of standardized surveys increases the reliability and comparability of research data (Lakshman et al., 2000). Check and Schutt (2012) defined survey research as “the collection of information from a sample of individuals through their responses to questions” (p. 160).

Participants and Sampling Strategy

The target population for this study was African Americans, aged 18 years and older, who resided in a greater metropolitan area of Ohio, and were able to sign an informed consent form. Only participants who met the study inclusion criteria were consented and allowed to participate in the study. I employed a sampling strategy in this study since it was not feasible to collect data from the entire African American population in the targeted greater metropolitan area of Ohio. Sampling strategies in survey research aim to attain an adequate sample that is representative of the population of interest (Ponto, 2015). To ensure a homogenous sample, the sampling frame included the members of up to 10 predominantly African American churches. I achieved access to this population through contact with the church leadership in person or via e-mail; they granted the necessary approval for me to approach their congregation for participation in this study. My initial assumption was that this approval would be granted if I provided proper information regarding the social implications of this research study to the church leaders. If necessary, I planned on expanding this sampling pool to include other predominantly African American organizations as needed to meet the statistical power requirements for the study.

With approval from the church leadership, I approached the members of the congregation at specified times for informed consent and receipt of the surveys. To ensure only consenting participants completed the survey, the informed consent forms were attached to the surveys distributed to each participant. For the inclusion of the members of the congregation who were not present at the specified times, I also sent the surveys via e-mail.

Sample Size Calculation

For the data analysis, I calculated a necessary sample size of 371 participants using the formula outlined in Figure 2. For this calculation, I used data from the U.S. Census Bureau (2016) report for the city and African American population estimate. Power analysis for a regression analysis with two predictors was conducted in G*Power using an alpha of 0.05, a power of 0.80, and a medium effect size ($f^2 = 0.15$) to determine that out of the sample size of 376, a minimum of 43 responses were required to achieve 80% power.

$$SS = \frac{Z^2 * (p) * (1-p)}{c^2}$$

Z = Z value (1.96 for 95% confidence level)
p = African American population percentage > 18 years expressed as decimal (41% = .41)
c = confidence interval, expressed as decimal (.05)

Figure 2. Sample size calculation formula. p represents data from U.S. Census Bureau (2016).

Data Collection

I provided eligible participants with an informed consent form that highlighted the objectives of the study as well as the risks and benefits of participation. Participation was not mandated, and no names or other identifying information were collected from the participants. Data were collected using a self-administered questionnaire, which was distributed to members of 6 predominantly African American churches in a greater metropolitan area of Ohio. A self-administered survey is specifically designed for completion by participants in the research without the involvement of an interviewer (Lavrakas, 2008). The use of self-administered questionnaires has been demonstrated to be inexpensive, while requiring less involvement on the part of the researcher; it creates a valuable and valid approach, providing clarity in the method used to explore and explain variables and theories of interest (Ponto, 2015). I disseminated paper surveys to the members of the church congregation who had consented to participate in this study. Participants were allowed privacy and adequate time to complete the survey within the church premises, and sealed submission boxes were provided to ensure the anonymity of all submissions.

Instrumentation

For this study, I developed a survey to include the factors identified in the literature review as having an impact on the willingness to participate in clinical trials. I developed the survey myself because there was no readily available survey that captured all the items needed to answer the research questions of this study. I identified four validated scales and used them in combination to develop different sections of the survey for this study, including: The Perceived Social Influence on Health Behavior Instrument (PSI-HBS; Holt et al., 2010), the Distrust of the Healthcare System Scale (DHS; Katapodi, Pierce, & Facione, 2010), the Group-Based Medical Mistrust Scale (GBMMS; Thompson et al., 2004), and the Attitudes and Factors Affecting Young Adults' Willingness to Participate in Clinical Research Scale (Brandt, 2013). Adequate effort was made to ensure that proper permissions were obtained as needed for the use of these instruments. Following the development of the new survey, an expert review panel reviewed the survey and all feedback that I received was incorporated into the final survey instrument.

Description of Instruments and Validation Studies

Perceived Social Influence on Health Behavior Scale (PSI-HBS)

The PSI-HBS (Holt et al., 2010) is readily available in the public domain with no restrictions on utilization for research purposes. The scale was developed to evaluate the perceived part played by others in the health behavior choices and decisions of individuals and consists of 10 items assessed in 4-point, Likert-type format (*strongly disagree, disagree, agree,* and *strongly agree*). The researchers measured perceived social influence on health behavior based on utilitarian influence, value-expressive influence, and informational influence (Holt et al., 2010). The instrument has a possible range of 10–40, with higher scores indicative of higher levels of beliefs (Holt et al., 2010). The PSI-HBS was validated through a series of six systematic steps: review of literature to locate existing scales, modification of existing instrument items, cultural appropriateness and face validity review of item, item revision, finalization of instrument, and psychometric testing of final instrument (Holt et al., 2010). Test-retest reliability was determined by administering the instrument via telephone to a national probability sample of 55 African Americans, and item-total correlations, internal consistency, discriminant validity, and factorial validity were determined administering the instrument by telephone to another national probability sample of African Americans (Holt et al., 2010). African Americans, aged 21 years and older, living in a private residence with a telephone were recruited by professional interviewers with contact information randomly selected from a nationally representative pool developed based on census tract (Holt et al., 2010). The internal consistency of the overall instrument was α = .90 (with subscales reported as α = .84 for utilitarian influence, α = .85 for value-expressive influence, and α = .81 for informational influence; Holt et al., 2010).

Distrust of the Healthcare System Scale (DHS)

The DHS (Katapodi et al., 2010) is readily available in the public domain with no restrictions on utilization for research purposes. This four-item scale addresses the negativity and confirmatory biases, targeting distrust as an influencer of health behavior and was developed within the framework of a study of if, and in what way, distrust of the health system and tendency to use healthcare services influence frequency of mammograms and clinical breast exams (Katapodi et al., 2010). The internal reliability and convergent validity of the DHS scale were supported when administered to a multicultural sample of 184 women (Cronbach alpha = 0.71; Katapodi et al., 2010). Responses are made on a 4-point, Likert-type scale (*strongly agree* to *strongly disagree*) where higher scores indicate greater distrust.

Group-Based Medical Mistrust Scale (GBMMS)

The GBMMS (Thompson et al., 2004) is readily available in the public domain with no restrictions on utilization for research purposes. It was developed to measure suspicion of health care systems and professionals using a 12-item Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*) with a 12 to 60 score range. Validation was achieved in a study which investigated the psychometric properties of GBMMS and its association with cancer screening attitudes and breast cancer screening practices among African American and Latina women (Thompson et al., 2004). The results supported the validity of the scale and suggested that the scale can be used to investigate medical mistrust (Thompson et al., 2004).

Measures

The new survey incorporated only components of existing validated instruments which address the research questions for this study. No modifications to the wordings were made in the new survey. The survey started with an introduction which covered the purpose of the study, definition of clinical trials, participants' rights to their preference to answer or refuse to answer any of the questions, an acknowledgement of gratitude and instructions for submitting the survey. The survey was divided into multiple sections for ease of data collection. Appropriate Institutional Review Board approval was obtained for the final instrument. The following measures were captured in the survey:

KAB: The survey included questions that were used to examine demographic and informational factors which are associated with knowledge attitudes and beliefs regarding clinical trials, as well as identified by previous research as potentially impacting willingness to participate in clinical trials.

- Demographic Factors: Demographic questions consisted of five items including: age, gender, race, ethnicity, and level of education. For this study level of education was used as a proxy for socioeconomic status. Education is often considered a critical indicator of socioeconomic status because it conveys information regarding earning potential across the lifespan of an individual (Shavers, 2007; Winkleby et al., 1992).

- Informational Factors: According to the theory of planned behavior, informational factors are part of the background factors that may affect an individual’s beliefs and attitude towards clinical trials. These informational factors are made up of knowledge acquired through both formal and informal education. Thus, participants were asked questions to determine if they have knowledge regarding clinical trials as well as the source of their knowledge.

Items from the survey Attitudes and Factors affecting Young Adults’ Willingness to Participate in Clinical Research (Brandt, 2013) were utilized to capture data for this measure.

Willingness to participate: Using a closed-ended response of “yes”, “no”, or “don’t know” / “unsure” response, the second section of the survey examined three different situations related to willingness to participate. These include:

- Willingness to participate in a clinical trial related to the health of the individual completing the survey,
- Willingness to participate in a clinical trial related to the health of a close friend or family member, and
- Willingness to participate in a clinical trials study that only contributed to scientific knowledge**.**

Items from the survey Attitudes and Factors affecting Young Adults’ Willingness to Participate in Clinical Research (Brandt, 2013) were used to develop this section.

Social influence: The survey was made up of questions that aim to examine the perceived role of others in the health behavior choices and decisions of individuals and consists of 10 items assessed in four-point Likert-type format (*strongly disagree*, *disagree*, *agree*, *strongly agree*, *neither disagree nor agree*). Items from the PSI-HBS (Holt et al., 2010) were used to develop this section of the survey.

Distrust: The survey included items from the GBMMS (Thompson et al., 2004) and the DHS (Katapodiet al., 2010) to assess individual and group levels of distrust among participants in this research study.

Data Analysis Plan

Descriptive statistics was used to characterize the study population. Frequency/percentage were reported for categorical variables (race, gender, socioeconomic status, education etc.) while mean and standard deviation were reported for continuous variables (age). Our outcome of interest is willingness to participate in clinical trials. Our predictors of interest include social influence, distrust of the health care system, demographic and informational factors. Regression and correlation analyses were utilized to assess if willingness is associated with any predictor of interest. A final regression model was performed to jointly test the associations between willingness and all the potential predictors. The regression model included the significant predictors/variables as covariates to account for potential confounding. The study population was characterized and the association between demographic variables and willingness to participate in clinical trial were described. Categorical variables were reported as percentages and for continuous variables, descriptive statistics were presented as means with standard deviations.

A *p* value adjustment can be used to control for family-wise error rate in a study with multiple hypotheses. However, given the exploratory nature of this study, a nominal *p* value threshold ($p < 0.05$) was applied for significance. All the analyses were performed in the Statistical Package for Social Sciences (SPSS).

These analyses were guided by the following aims of the study and only the items which address these aims were utilized from the validated scales:

- Aim 1: To describe the associations between KAB and willingness to participate in clinical trials among African Americans age 18 years and over. Correlation analyses were employed to test the association and to examine the direction of the association (positive or negative).
- Aim 2: To describe the associations between social influence and willingness to participate in clinical trials among African Americans age 18 years and over. Correlation analyses were employed to test the association and to examine the direction of the association (positive or negative).

Summary

In this section, I discussed the research design, study population, sample size consideration, instrumentation, and data analysis plan. I provided a detailed review of the planned analysis for this study which ensured that the research questions were adequately answered. I was aware of various opportunities for additional analyses with collected data but focused on the analyses that satisfied the current study, as well as set the stage for future studies. In the next chapter, the results of the analyses of the data collected for the study will be presented.

Chapter 4: Results

Introduction

The purpose of this quantitative study was to estimate the role of social influence in potentially diminishing the willingness of African Americans, 18 years old or older, to participate in clinical trials. In this study, I aimed to determine (a) the relationship between KAB towards clinical trials and African Americans’ willingness to participate in clinical trials and (b) whether social influence affects their willingness to participate in clinical trials. Quantitative data, in the form of a one-time questionnaire administered by paper instrument, were collected from research participants. I measured social influence and willingness to participate in clinical trials using items from the PSI-HBS (Holt et al., 2010) and Attitudes and Factors Affecting Young Adults’ Willingness to Participate in Clinical trials survey (Brandt, 2013) respectively. All survey instruments were utilized with permissions from their respective authors.

As discussed in the previous chapter, I used a cross-sectional design to estimate the prevalence of the outcome of interest for this population as well as to collect data on individual characteristics, including exposure to social factors, alongside information about the outcome of interest. This research design allowed for the inclusion of multiple variables at the time data were collected. Regression and correlation analyses were used to assess the relationship between willingness and any predictor of interest.

In this chapter, I will present the research questions, specific aims of the study, data collection process, study results, and the summary of the study. Narratives will be used to discuss study results and answer the following research questions with the aim of either failing to reject or rejecting the null hypothesis:

Research Question 1: What is the relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans?

$H_0$1: There is no statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

H_A1: There is a statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

Research Question 2: What is the relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans?

$H_0$2: There is no statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans.

H_A2: There is a statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans.

Research Question 3: Does social influence within the African American community affect the willingness of an African American to participate in clinical trials?

$H_0$3: There is no statistically significant relationship between social influence within the African American community and the willingness of an African American to participate in clinical trials.

H_A3: There is a statistically significant relationship between social influence within the African American community and willingness of an African American to participate in clinical trials.

Data Collection

I collected data for this study using a self-administered questionnaire, which was distributed to members of 6 predominantly African American churches in a greater metropolitan area of Ohio. Following the receipt of approval from the Walden University Institutional Review Board (Approval Number 05-21-18-0572997), paper surveys were distributed to the members of each church congregation, 18 years and older, who consented to participate in this study. Out of the 10 African Methodist Episcopal Churches approached, six agreed to allow me access to their congregation for this study. Over a period of 12 weeks, 300 study surveys were distributed, and 119 surveys were completed and collected. I deemed four completed surveys unusable because the demographic and other pertinent data were missing, so these participants who did not indicate their race and/or age were not included in the analysis. The completed surveys were securely stored, and data from the surveys were double entered into a password-protected computer file for analysis. No participant identifiable information was collected on the surveys, so no participant can be linked back to their completed survey.

Review of Survey Responses

Demographic Factors

All respondents were African American, and there were 48 males (42%) and 67 females (58%). With an average age of 52 years, 35% (*n* = 40) of respondents were ages 18 to 44 years, 37% (*n* = 42) were ages 45 to 64 years, 22% (*n* = 25) were ages 65 to 74 years, and 7% (*n* = 8) were ages 75 years and above. Most of the respondents had received formal education with only 14 (12.2%) reporting not having a high school diploma or general education development (GED). Table 1 provides a detailed summary of the demographic characteristics of the survey respondents.

Table 1

Descriptive Statistics for Demographic Variables

	%	*n*	*M*
Gender			
Male	41.7	48	
Female	58.3	67	
Age (in years)			52
18–44	34.8	40	
45–64	36.5	42	
65–74	21.7	25	
75 and above	7.0	8	
Education			
No high school diploma	12.2	14	
Undergraduate degree	33.9	39	
Graduate degree	15.7	18	
Postgraduate degree	6.1	7	

Note. *N* = 115.

When asked about their health status, respondents answered that they are generally healthy, reporting their health to be excellent (3.5%), very good (40%), good (47.8%), and fair (8.7%). A majority of respondents reported not having an illness that lasted more than 3 months (65.2%) and not being hospitalized in the past year (76.5%). When asked if a family member or friend had been ill or had an illness that lasted more than 3 months, approximately half of the respondents (52.2%) gave a positive response. Table 2 provides details of reported health status.

Table 2

Reported Health Status

	%	*n*
Excellent	3.5	4
Very good	40.0	46
Good	47.8	55
Fair	8.7	10

Note. *N* = 115.

Informational Factors

Formal education. To assess the impact of formal education in their knowledge of clinical trials, I asked respondents about "the education I received during school included learning about clinical trials." Respondents (see Table 3) did not believe that the education they received during school improved their knowledge about clinical trials with a majority answering that they disagreed (63.5%) or strongly disagreed (13%). A smaller number of respondents reported that they agreed (8.7%) or strongly agreed (2.6%) that the education they received through formal schooling improved their knowledge about clinical trials.

Table 3

Formal Education

	%	*n*
The education I received during school included learning about clinical trials…		
Strongly agree	2.6	3
Agree	8.7	10
Not sure	8.7	10
Disagree	63.5	73
Strongly disagree	13.0	15
Prefer not to answer	3.5	4

Note. *N* = 115.

To assess respondents' knowledge of clinical trials, I presented seven questions (i.e., three questions related to process/procedures of clinical trials and four questions related to the informed consent process) in the survey. A review of responses to the three questions that assessed knowledge associated with the procedures of clinical trials revealed that a high number of the respondents were not familiar with the clinical trials process. Twenty-one percent (*n* = 25) of respondents agreed that the statement "clinical trials studies determine how well treatment works" was sometimes true, and only one respondent (0.9%) agreed that this is always true. Similar responses were provided to the other two questions: (a) "Clinical researchers start with a set of research questions they want to answer before starting clinical trials studies," with 22.6% responding sometimes true, and only one (0.9%) responding agreed to this being always true; and (b) "In a randomized clinical trials study, you get to choose the treatment you want," with 16.5%

responding sometimes true, and only one (0.9%) respondent agreed to this being always true.

The responses to questions used to assess respondents' knowledge of the existence of a regulated informed consent process aimed at protecting the safety of participants in clinical trials showed that most of the participants did not understand the process of informed consent. Regarding awareness of participants, 19 respondents (16.5%) agreed this is sometimes true, and one respondent (0.9%) agreed that this is always true. Regarding awareness of potential participation risk, 13 respondents (11.3%) agreed this is sometimes true, and no respondent agreed that this is always true. Regarding awareness of potential benefits to participants, 20 respondents (17.4%) agreed this is sometimes true, and no respondent agreed that this is always true. Finally, regarding possible coercion to participate in clinical trials, 23 respondents (20%) agreed this is sometimes true, and four respondents (3.5%) agreed that this is always true. Overall, a high percentage of participants stated that they were unsure in all categories, which shows a high level of misinterpretation of the regulated process of clinical trials. Table 4 provides a complete report of respondents' knowledge scores.

Table 4

Knowledge about Clinical Trials

	n	%
Clinical trials studies determine how well treatment works		
Prefer not to answer	23	20.0
Don't know/unsure	63	54.8
Never	1	.9
Rarely	2	1.7

(table continues)

Clinical trials studies determine how well treatment works		
Sometimes	25	21.7
Always	1	.9
Clinical researchers start with a set of research questions they want to answer before starting clinical trials studies		
Prefer not to answer	22	19.1
Don’t know/unsure	63	54.8
Rarely	3	2.6
Sometimes	26	22.6
Always	1	.9
In a randomized clinical trials study, you get to choose the treatment you want		
Prefer not to answer	21	18.3
Don’t know/unsure	71	61.7
Never	1	.9
Rarely	2	1.7
Sometimes	19	16.5
Always	1	.9
Told that they are participating in a research project		
Prefer not to answer	10	8.7
Don’t know/unsure	73	63.5
Rarely	12	10.4
Sometimes	19	16.5
Always	1	.9
Told about the possible risks of the clinical trials study		
Prefer not to answer	17	14.8
Don’t know/unsure	83	72.2
Never true	1	.9
Rarely true	1	.9
Sometimes true	13	11.3
Told how they might benefit from the clinical trials study		
Prefer not to answer	26	22.6
Don’t know/unsure	65	56.5
Never true	2	1.7
Rarely true	2	1.7
Sometimes true	20	17.4

(table continues)

Told they must participate in order to receive medical care		
Prefer not to answer	7	6.1
Don’t know/unsure	52	45.2
Never true	22	19.1
Rarely true	7	6.1
Sometimes true	23	20.0
Always true	4	3.5

Note. *N* = 115.

Informal education. Using the following questions, I asked respondents if they had participated or ever been asked to participate in a clinical trial to assess their knowledge of clinical trials:

- Prior to today, have you ever been asked to participate in a clinical trials project?
- Prior to today, have you ever participated in a clinical trials project?
- To the best of your knowledge, has someone close to you, such as a family member or friend, ever participated in a clinical trials project?

Less than a fourth of the respondents (*n* = 23) reported that they had been asked to participate in a previous clinical trial (20%), and 19 respondents (16.5%) reported that they had participated in a previous clinical trial. A small group of respondents (13.9%) reported knowing someone close (family member or friend) who had participated in a clinical trial. The rest of the responses included respondents who did not know or chose not to respond. Table 5 provides additional details regarding respondents.

Table 5

Prior participation in Clinical Trials

	n	%
Previously asked to participate		
Yes	23	20
No	86	74.8
Don’t know/unsure	5	4.3
Previously participated		
Yes	19	16.5
No	96	83.5
Someone close participated		
Yes	16	13.9
No	79	68.7
Don’t know/unsure	19	16.5
Prefer not to answer	1	.9

Note. *N* = 115.

Beliefs and Attitudes About Clinical Trials

To assess behavioral beliefs and attitudes about clinical trials, respondents were asked a series of questions aimed at measuring attitudes, beliefs, and stance on clinical trials, as well as trust in researchers. The five-item statement scale below was used to assess attitudes and beliefs about clinical trials:

- Clinical trials will result in cures for many diseases.
- Research on humans goes against my religious beliefs.
- If I donate blood, for example to the Red Cross, it would be OK with me to use a small part of it (1 tablespoon) for research.
- If I had surgery, I would be willing to allow the use of some of my surgical tissue for clinical trials.

- I would allow my name to be put on a registry or list to be contacted for future research.

Individual item scores were added to produce a raw score, which was used to calculate the percent score. According to the scoring system specified by the developer Al-Jumah et al. (2011), positive attitude statements were scored from 5 (*strongly agree*) to 1 (*strongly disagree*). Percent score greater than 60% were considered positive attitude while a score less than 60% score was considered negative. The sample mean was 53.4% (median = 52%, SD = 12.31), thus indicating that most respondents had a negative attitude towards clinical trials (72%). Based of review of individual scores, most of the respondents agreed that clinical trials will result in cures for many diseases (52.2%) and reported that clinical trials do not go against their religious beliefs (49.6%). Most respondents would allow use of some of their blood in research (60%), as well as tissue (52.2%). Most respondents reported that they would allow their names to be added to a registry for future research contact (31.3%). Table 6 below shows the individual scores.

Table 6

Beliefs and Attitudes About Clinical Trials

	n	%
Clinical trials will result in cures for many diseases		
Strongly agree	22	19.1
Agree	60	52.2
Not sure	22	19.1
Disagree	7	6.1
Strongly disagree	0	0
Prefer not to answer	4	3.5
Research on humans goes against my religious beliefs		
Strongly agree	1	.9
Agree	17	14.8
Not sure	14	12.2
Disagree	57	49.6
Strongly disagree	22	19.1
Prefer not to answer	4	3.5
If I donate blood, for example to the Red Cross, it would be OK with me to use a small part of it (1 tablespoon) for research		
Strongly agree	20	17.4
Agree	69	60.0
Not sure	7	6.1
Disagree	13	11.3
Strongly disagree	6	5.2
Prefer not to answer	0	0
If I had surgery, I would be willing to allow the use of some of my surgical tissue for clinical trials		
Strongly agree	20	17.4
Agree	60	52.2
Not sure	16	13.9
Disagree	18	15.7
Strongly disagree	0	0
Prefer not to answer	1	.9
I would allow my name to be put on a registry or list to be contacted for future research		
Strongly agree	17	14.8
Agree	36	31.3
Not sure	32	27.8
Disagree	27	23.5
Strongly disagree	2	1.7
Prefer not to answer	1	.9

Note. N = 115.

In addition to measuring attitudes and beliefs, respondents were also asked if they favor or oppose the use of human beings for clinical trials. Responses were based on a 5-point Likert scale (5 = *strongly favor,* 4 = *favor,* 3 = *neutral*, 2 = *oppose*, 1 = *strongly oppose*). Most of the respondents reported that they were neutral to this question (40.9%) and a handful (11.3%) were not sure. To review the positive responses, a combination of "strongly favor" and "favor" responses indicated that about half of the respondents (40.9%), favored the use of humans in clinical trials. Table 7 provides the details of responses.

Table 7

Favoring Human Score

	n	%
In general, would you say that you favor or oppose the use of human beings for clinical trials?		
Strongly favor	6	5.2
Favor	41	35.7
Neutral	47	40.9
Oppose	6	5.2
Strongly oppose	2	1.7
Don't know/unsure	13	11.3

Note. N = 115.

Social Influence on Health Behavior

Respondents were asked a series of questions to assess to evaluate the perceived part played by others in the health behavior choices and decisions. These 10 items were assessed in 4-point Likert-type format (1 = *strongly disagree*, 2 = d*isagree*, 3 = a*gree*, 4 = *strongly agree*). Perceived social influence on health behavior was measured based on utilitarian influence, value-expressive influence, and informational influence. The instrument has a possible range of 10–40, with higher scores indicative of higher levels of beliefs (Holt et al., 2010). The responses to the 10 survey questions were totaled to produce raw scores. Respondents social influence on behavior scores ranged from 10 to 30 (mean = 20.77; SD± = 4.11). These scores indicate that, in general, respondents' health behaviors are impacted by social influence. A review of the individual responses showed that majority of respondents (55%) will seek advice from friends regarding health behaviors for which they have limited knowledge. Table 8 below provides details on individual responses.

Table 8

Social influence on health behavior

	n	%
I rarely engage in health behaviors until I am sure my friends approve of them		
Strongly disagree	28	24.3
Disagree	69	60.0
Agree	15	13.0
Strongly agree	3	2.6
It's important that others agree with my health lifestyle (before I act)		
Strongly Disagree	23	20.0
Disagree	68	59.1
Agree	17	14.8
Strongly agree	2	1.7
Missing	5	4.3
When engaging in health behaviors, I generally do things that I think others will approve of.		
Strongly disagree	31	27.0
Disagree	75	65.2
Agree	9	7.8
Strongly agree	0	0
I like to know what health behaviors make good impressions on others		
Strongly disagree	18	15.7
Disagree	70	60.9
Agree	27	23.5
Strongly Agree	0	0
I achieve a sense of belonging by making the same healthy choices that others do		
Strongly Disagree	27	23.5
Disagree	67	58.3
Agree	16	13.9
Strongly agree	4	3.5
Missing	1	.9
If I want to be like someone, I often try to make the same healthy choices that they do		
Strongly disagree	26	22.6
Disagree	62	53.9

(table continues)

If I want to be like someone, I often try to make the same healthy choices that they do		
Agree	23	20.0
Strongly agree	3	2.6
Missing	1	.9
I often identify with other people by making the same healthy choices that they do		
Strongly disagree	26	22.6
Disagree	72	62.6
Agree	15	13.0
Strongly agree	2	1.7
If I have little experience with a health behavior, I often ask my friends about it		
Strongly disagree	17	14.8
Disagree	40	34.8
Agree	55	47.8
Strongly agree	3	2.6
I often consult other people to help choose the best alternative available for a health behavior		
Strongly disagree	18	15.7
Disagree	45	39.1
Agree	49	42.6
Strongly agree	3	2.6
I frequently gather information from friends and family before I engage in a health behavior		
Strongly disagree	7	6.1
Disagree	55	47.8
Agree	48	41.7
Strongly agree	5	4.3

Measuring Distrust of Healthcare System

The level of distrust of the healthcare system was evaluated using a four-item DHS, developed by Katapodi et al., 2010) and a 12-item GBMMS developed by Thompson et al. (2004). For the DHS, responses are made on a 4-point Likert-type scale (*strongly agree* to *strongly disagree*) with a 4 to 16 score range, where higher scores indicate greater distrust. For the GBMMS, possible responses were scored from 5 (*strongly agree*) to 1 (*strongly disagree*) with a 12 to 60 score range (higher scores indicating higher level of distrust). The responses to the questions in each scale were totaled to produce raw scores. A review of the DHS responses showed that respondents' distrust for health care providers scores ranged from 5 to 13 (mean = 8.53; SD± = 1.546). These scores indicate that, in general, respondents' do not have high level of trust for their health care providers. The GBMMS results review showed scores ranging from 18 to 46 (mean = 32.59; SD± = 3.651), indicating, like the DHS, that respondents have a low level of trust for health care providers. A review of the individual responses from the DHS showed that 70% of respondents disagree, and 15.7% strongly disagree with the statement "I trust my health care providers." In the GBMMS, 39% of the respondents did not believe that African Americans received the same care from doctors and health care workers as people from other ethnic groups. Table 9 provides details on individual responses for both scales.

Table 9

Measuring Distrust in Health Care Providers

	n	%
I trust my healthcare providers		
Strongly disagree	18	15.7
Disagree	81	70.4
Agree	5	4.3
Strongly agree	11	9.6
I always believe someone when they say that their healthcare provider hasn't been nice to them		
Strongly disagree	6	5.2
Disagree	64	55.7
Agree	40	34.8
Strongly agree	5	4.3
In general, the healthcare system is not sensitive to the patients' needs.		
Strongly disagree	12	10.4
Disagree	65	56.5
Agree	33	28.7
Strongly agree	4	3.5
I've been treated poorly by healthcare providers often more than I've been treated with respect		
Strongly disagree	25	21.7
Disagree	85	73.9
Agree	4	3.5
Strongly agree	1	.9
People from my ethnic group cannot trust doctors and health care workers		
Strongly disagree	15	13.0
Disagree	34	29.6
Neither	48	41.7
Agree	10	8.7
Strongly agree	8	7.0
People from my ethnic group should be suspicious of information from doctors and health care workers		
Strongly disagree	8	7.0
Disagree	54	47.0
Neither	41	35.7
Agree	8	7.0
Strongly agree	4	3.5

(table continues)

People from my ethnic group should not confide in doctors and health care workers because it will be used against them		
Strongly disagree	22	19.1
Disagree	66	57.4
Neither	20	17.4
Agree	5	4.3
Strongly agree	2	1.7
People from my ethnic group should be suspicious of modern medicine		
Strongly disagree	20	17.4
Disagree	61	53.0
Neither	23	20.0
Agree	10	8.7
Strongly agree	1	.9
Doctors and health care workers treat people of my ethnic group like “guinea pigs		
Strongly disagree	16	13.9
Disagree	50	43.5
Neither	29	25.2
Agree	15	13.0
Strongly agree	5	4.3
Doctors and health care workers do not take the medical complaints of people of my ethnic group seriously		
Strongly disagree	7	6.1
Disagree	59	51.3
Neither	32	27.8
Agree	15	13.0
People of my ethnic group are treated the same as people of other groups by doctors and health care workers		
Strongly disagree	3	2.6
Disagree	36	31.3
Neither	23	20.0
Agree	43	37.4
Strongly agree	8	7.0
People of my ethnic group receive the same care from doctors and health care workers as people from other groups		
Strongly Disagree	4	3.5
Disagree	35	30.4
Neither	31	27.0
Agree	35	30.4
Strongly Agree	10	8.7

(table continues)

In most hospitals, people of different ethnic groups receive the same kind of care		
Strongly disagree	5	4.3
Disagree	25	21.7
Neither	31	27.0
Agree	36	31.3
Strongly agree	18	15.7
Doctors have the best interests of people of my ethnic group in mind		
Strongly disagree	6	5.2
Disagree	17	14.8
Neither	43	37.4
Agree	36	31.3
Strongly agree	13	11.3
Doctors and health care workers sometimes hid information from patients who belong to my ethnic group		
Strongly disagree	8	7.0
Disagree	36	31.3
Neither	32	27.8
Agree	35	30.4
Strongly agree	4	3.5
I have personally been treated poorly or unfairly by doctors or health care workers because of my ethnicity		
Strongly disagree	16	13.9
Disagree	63	54.8
Neither	17	14.8
Agree	16	13.9
Strongly agree	3	2.6

Note. *N* = 115.

The Stated Intention of Willingness to Participate

For this study, three scenarios which have varying levels of risks were used to measure individual’s willingness to participate in clinical trials. For each scenario, respondents’ perception of the physical risk associated with clinical trials was measured using the following responses on a Likert scale: “very safe”, “safe”, “neutral”, “risky”, or “very risky”. These were followed by questions regarding willingness to participate based on personal health benefit, adding to scientific knowledge, and benefit to someone close.

- Scenario 1 – You are asked to participate in a clinical trials study that consisted of taking a small amount of blood out of my arm
- Scenario 2 – You are asked to participate in a clinical trials study that consisted of cutting off a small amount of skin (about the size of a pencil eraser), called a biopsy. This would require an injection (shot) of numbing medicine so that you did not have any pain and two to three sutures (stitches). The biopsy would be on a place where the scar would not be seen, such as you're the top of your hip. There may be mild discomfort or pain for one to two days.
- Scenario 3 – You are asked to participate in a clinical trials study that consisted of taking a medication (drug) that will have some side effects from the medicine, such as feeling sick to your stomach (nausea) or throwing up (vomiting).

For Scenario 1 (blood draw), most respondents thought that it was safe (48.7%). Majority of the respondents asserted that they would be willing to take part in such research to benefit their own health (64.3%) and benefit the health of someone close to them (70.4%). However, willingness among respondents was decreased if the study only contributed to scientific knowledge (41.7%). Majority of the respondents (30%) thought that $50 was fair compensation for the stated scenario and assumed risk.

For Scenario 2 (skin biopsy), respondents were evenly split on their assessment of the risk; safe (27.8%) vs. risky (28.7%). With regards to a benefit to their health, approximately half of the respondents (51%) expressed willingness to participate, one third (33%) expressed willingness to participate to contribute to scientific knowledge, and over half (53.9%) expressed willingness to participate if it benefited someone close. The response to a “fair” compensation was almost evenly split between the choice of $100 and $500 among respondents ($100 = 33% and $500 = 26.1%).

For Scenario 3 (drug trial), majority of the respondents did not believe this was safe (risky = 38.3%; very risky = 25.2%). Only less than a fourth of the respondents (15.7%) thought it was either safe or very safe to take a drug with some side effects. About one third expressed willingness to participate to benefit their own health (31%), over half of respondents would not be willing to participate to add to scientific knowledge (54%), and about half of the respondents would be willing to participate to benefit someone close (43%). Majority of the respondents (40%) thought that the highest compensation ($500) was fair and commensurate with the risk. This was followed by a third of the respondents (26.1%) who thought $100 compensation was fair.

Table 10

Measuring Willingness to Participate and Compensation

	n	%
Do you think the physical risk (the chance of being hurt or injured in this study) of this study is		
Very risky	1	.9
Risky	11	9.6
Neutral	31	27.0
Safe	56	48.7
Very safe	13	11.3

(table continues)

Do you think the physical risk (the chance of being hurt or injured in this study) of this study is

Prefer not to answer	3	2.6
If you were asked today, would you be willing to take part in this clinical trial project if you felt it WOULD benefit your health now or in the future?		
Yes	74	64.3
No	23	20.0
Don’t know/unsure	14	12.2
Prefer not to answer	4	3.5
If you were asked today, would you be willing to take part in this clinical trial project if it would NOT benefit your health now or in the future but will add to scientific knowledge?		
Yes	48	41.7
No	33	28.7
Don’t know/unsure	29	25.2
Prefer not to answer	5	4.3
If you were asked today, would you be willing to take part in a study that you felt would NOT benefit YOUR health but would benefit the health of SOMEONE CLOSE TO YOU?		
Yes	81	70.4
No	14	12.2
Don’t know/unsure	19	16.5
Prefer not to answer	1	.9
If a person was willing to participate in Scenario 3, what do you think would be FAIR compensation?		
No compensation	9	7.8
$5	8	7.0
$10	10	8.7
$50	38	33.0
$100	26	22.6

(table continues)

If a person was willing to participate in Scenario 3, what do you think would be FAIR compensation?		
Prefer not to answer	24	20.9

Do you think the physical risk (the chance of being hurt or injured in this study) of this study is		
Very risky	12	10.4
Risky	33	28.7
Neutral	27	23.5
Safe	32	27.8
Very safe	5	4.3
Prefer not to answer	6	5.2
If you were asked today, would you be willing to take part in this clinical trial project if you felt it WOULD BENEFIT YOUR health now or in the future?		
Yes	59	51.3
No	25	21.7
Don’t know/unsure	26	22.6
Prefer not to answer	5	4.3
If you were asked today, would you be willing to take part in this clinical trial project if it would NOT benefit your health now or in the future but will add to scientific knowledge?		
Yes	38	33.0
No	48	41.7
Don’t know/unsure	28	24.3
Prefer not to answer	1	.9
If you were asked today, would you be willing to take part in a study that you felt would NOT benefit YOUR health but would benefit the health of SOMEONE CLOSE TO YOU?		
Yes	62	53.9
No	25	21.7
Don’t know/unsure	28	24.3

(table continues)

If a person was willing to participate in Scenario 2, what do you think would be FAIR compensation?		
No compensation	1	.9
$5	9	7.8
$25	13	11.3
$100	38	33.0
$500	30	26.1
Prefer not to answer	24	20.9
Do you think the physical risk (the chance of being hurt or injured in this study) of this study is…?		
Very risky	29	25.2
Risky	44	38.3
Neutral	17	14.8
Safe	17	14.8
Very safe	1	.9
Prefer not to answer	7	6.1
If you were asked today, would you be willing to take part in this clinical trial project if you felt it WOULD benefit your health now or in the future?		
Yes	31	27.0
No	36	31.3
Don’t know/unsure	45	39.1
Prefer not to answer	3	2.6
If you were asked today, would you be willing to take part in this clinical trial project if it would NOT benefit your health now or in the future but will add to scientific knowledge?		
Yes	19	16.5
No	54	47.0
Don’t know/unsure	39	33.9
Prefer not to answer	3	2.6

(table continues)

If you were asked today, would you be willing to take part in a study that you felt would NOT benefit YOUR health but would benefit the health of SOMEONE CLOSE TO YOU?		
Yes	43	37.4
No	25	21.7
Don’t know/unsure	44	38.3
Prefer not to answer	3	2.6
If a person was willing to participate in Scenario 3, what do you think would be FAIR compensation?		
No Compensation	3	2.6
$5	6	5.2
$25	5	4.3
$100	30	26.1
$500	46	40.0
Prefer not to answer	25	21.7

Research Questions

The theory of planned behavior, which serves as the conceptual framework for this study, highlights the existence of a linear path from KAB, to the intention of willingness to participate, to participation. Associations between knowledge, social beliefs and attitudes and willingness to participate in clinical trials were tested.

RQ 1: What is the relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans?

$H_0$1: There is no statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

H_A1: There is a statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans.

As described earlier, three scenarios, with perceived physical risk increasing from the first to the third, were presented to the participants (Scenario 1: a blood draw; Scenario 2: a biopsy, an injection and sutures; and Scenario 3: anticipated side effects). Using response choices of “yes”, “no”, and “don’t know/unsure”, the following questions assessed the willingness to participate in three situations within each scenario: a) if the research would benefit that individual’s health, b) if the research would benefit the health of someone close to them, and c) if the research add to scientific knowledge. Total scores were computed for responses to the survey questions used to assess willingness as well as the survey questions used to assess knowledge of clinical trials. Higher scores in each case indicated a higher level of willingness and greater knowledge of clinical trials respectively. Regression and correlation analyses were utilized to test the association between knowledge of clinical trials and willingness to participate in trial.

A Pearson Correlation (see Table 11) was used to test the relationship between Knowledge score 1 (three questions which assessed knowledge associated with the procedures of clinical trials) and Knowledge score 2 (four questions related to the informed consent process), and the overall willingness to participate score. The result showed a negative correlation between Knowledge 1 (-0.063) and Knowledge 2 (-0.045) and willingness to participate. Based on these results, we can accept the null hypothesis that there is no statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans. Knowledge of the procedures of clinical trials (p = 0.501) and the informed consent process (p = 0.635) is not a valuable predictor of overall willingness to participate in clinical trials.

Table 11

Correlation Analysis of Knowledge of Clinical Trials and Willingness to Participate

		Knowledge Score 1	Willingness Score
Knowledge Score 1	Pearson Correlation	1	-.063
	Sig. (2-tailed)		.501
	N	115	115
Willingness Score	Pearson Correlation	-.063	1
	Sig. (2-tailed)	.501	
	N	115	115
		Knowledge Score 2	**Willingness Score**
Knowledge Score 2	Pearson Correlation	1	-.045
	Sig. (2-tailed)		.635
	N	115	115
Willingness Score	Pearson Correlation	-.045	1
	Sig. (2-tailed)	.635	
	N	115	115

A linear regression analysis (see Table 12) was also conducted using "willingness" as the dependent variable, and the results showed that the R in the Model Summary equals Pearson Correlation. R-squared, which examines the goodness of fit, was 0.4% and 0.2% respectively, indicating a very poor goodness of fit. The regression coefficient shows that for each increase in knowledge by 1, there will be a decrease in willingness by 0.086 and 0.099 respectively.

Table 12

Regression Analysis of Knowledge of Clinical Trials and Willingness to Participate

Model Summary

Model	*R*	R Square	Adjusted R Square	Std. Error of the Estimate
1	.063[a]	.004	-.005	5.006

a. Predictors: (Constant), Knowledge Score

Coefficients[a]

Model		Unstandardized Coefficients B	Unstandardized Coefficients Std. Error	Standardized Coefficients Beta	*t*	Sig.
1	(Constant)	19.791	1.108		17.862	.000
	Knowledge Score	-.086	.128	-.063	-.675	.501

a. Dependent Variable: Willingness

Additional analyses were conducted to test the association between knowledge of the procedures of clinical trials and each individual research scenario described earlier, used to assess willingness (Table 13). The results showed a negative correlation between knowledge and willingness in Scenario 1 and 3, and a positive correlation in Scenario 2. The results were consistent with the conclusion that knowledge of the procedures of clinical trials is not a valuable predictor of willingness to participate in clinical trials for Scenarios 1 and 2 ($p = 0.620$; 0.227). However, for Scenario 3, the results showed that knowledge of the procedures of clinical trials is a good predictor of willingness to participate in clinical trials which involve a higher risk to the participant ($p = 0.010$).

Table 13

Correlation Analysis of Knowledge of Clinical Trials and Willingness to Participate (All Scenarios)

		Knowledge Score 1	Willingness Scenario 1
Knowledge Score	Pearson Correlation	1	-.047
	Sig. (2-tailed)		.620
	N	115	115

Willingness Scenario 1	Pearson Correlation	-.047	1
	Sig. (2-tailed)	.620	
	N	115	115

		Knowledge Score 1	Willingness Scenario 2
Knowledge Score	Pearson Correlation	1	.114
	Sig. (2-tailed)		.227
	N	115	115
Willingness Scenario 2	Pearson Correlation	.114	1
	Sig. (2-tailed)	.227	
	N	115	115

		Knowledge Score 1	Willingness Scenario 3
Knowledge Score	Pearson Correlation	1	-.238*
	Sig. (2-tailed)		.010
	N	115	115
Willingness Scenario 3	Pearson Correlation	-.238*	1
	Sig. (2-tailed)	.010	
	N	115	115

*Correlation is significant at the 0.05 level (2-tailed).

Analysis of the association between knowledge of the informed consent process in clinical trials and each individual research scenario also supported the conclusion that knowledge is not a valuable predictor of willingness to participate in clinical trials. Details of the *p* values are presented in Table 14.

Table 14

Correlation Analysis of Knowledge of Clinical Trials and Willingness to Participate (All Scenarios)

		Knowledge Score 2	Willingness Scenario 1
Knowledge Score	Pearson Correlation	1	-.022
	Sig. (2-tailed)		.814

	N	115	115
Willingness Scenario 1	Pearson Correlation	-.022	1
	Sig. (2-tailed)	.814	
	N	115	115
		Knowledge Score 2	Willingness Scenario 2
Knowledge Score	Pearson Correlation	1	.048
	Sig. (2-tailed)		.610
	N	115	115
Willingness Scenario 1	Pearson Correlation	.048	1
	Sig. (2-tailed)	.610	
	N	115	115
		Knowledge Score 2	Willingness Scenario 3
Knowledge Score	Pearson Correlation	1	-.143
	Sig. (2-tailed)		.126
	N	115	115
Willingness Scenario 1	Pearson Correlation	-.143	1
	Sig. (2-tailed)	.126	
	N	115	115

RQ 2: What is the relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans?

$H_0$2: There is no statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans.

H_A2: There is a statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans

The results of a Pearson Correlation (Table 15) analysis of attitude and beliefs score and overall willingness score showed a positive correlation (0.357) between attitude and beliefs and willingness to participate in clinical trial (*p* = 0.000). This was confirmed by the regression analysis (*p* = 0.000), and a regression coefficient which shows that for each increase in attitude and beliefs by 1, will result in an increase in willingness by 0.449.

Table 15

Pearson Correlation Analysis of Attitude and Beliefs Score and Overall Willingness Score

		Attitude/Belief Score	Willingness
Attitude/Belief Score	Pearson Correlation	1	.357**
	Sig. (2-tailed)		.000
	N	115	115
Willingness	Pearson Correlation	.357**	1
	Sig. (2-tailed)	.000	
	N	115	115

**. Correlation is significant at the 0.01 level (2-tailed).

Model Summary

Model	*R*	R Square	Adjusted R Square	Std. Error of the Estimate
1	.357a	.127	.119	4.687

a. Predictors: (Constant), Attitude/Belief Score

Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	*t*	Sig.
1	(Constant)	8.925	2.549		3.501	.001
	Attitude/Belief Score	.449	.111	.357	4.057	.000

a. Dependent Variable: Willingness

Based on these results we can reject the null hypothesis in lieu of the alternative hypothesis that there is a statistically significant relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans. Attitude and beliefs about clinical trials is a good predictor of willingness to participate in clinical trials (*p* = 0.000).

RQ 3: Does social influence within the African American community affect the willingness of an African American to participate in clinical trials?

$H_0$3: There is no statistically significant relationship between social influence within the African American community and the willingness of an African American to participate in clinical trials.

H_A3: There is a statistically significant relationship between social influence within the African American community and willingness of an African American to participate in clinical trials.

Understanding the impact of social influence on the willingness of African Americans to participate in clinical trials was the focus of this research question. Survey question used to assess social influence were obtained from the perceived social Influence on health behavior instrument which has a possible range of 10–40, with higher scores indicative of higher levels of beliefs. Pearson Correlation was used to test the association between perceived social Influence on health behavior score and willingness to participate score. As shown in Table 16, there was a negative correlation (-0.141) between social influence and willingness to participate in clinical trial, but with no statistical significance (*p* = 0.132). This was confirmed by the regression analysis (*p* = 0.132), and a regression coefficient which shows that for each increase in attitude and beliefs by 1, will result in a decrease in willingness by 0.172. Based on these results, we can accept the null hypothesis that there is no statistically significant relationship between social influence and willingness to participate in clinical trials among African Americans.

Table 16

Correlation Analysis of Social Influence and Willingness to Participate in Clinical Trials

		PSI_HB SCORE	Willingness
PSI_HB SCORE	Pearson Correlation	1	-.141
	Sig. (2-tailed)		.132
	N	115	115
Willingness	*Pearson Correlation*	-.141	1
	Sig. (2-tailed)	.132	
	N	115	115

Model Summary

Model	*R*	R Square	Adjusted R Square	Std. Error of the Estimate
1	.357a	.127	.119	4.687

a. Predictors: (Constant), PSI_HB Score

Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	*t*	Sig.
1	(Constant)	22.684	2.396		9.468	.000
	PSI_HB Score	-.172	.113	-.141	-1.519	.132

a. Dependent Variable: Willingness

Additional analyses were conducted to test the association between social influence and each individual research scenario described earlier, used to assess willingness. The results for Scenarios 2 and 3 were consistent with the conclusion that social influence is not a valuable predictor of willingness to participate in clinical trials ($p = 0.943$; 0.085). However, for Scenario 1, which represents the least risk to a research participant, the results showed that social influence is a good predictor of willingness to participate in clinical trials (*p* = 0.047).

Table 17

Correlation analysis of Social Influence and Willingness to Participate in Clinical Trials (All Scenarios)

		PSI_HB SCORE	Willingness Scenario 1
PSI_HB SCORE	Pearson Correlation	1	-.185*
	Sig. (2-tailed)		.047
	N	115	115
Willingness scenario 1	Pearson Correlation	-.185*	1
	Sig. (2-tailed)	.047	
	N	115	115

Summary

In this chapter, I provided a detailed overview and interpretation of the study results. Three research questions were evaluated using statistical analysis. The first research question evaluated the relationship between knowledge of clinical trials and willingness to participate in clinical trials among African Americans. The results showed that knowledge is not a valuable predictor of willingness to participate in clinical trials. The second research question evaluated the relationship between attitude and beliefs and willingness to participate in clinical trials among African Americans. The results showed that attitudes and beliefs about clinical trials is a good predictor of willingness to participate in clinical trials. The third research question evaluated the impact of social influence within the African American community on the willingness of an African American to participate in clinical trials. The results showed that social influence is a good predictor of willingness to participate in clinical trials in trials that pose minimal risks to participants. Discussion of the findings will be presented in chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendation

Introduction

The purpose of this quantitative study was to form a discussion regarding social influence and its impact on the willingness of African Americans, 18 years or older, to participate in clinical trials. I collected quantitative data, in the form of a one-time questionnaire administered by paper instrument, from research participants over a period of 12 weeks from June to August 2018. Social influence and willingness to participate in clinical trials were measured using items from the PSI-HBS (Holt et al., 2010) and Attitudes and Factors affecting Young Adults' Willingness to Participate in Clinical Research survey (Brandt, 2013), respectively. In this study, I collected and analyzed data to address three research questions and corresponding hypothesis. Data were analyzed using correlation and regression analysis in SPSS. My aim was to understand the relationship between African Americans' KAB towards clinical trials and willingness to participate in clinical trials and whether social influence affects their willingness to participate in clinical trials.

Interpretation of Findings

The conceptual framework that I used for this study was Fishbein and Ajzen's TPB. The use of this well-established and recognized social cognitive theory was applicable to this study because the model is based on beliefs that assume that the intention of an individual to exhibit a behavior is an important determinant for exhibiting that behavior (see Ajzen & Madden, 1986). The TPB provided a perspective that allowed me to evaluate individual intentions and attitudes towards participation in clinical trials as well as consider objective norms that influence this behavior. In this study, I considered that subjective norms are affected by an individual's perceptions of their family and social beliefs (i.e., a consideration of whether these close social networks will approve or disapprove of the planned behavior; see Ajzen & Fishbein, 1980). The constructs of social influence were measured in the framework of attitudes and self-efficacy opportunities, intention, and past behavior (see Vries et al., 1995). Social influence was defined as an individual's conformity, compliance, and obedience to social factors within the community with which the individual identifies (Vries et al., 1995).

Knowledge of Clinical Trials and Willingness to Participate

A majority of the survey respondents did not believe that the education they received during school improved their knowledge about clinical trials (76.3%), were not familiar with the clinical trial process, and did not understand the process of informed consent. Only a small percent of participants reported having prior knowledge of clinical trials through their own or a family member's participation. Researchers that examined the relationship between knowledge of clinical trials and willingness to participate and reported a positive correlation (i.e., Advani et al., 2003; Boulware et al., 2016; DeFreitas, 2010) concluded that individuals who are more knowledgeable about issues related to clinical trials have more favorable attitudes toward clinical trials and are more willing to contemplate participation in a clinical trial (Ojukwu et al, 2018). However, for the first research question, I concluded that there is no statistically significant relationship between knowledge of clinical trials and willingness to participate in clinical trials among the African Americans surveyed for this study. Knowledge of the procedures of clinical trials (p = 0.501) and the informed consent process (p = 0.635) were not valuable predictors of willingness to participate in clinical trials.

Attitude and Beliefs and Willingness to Participate

To assess behavioral beliefs and attitudes about clinical trials, I asked respondents a series of questions aimed at measuring their attitudes, beliefs, and stance on clinical trials as well as their trust in researchers. Previously, other investigators have concluded that African Americans have more negative attitudes about clinical trials and as a result are less willing to participate (Pariera, Murphy, Meng, & McLaughlin, 2017). These negative attitudes are mostly fueled by the lack of trust in health care providers and an increasing interest in complementary and alternative medicine (Pariera et al., 2017).

The findings from this study suggest that the respondents’ attitudes and beliefs were associated with their willingness to participate in clinical trials. There was a positive correlation (0.357) between attitudes and beliefs and willingness to participate in clinical trial (p = 0.000). This was confirmed by the regression analysis (p = 0.000), and a regression coefficient that shows that for each increase in attitudes and beliefs by 1, an increase in willingness by 0.449 will result. There is a statistically significant relationship between attitudes and beliefs and willingness to participate in clinical trials among African Americans. Attitudes and beliefs about clinical trials are a good predictor of willingness to participate in clinical trials (p = 0.000).

Social Influence and Willingness to Participate

Understanding the impact of social influence on the willingness of African Americans to participate in clinical trials was the focus of this study. I obtained the survey questions used to assess social influence from the PSI-HBS, which has a possible range of 10–40, with higher scores indicative of higher levels of beliefs. A Pearson correlation was used to test the association between PSI-HBS score and willingness to participate score. For the analysis, which included perceived social influence and all scenarios of clinical trials, the result was a negative correlation (-0.141) between social influence and willingness to participate in clinical trial but with no statistical significance ($p = 0.132$). This was confirmed by the regression analysis ($p = 0.132$), and a regression coefficient that shows that for each increase in perceived social influence by 1, a decrease in willingness by 0.172 will result. However, analyses to test the association between perceived social influence and each individual research scenario revealed that for Scenario 1, which represents the least risk to a research participant, social influence is a good predictor of willingness to participate in clinical trials ($p = 0.047$). Based on this finding, I rejected the null hypothesis in lieu of the alternative hypothesis that there is a statistically significant relationship between social influence and willingness to participate in clinical trials with minimal risk among African Americans.

Limitations

There were limitations to this research. The response rate limited access to the desired study population. Only 115 participants completed the survey, which created a limitation since the analysis required a larger sample size to accurately detect statistically significant relationships between variables. The participants in this study were not representative of the entire African American population in a greater metropolitan area of Ohio because only church attendees who agreed to the research were included. Although a previous study reported that religiously based differences on social issues are less evident among African-Americans compared to the overall population, with 53% of African Americans polled reporting attending religious services at least once a week (Sahgal & Smith, 2016), the result of this study may not be generalizable to the entire African American population because of differences in opinions that may exist among church goers vs. non-church goers. Another limitation was that all indication of willingness to participate in clinical trial was based on hypothetical scenarios, which may lead to responses that may not accurately reflect the individuals' intention or future action (see Schoenberg & Ravdal, 2000). In the conduct of this study, there were variables whose presence could affect the variables of focus. A final limitation was that the analyses used in this study did not effectively control for these variables which were potential confounders.

Recommendations

The results from this study provide evidence of the existence of a relationship between social influence and willingness to participate in clinical trials involving minimal risk among African Americans. In this study, I only evaluated responses from a small non-representative sample of African Americans, but future research should utilize a broader inclusion of this population and other ethnicities to efficiently detect this relationship. Confounders should be clearly identified and controlled in future research using Multivariate methods because there is a high potential for confounding even after data adjustment, leading to unjustified results. Additional analyses should also be conducted to understand the roles played by socioeconomic factors in the process of formulating and retaining social norms in this population.

Implications for Social Change

Failure to increase the participation rates of African Americans in clinical trial will inhibit the progress of clinical trial research into novel and effective methods in drug development (Frew et al., 2015). I designed this study to identify how social influence affects African Americans' willingness to participate in clinical trials as a platform for the development and implementation of interventions to improve clinical trial participation among this population. Researchers involved in the development of novel therapies can use the information from this study to improve the clinical trial patient recruitment process. A clear understanding of these social factors and how they interact to impact the health behavior of African Americans will create a path to the development of viable and sustainable intervention.

Conclusion

The purpose of this quantitative study was to identify the interactions between social influence and the intended willingness of African Americans to participate in clinical trials. The findings may be used as a platform for the development and implementation of interventions aimed at improving clinical trials participation among this population. In this study, I examined and elucidated the potential association between social influence and willingness of African Americans to participate in clinical trials. The results were in line with findings from existing literature; however, more research is needed to gain a better understanding of how social influence is developed and fostered in the African American community. African Americans deserve the chance to be represented in the process of developing therapies aimed at treating diseases that burden their community, and the results of this study create a starting point for more research to emerge from.

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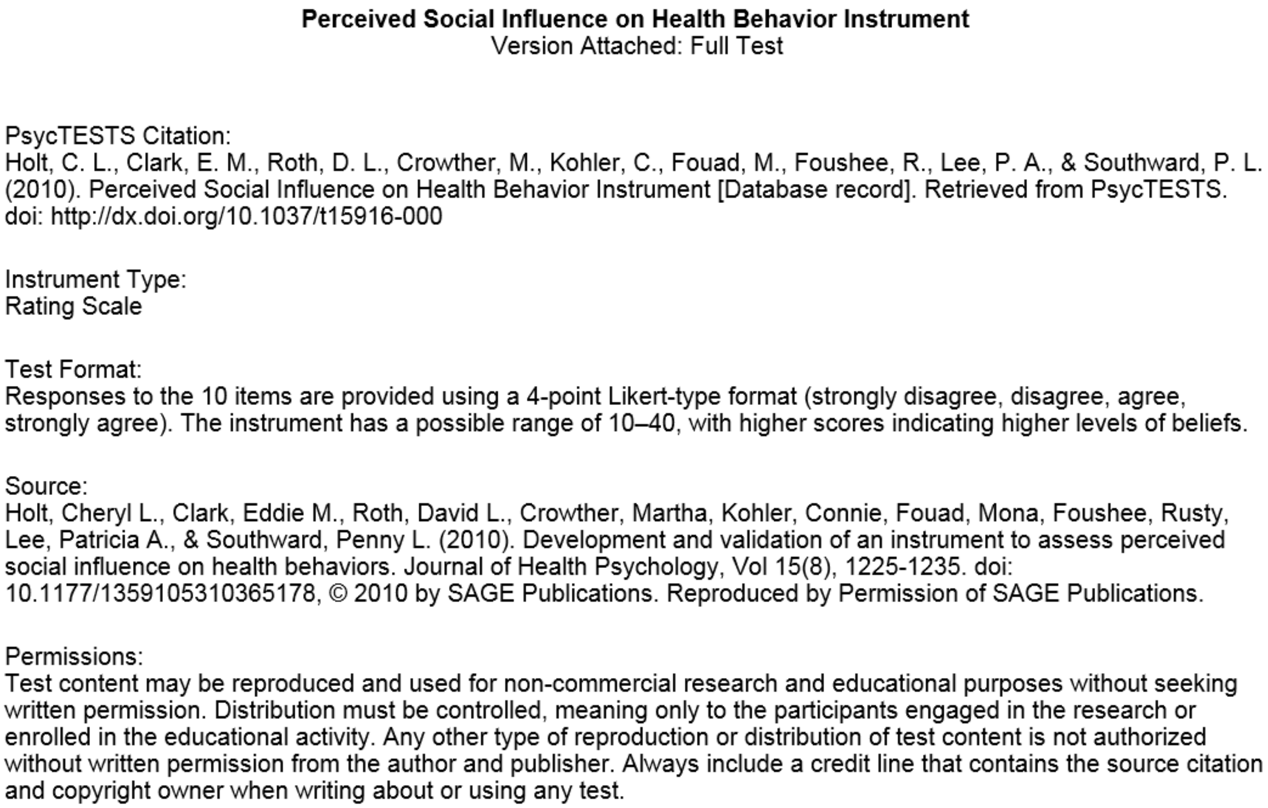
Appendix A: Permission to Use Perceived Social Influence on Health Behavior Instrument



Perceived Social Influence on Health Behavior Instrument
Version Attached: Full Test

PsycTESTS Citation:
Holt, C. L., Clark, E. M., Roth, D. L., Crowther, M., Kohler, C., Fouad, M., Foushee, R., Lee, P. A., & Southward, P. L. (2010). Perceived Social Influence on Health Behavior Instrument [Database record]. Retrieved from PsycTESTS. doi: http://dx.doi.org/10.1037/t15916-000

Instrument Type:
Rating Scale

Test Format:
Responses to the 10 items are provided using a 4-point Likert-type format (strongly disagree, disagree, agree, strongly agree). The instrument has a possible range of 10–40, with higher scores indicating higher levels of beliefs.

Source:
Holt, Cheryl L., Clark, Eddie M., Roth, David L., Crowther, Martha, Kohler, Connie, Fouad, Mona, Foushee, Rusty, Lee, Patricia A., & Southward, Penny L. (2010). Development and validation of an instrument to assess perceived social influence on health behaviors. Journal of Health Psychology, Vol 15(8), 1225-1235. doi: 10.1177/1359105310365178, © 2010 by SAGE Publications. Reproduced by Permission of SAGE Publications.

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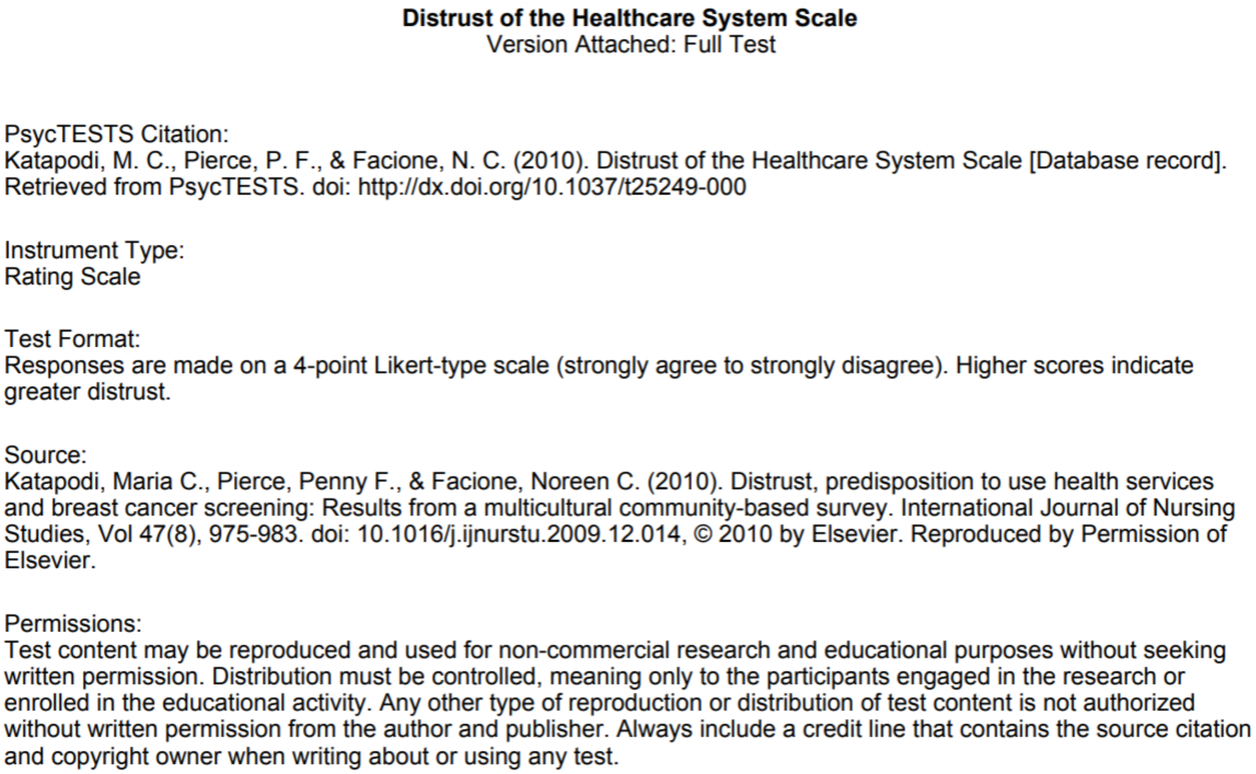
Appendix B: Permission to Use Distrust of the Healthcare System Scale



Distrust of the Healthcare System Scale
Version Attached: Full Test

PsycTESTS Citation:
Katapodi, M. C., Pierce, P. F., & Facione, N. C. (2010). Distrust of the Healthcare System Scale [Database record]. Retrieved from PsycTESTS. doi: http://dx.doi.org/10.1037/t25249-000

Instrument Type:
Rating Scale

Test Format:
Responses are made on a 4-point Likert-type scale (strongly agree to strongly disagree). Higher scores indicate greater distrust.

Source:
Katapodi, Maria C., Pierce, Penny F., & Facione, Noreen C. (2010). Distrust, predisposition to use health services and breast cancer screening: Results from a multicultural community-based survey. International Journal of Nursing Studies, Vol 47(8), 975-983. doi: 10.1016/j.ijnurstu.2009.12.014, © 2010 by Elsevier. Reproduced by Permission of Elsevier.

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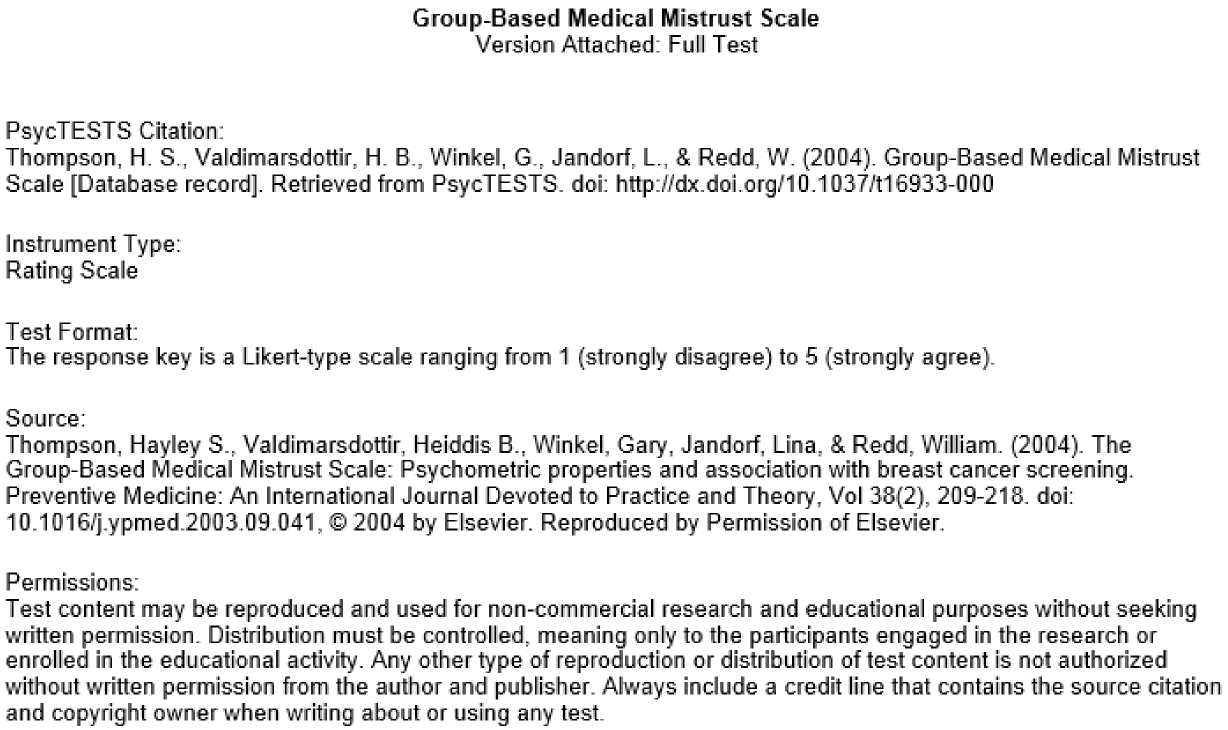
Appendix C: Permission to Use Group-Based Medical Distrust Scale



Group-Based Medical Mistrust Scale
Version Attached: Full Test

PsycTESTS Citation:
Thompson, H. S., Valdimarsdottir, H. B., Winkel, G., Jandorf, L., & Redd, W. (2004). Group-Based Medical Mistrust Scale [Database record]. Retrieved from PsycTESTS. doi: http://dx.doi.org/10.1037/t16933-000

Instrument Type:
Rating Scale

Test Format:
The response key is a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree).

Source:
Thompson, Hayley S., Valdimarsdottir, Heiddis B., Winkel, Gary, Jandorf, Lina, & Redd, William. (2004). The Group-Based Medical Mistrust Scale: Psychometric properties and association with breast cancer screening. Preventive Medicine: An International Journal Devoted to Practice and Theory, Vol 38(2), 209-218. doi: 10.1016/j.ypmed.2003.09.041, © 2004 by Elsevier. Reproduced by Permission of Elsevier.

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