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Beliefs and Preferences for Medical Research Among African-Americans

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Abstract

Background and Objectives—Numerous factors contribute to underrepresentation of African-Americans in medical research, including beliefs, historical events, structural, and health access obstacles. This study examined beliefs about medical research and the types of study methods preferred among potential African-American research participants.

Methods—A sample of 304 African-American participants from the Washington, DC Metropolitan area, completed a survey evaluating beliefs about medical research and preferred research study methods. Multiple Regression analyses were performed to examine how age, gender, and education may influence these beliefs and preferences for research study methods.

Results—The beliefs and preferences surveyed did not differ by age, gender, or educational attainment. There was an overwhelmingly favorable belief (90 %) that medical research was necessary and assists in finding a cure for a disease. Most respondents preferred participating in research related to issues with which they were familiar (e.g., diabetes, hypertension) or working with researchers of a similar ethnic background to themselves. Interestingly, though nonsignificant, those with higher levels of education trended toward the belief that participation in research was risky.

Conclusion—The findings of this study indicate that certain beliefs about medical research participation and preferred study methodologies reported by African-Americans did not differ by age, gender, or level of education. This information about African-American's beliefs and preferences regarding medical research should lead to an awareness of potential gains in African-

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Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study. The study protocol was approved by the Howard University Institutional Review Board (IRB).

Conflict of Interest Gloria E. Cain, Nnenna Kalu, John Kwagyan, Vanessa J. Marshall, Altovise T. Ewing, Walter P. Bland, Victor Hesselbrock, Denise M. Scott, and Robert E. Taylor declare no financial conflicts of interest related to this study.

American participation through the development of culturally sensitive medical research studies and methodologies.

Keywords

Beliefs; Preferences; African-Americans; Medical research

Introduction

Participation in medical research among African-Americans has consistently been of concern to health and government researchers. The National Cancer Institute reported that African-Americans represented less than 10 % of research participants enrolled in cancer clinical trial studies [1]. Although the National Institutes of Health Revitalization Act of 1993 PL 103-43 outlines provisions to improve the inclusion of minorities, low representation among all minority groups, including African-Americans, in medical research still persists [2]. Among medical researchers, there is the opinion that minority research participation is influenced by the research process and perceptions that potential minority participants hold about medical research [3]. Without adequate representative samples of African-American research participants, health researchers are hindered from investigating methods of treatment for disorders that disproportionately affect this population. The results from medical research studies and clinical trials that do not include African-American participants are typically not generalizable to this group [4, 5]. Importantly, low participation in medical research contributes to a lack of understanding as to why African-Americans have less than positive outcomes for certain health disorders and missed opportunities to participate in medical research [6].

African-Americans and other minorities with common medical disorders such as diabetes, hypertension, cardiovascular disease, and cancer suffer from poor health outcomes when compared to persons of European descent [7]. Numerous studies have been conducted on the development of prevention and treatment interventions for these disorders; however, due to low participation in these studies, African-Americans often continue to be inadequately treated. For instance, the results of a review of cancer clinical trial prevention and treatment studies in underrepresented groups showed a lack of knowledge and awareness about clinical trials due to age, social status, amount of time involved, type of intervention, and income loss that were cited as barriers to enrollment in cancer clinical trials [8, 9]. A study of cancer clinical trials attributes stringent study designs as a limiting factor for African-American participation in cancer clinical research [10]. The Jackson Heart Study employed recruitment methods to strategically address enrollment barriers for African-Americans in order to investigate factors associated with cardiovascular disease. Unfortunately, African-American participants in this study expressed concerns about being taken advantage of and experiencing the same infractions that occurred in the US Public Health Syphilis Study at Tuskegee [11]. Other studies such as those regarding attitudes and beliefs about schizophrenia and lung cancer have shown that African-American participation is influenced by stigma and how the illness is perceived [12, 13].

Beliefs about medical research and the willingness to participate have been influenced by published reports and by past experiences of African-Americans serving as study participants [14]. As early as slavery, African-American women were forced against their will to participate in experimental gynecological studies; more recently, the public was made aware that cervical cancer cells taken from Henrietta Lacks resulted in the pioneering of medical research advances all over the world and the awarding of two Nobel Peace Prizes [15–17]. In both medical research events, informed consent was not obtained and the participants' individual integrity was compromised. Over a 47-year time span (1932–1972), the US Public Health Service conducted the Tuskegee Public Health Study to investigate the clinical course of syphilis in a cohort of African-American male farm laborers who were misinformed about their syphilis diagnosis and not given the opportunity to receive appropriate therapeutic intervention [2, 18]. While ethical standards for research participation were in existence prior to the mid-twentieth century, researchers were not required by law to adhere to these standards [19] until the 1970s following the Belmont Report. The current National Institutes of Health Revitalization Act of 1993, PL 103-43, mandates such high standards for current research studies involving human subjects.

Several studies have examined low participation in medical research among African-Americans and suggest that a lack of awareness about research opportunities, family, employment obligations, and minimal access to major research institutions due to transportation limitations contributes to low participation rates [20, 21]. While some studies have investigated barriers that contribute to a lack of participation in medical research by African-Americans, it is equally as important to evaluate African-Americans beliefs about medical research and preference for the types of study methodologies used in research studies. A qualitative study of African-American attitudes toward medical research found that most respondents were concerned about mistrust, the consenting process, the belief that benefits are reaped more by the researcher than the participant, and the history of past research participation by African-Americans that resulted in exploitation [22]. Another qualitative study investigating gender differences regarding beliefs about medical research among socioeconomically diverse sample of African-Americans found that men reported concerns about the benefits and level of compensation associated with participation, while women were concerned with the researcher-participant relationship [23].

Previous studies have shown that African-Americans may have an interest in participating in medical research [24–26], but there is a paucity of knowledge as to the types of research methodology preferred by this population. It may also be possible that African-Americans have concerns about the techniques used to collect data and whether or not the study procedures will cause harm. For instance, in a study to investigate factors that encourage research participation among African-American college students in South Carolina, providing a biological sample was preferred versus reporting confidential information. In this same study, students also reported preferring working with an African-American researcher when participating in a research study [27]. The Tuskegee Legacy project assessed willingness to participate in biomedical research and found that African-American participants preferred exercise more favorably as a study task versus receiving intravenous administrations or undergoing surgical procedures [28]. Additionally, other studies have

shown that some African-American participants do not always have clarity on the types of research methods and procedures that are used [29, 30].

It is imperative to further investigate beliefs about medical research and preferences for study methodologies among African-Americans as this minority group carries the burden of excess morbidity and mortality for many treatable and preventable illnesses. African-American attitudes and beliefs regarding medical research are important to health care treatment and outcomes [31]. The purpose of this study was to evaluate the role of socio-demographic factors such as age, level of education, and gender on beliefs about medical research and to investigate preferences for research study methods among African-Americans. This study will add to the growing body of knowledge about factors that influence African-American participation in medical research.

Methods

The study sample included volunteer African-American participants from communities in the Washington, DC Metropolitan area. Male and female participants had varying levels of age, education, income, and marital status. Participants were recruited from local hospitals, primary care settings, local colleges, faith-based centers, health fairs, and social, civic, and professional meetings. Participants were also recruited through newspaper advertisements, community health events, word of mouth, and flyers. There were no study refusals or dropouts. The study required a 1- to 2-h face-to-face interview at the Howard University Hospital's General Clinical Research Center (GCRC). Research participants were provided \$20 for the completion of the study. The study was approved by the Howard University Institutional Review Board.

Study data regarding participant beliefs about medical research and types of preferences for study methodology (Fig. 1) were generated from subscales on research participation included in the Genetic Testing for the Susceptibility of Alcohol Dependence: Psychosocial Implications (GPSI) study questionnaire. The GPSI questionnaire is a 90-item Likert response scale that was developed based upon the findings of previous studies on presumptive interest in the testing of family members on their genetic risk of alcohol dependence [32] and on studies of African-American women's attitudes concerning genetic testing for heritable factors of breast cancer [33, 34]. The GPSI questionnaire consisted of additional subscales that assessed the following domains: (1) the participant's interest in predisposition genetic testing for alcohol dependence and their beliefs regarding the possible impact of this type of testing, (2) the participant's concerns about genetic susceptibility testing for the risk of developing alcohol dependence, (3) the participant's beliefs about the causes of alcohol dependence and the possible role of genetic factors, (4) the participant's feelings of personal control over his/her fate with alcoholism, and whether beliefs in the role of genetic factors influences those feelings, and (5) the participant's beliefs about research in general. Demographic data, including age, gender, and education, was collected from each participant.

A pilot test of the questionnaire was conducted using a convenience sample of ten individuals that were representative of the proposed study population [35]. The

questionnaire was re-administered to the same group of ten individuals within 7 days later as a test-retest measure of the internal consistency of individuals' response. The overall reliability coefficient for the questionnaire resulted in a Cronbach's Alpha ($\alpha=.76$). The influence of age, gender, and level of education was also examined (see Appendix). Questions on beliefs about medical research and preferences for study methods were recoded from a Likert scale of five responses (agree strongly, agree, uncertain, disagree, and disagree strongly) to a scale of three responses (agree, uncertain, or disagree) by collapsing agree strongly and agree into agree, and disagree strongly and disagree into disagree.

Data was analyzed using SPSS (Version 16, SPSS Inc., 2007). Missing data was handled by list wise exclusion, where missing data points rather the entire individual were indicated as missing and excluded from analysis. Due to the nonnormal distribution of the outcomes measures, data from several variables were collapsed into more meaningful categories using a principal components analysis (PCA). This revealed an initial two-component model for beliefs and a five-component model for preferences of study methods resulting with an eigenvalue of 1.0 or greater. Utilizing the results of the PCA Scree plot and a second PCA with a Varimax rotation, four viable components emerged accounting for 60.04 % or more of total common variance explained. This resulted in two components each for beliefs and preferences about medical research (see Table 1). Thus, the three initial components no longer provided an appropriate fit and were excluded from further analysis. This resulted in two components each for beliefs and preferences about medical research (see Table 1). The two factors for beliefs were (1) beliefs about research being beneficial and (2) beliefs about research participation as a risky endeavor. The two factors for preferences were (1) preference to participate in research that requires DNA sample and (2) preference for participating in noninvasive research.

Multiple regression models were then used to analyze beliefs about medical research and preferences for study method components in relation to age, gender, and education levels. Because the models were run repeatedly with the same dataset, significance level adjustments were made using the Bonferroni correction method where there are four models of dependent variables: (1) *the belief that research is beneficial*, (2) *belief that research is risky*, (3) *prefer noninvasive research*, and (4) *prefer research with DNA sample* that was divided by the initial p value of (0.05). This resulted in a p value of .0125 and was rounded up two decimal points resulting in a final p value of .013 for determining statistical significance.

Results

The demographic characteristics of the sample are shown in Table 2. The sample consisted of a total of 304 adult African-Americans (113 men and 191 women (62.8 %). Most of the participants had completed some college education (43.75 %). The mean age of the participants was 39 years old.

Figures 1 and 2 illustrate the frequency of beliefs about medical research and preferences for study methodology in this sample. Participants were overwhelmingly in favor of medical research. Over 90 % of the participants agreed that medical research was necessary and

assisted in finding cures (Fig. 1). Very few participants agreed that it was not personally beneficial (8.88 %) or harmful (13.8 %). In terms of preferences (Fig. 2), most participants preferred medical researchers of the same ethnic/racial background (94.41 %) and genetic testing for diabetes (94.41 %) or hypertension (93.75 %). The least endorsed preferences for research study methods were those that could be perceived as invasive or involve some expense on the part of the participant such as no cash payment options (53.62 %), and research requiring oral (26.64 %) or intravenous (20.39 %) medications.

Table 3 shows the results of the multiple linear regression analysis of beliefs about medical research and preferred study methods in relation to demographic factors (age, gender, and education). While none of the beliefs or preferences components vary significantly by age, gender, or education, the belief that “research is risky” approaches significance ($p=.018$). There appears to be a trend toward the belief that research can be harmful among those subjects who have attained higher educational levels ($\beta = -.14$, 95 % CI $[-0.264, -0.025]$). In terms of gender and age, there were no trends toward significance. Males were as likely as females to believe that research participation was risky. Older participants were also likely to believe that research participation was risky. The other beliefs about medical research (belief that research is beneficial) and preferences for study methods (prefer noninvasive research and prefer research with DNA samples) were not significant.

As this analysis did not include a priori research hypotheses, the power to detect an association between demographics (age, gender, and education) and beliefs/preferences was estimated using G*Power version 3.1.9.2 [36–38]. Sample size was estimated using $\alpha=0.0125$, power=0.95, and beta coefficients (ranging from 0.1 to 0.2) as a measure of effect size for each outcome variable which approached statistical significance (*belief that research is beneficial*, *belief that research is risky*, and *prefer research with DNA samples*). The G*Power analysis applied used a linear multiple regression fixed models with a single regression coefficient analysis. The result suggested that a sample size of 150 (range 125–150) was necessary to achieve the specified statistical power of 0.95; this sample requirement is less than half of the actual sample size of 304. This indicates that the current sample size was sufficient to observe changes in beliefs/preferences due to demographic factors (age, gender, and education) and reducing type I and type II errors to 0.0125 and 0.05, respectively.

Discussion

Medical research participation by African-Americans is necessary to improve the health outcomes, medical intervention, and treatment of this population. Participation in medical research studies is needed in order to decrease the mortality rates of African-Americans especially among medical disorders that are preventable and treatable. The National Institutes of Health Revitalization Act of 1993, PL 103-43, consists of provisions for the inclusion of underrepresented minorities including African-Americans, in clinical research studies. The present study examined beliefs about medical research and preferences for study methods among a diverse community sample of African-Americans living in the Washington, DC Metropolitan area. Quantitative methods were utilized to assess the effect

of socio-demographic variables (such as age, gender, and level of education) on African-American beliefs about medical research and preferences for research study methods.

The overall results of this quantitative study did not find any significant differences among African-American participants in relation to age, gender, or educational background with respect to their beliefs about medical research participation or preferences for study methodology. However, other studies such as the one by Corbie-Smith et al. [22] utilized focus groups and found age, gender, and level of education significant in African-Americans feeling distrustful of medical research, the belief that the researcher benefits more from the results than the participants, and the fear of being treated like a guinea pig. Unlike the current study which collected quantitative data with a larger sample size from a variety of medical, community-based, and media outlets, Corbie-Smith et al. [22] obtained qualitative responses that provided more contextual information from a smaller sample recruited only from outpatient medical clinics.

In the present study age, education and gender were examined in relation to 14 preferences for research study methods but did not yield any significant findings among this African-American sample. However, Lang et al. [30] assessed age, education, and gender in a study of factors that influenced research participation and found that both men and women were more likely to participate in research if there is compensation, older participants preferred participating as a civic duty, and persons with higher levels of education would agree to participate if the study involved a condition in which they were diagnosed. Lang et al. [30] also assessed if persons would be willing to participate in research. Russell et al. [23] examined gender differences in preferences for participating in research and found that men preferred financial compensation, while women were more likely to prefer the researcher-participant relationship if participating in a research study.

There are several limitations that could have influenced the results of this study. The data collection method consisted of self-report interviews in which respondents could have provided socially desired responses to appear to have favorable beliefs about medical research and preferences of study methods. Furthermore, this study utilized a cross-sectional design which limited the ability to determine causality between age, education, and gender that could have influenced the responses or if participant responses may change over time. This study did not measure preexisting knowledge of historical medical research events, such as the Tuskegee Experiment, which may have impacted participants' responses. As with Corbie-Smith et al. [22], the use of a focus group may have resulted in the discovery of additional beliefs about medical research and preferences for research methodology that may have varied due to age, level of education, or gender. A final limitation of this study is the remaining need to identify whether the responses received would vary between African-American respondents who would or would not participate in a research study and among other ethnic and racial groups. Such findings should also be examined to determine if the beliefs and attitudes identified in this study are specific to African-Americans or common across a variety of ethnically diverse populations.

Despite the limitations of this study, we were able to collect data on beliefs about medical research and preferences for study methodology from a large African-American adult

sample diverse in age, level of education, and gender. It was equally important that this study was conducted at a historically black college (HBCU) and medical center which demonstrates that an HBCU has the capacity to engage in strategic recruiting to build a robust and diverse sample of African-American research participants. As in many studies on research participation, African-American participants demonstrated that when the researcher is of the same ethnic or racial status, the likelihood of participation is increased. HBCUs consist of a large number of minority researchers that help to remove certain barriers for participation.

There are a wealth of resources that are currently available to address research participation barriers in minority communities in terms of improving trust building, increasing enrollment in research, and developing culturally sensitive adapted research studies. In the Washington, DC metropolitan area, the Georgetown and Howard University Center for Clinical and Translational Science (GHUCCTS) offers programs on minority research participation including a research patient advocate that coordinates community access to help identify current studies and to provide education on the consenting process. The University of Maryland's School of Public Health's Center for Health Equity provides education and training on trust building with minority communities. It is also necessary for health researchers to provide education and information to minority communities on Institutional Review Boards and their role and responsibilities in overseeing research activities involving human subjects.

In order to eliminate health disparities and reduce poor health outcomes among African-Americans who suffer disproportionately from a number of health conditions, African-Americans should be included in the medical research process of study development. The present study on the beliefs about medical research and preferences for study methods was initiated to add the African-American perspective about medical research and what is preferred if considering participation. This study in concert with previous efforts to understand and identify factors that influence research participation should encourage further improvements in designing programs and studies that lead to an increase in the enrollment of African-Americans in research studies and clinical trials.

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Appendix

1 Disagree Strongly	2 Disagree	3 Uncertain	4 Agree	5 Agree Strongly
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What is your belief about medical research?

(a.) It is necessary	1	2	3	4	5
(b.) It assists in finding a cure	1	2	3	4	5
(c.) It is harmful	1	2	3	4	5
(d.) You will feel like a guinea pig	1	2	3	4	5

	1 Disagree Strongly	2 Disagree	3 Uncertain	4 Agree	5 Agree Strongly
(e.) You might not be told the entire truth about the risks and benefits	1	2	3	4	5
(f) It is not personally beneficial	1	2	3	4	5
(g) Other (Specify) _____					
You would participate in medical research if it involves:					
(a.) Completing forms with paper and pencil	1	2	3	4	5
(b) Completing forms on the computer	1	2	3	4	5
(c.) Taking medication orally	1	2	3	4	5
(d) Taking medication intravenously	1	2	3	4	5
(e.) Drawing blood for DNA testing	1	2	3	4	5
(f.) Providing a saliva sample for DNA testing	1	2	3	4	5
(g.) Providing cheek cells for DNA testing	1	2	3	4	5
(h.) More than 2 hours of your time	1	2	3	4	5
(i.) Multiple follow-up appointments	1	2	3	4	5
(j.) No cash payment	1	2	3	4	5
(k.) A disease and/or condition you or your family members are diagnosed with	1	2	3	4	5
(l.) A genetic test to give your risk for diabetes	1	2	3	4	5
(m.) A genetic test to give your risk for high blood pressure	1	2	3	4	5
(n.) Working with doctors and researchers that are the same racial and ethnic background as you	1	2	3	4	5
(o.) Working with doctors and researchers that are not the same racial and ethnic background as you	1	2	3	4	5
(p.) Working with doctors and researchers that are the same gender as you	1	2	3	4	5
(q.) Working with doctors and researchers that are not the same gender as you	1	2	3	4	5
(r.) No form of payment	1	2	3	4	5
(s.) Other (Specify) _____

*Beliefs items listed prior to categorization into more meaningful groups.

Fig. 1.
Participants ($N=304$) medical research beliefs (%). Beliefs items listed prior to categorization into more meaningful groups

*Preference items listed prior to categorization into more meaningful groups

Fig. 2. Participants ($N=304$) medical research preferences (%). Preference items listed prior to categorization into more meaningful groups

Table 1

Beliefs and preferences rotated components matrix loadings

	Loading
Component 1: believe medical research is a risky endeavor	
Will make you feel like a guinea pig	0.821
Might not disclose entire truth about the risks and benefits	0.743
It is harmful	0.725
Component 2: believe medical research is beneficial	
Assists in finding a cure	0.872
Is necessary	0.870
Is not personally beneficial	−0.459
Component 3: prefer participating in noninvasive research	
Doctors and researchers are not the same gender as you	0.857
Doctors and researchers are the same gender as you	0.837
Doctors and researchers are the same racial and ethnic background as you	0.811
Completing forms with paper and pencil	0.786
Completing forms on the computer	0.780
Doctors and researchers not the same racial and ethnic background as you	0.778
Component 4: prefer participating in medical research with DNA samples	
Providing cheek cells for DNA testing	0.855
Providing a saliva sample for DNA testing	0.852
Drawing blood for DNA testing	0.716

Table 2Demographics of the study sample ($N=304$)

Age (mean $\pm$ SD)	39.39 $\pm$ 14.78
Gender (n , %)	
Male	113, 37.17
Female	191, 62.83
Education (n , %)	
7th–12th grade	32, 10.53
High school graduate/GED	52, 17.11
Some college/technical school	133, 43.75
College graduate	45, 14.80
Some graduate school/advanced degree	42, 13.82

Table 3
Multiple regression analysis of differences in categorized beliefs and preferences based on age, gender, and education

	Age					Gender					Education				
	β	95 %	CI	p		β	95 %	CI	p		β	95 %	CI	p	
Belief that research is beneficial	.046	-0.003	0.007	.428		.071	-0.059	0.260	.216		-.117	-0.123	-0.002	.041	
Belief that research is risky	-.072	-0.017	0.004	.229		.016	-0.278	0.366	.788		-.141	-0.264	-0.025	.018	
Prefer noninvasive research	-.023	-0.013	0.009	.692		.056	-0.168	0.492	.335		.036	-0.085	0.164	.535	
Prefer research with DNA samples	-.028	-0.011	0.007	.631		.019	-0.224	0.311	.750		-.125	-0.211	-0.008	.034	