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RESEARCH ARTICLE

Attitudes Toward Genomic Testing and Prostate Cancer Research Among Black Men

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Introduction: Black men are diagnosed with prostate cancer at nearly twice the rate of white men and are underrepresented in prostate cancer research, including validation studies of new clinical tools (e.g., genomic testing). Because healthcare system mistrust has contributed to these disparities for centuries, black men may be less inclined to pursue novel testing, and identification of facilitators to their participation in prostate cancer research studies remains warranted.

Methods: A community-engaged approach involving a partnership with a community organization was used to conduct seven focus groups in Minnesota, Alabama, and California to explore black men's attitudes toward prostate cancer research participation and genomic testing for prostate cancer. Data were collected and analyzed from April 2015 to April 2017.

Results: Identified genomic testing barriers included a lack of terminology understanding, healthcare system mistrust, reluctance to seek medical care, and unfavorable attitudes toward research. Facilitators included family history, value of prevention, and the desire for health education. Lack of prostate cancer knowledge, prostate-specific antigen testing confusion, healthcare system distrust, and misuse of personal health information were barriers to research study participation. Some black men were motivated to participate in research if it was seen as constructive and transparent.

Conclusions: Disparities for black men can both motivate and disincentivize participation depending upon a positive or negative view of research. Confusion over prostate cancer clinical care has fueled some mistrust among black men affecting both clinical care and research participation. With increased education, health literacy, and assurances of research integrity and transparency, black men may be more willing to participate in prostate cancer testing and research.

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INTRODUCTION

Prostate cancer (PCa) remains the third leading cause of cancer death in American men.[1] Black men are diagnosed with and die from PCa at nearly twice the rate of white men.[1] PCa is most commonly diagnosed through the prostate-specific antigen (PSA) blood test, which discriminates poorly between clinically significant and insignificant disease. Current clinical tools have limited ability to provide the risk assessment needed for men to make informed treatment decisions. Recently available genomic tests (e.g., Oncotype DX, Prolaris, Decipher), run on prostate cancer tissue,[2–4] can help decide appropriateness for active surveillance or timing of salvage therapies. Although black men may benefit from personalized approaches enhanced by genomic testing, little is known about their willingness to accept such testing.

Despite the increased disease burden borne by blacks, they remain underrepresented in PCa clinical trials.[5,6] For example, less than 50% of U.S. PCa RCTs performed between 1991 and 2015 reported black male enrollment.[6] Black men have previously reported higher levels of distrust of clinical research and healthcare systems because of the impact of past clinical research abuses (e.g., the Tuskegee Syphilis Study).[7] Thus, "new" tests/treatments that may improve risk stratification and target therapies could be met with resistance, possibly increasing PCa outcomes disparities among blacks.[8] The twofold purpose of this study is to explore barriers and facilitators of: (1) genomic testing for PCa in black men, and (2) black men's participation in PCa research to provide a framework to design future PCa outcomes disparity research.

METHODS

Study Population

Black community members/stakeholders were recruited in Minneapolis, Minnesota; Birmingham, Alabama; and Sacramento and Oakland, California, to participate in focus groups (FGs). Participants were recruited by a variety of methods at different sites, including through clinical practices, meetings of the 100 Black Men of America, and word of mouth through a community agency. Eligible participants were adults, aged >18 years, who self-identified as black or expressed interest in PCa among black men. Women were included due to their influence over family members' (i.e., spouse's) health; non-blacks were included to allow non-black spouses of black men to participate.

Seven 90-minute FGs were held (two each in Minneapolis, Birmingham, and Oakland; one in Sacramento) with 2–15 participants, each facilitated by one team member (a black male with a PhD). Four FGs (n=39) focused on barriers to and facilitators of PCa genomic testing in black men. Three FGs (n=17) explored attitudes toward black men's participation in PCa research. Participants were incentivized with refreshments and a $20 gift card. The IRBs of the University of Minnesota, University of Alabama at Birmingham, and University of California, Davis, approved this study.

Measures

Before each FG, participants completed a brief anonymous demographic questionnaire. A semi-structured interview guide was developed to achieve the study purpose. Two sets of FG questions addressed both uptake of genomic testing and attitudes toward PCa research.

Statistical Analysis

All FGs were recorded, transcribed, and analyzed between April 2015 and April 2017. De-identified data were analyzed using NVivo, version 11. Investigators used the social constructivist approach to Grounded Theory to identify study themes.[9] Two investigators independently read and annotated the transcripts to identify thematic structures among the data. Double coding of two FGs aided in codebook development, revealing major themes that were used to annotate the remaining five transcripts. Research team conferencing on the emerging analysis provided further validation of the design's rigor. Researchers resolved discrepancies by consensus. The sample's demographic information was summarized using Stata, version 14.

RESULTS

Fifty-six unique participants met inclusion criteria. Participants' mean age was 55 years and 18 (38%) reported previously having PCa (Table 1).

Barriers to Genomic Testing

Most participants stated they had heard of genetic testing, but most were unfamiliar with genomic testing. When asked to provide words or definitions describing the terms genetics and genomics, numerous participants stated the environment affects one's genomic makeup; others questioned whether genomics was related to race and ethnicity, and genomics was of more concern than genetics. One participant stated the words "genomic testing" reminded him of the Tuskegee Syphilis Study (Table 2-A).

Participants were more familiar with the term genetics, stating that it described how an individual might inherit certain traits or conditions. Participants commonly used the terms genomic and genetic interchangeably, suggesting a belief that undergoing genomic testing may reveal heritable traits. At the end of this discussion topic, participants were given the following definitions: (1) genetic testing refers to testing of genetic material that can be passed on to future generations, and (2) genomic testing refers to testing genetic material that will not be passed on to future generations.

Participants described mixed experiences with healthcare providers. For some, this mistrust generalized to the healthcare system, including the medical profession. For

Table 1. Participant Demographic Characteristics[a]

Sample characteristics	Study sites				Total (N=56)
	Birmingham (*n*=15; 26.8%)	Minneapolis (*n*=10; 17.9%)	Oakland (*n*=23; 41.1%)	Sacramento (*n*=8; 14.3%)	
Age, years					
18–34			7 (12.5)		7 (12.5)
35–64	11 (19.6)	2 (3.6)	11 (19.6)	4 (7.1)	28 (50)
≥65	4 (7.1)	8 (14.3)	5 (8.9)	4 (7.1)	21 (37.5)
Education					
<12th grade	2 (3.6)	1 (1.8)	1 (1.8)		4 (7.1)
High school graduate			4 (7.1)		4 (7.1)
Some college	7 (12.5)	4 (7.1)	4 (7.1)	1 (1.8)	16 (28.6)
College graduate	4 (7.1)	1 (1.8)	7 (12.5)	4 (7.5)	16 (28.6)
Some graduate school		3 (5.4)	3 (5.4)	1 (1.8)	7 (12.5)
Graduate school		1 (1.8)	4 (7.1)	2 (3.6)	7 (12.5)
Graduate/Professional school graduate	2 (3.6)				2 (3.6)
Employed					
Yes	8 (14.3)	6 (10.7)	15 (26.8)	2 (3.6)	31 (55.4)
No	7 (12.5)	4 (7.1)	8 (14.3)	6 (10.7)	25 (44.6)
Gender					
Male	15 (26.8)	7 (12.5)	18 (26.8)	8 (14.3)	48 (85.7)
Female		3 (5.4)	5 (8.9)		8 (14.3)
Income					
Not reported			1 (1.8)		1 (1.8)
<$10,000	2 (3.6)	1 (1.8)			3 (5.4)
$10,000–$49,999	6 (10.7)		9 (16.1)		15 (26.8)
$50,000–$99,999	5 (8.9)		8 (14.3)	2 (3.6)	15 (26.8)
$100,000–$150,000		3 (5.4)	3 (5.4)	5 (8.9)	11 (19.6)
>$150,000	2 (3.6)	6 (10.7)	2 (3.6)	1 (1.8)	11 (19.6)
PCa history					
Yes		7 (12.5)	6 (10.7)	5 (8.9)	18 (26.8)
No	15 (26.8)		12 (21.4)	3 (5.4)	30 (53.6)
Not applicable		3 (5.4)	5 (8.9)		8 (14.3)

Note: Data presented as *n* (%).
[a]Percentages calculated by dividing the number of participants at each site by 56 and multiplying by 100.
PCa, prostate cancer.

others, the potential for providers to gain financially by writing prescriptions or ordering tests undermined the provider–patient relationship (Table 2-B). Other participants expressed concerns about hidden agendas working against blacks, possibly reflecting broader experiences of racism and historic abuse. This mistrust extended to how findings or test results might be used and by whom. One participant was concerned this information could influence blacks' ability to obtain health insurance or access care and was a disincentive for testing (Table 2-C).

Some participants identified lack of health insurance as a reason blacks do not undergo genetic or genomic testing. Other participants described black men as reluctant to seek health care until they have symptoms, as going to the doctor was seen as weak or admitting to pain or discomfort would appear unmanly (Table 2-D).

A variety of attitudes were reported pertaining to participant willingness to undergo genetic or genomic testing in a research setting. One participant, for example, believed black men have no interest in research because participation does not affect them immediately or directly. Another stated that cancer research is unsuccessful because people continue to die of cancer, suggesting treatments are inadequate and unsafe (Table 2-E). Other participants, however, expressed more supportive attitudes about cancer research, emphasizing its positive implications, such as determining causation and finding cures. Others perceived blacks as having a greater genetic

Table 2. Participant Quotes From Focus Groups on Genomic Testing for PCa

Theme	Participant quotes
A. Lack of understanding of the terminology	". . .I'm trying to think of all the testing that they did on African American black men . . . when they gave them syphilis. . .What was the purpose? What was the outcome to be? . . . Genomics could be something . . . Is it private? Is it something that's industrial that . . . we all could be able to look up and check out? (Sacramento male participant)
B. Healthcare system mistrust	" . . . It seems like people are just trying to get our money...Run all sorts of tests so they can get paid. This stuff is expensive." (Alabama male participant)
C. Healthcare system mistrust	"My concern would be to have it used in a way that would deny you something. . . . I think that's something that hangs over people's heads. If I'm predisposed to have cancer, would that cost me a medical coverage?" (Oakland male participant)
D. Reluctance to seek medical care	"There was a time when it was thought if you went to the doctor you would have been a sissy. You're supposed to man up, take a little pain . . . .That's why I don't know that much about certain generations of my family because no one ever said anything." (Sacramento male participant)
E. Unfavorable attitudes toward research	"For 100 years they have been trying to get a cure for cancer....The new forms of cancer are more aggressive so you have more people dying even with all this research. . . . So, what is the problem? If you are doing all this research why is it such an elusive enemy?" (Alabama male participant)
F. Family history	"Because my family has a history of it from my grandfather on down, soon as I found out, I called everybody in my family. I said I want all the guys tested." (Sacramento male participant)
G. Value of prevention	" . . . I've learned that early detection saves lives. If there is something that is capable of killing me and I have got the capability of doing something about it, then I have got to check and do it." (Alabama male participant)
H. Value of prevention	" . . . I think black people . . . need to be able to see the person themselves because then they can see themselves in that person. So, to me, that's how you can get them more interested, not only in medicine, but interested in going to seek out help." (Minneapolis male participant)
I. Desire for health education	"Because it's such a personal topic, and it's very scary, the closer you get to 50 and beyond . . . .I would like to educate . . . people in my family or people that I have influence over at a younger age, like 30, so that they can get used to . . . some of the language and the fact that . . . education is going to allow you . . . that time to get rid of some of that fear." (Sacramento male participant)
J. Desire for health education	"For me being diagnosed with PCa was a turning event . . . and I think the more education I had earlier on the more I was able to cope with it better and therefore I was able to communicate about my PCa on a more intelligent level. I think education is really the key to getting you in the door at the doctor's office to talk about what the risk factors are, how to control it, how to manage it and how to cope with it. Even though you have had it and every year I get my prostate test." (Minneapolis male participant)

PCa, prostate cancer.

predisposition to diseases and therefore valued research as important for the black community.

Facilitators of Genomic Testing

Despite their unfamiliarity with genetic and genomic testing, participants said they would recommend family members undergo testing if doing so would detect PCa. Participants also described the important role of family history as a facilitator of engagement in genomic testing for PCa. Those who had had PCa themselves or knew of it in their family valued the idea of testing (Table 2-F).

Despite mistrust of medical testing and practice, many participants stated that they valued the opportunity to receive preventive care for themselves and their families and to learn of inherited conditions among offspring. Others stated that early detection could save lives and expressed support for testing both for themselves and their families (Table 2-G). Participants stated that positive relationships with providers were helpful for making decisions about testing, and having more black providers would help to encourage greater medical care engagement (Table 2-H).

An additional theme across FGs was a desire for education about PCa and genomic testing. Many participants expressed a strong desire for community-wide, multigenerational education about the value of preventive health care. Participants believed education starting early in life would help reduce PCa fear and be more useful than promoting testing (Table 2-I). Others noted that the education they received following a PCa diagnosis helped them deal with their own disease and was useful to share with others (Table 2-J).

Prostate Cancer Research Participation Barriers

Healthcare system mistrust was the most common reason given for lack of PCa research participation. Participants in all geographic regions expressed this sentiment. Participants expressed concern over historic abuses of black men in research, namely, the Tuskegee experiments. Participants also expressed feelings of fear and

Table 3. Participant Quotes From Focus Groups on PCa Research

Theme	Participant quotes
A. Healthcare system mistrust	"That is a tricky subject because of the Tuskegee study. There is a lot of history that doesn't favor. It makes you extremely cautious to participate in studies." (Alabama male participant)
	"Tuskegee has crippled this community in many ways. Young folks don't know about that, but many people my age know about the study. That creates some fear." (Minnesota male participant)
	"You know the thing that I, that happened. . .they gave all these guys syphilis. That has been a black mark on the medical society and the relationship with African Americans, especially men, and it has not changed in terms of being able to be trustworthy for doctors." (Sacramento male participant)
B. Patient-provider relationship	"They're telling me you don't need it, you don't need a PSA. So now they are automatically telling me you're going to die. If I don't get a PSA and find out that I got prostate cancer, what are they telling me? That there is no other way to detect it, but I don't need it? So now you know why black people don't want to go to the doctor." (Minneapolis male participant)
C. Patient-provider relationship	"I think that in the black community, there's a couple things going on. But one of them is that, you know, we have a justifiable mistrust for the healthcare system, and I think that, even with a lot of education, there still is a mistrust about going into the doctors and seeing this white doctor. You know, and I think that, even if we have a black doctor, we still look at these institutions as white institutions." (Oakland male participant)
D. Fear	"I just find that, just honestly in my heart, I just believe that the issue of cancer is, is one that probably was settled back in the 40s, and it just has not been uh revealed to the public uh as we're you know designed for whatever they wanna do, and I just think there's been so much manipulation of information, that uh we just, we just really don't know who is lying and who is not. And uh, I mean after a hundred years, I mean this is the only disease that we're no closer to curing than it was when we started." (Alabama male participant)
E. Transparent process	"I do not have any problem with that. If it is true constructive research done by doctors with integrity then I don't have a problem with it. Without research then we are not going to find out about it. We need to have some testing." (Alabama male participant)
F. Transparent process	"I would like the results. I would also want to know if it helped. I am not hostile towards researchers, but I am hostile towards deception. I will always be hostile towards deception. If we aren't going to discuss it openly and truthfully then there is no point in the discussion." (Alabama male participant)
G. Additional facilitators and research priorities	"You all should be interested because it's killing us. It's killing us faster than everybody else. And they don't know why. You know, that's my whole thing. Because I would love to know why, but they said, they just don't know why." (Minneapolis male participant)
H. Additional facilitators and research priorities	"Absolutely we should participate because it's too prevalent. And it's treatable if it gets caught early enough. The consequences of not doing that are too severe." (Sacramento male participant)

PCa, prostate cancer.

distrust extending from research to general mistrust of the medical system (Table 3-A).

Many participants expressed a distrust of healthcare providers, whom they saw as unknowledgeable or nontransparent (Table 3-B) because of confusion stemming from recent changes in PCa screening guidelines. Other participants stated that the relationship with their provider could help build trust, but that having a black doctor was insufficient. Participants indicated that mistrust goes beyond an individual physician to the healthcare system at large (Table 3-C).

Some participants expressed fear of participation in research as fear of being treated "...like a guinea pig," whereas others expressed deeper mistrust, suggesting researchers held sinister motives for wanting to involve black men in research (Table 3-D). In addition to personal-harm concerns, participants expressed apprehension about the use of gathered personal information that might be hacked or used by third parties, such as insurance companies, to later deny the participants insurance or services.

Prostate Cancer Research Participation Facilitators

Some participants said PCa research participation could be positive when conducted transparently, with a clear agenda, and with nothing "sneaky" being done to subjects (Table 3-E). Participants also voiced how receiving their personal results from a research study would help dispel suspicions of deception (Table 3-F).

Participants also described PCa disparities as a motivation for participation in PCa research. Recognition of the higher mortality rates for blacks than whites and a desire to identify the causes of these disparities were particularly important motivators (Table 3-G).

Participants identified prevention and screening/early detection as the most important priorities for future PCa research. Participants were very interested in the effects of diet, lifestyle, and environmental toxins on PCa

development. Continuing research on PCa screening was discussed frequently (Table 3-H).

DISCUSSION

Compared with their white counterparts, black men are approximately twice as likely to be diagnosed with, and die from, PCa. Novel precision medicine approaches, including genomic testing, offer the potential to improve patient PCa outcomes, including appropriate selection of men for observation, timing of salvage radiation therapy,[10] and prediction of drug response.[11] Yet recruitment to government initiatives, such as the "All of Us" precision medicine research program, remains a challenge despite efforts to partner with black faith-based groups to increase minority participation.[12,13] There is concern that lack of black participation in such research may exacerbate health disparities. Accordingly, this qualitative study probed attitudes toward PCa genomic testing and PCa research in a geographically diverse sample of black men and community stakeholders. These findings may be applicable beyond PCa to black men's participation in medical research generally.

The current study's findings expand on previous studies demonstrating lower consent rates for genetic-variation research among blacks compared with other ethnic groups[14] by examining minority-male perceptions of genomic testing. Past research[15,16] has addressed the effectiveness of genomic testing with little attempt to dissect behavioral predictors of testing uptake among ethnic subpopulations. Although research on the issue is scant, this study's findings mirror reported notions that hesitancy about genomic testing participation may stem from lack of knowledge rather than from the procedure itself.[17,18] Study participants used the terms genomics and genetics interchangeably and expressed concern about how others may use such genetic information (heritable traits). Participants did not appreciate the benefits of the results of genomic tests (i.e., not revealing information about heritable traits), raising the question whether misunderstanding of the terms (i.e., genomic versus genetic testing and which test reveals information about heritable traits) could influence acceptance of such testing. Considering the extant-literature emphasis on patient education to improve health literacy[19,20] and the interest expressed by this study's participants in becoming better educated about genomic testing, improvement of patient-centered education is essential. Decision aids have been shown to effectively provide concise education about complex medical issues, including PSA testing,[21,22] and could possibly be applied to genomic testing.

Blacks are generally reluctant to participate in medical research, including PCa-centered studies, despite the disproportionate burden of PCa borne by black men.[5,23–27] Durant et al.[28] found 21% of black men distrusted clinical research, compared with 7% of whites. Published reasons for lack of participation include significant levels of healthcare-system mistrust because of: (1) general experiences with racism/discrimination, (2) previous treatment within the healthcare system, and (3) previous research abuses within the black community.[7,29–31] The current study suggests that healthcare system mistrust continues to be a reason many black men do not seek care and have negative feelings toward research. Although the "Tuskegee Study of Untreated Syphilis in the Negro Male" ended 46 years ago, its history continues to haunt the minds of many black men and influence their healthcare decisions. Consequently, a clear need exists to address historic healthcare-system mistrust in all generations of black men. Because roughly six in ten PCas are diagnosed in men aged 65 years or older,[32] these older men may be particularly subject to this "Tuskegee effect," posing a unique problem for PCa-related treatment and research involving black men. Hoffman and colleagues[33] however, recently reported on a community outreach approach with potential for bridging the trust gap and increasing community-wide health literacy among blacks.

Although current study participants echoed some previously menitoned barriers to PCa research participation, dichotomous feelings were identified, fueled by a concern for PCa disparities among black men. Participants who deeply mistrusted research saw PCa disparities among black men as a rationale for their mistrust, believing research was a possible contributor. However, individuals with a neutral or favorable view of research perceived disparities as motivators to participate. It may be important to acknowledge both sets of concerns, emphasizing different motivating factors to maximize black men's research participation.

Previous researchers identified several facilitators of blacks' clinical research participation, including providing safety assurances and reporting results to participants.[29,34] Similarly, this study's participants expressed a desire to receive their personal results from research testing. Although individual results from research studies are generally not provided, affording this information to black men may demonstrate transparency and improve trust, thus facilitating future participation. Provision of such results would need to be accompanied by a careful explanation, emphasizing their limitations.

One important study finding was community-member insight for future PCa research priorities. Participants expressed a desire for PCa research pertaining to prevention and early detection, which stemmed in part

from confusion over recent changes in PSA screening recommendations. In 2012, the U.S. Preventive Services Task Force (USPSTF) recommended against routine PSA screening for all men of average risk.[35] This ran counter to many public outreach campaigns to increase screening, especially among high-risk populations, such as black men. Although the USPSTF statement made no specific recommendations for high-risk men, screening rates fell for all men,[36–38] leaving many black men confused and feeling abandoned by doctors regarding PCa. The USPSTF recently released an updated resolution no longer discouraging PSA screening but advocating shared decision making on the topic.[39] This change in stance may have further contributed to patients' confusion, as expressed by current study participants.

Study participants also expressed interest in environmental risk factors for developing PCa, including dietary habits. This is an active area of research, including studies of the effects of charred-meat consumption on PCa carcinogenesis.[40,41] Previous studies suggest that blacks consume more charred meat than whites, which may contribute to PCa development in these men.[41] Although family history, age, and race/ethnicity are established PCa risk factors, future studies should further examine the role of environment—including diet—on PCa development among black men.

For many study participants, feelings about PCa clinical care and PCa research overlapped. Thus, further general education about PCa may also facilitate willingness to participate in research. Previous studies have demonstrated both individual- and community-based strategies to accomplish this.[42] Future studies should employ educational interventions to promote PCa research.

Limitations

Despite this study's contributions, its limitations must be considered. The sample size precludes drawing definitive conclusions, but does allow hypothesis generation. Although the convenience-sampling technique may limit the generalizability of study findings, the geographic diversity of the data collection sites is a unique strength that lays a foundation for future analyses of regional differences or between those with or without a PCa diagnosis. Another limitation of this sample was its biased educational level: more than half had at least some college experience, possibly a result of the study team's recruitment strategies. Participants nevertheless desired more education about PCa, a sentiment likely to be amplified in less-educated groups who may have even less baseline knowledge. This issue could be explored in future studies. Lastly, some men may have been restrained in their comments because of the presence of women. However, because only a few women participated, and the PCa topics discussed were deemed less sensitive than PCa treatment effects, the authors feel the impact of the presence of women was likely minimal.

CONCLUSIONS

The disproportionate burden of PCa on black men gives this population a vested interest in PCa research and the development of new clinical tools. Yet black men's willingness to accept novel genomic tools for PCa or participate in PCa research studies is limited by attitudes toward the healthcare system and medical research in general. This includes limited health literacy and lack of trust because of the lingering effects of historical clinical research abuses targeting black men, as well as concerns within the black community about potential loss of privacy and uncertainty about how data will be used. These barriers may be overcome by understanding and acknowledging this mistrust, increasing PCa health literacy, and assuring transparency in the research process.

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