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African Americans' Perceptions of PSA Prostate Cancer Screening

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Abstract

Background—In 2012, the US Preventive Services Task Force (USPSTF) released a hotly-debated recommendation against prostate-specific antigen (PSA) testing for all men. The present research examines African Americans' beliefs about their susceptibility to prostate cancer (PCa) and the effectiveness of PSA testing in the context of the controversy surrounding this recommendation.

Methods—This study used a qualitative design to examine perceptions regarding susceptibility along with screening and facilitators of and barriers thereof. Data were collected at a community health center and three predominantly African American churches in North Carolina. Study participants were 46 African American men and women who attended one of four “listening sessions” for pretesting PCa educational materials (average age: 55 years). One-and-a-half-hour listening sessions were conducted to pretest materials; while presenting the materials, researchers probed beliefs and knowledge about PCa screening. The sessions were recorded and transcribed, and the transcripts were qualitatively analyzed using grounded theory.

Results—The four emergent themes indicated that participants: (1) cited behavioral, psychosocial, and biological reasons why African American men have higher PCa risk compared to others; (2) knew about the controversy and had varying responses and intentions; (3) believed screening could save lives, so it should be utilized regardless of the 2012 recommendation; and (4) felt that women can help men go to the doctor and make screening decisions.

Conclusions—Health education efforts to help community members understand health controversies, screening options, and how to make informed screening decisions are critical.

Keywords

African American; prostate cancer; screening; USPSTF; PSA

Introduction

While on the decline overall, prostate cancer (PCa) remains a leading killer of men living in the United States (US) (NCI, 2014). Historically, the prostate-specific antigen (PSA) test has been used routinely in conjunction with the digital rectal exam (DRE) to screen for this cancer with the explicit purpose of reducing deaths; however, like most other screening tools, it is imperfect.

In October of 2011, the United States Preventive Services Task Force (USPSTF) released a draft of evidence for a recommendation against PSA screening for the general population of men in the US, regardless of age or high risk status (family history or African American race); the recommendation itself emerged in 2012 (Moyer, 2012). This decision was based on the questionability of the test's sensitivity to detect PCa at early stages (Potts, Lutz, Walker, Modlin, & Klein, 2010) and the fact that it has a relatively high (12-13%) rate of false positive results, which can result in men receiving biopsies and treatment that may not be medically necessary (Chou et al., 2011; Moyer, 2012). Furthermore, PCa screening has not been shown to reduce the risk of death significantly among the general population of men (Chou et al., 2011; Moyer, 2012); for every 1,000 men screened, only approximately 1 will avoid 10-year death (Lefevre, 2013). Critics of this decision, however, argue that the studies upon which the recommendation was based suffered from incomplete data, underpowered analyses, and methodological flaws such as combining data from incompatible trials (Carlsson et al., 2012).

While the USPSTF felt that the ratio of risks to benefits of PSA screening should not differ between Caucasian men and African American men, the studies upon which they made their recommendation were underpowered for African Americans (Slomski, 2011), who have a higher risk for developing and dying from PCa than Caucasian men (DeSantis, Siegel, & Jemal, 2013; NCI, 2014). A recent study found that African American men have more voluminous and potentially dangerous tumors than their Caucasian counterparts, as discovered through radical prostatectomy (Powell, Bock, Ruterbusch, & Sakr, 2010). Biological differences in tumor markers may be responsible for such racial disparities in disease aggressiveness (Martin, Starks, & Ambs, 2013). Moreover, African American men tend to develop PCa at statistically significantly younger ages than Caucasian men (Parker et al., 2011; Shao et al., 2009). It is clear that the burden of PCa in the African American community is staggering, and some researchers advocate for aggressive testing in this group (Powell et al., 2010).

Because the controversy surrounding PSA testing is especially germane to the African American community, it is critical to understand how African American men and women feel about PSA testing in the wake of the USPSTF recommendation to discontinue its use. A recent study found that individuals were familiar with the USPSTF recommendation and remained in favor of PSA screening in spite of knowing the risks; in fact, African American survey respondents were more than twice as likely as Caucasian respondents to declare that they intended *not* to follow the recommendation (Squiers et al., 2013). There remains, however, a paucity of qualitative data describing African American's views of testing in the

wake of the recommendation. This information is critical for developing informed decision-making tools and interventions.

The purpose of this manuscript is to describe African Americans' perceptions and beliefs regarding PCa risk and PSA testing. Our goal is to enhance understanding of deep-held feelings, beliefs, and intentions that could drive health behavior specific to PCa.

Methods

The National Cancer Institute funded the Carolina Community Network (CCN) at the University of North Carolina at Chapel Hill (UNC) to address breast, colorectal, and prostate cancer disparities among African American adults in North Carolina (NC) using evidence-based interventions in partnership with the community. The community outreach arm of the center identifies and develops culturally-sensitive educational material and uses evidence-based practices for topics like informed decision-making for PCa screening. The present study examined data collected during the process of creating educational materials to fulfill this charge.

Participants and recruitment

The CCN partnered with four host sites—a community health center and three churches—to recruit participants using word-of-mouth and flyers. The purpose of the sessions was to share and discuss the types of educational materials on PCa screening that were previously identified as needed in the community. Participants were men and women living in four NC counties, three of which were rural. They included lay health advisors, PCa survivors and their loved ones, and others interested in the health of their community. To participate in this study, individuals had to be African American adults (aged 18 years or older) without a speech or hearing impairment.

Procedure

Four “listening sessions” were conducted from mid-April to May of 2012, in the midst of the controversy over screening. The project team showed the participants a Microsoft PowerPoint presentation developed for lay health advisors, which detailed steps to informed decision-making for PCa screening. During these one-and-a-half-hour sessions, participants engaged in conversation with one another about issues related to prostate health, guided by the facilitator. The goal of the presentation and discussion was to glean participants' feedback on content, format, and dissemination strategies for sharing the information with the African American community. The sessions were audio-recorded, and the recordings were transcribed in full; these blinded transcripts became the data for the present analysis.

Analysis

Three research team members analyzed transcript data using grounded theory (Charmaz, 2000) to allow themes to emerge from the data. This approach was appropriate because we wanted to keep an open mind about what we might learn, rather than approaching the data with a predefined theory in mind. Each team member individually reviewed each transcript and noted concepts that appeared. We discussed these concepts at-length and formulated

them into categories, then created a codebook and data dictionary, with examples. We assigned microcodes to utterances in the data; if an utterance was not captured by any of the codes, we created a new code, and reviewed it and, if appropriate, recoded previously coded material in an iterative process. When all relevant utterances were coded, we sorted the data by code. The team reviewed the reduced, coded data and together determined emergent themes. We used Atlas.ti version 6 (Scientific Software, Berlin) for all qualitative analyses. Coefficient kappa was calculated for each theme as a robust measure of interrater agreement, and Kendall's coefficient of concordance was used as a measure of overall agreement.

The Institutional Review Board (IRB) at UNC reviewed this project and deemed it exempt research.

Results

In all, 46 participants took part in the listening sessions. Table 1 shows their demographic characteristics. The mean age was 55 years (standard deviation: 15 years, range 24 to 77 years); all participants were African American, and 8 (17%) were female. About one-third had less than a high school education, one-third had some college, and the final third had earned a college degree. Most participants (76%) were married, and most (65%) were employed.

Kappa statistics for the themes ranged from 0.29 to 1.0, indicating moderate to strong agreement between the three raters. Kendall's coefficient of concordance was 0.57 [$F(47.30, 94.67) = 2.70, p < 0.0001$].

Four themes emerged from the listening session data: (1) perceived behavioral, psychosocial, and biological reasons for the disproportionate susceptibility of African Americans to PCa; (2) knowledge of the controversy and varying intentions in response to it; (3) the importance of screening in spite of the barriers to it; and (4) the importance of women in helping their loved ones obtain care and make screening decisions.

Perceived behavioral, psychosocial, and biological reasons for prostate cancer disparities

The participants discussed genetic risk for PCa, knowing risk could be passed down through generations. As one person described, "My ancestors would put me at risk if they had cancer. Like my daddy's daddy, and his daddy." However, genetic risk was mentioned only in passing. Participants believed that African Americans have a higher risk for PCa beyond that found in Blacks in Africa, so ensuing discussion focused on the psychosocial and behavioral factors that conferred increased risk.

When asked why African American men are more likely to develop PCa than men of other races, most participants surmised that it was because African American men eat more unhealthy foods and do not go to the doctor regularly. Many participants felt that poverty drove these health behaviors, as they believed many African American men do not have the funds to eat healthily or to obtain regular health care or screening tests. Participants also

held that African American men do not go to the doctor because of low perceived need. As one participant stated, “you feelin’ pretty good, you just never go to the doctor.”

Participants also postulated that unequal treatment in the healthcare system impacts the etiology of PCa above and beyond the effect of genes or health behaviors. Participants believed that, even when African American men go to the doctor and even when the cost of care is factored out, they do not receive the same quality of care as men of other racial heritages. One participant said, “Sometimes we don’t receive the medical part the same as our brothers, the same medical attention. It may be because of insurance reasons. It may be a lot of different reasons, but we don’t get the treatment.”

Some participants endorsed intergenerational stressors as important risk factors. For instance, they described changes in diet, which were often pursuant to changes in lifestyle from tenant farming and slavery to working in less active avocations, as contributing to the unequal burden of PCa among African American men. Participants also expressed that, over the generations since African Americans were brought to the United States as slaves, they stopped eating foods that were natural and healthier for them: “You got to remember, too, now, we didn’t come over here voluntarily. We were brought over here, and so we had to assimilate by eating scraps like chitlins and pig tails and pig ears.”

Many participants recognized being African American as a unique risk factor for PCa, owing to social factors, such as discrimination and oppression, which create illness:

We continuously, by no choice, have to be in environments where there’s lack of trust, such as folks that we work with, even just going out to a movie encountering law enforcement. And my personal belief, living under such stress at times, it makes you vulnerable, and it kind of breaks down your immune system when you’re stressed, and makes you more susceptible to these things because when you have to live in a society where there’s all these mind games, it’s tough.

Knowledge of and responses to the screening controversy

Participants knew that the prostate specific antigen (PSA) screening test was often useful, but they were aware that it had flaws with regard to sensitivity to detect cancer. Some participants felt that the PSA test could not detect PCa with certainty: “Even though you got tested, you still wasn’t 100% sure that they’s gonna catch it.” A few participants believed a provider using PSA blood testing in combination with a digital rectal exam (DRE) should be able definitively to find cancer if it were present. One uncertain participant queried, “I would think, between the two, you should [be able to tell] because you do the lab work, and then you do the examination, and that says no, and then is that a sure sign that you don’t [have it]?”

Most participants were aware of the controversy regarding the appropriateness of the PSA test as a screening tool for PCa, and they had varying beliefs and intentions in response. A couple of participants felt that, given uncertainty regarding accuracy of results, screening “may not be worth bothering.” Some thought that the recommendation stated that only those with a family history of PCa needed to be tested. Others were favorably disposed toward screening in spite of the controversy: “I heard that they just can’t agree. That one doctor will

say something, then another doctor will counter that, so I guess the conclusion I came away with was that it's better to get screened than to not get screened." The controversy drove others to not want to be screened; as one man stated, "I'm already about to skip the whole process. It's too much, personally; it's just too much; not enough information that they [know]." In the end, as will be explained later in this manuscript, the majority consensus was that it was important to screen.

In spite of its potential harms, participants believed that screening can save lives

The majority of participants were wary of possible sequelae of a positive screening result, such as biopsies, and this wariness was a primary barrier to screening. The barrier was compounded or reinforced by the experiences of others in their community, demonstrating the influence members of this community have on one another. Many participants believed, had heard, or had experienced the biopsy to be painful or traumatic and perhaps not worth the suffering it causes. One participant discussed urinating "chunks of blood," leading another participant to state, "Now this stuff right here is really what keep Black men from going up [inaudible] this stuff. I'd rather just die, die with it." Moreover, participants were deterred by the idea that biopsies and ensuing treatment could interfere with sexual functioning; this knowledge led a couple of them to the conclusion that "the treatment could be worse [than the disease]."

Nevertheless, participants saw the value in screening, and most of them cited staying alive as a critical benefit to screening. The possibility of benefit remained critical even in the face of barriers, as participants felt that even the most seemingly intolerable discomfort from the DRE or the biopsy paled in comparison to death. They believed screening could lead to early detection of PCa, which would improve a patient's chances for survival. Stating "better safe than sorry," many participants indicated that they would prefer the risks of screening to not knowing that they have a potentially dangerous and aggressive cancer. Even with the perceived unpleasantness of the biopsy, participants felt that "if you want to live, you go through [it]." As one person explained, "I'd rather be here than not. So what I'm saying is even though it would be not that great, I guess it wouldn't be that great, but you'll still be here, you know, to see your grandkids." When confronted with the possibility of losing sexual function, commonly believed to be a consequence of a biopsy, someone noted, "What's more important: your sex life, or your real life?"

Women as allies in making decisions about prostate cancer screening

Many participants identified women as partners for men in making decisions about PCa screening and caring for their overall health. A key facet of this role is that women can influence their loved ones to go to the doctor. One man explained, "Myself in particular, I never thought about going to the doctor. I think my wife, she told me I need a family physician, and so how many of us don't take that time to get a family physician, and catch the thing before it happens."

In their roles, women can help their loved ones make critical decisions about their health, such as whether to screen and whether and how to treat cancer should it be detected. They can present information to their loved ones in less intimidating ways than other men can and

thus may be heard more clearly. A male participant explained, “Sometimes, we as men, we got pride ... but if I go to your [wife], and you drop a line or whatever, if you think that she needs it for her significant other, a lot of times she’s gonna find a way to present it to him in a non-threatening way.”

Discussion

Consistent evidence documents the elevated PCa risk for African American men in comparison to Caucasian men (DeSantis et al., 2013; NCI, 2014). Yet, understanding of perceptions regarding etiology and pathogenesis of the disease and methods to identify the cancer in its early stage is limited, especially among African American men. The accuracy of the PSA blood test, once used routinely to screen for PCa among men, is in doubt, leaving scientists and clinicians with no reliable options for detecting PCa early. Our study is one of the first, to our knowledge, to identify how African Americans in particular felt about screening in the wake of the PSA controversy. Participants in our study recognized both the positive potential of the test and its shortcomings.

Participants were acutely aware that African Americans suffer disproportionately from prostate cancer and other health concerns and believed that this increase in risk resulted from genetics, health behaviors, and intergenerational psychosocial factors such as oppression, changes in dietary and exercise patterns, and stress. They independently and intuitively drew connections between stress associated with perceived discrimination in daily living and historical oppression and present-day health outcomes. This is consistent with the findings from the North Carolina-Louisiana prospective cohort study that reported mistrust and racism as important cultural factors that have limited African American men’s satisfaction and willingness to access health care services (Moore et al., 2013). These perceptions, experiences, and behaviors are critical because they contribute lived validity and lay explanation to the knowledge that African American men have the highest burden of PCa of all racial or ethnic groups. This finding also underscores the need for tailored interventions that ground these perceptions with facts and statistics to mobilize people to become educated about taking action to improve prostate health and health overall.

The present findings can inform the development of interventions to help African Americans make decisions about screening. The most significant barrier to screening identified in each of the four groups was the fear of negative side effects, such as blood in the urine and sexual difficulties, arising from the sometimes subsequent need for a biopsy. Nevertheless, participants saw screening as a tool to help save lives, believing that the potential benefit was worth the risk. Health behavioral and educational interventions are critical at this stage to clarify misconceptions concerning both risks and benefits of screening using facts presented clearly and succinctly for people to understand.

Through participants’ discussions, they learned from one another; for example, when one man remarked that he “peed blood” following his biopsy, another man responded that stories like that kept him from getting screened. This finding implies that community members listen to one another, and this implicit trust can be leveraged by training community members as lay health advisors to deliver accurate information about the pros and cons of

PSA screening as well as other health information. Because the participants identified women as vital partners for helping men obtain prostate care, training female lay health advisors may also prove effective. On the other hand, one empirical study found that, while 16% of men surveyed had asked a spouse or other family member to search for cancer information for them, only 1% looked to their families as their first source of cancer information (Thomas, Simpson, Tarver, & Gwede, 2010).

Although it was beyond the purview of our study to measure whether participants decided to get screened for prostate cancer, considering our findings with current empirical literature may provide a clue. Squiers and colleagues (2013) found that many African Americans intended to pursue screening in spite of the USPSTF recommendation against it, and sentiments shared during our listening sessions indicated that most participants felt the same way. Another study found that, while African American men are 85% more likely to be screened than Caucasian men are (OR=1.85, 95% CI:1.05-3.25), having a positive family history for PCa did not make a difference in screening rates (Drake, Lathan, Okechukwu, & Bennett, 2008). This finding is consistent with ours in that, while a couple participants expressed their interest in screening based on their positive family histories, the interest in being screened extended beyond just those individuals.

Our study had several notable strengths. We used grounded theory methodology, allowing themes to emerge from the raw data rather than fitting the raw data around preconceived notions or topics. Our loosely guided discussion session allowed a diverse array of opinions and beliefs to emerge. Even though the original purpose of the study was to learn new ways to present information about PCa screening to the North Carolina African American community using an informed decision-making approach, rich data concerning beliefs and knowledge of screening arose from the discussion without prompting. This methodology is also a strength because it limited potential bias; we had no leading questions or directions. Also, we included both men and women in our study to obtain a wider perspective of beliefs, knowledge, and facilitators and barriers surrounding prostate cancer screening. Our sample was diverse, too, in that it included individuals from different stages of the PCa screening process; participants included those naïve to the process as well as those who have experienced screening, biopsies, and treatment for cancer. This diversity enriched the dialogue and facilitated interactivity.

The study is not without limitations. Because of the study's qualitative nature, it is inappropriate to connect a person's PCa experience with their discussion points to determine whether a stated belief comes from a survivor versus a screening/treatment naïve person. We also do not know whether people followed up with discussions about screening with their physicians or loved ones. Nevertheless, it is the purpose of qualitative analysis to examine the group, not the individual, as the unit of analysis. Another limitation was our small sample size of four listening sessions; this small sample limits generalizability of results in that our findings among African American adults in NC may not be applicable to other African American communities. However, it is not appropriate to power a qualitative study, and this study is not meant to be generalized beyond the specific communities from which the data were drawn.

The study also has implications for public health research. Including women in our discussions enriched our data by providing points-of-view of both partners and caretakers. Furthermore, there is a distinct need for more diverse study samples in PCa research to help provide context for the data and identify patterns that lead to disparities and risk factors that may be unique or higher in underserved populations. Bench-to-bedside research in this area should be accelerated to benefit as many patients as possible. It is imperative that we develop a better screening tool, one that is sensitive not only to individual risk based on health behaviors and outcomes, but also to genetic risk and sociocultural risk. Research funding to elucidate the role of race-based discrimination on the development of cancer is critical at this juncture to help understand these unique risks.

Our findings provide unique insight into the psychosocial factors behind patients' screening decisions, offering a glimpse of the factors that African American men consider when making PCa screening decisions. They should prove useful to clinicians, community health workers, and other caregivers. Our participants shared unique, deeply personal stories that shed light on beliefs that have frequently gone unvoiced, and their words can be shared with providers and the community at-large to provide an even clearer understanding of the delicate nature of PCa screening decisions. As such, our research helps fill a critical gap in current knowledge about screening for PCa.

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Table 1

Demographic characteristics of participants (n=46)

Demographic		Number (%)
Age	Under 40	9 (20%)
	40-50	3 (7%)
	51-60	17 (37%)
	61-70	14 (30%)
	71+	2 (4%)
	No answer	1 (2%)
Gender	Male	38 (83%)
	Female	8 (17%)
Education	High school or less	13 (28%)
	Some college	15 (33%)
	College degree	15 (33%)
	No answer	3 (6%)
Marital status	Single (never married)	5 (11%)
	Married	35 (76%)
	Divorced, Separated, or Widowed	6 (13%)
Employment status	Employed	30 (65%)
	Unemployed	3 (7%)
	Disabled	4 (8%)
	Retired	9 (20%)
Ever had a family member or friend diagnosed with any cancer	Yes	43 (93%)
	No	3 (7%)

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