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Understanding Participation by African Americans in Cancer Genetics Research

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Abstract

Purpose—Understanding genetic factors that contribute to racial differences in cancer outcomes may reduce racial disparities in cancer morbidity and mortality. Achieving this goal will be limited by low rates of African American participation in cancer genetics research (CGR).

Method—We conducted a qualitative study with African American adults (n=91) to understand attitudes about participating in CGR and to identify factors that are considered when making a decision about participating in this type of research.

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CONFLICT OF INTEREST

None disclosed.

Results—Participants would consider the potential benefits to themselves, family members, and their community when making a decision to participate in CGR. However, concerns about exploitation, distrust of researchers, and investigators' motives were also important to participation decisions. Individuals would also consider who has access to their personal information and what would happen to these data. Side effects, logistical issues, and the potential to gain knowledge about health issues were also described as important factors in decision-making.

Conclusion—African Americans may consider a number of ethical, legal, and social issues when making a decision to participate in CGR. These issues should be addressed as part of recruitment efforts.

Keywords

African American; Participation; Cancer Genetics Research; Barriers and Facilitators

INTRODUCTION

Cancer is the second leading cause of death in the US that disproportionately affects African Americans in terms of morbidity and mortality.¹ Since all forms of cancer involve genetic changes that are either inherited or somatic, the molecular basis of cancer is a focus of ongoing research.^{2–5} Studies are now being conducted to develop a better understanding of genetic factors that contribute to racial disparities in cancer outcomes. This information may potentially contribute to the development of personalized approaches for cancer prevention, diagnosis, and treatment.^{6–8} Ultimately, it is anticipated that these results will reduce racial disparities in cancer morbidity and mortality. However, progress towards achieving these goals will be severely limited by low rates of African American participation in cancer genetics research.

Participation by African Americans in genetics research has been lower than whites regardless of whether the purpose of the study is to understand genetic factors involved in disease or to provide individualized risk information. For example, the Cancer Genetics Network (CGN) was established by the NCI to conduct collaborative studies on genetic risk factors for cancer. Data from one CGN center demonstrated that African Americans were significantly less likely than whites to enroll in the registry.⁹ Further, although 80% of non-Hispanic blacks who were enrolled in the National Health and Nutrition Examination Survey (NHANES) provided consent for their DNA to be used in future genetics research, consent rates were significantly lower than those reported in whites.¹⁰ African American women were also significantly less likely than white women to participate in a case-control study evaluating gene-environment interactions in breast cancer.¹¹ Similarly, only 49% of African American women participated in pre-test education about genetic testing for BRCA1 mutations that was offered as part of a randomized trial¹² and about 30% of African American women at high and moderate risk for having a BRCA1/2 mutation declined to participate in a randomized trial comparing alternate methods of genetic counseling.¹³

There is a growing body of research on beliefs and attitudes about participation in genetics research. For instance, Bussey-Jones et al. found that subjects who had already enrolled in a cancer genetic epidemiology study were unlikely to spontaneously identify negative outcomes of participation; these concerns emerged only when specifically prompted.¹⁴ In another study with this same cohort, Henderson et al. found that most participants had positive views about genetics research and were willing to participate in future research.¹⁵ Recent research has shown that positive attitudes and strong intentions may not translate into similar rates of participation in this cohort and trust is important to the donation of samples

for future studies.¹⁶ But, trust may not be the only factor that is important to participation decisions. Investigators are required to provide potential subjects with information about the procedures involved in participation and the possible risks and benefits of enrollment so that they can make an informed decision about participating. Several ethical, legal, and social concerns (e.g., privacy, disclosure of results)^{17–19} have been raised about some types of genetics research; but, it is unknown if these issues would be important to participation decisions among African Americans.

We conducted a qualitative study with a sample of adult African American men and women to identify factors that would be considered when making a decision about participating in cancer genetics research. While attitudes and beliefs about participating in genetics research has been explored in previous studies,^{15,16,20} these findings may have limited generalizability because they included subjects who had already made a decision to participate in research related to genetics. Our study explores attitudes and beliefs about participating in genetics among African Americans who were not currently engaged in a specific study that was evaluating genetic factors involved in chronic diseases

METHODS

Study Population

This research was approved by the Institutional Review Board at the University of Pennsylvania. Participants in this study were adult African American men and women. To be eligible, individuals had to be at least 18 years of age, self-identify as being African American and/or Black, and be able to speak and understand English. Individuals who were currently participating in cancer research and those who had a personal history of cancer were excluded from participation.

Procedures

Participants were recruited into the study from the Philadelphia metropolitan area through self-referrals from newspaper advertisements that described the study as research that was evaluating how people make decisions about participation in research. Interested individuals were directed to contact the study line for information; individuals who self-referred completed a screening interview after giving verbal consent. Those who were eligible completed a structured survey to obtain sociodemographic characteristics. At the end of the survey, individuals were invited to participate in a focus group and those who accepted the invitation were mailed logistical information about the session.

We conducted seven focus groups ranging in size from 8 to 10 participants that were stratified by gender, age (under age 50 versus 50 and older), and education level (at least high school graduate versus not a high school graduate). After obtaining written informed consent, a semi-structured guide was used to facilitate discussion about participating in cancer genetics research. Specifically, a brief introduction that included a description of cancer genetics research as studies that were being conducted to identify the role that genes play in cancer development was given and then, participants were asked to discuss their attitudes about participating in medical research. We started with this topic because attitudes about participating in cancer genetics research may be a specific manifestation of general attitudes about medical research. As part of this discussion, we specifically asked participants to describe how they would make a decision about participating in cancer research and studies on genetics and cancer genetics using a modified version of the nominal group technique.²¹ During this component of the session, we asked participants to write down four to five reasons for why they would and would not be willing to participate in a study related to genes and cancer. Each participant described their list and gave reasons for

the items on their list. After the group preferences were known, the moderator summarized the ideas that emerged and then asked the participants to rank the top three issues that would be most important to their decision to accept or decline participation in cancer genetics research. This yielded a ranked list of barriers and facilitators to participation. These discussions were audiotaped and transcribed and entered into QSR N6 software for analysis.

Groups were facilitated by the PI (CHH) or senior project manager (BW) and lasted about 2 hours. All focus groups were audio-taped and transcribed verbatim. Participants were given \$20 in appreciation for completing the focus groups.

Data Analysis

We used grounded theory to identify key themes in the discussion that accompanied the rating task for reasons related to participation in cancer genetics research.^{22,23} Specifically, we used the constant comparative method to compare themes across groups and to determine relationships among them.²⁴ Focus group transcripts were coded and analyzed by study investigators and trained research assistants using QSR N6 software. Themes that illustrated attitudes about medical research and factors that were important to decisions about participating in cancer genetics research were abstracted from transcripts. To determine the frequency of the identified factors, we itemized responses to three questions that were asked in each group using talk turns.^{25–27} Talk turns were defined as words spoken by one participant until another participant spoke. Participants were asked to respond to three questions: (1) how would you make a decision about whether or not to participate in a study on cancer? (2) how would you make a decision about whether or not to participate in a study on genetics? and (3) how would you make a decision about whether or not to participate in a study on cancer genetics? In a single talk turn, participants often discussed many factors that were important in making a decision to participate in cancer genetics research. To determine the dominance of each factor, we totaled the number of times it appeared in a talk turn. If a factor appeared more than once in a talk turn, it was only counted once. The prevalence of each factor was reported as the proportion among the total number of talk turns (N=227). Quotes referenced throughout the manuscript are from the responses to the three questions described above.

RESULTS

Sample Characteristics

A total of 91 African Americans participated in the focus groups. There were 50 men (55%) and 41 (45%) women. A little more than half of participants (56%) were high school graduates. The average age of participants was 47 (SD=8.9); 64% were under 50 and 36% were older than 50.

Knowledge and Attitudes about Medical Research

Participants described medical research as a search for a greater understanding and control of diseases using information that is obtained from experiments that may involve blood samples and medications. Participants held complex, and sometimes contradictory, attitudes about medical research. On the one hand, individuals had positive views about research and the potential for the results of studies to benefit them personally and to benefit the African American community. Participants also indicated that research is very important and is necessary to help future generations. Thus, it is not surprising that participants emphasized the importance of African American participation in medical research and suggested that studies should be conducted to specifically address the health issues and concerns in this population. At the same time, however, concerns about trust and exploitation were expressed.

Medical research is a game that the rich man play[s] on the poor man.

Is there a benefit to us or not. Is it gonna be used against us or for us. They have a habit of gathering documentation based on one cultural group... and that could be used as a plus or minus.

Participants questioned whether or not studies were conducted to find a cure for disease or to generate profits. Some participants believed that generating income was the primary motivation for conducting studies among researchers.

... you got to remember something, living in America as a black person, you are dealing with masses of deception. They are not true with a whole lot of things. If it is not profitable they don't do it... all the millions of billions of dollars allocated for years for cancer research and they can't find a cure, but they can go to the moon.

Anybody can misrepresent the facts; shape the facts to represent what they want them to be depending on what they want to get out of it. ...it might be the doctor trying to make sure he gets his research grant for next year so he is going to say he is having this outcome... a study just makes it so easy for somebody to manipulate the results for what they want.

Decision Making Factors

We asked participants how they would make a decision to participate in cancer research and research that involves genetics. Several different factors emerged during the discussions about participation decisions. Specifically, barriers that were ranked by study participants included distrust, lack of information about the study, the procedures involved in participation, and the potential to experience negative side effects. As shown in the Table, 14% of the participant discussion related to concerns about exploitation and the extent to which the investigators and study sponsors (e.g., government, pharmaceutical company) were trusted. Participants also expressed apprehension regarding possible side effects and these issues were found in 11% of talk turns (Table).

...but my understanding of the study when I went into it, that they were going to help me, when I finished this study that I would have the proper medicine that I needed for my blood pressure.... I left there with nothing. I felt like they used me and didn't do anything for me. I thought the benefit of doing the study was to get me the proper medicine that I needed. But when I finished it I just felt used.

Whoever is giving the study. They might have other motives. They might say they are looking for one thing but they are looking for something else.

I'm scared. Like I might be the one to pass out....sometimes I look in the paper and I think about it and I am like no. I might be the one to get the medicine that gives me side effects or something like that. But I think it is a good thing for the future for the next generation as far as them finding answers.

Participants also indicated that they would consider the information provided about the details of the study (11% of the talk turns, see Table), including being informed about the purpose of the study and the procedures involved in participation, who has access to the data, what would happen to their information once the research was over, and whether or not participants would have access to the results once the study was over. Participants acknowledged that genetics research studies primarily involve minimally invasive procedures (e.g., cheek swabbing, blood draw) and some remarked "*there is a lack of risk in participating in genetics... there is no invasive procedures, no blood, no medications.*" However, some still had concerns about participating in cancer genetics research.

My concern would be what would be done with my DNA. Like after they used their research how would they, what would they do, how would they dispose of it? It would go into a bank. Who would have access to it? Who is it going to? How is going to be used? Is it going to be disposed of? Is it going to be stored for later usage?

Once you start dealing with some of this personal identifier like the blood or DNA. Where does it end up at?

I would say get the real results because a lot of studies that are done I don't feel as though we get the real results.

Participants also emphasized the importance of individuals seeking out information about studies for themselves by researching the researchers to determine who is conducting the study, why the study is being conducted and whether deception is a possibility.

A lot of our people... get misinformation or they don't get any information at all. ... we need to step up and get involved in research and find out what's going on with the disease and medication. We need to get out there so that we can take back and give the necessary information back to our people.

I want to make sure when I am signing I really understand because you can sign yourself away to things you don't even realize you did that.

Facilitators of participation that were ranked by study participants included individual and community benefits, the future implications of the results, and the potential to educate oneself. As shown in the Table, the potential benefits of the study were identified as a primary factor in individual's decisions about participating in cancer genetics research accounting for 34% of the participant talk turns. Personal benefits as well as those to the general public and to African Americans were among the factors that participants would consider when making a decision about participating in research, regardless of the focus of the study.

... if I had it then I would definitely want to get into it to see if it would help my disease... That's how a lot of people feel, you know, they don't want to be involved in something that is not involving them.

I would want to know... how does this research going to make this person fighting cancer, how is it going to make their life better?

It is culturally beneficial to African Americans. That has to be a key point in these research studies because... we have a higher rate of high blood pressure, cancer, across the board. I mean if they can focus on what are the determining factors that make us more receptive... but the studies need to focus on us culturally as a people...

Let's be just as healthy as foreigners, white people... Say I want this for my race. I want this for my family, my future family, whatever. So that when they have the studies it won't be white people live 100 years and black people live 75 years... I think that we need to be involved to make that happen.

The potential to gain knowledge about health issues (7%) was also ranked as a facilitator to participation (Table).

Because I believe a lot of what affects our genes is based on environment and... If I personally knew that I was subjecting myself to carcinogenics then I'd change.

I consider myself healthy because of clinical research and genetic research. I learned a lot about my body. Like how to keep my cholesterol down.

Logistical issues (9%) (e.g., financial compensation, the length of study participation) were also described as being important to decisions about participating in cancer research and research that involves genetics, but were discussed to a lesser extent (Table). Issues related to the travel distance to the research facility were described as being a barrier and facilitator.

DISCUSSION

The purpose of this study was to explore how African Americans would make a decision about participating in studies on cancer and genetics. Since attitudes about participating in these types of studies may be a manifestation of general attitudes about medical research, we also explored these general issues in our sample. Our research sheds new light on some of the factors African Americans may consider when making a decision to participate in cancer genetics research and extends previous research on attitudes about cancer genetics research.^{15,16}

We found that participants had complex and sometimes conflicting views about medical research. Consistent with previous research,^{15,20} participants in this study held positive attitudes about research and the potential for the results of studies to benefit them personally and to also lead to health benefits for the African American community. Thus, it is not surprising that participants emphasized the importance of African American participation in research and suggested that studies should be conducted to specifically address health issues and concerns in this population. At the same time, however, participants believed that there was the potential for individuals to be exploited and deceived in studies. Some participants questioned the investigator's and sponsor's motives for conducting the study, some were concerned about the potential for the results of study to have a negative impact on African Americans, and others expressed concern about potential for study results to be manipulated. It is possible that these beliefs were based on personal experiences with prior research participation, the experiences of others in studies, knowledge about the Tuskegee Syphilis Study, or lack of knowledge about research process. Previous research has shown that knowledge about the Tuskegee Syphilis Study is significantly more likely to be associated with distrust among African Americans compared to whites.²⁸ But, Tuskegee was not mentioned during the discussion about participation barriers; knowledge about this study was not associated with racial differences in intentions to participate in research.²⁸ Recent work has shown that African Americans are more likely than whites to be distrustful of the healthcare system;²⁹ it could be that distrust is the reason why participants had concerns about exploitation and deception. Individuals who do not feel as if they are valued may easily believe that researchers and others involved in the research enterprise care more about their own personal gain than improving their health. Studies are needed to identify the sources of concerns about exploitation and deception and identify strategies for addressing these beliefs. When asked how they would make a decision to participate in cancer research and studies involving genetics, participants emphasized the importance of many elements that investigators are required to address as part of the informed consent process. In fact, some of the issues that participants raised have been described as barriers (e.g., distrust) to participating in all types of research. But concerns that were specific to genetic research included what would happen to one's DNA and other health information. Previous studies have shown that distrust of healthcare providers is a barrier to participation, but our findings show a concern for misrepresentation of study objectives and the use of their DNA. For instance, participants stressed having details about the study and knowledge of the possible benefits and risks of participation. However, our findings provide more nuanced information about how distrust may act as a participation barrier. These issues accounted for the majority of talk turns about making participation decisions. Recent research has shown that individuals who provide consent for some types of genetics research (e.g., biobanks) understand the purpose of this type of study, are aware of the potential benefits, and know

that participation is voluntary; however, the possible risks and the experimental nature of this type of research are understood less.³⁰ Our findings suggest that there may be a more nuanced understanding of informed consent issues for genetic research among African Americans. Many of the factors that participants in our study would consider when making a decision about enrollment were similar to the consent issues in genomic research that are now being debated.^{31,32} For example, participants reported that they would consider who has access to the study data, what would happen to their information once the study was over, and whether or not results would be provided to them. Similar concerns were reported about the Human Genome Project by minorities³³ and African Americans were less willing than whites to provide access to their past medical records as part of biobank research and were also more concerned about protecting their privacy.¹⁷ Further, African Americans were less likely than whites to prefer blanket consent for participating in genomic biobanks.³⁴

Considerable attention has been given to informed consent issues in genetics research, especially in studies that involve disclosure of genetic risk information as part of counseling and testing protocols.³⁵ But, new issues are emerging as genomic studies that involve the collection, storage, and in some cases, sharing, of genetic information are being planned^{17,32} and implemented.^{30,36,37} For instance, data collected and stored in biobanks may be shared with other investigators for use in studies that were not specified at the time of original consent and withdrawal of samples may be complicated if they were shared with other investigators.^{31,32} Research has been conducted to evaluate the quality of informed consent for participating in genetic research, but African Americans were under-represented in this research.³⁰ Thus, empirical data are lacking on the extent to which African Americans adequately understand the risks and benefits of participating in this type of research. Our findings suggest that some issues related to the risks (e.g., lack of privacy) and benefits of participating in cancer genetics research are salient to African Americans, but other research has shown that African Americans may not have an adequate understanding of the genetic terminology that may be used in informed consent documents. For instance, only 26% of African Americans in a community-based sample knew what the genome is and 22% knew the number of chromosomes that humans have.³⁸ Literacy is critical to the informed consent process; individuals with low literacy were least likely to understand common medical terms used in prostate cancer education materials to obtain informed consent among African American men.³⁹ Recent reports have emphasized the importance of tailoring the informed consent process for genomic and genetic research among diverse racial and ethnic groups and highlighting the importance of study design, data and biological sample sharing, and the disclosure of study results to participants.³² Future studies should evaluate the relationship between literacy and the quality of informed consent for genetics research among African Americans and decisions about participating.

Overall, the potential benefits to oneself and the African American community accounted for 34% of the participant discussion related to how individuals would make a decision about participating in cancer genetics research. This finding is consistent with the results from a previous qualitative study with a racially diverse sample which found that adults would consider participating in genetics research in order to benefit individuals and society.³⁶ However, in our study, participants often raised concerns as part of discussing the potential benefits of research and participating in studies. Similar results were found in a cohort of individuals who had already provided consent to participate in genetic epidemiology research; participants had generally positive attitudes and beliefs about genetics research, but when prompted, some expressed concerns about these types of studies.¹⁴ This process may reflect how individuals are likely to weigh the risks and benefits of participating in cancer genetics research and should be expected and encouraged. Future research is needed to identify the most effective strategies for obtaining informed consent for cancer genetics research among African Americans.

While our study extends previous work on African American participation in medical research^{14,15,40} by identifying factors that individuals may consider when making decisions about participating in cancer research among an urban sample that had not previously participated in genetics research, it is important to consider some possible limitations such as the small sample and the methods we used to recruit participants. Even though qualitative studies typically enroll a smaller number of participants from a single geographic area using self-referrals, it is important to note that these features may limit the generalizability of our findings. Only a few studies have evaluated attitudes about participating in genetics research specifically in African Americans or included members of this group in sufficient.^{36,40} It should also be noted that we did not evaluate actual participation in genetics research or donation behaviors, but our study makes a unique contribution by exploring factors that African Americans are likely to consider when making a decision to participate in this type of research. While additional research is needed to identify and understand barriers and facilitators to participating in cancer genetics research in larger samples using qualitative and quantitative methods in geographically diverse samples of African Americans, the results of our study could be used to inform the development of instruments that evaluate the effects of these factors on actual and intended participation.

Understanding the factors that affect decisions about participating in cancer genetics research among African Americans is a critical first step towards developing more effective strategies for recruiting this population into these types of studies. In addition to ensuring that structural factors (e.g., eligibility criteria, recruitment sources) do not limit access to cancer genetics research^{41,42} and efforts are made to ensure awareness about studies¹² among African Americans, recruitment protocols may need to address the concerns that African Americans have about participating in cancer genetics research. Our results show that trust is important to participation decisions, but it is not the only factor that individuals would consider when making a decision to participate in cancer genetics research. It may be useful to develop strategies that address concerns related to how their information will be used in these types of protocols.

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Table

Top factors involved in making a decision to participate in cancer genetic research reported in percentage of talk turns

Decision Making Factors	% of total talk turns
Participation would benefit self and others	34
Trust of study investigators	14
Side effects	11
Information provided on details of the study	11
Logistics of the study (i.e. compensation)	9
General gain of knowledge of disease and health	7

Note: N = 227 talk turns

Categories are not mutually exclusive