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Word on the Street: Engaging Local Leaders in a Dialogue About Prostate Cancer Among African Americans

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Abstract

African American men face the highest rates of prostate cancer, yet with no consensus for screening and treatment, making informed health care decisions is difficult. This study aimed to identify approaches to empowering African American men as proactive participants in prostate cancer decision making using an established community–campus partnership employing elements of community-based participatory research methods. Community stakeholders with an interest in, and knowledge about, health care in two local African American communities were recruited and completed key informant interviews ($N = 39$). Grounded theory coding identified common themes related to prostate cancer knowledge, beliefs, attitudes, and responses to them. Common barriers such as gender roles, fear, and fatalism were identified as barriers to work-up and treatment, and both communities' inadequate and inaccurate prostate cancer information described as the key problem. To build on community strengths, participants said the change must come from inside these communities, not be imposed from the outside. To accomplish this, they suggested reaching men through women, connecting men to doctors they can trust, making men's cancer education part of broader health education initiatives designed as fun and inexpensive family entertainment events, and having churches bring community members in to speak on their experiences with cancer. This study demonstrated the success of community engagement to identify not only barriers but also local strengths and facilitators to prostate cancer care in two suburban/rural African American communities. Building collaboratively on community strengths may improve prostate cancer care specifically and health care in general.

Keywords

prostate cancer; case study method; qualitative research; men's health programs; community research

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Introduction

Prostate cancer is the leading cancer in African American men and the second leading cause of cancer related mortality among these men (American Cancer Society, 2013, 2014). The incidence of prostate cancer among African American men is 60% higher than among non-Hispanic White men and the mortality from prostate cancer is twice as high as any other group of men (American Cancer Society, 2014). With no consensus on screening for prostate cancer, it is difficult for African American men and their health care providers to make decisions about having a prostate specific antigen (PSA) test and possible next steps if the PSA is elevated (American Cancer Society, 2012; Chou et al., 2011; Smith, Cokkinides, & Brawley, 2009; Taylor et al., 2012; U.S. Preventive Services Task Force, 2012). Limited access to medical services, socioeconomic factors, biologic/tumor aggressiveness factors, clinical staging, and patient/provider beliefs and attitudes toward treatment have all added to this screening conundrum for African American men (Peters & Armstrong, 2005; Shavers & Brown, 2002; Taylor et al., 2012). Adding to the fear of treatment for prostate cancer among African American men is the potential for sexual dysfunction resulting from treatment (Jenkins et al., 2004). As a result of the multitude of complicating factors, African American men have lower screening participation rates, are diagnosed at a later stage, and generally have lower involvement with health care providers, creating additional barriers to the continuum from screening, through diagnosis to treatment (Peters & Armstrong, 2005; Shavers & Brown, 2002).

To identify programs to help address this ongoing health concern for Black men of African descent, a number of international studies have sought to determine factors influencing screening and treatment-related decision making. Employing qualitative and quantitative methodologies, previous studies have identified barriers and facilitators of constructive decision making about prostate cancer among Black men of African descent. Fear of cancer, “machismo” in both aversion to digital examinations and in unwillingness to admit weakness, competing responsibilities, and the priority of need to provide for family were identified barriers to both prostate cancer screening and treatment (Blocker et al., 2006; Ford, Vernon, Havstad, Thomas, & Davis, 2006; Friedman, Johnson, et al., 2012; Friedman, Thomas, Owens, & Hebert, 2012; Ng et al., 2013; Sanchez, Bowen, Hart, & Spigner, 2007). Common supportive themes included the church, family, and the women in their lives (Blocker et al., 2006; Friedman, Johnson, et al., 2012; Friedman, Thomas, et al., 2012; Holt, Schulz, & Wynn, 2009; Hughes, Sellers, Fraser, Teague, & Knight, 2007; Husaini et al., 2008; Odulana et al., 2013; Rowland & Isaac-Savage, 2013). Few studies, however, have developed any culturally sensitive or community-focused strategies to aid in the decision-making process (Evans et al., 2010; Lepore et al., 2012; Ross, Ashford, Bleechington, Dark, & Erwin, 2010; Watson et al., 2006).

The current study sought to address this shortcoming by asking African American residents and the professionals who support them to report the “word on the street,” perceptions about prostate cancer as a health problem for African American men in two New York suburbs. Building on a strong community–campus partnership, local government and religious leaders, health care providers, and high-profile community residents were engaged in a dialogue about problems and potential solutions. The overall goal of the study was to identify methods of empowering residents as proactive participants in prostate cancer screening and treatment decision making. The specific aims were (a) to assess local knowledge, beliefs, and attitudes about prostate cancer and determine if there were any unique community issues and (b) to elicit insights from community leaders and residents on how these community characteristics could be built on in ways that support informed decision making. The study attempted to move beyond identifying barriers to outlining locally based, culturally responsive, and community-endorsed solutions.

Method

Study Design

The concept and need for a study of this type was formulated in response to a request from participants in the Witness Project of Long Island (WPLI), a faith-based breast health education program for African American women that began in 2002. This qualitative case study built on established WPLI community–campus collaborations founded on principles of community-based participatory research (CBPR; Israel, Eng, & Schulz, 2005; Schoenfeld et al., 2006). At a WPLI sponsored event, a gentleman approached this study's principal investigator (PI), a founding member of the WPLI, inquiring about starting a similar program for prostate cancer. He explained that he was a prostate cancer survivor, and remarked how prostate cancer was affecting his friends and family, and how help was needed. He described a program in his own church that successfully aided men to obtain a PSA, and how he supported those found to have an elevated PSA to seek follow-up. He felt it was now time to develop a program that would reach African American men throughout the region and not just in his own church. After meeting with the WPLI executive committee to further explore interest and need, the study was conceived and initiated.

CBPR recognizes that health problems in a community cannot be solved without the direct involvement of community members. Progress toward eliminating disparities will occur only when communities are committed to investing themselves and their resources toward these ends (Israel et al., 2005; Minkler & Wallerstein, 2008; O'Fallon, Tyson, & Dearry, 2000). The WPLI success was a result of support and collaboration of the Town Supervisor, County Executive, African American religious and community leaders, organizations, local hospitals, health care providers, residents, and university partners. Building on this success, a working group was assembled of individuals interested in prostate cancer among African Americans. Initial members were identified with the assistance of the WPLI leadership and included researchers, community, government, and religious leaders; persons affected by prostate cancer; health care providers; and representatives from fraternal and educational institutions in the region. As the study developed, the role and membership of this working group expanded and evolved into the study's community advisory committee who were involved in all aspects of the study from conception through translating findings into a community program. The first steps were to determine opinions and knowledge around prostate cancer using scripts that were developed and pilot tested by the committee. The committee recommended and identified a study coordinator and an interviewer both African Americans with ties to the study communities. The study continued to interview participants until information saturation was achieved.

Participant Recruitment

County Demographics—The study was conducted within two towns of a county in New York State where the WPLI was ongoing; these two towns also reflected the necessary demographics for the study. The county is composed of 10 towns with a myriad of smaller communities. Home to 1,499,273 residents, the county includes both suburban and more rural regions. Close to 90% of county residents have health insurance with fewer African Americans insured (87%). The two participating towns were home to 34% of African American county residents. Town 1, a suburban town on the outskirts of a large city, had the largest percentage of African American residents in the county (16%; population: 213,603). This town is composed of 12 communities; 3 having between 55% and 65% African American residents. In Town 2 (population 33,506), a more rural region of the county, 8% of residents are of African descent (Suffolk County, 2014). Town 1 has the highest population density of the county and Town 2 among the lowest. A recent county-wide health survey revealed prostate cancer as the most common cancer in men. Among African American men, the incidence is 1.4 times higher, and the mortality 2.3 times greater compared with White men. Overall, county residents are being diagnosed at a later stage than other parts of New York State (Ballone & Tomarken, 2014).

Recruitment Methods—Individuals were recruited to represent the following four stakeholder groups—local community, government, and religious leaders and health care professionals. The study initially focused recruitment and engagement efforts to Town 1 whose residents and leadership had successfully partnered for the design and implementation of the WPLI. Using this established network in concert with the study's community advisory committee, study personnel identified key community stakeholders and community groups from whom participants were recruited to obtain an array of perspectives of what individuals were saying, doing, and thinking about prostate cancer. Recruitment was expanded to Town 2, another WPLI partner town, with the intent of including a more rural location within the county to broaden knowledge gained about access to care. Hence, for the current study, "community" refers to African American residents from the two collaborating towns and the professionals (i.e., religious and government leaders, health care providers) who support them. Residents from the collaborating towns represent more than one third of all African American residents of the county (U.S. Census Bureau, 2010).

In addition to advisory committee and snowballing referrals, the study coordinator attended numerous health, fraternal, and religious events talking about the value of collaborative research, introducing the study, and recruiting participants. The study PI conducted a number of community forums to provide an introduction to the study goals and the process of CBPR. These strategies resulted in the identification of community, medical, religious, and government leaders in the region to serve as key informants. Individuals who were selected as key informants were selected because of their leadership role in their respective communities and their knowledge of and interaction with others in their community. Although it was not possible to limit participants to residents of the two chosen towns, all were required to either reside in the study towns or serve residents of these towns. Once key informant interviews were completed, town hall meetings were convened to expand community involvement through presentations and discussion of ideas to synthesize findings into an actionable plan. Town hall meeting participants were recruited from announcements in local papers and word of mouth.

Key Informant Interview Topics

Scripts were designed to collect information about the key informant's tailored to the experiences and expertise of each of the four key informant stakeholder groups: (a) role in the community; (b) knowledge and beliefs about prostate cancer screening, work-up, and care; (c) available community resources for men facing prostate cancer; and (d) the impact of prostate cancer on African American men and their families. Participants were asked to speak about their own experiences and knowledge about prostate cancer, their experiences within the community addressing issues related to prostate cancer as well as their perspective on the health behaviors and health care seeking practices of African American men in their local community.

Data Collection

Interviews were conducted by the study coordinator and interviewer, both trained and certified during study start-up. In-person interviews were conducted at a location chosen by the informant. Written informed consent was obtained. Participants then completed a demographic questionnaire and the semistructured interview. Interviews were audio recorded for later transcription. The Stony Brook University Institutional Review Board approved the study prior to data collection.

Data Analysis

Demographic Questionnaire—

The demographic characteristics of the study participants are presented as frequencies with percentages for categorical variables, and mean ± *SD* and range for continuous variables.

Key Informant Interviews—

An independent transcriber with no knowledge of study objectives transcribed all interviews. Study staff reviewed transcripts for completeness and de-identification prior to analysis. Two investigators initially read through and manually coded interviews to categorize common topics and identify themes. Discrepancies were discussed producing additional or consolidated codes. Investigators were particularly interested in key informants' concerns related to the two specific aims: determining comparability of the sample in terms of issues identified in the literature and determining key strengths and weaknesses of local resources that could serve to focus intervention development. Aim 1 themes of interest included (a) informants' reports of inadequate knowledge and inaccurate prostate cancer beliefs; (b) perceived attitudes that affected decisions about prostate cancer work-up and treatment; and (c) perspectives about access/ barriers to health care. Aim 2 results suggested community engagement methods to overcome all three concerns illuminated in the Aim 1 analysis.

Once initial themes were determined, transcripts were uploaded to Qualrus text analysis software (The Idea Works Inc., 2013) to further refine themes using grounded theory coding techniques (Crabtree & Miller, 1992; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Within Qualrus, a coding list of covered topics identified from the manual review were employed, allowing for the emergence of unexpected or unique topics not identified from manual review. “Open” coding was then employed to capture the deeper intent and shades of meaning imbued in the text. Last, focused coding was used to identify patterns and relationships among the prior codes and seek meanings that emerged from the data. Themes were further analyzed as both problems/barriers and as potential avenues for solutions. Study team members and the community advisory committee met to review preliminary analyses to enable triangulation of findings before finalizing the analysis. Themes defined for each of the individual key informant groups were further synthesized to establish universal themes based on all interviews. Results from these analyses were presented to town hall meeting participants to help in further synthesizing study findings and to develop an action plan for community implementation.

Results

Participants

Key informants were recruited from the two participating towns. The total number of interviews completed was based on a knowledge gained saturation point, resulting in a total of 39 key informant interviews with stakeholders from the African American communities within these two towns. Interviews lasted between 30 and 65 minutes.

Participant Characteristics (Table 1)

Sixty-two percent of all individuals approached to serve as key informants consented and completed interviews ($n = 39/63$). These key informants consisted of local community, government, and religious leaders and health care professionals. The primary reasons for nonparticipation included lack of knowledge/interest in the topic, time commitment, or scheduling difficulty. Religious leaders tended to be older (mean age = 60.2 years) and along with community leaders tended to have longer county residence (36.7 and 38.5 years, respectively). The majority of key informants were community leaders. This group included a cross-section of stakeholders, men with a history of prostate cancer, educators, organization members, and family members of prostate cancer patients. Close to 60% of participants noted a personal experience with prostate cancer, their own or that of family members, friends, neighbors, or coworkers. This high rate in the study was a result of purposive sampling, seeking individuals with knowledge of, and an interest in, the topic under study.

Aim 1 Findings: Knowledge, Beliefs, Attitudes

Overall, the general themes of knowledge, beliefs, and attitudes represented here were similar to those found in prior studies. This confirmed the similarity to other African American communities and served as a basis for Aim 2. Those themes that also served as a basis for Aim 2 responses are detailed here.

One of the most pronounced findings of the study was the very first consistent theme that emerged. Despite a substantial increase in concern about prostate cancer screening in medical circles, and widespread health education efforts, the perceived level of knowledge in the community was extremely low. Most informants made claims similar to those of the community and government leaders below, arguing that information and education continued to be the greatest need.

> When you're talking about prostate cancer, we realize that it affects African American men greatly, the incidence rate is extremely high, especially in [our] County. … It's third in the state … it is affecting our communities. [We need] to get people from the community to participate, bringing in people who are knowledgeable, being creative in how you can talk to people or be in their level, providing them … with the information to help them make the informed decisions, letting them know what's possible. (Community leader)

> [I]t is unfortunate that … Black men are still dying from prostate cancer, because it is one of the cancer form that is definitely treatable and curable if you catch it early. And … we are not, Black men in particular, are not catching the disease early enough… . [W]e have to have some kind of an outreach and some kind of an educational thing whereby we will make sure that we get the information to them, by saying, if you catch it early, if you take the test and you have prostate cancer, then we can treat you, you don't have to worry about it. But I think, you know, the … the lack of information and the … outreach on the part of government, [and] the medical field, is still lacking, and that's why Black men are dying from it. (Government leader)

In addition, participants felt that people did not want to talk about "the problem," and would not seek out information on their own. Indeed, informants believed that not only prostate cancer, but health in general, was not a priority in the African American communities included in this study.

> Prostate cancer has an aura, mystique … and especially now that people are hearing that it's kind of centered on the Black male population … sometimes folks have a tendency to want to hide their head, you know, if there's a lack of information. (Health care provider)

> Health … tends not to be a priority in many of our communities … African American communities, and especially Black males [are] concerned about … their economics or their finances and they're worried about paying their bills. So health ultimately will … come second or last … in your daily life. So until … a lot of those factors are resolved, it's hard to prioritize health. (Government leader)

Informants own prostate cancer knowledge was limited, other than knowledge gained from working in the health field or from personal experiences with this cancer. Informants were unable to name any source of information other than primary care physicians that men could use to guide a decision to be screened or evaluated for prostate cancer. One informant stated that "I feel if the doctor doesn't tell it, I don't really know how else … the patient would get the information, outside of a few commercials, and that's about it." The underlying message seemed to be that the only way to learn about the importance of going to the doctor was by going to the doctor. Informants agreed that the community relied on word of mouth, rather than formal health information resources, and the knowledge base on the street was simply not adequate. This point came out repeatedly in different forms, with informants stressing the need for changes in the way that health information was presented to the community.

> Access to health information ends up being in their own community, in which it's a lot of information sharing, but unfortunately, a lot of it's probably wrong … or mythical of what they believe and what they've heard from each other. Which is I think key to understand the African American community, because we do rely on each other for our information. So if we can get information into our community by trusted sources…they at least offer the opportunity for accurate and right information, as well as trusted information. (Government leader)

The beliefs emphasized by key informants that influenced information and care seeking behavior included gender roles, fear, fatalism, and privacy. These were often reported as barriers to prostate cancer screening. Respondents noted the general fear of cancer, and the specific fear and negative reactions to prostate cancer screening because of the digital rectal exam. Informants believed that men do not want to know about cancer, emphasizing the men's belief that cancer is invariably fatal. African American men were described as having a tremendous amount of pride and machismo, combined with a strong desire for privacy; all possible barriers to seeking health care.

> Some men don't deal with healthcare unless and until they feel some pain or other symptom … what might be considered preventive healthcare in going and having an annual physical. If it's required by their job that might occur, but on their own, I don't think they take the initiative to have that done. (Government leader)

> A lot of Black men will not go to the doctor until they are having problems. And then it is usually too late… . They have to be sick to go to a doctor … I think it's a cultural thing, "If it ain't broke don't fix it mentality." It's lack of knowledge, the lack of understanding, the lack of priority. (Religious leader)

> They're afraid to find out that they … may have a problem, or is it that they're afraid to find out they don't have a problem. Or it's the thought of that particular examination, the fear just stands there and, say, you know, "I'm not going." (Community leader)

Key informants also thought that there were many socioculturally based *attitudes* that serve as inhibitors to screening and treatment for prostate cancer. Informants consistently noted that African American men tend to put their families first, and feel deeply concerned and pressured to provide for them, placing jobs first to provide for the family. Therefore, time to seek medical care had lower priority.

> Good, hard-working folk have been socialized … to put themselves last. If it's a Black man taking care of his family, and trying to eke out a living, "Listen, this is what I have to do." And then many times we are accustomed to struggle. We're accustomed to suffering, and it doesn't mean a whole lot… . Men particularly take on the attitude, "Well, I'm going to die of something, and tomorrow's not promised to me." (Religious leader)

During uncertain times, economics were noted to play a key role in all health care decisions.

> A lot [of] people in my community cannot afford to go to doctor(s) [for] check-ups. They cannot afford healthcare … a lot of them don't have jobs … they don't have income. And this community is really suffering in [that] regard. (Religious leader)

> If [a doctor] discover[s] something in my body that I don't even know that's there, it's going to cause me more problems economically and I cannot afford it. I can't even afford to take off from work to sit in a doctor's office, sometimes up to an hour, because I'm losing pay and I have to feed my family. (Religious leader)

Lost wages from taking time for doctor visits and costs related to treatment were considered barriers to screening and treatment for prostate cancer. This concern also reflected the economic status of the two towns included in this study.

Informants noted a general lack of trust of the medical community. Underlying many of these attributions were concerns stemming from the commonly identified distrust of the medical system and its history of not always acting in the best interests of African Americans. An emphasis was placed on medicine as a "White" institution and the need for more Black doctors.

> A major part … is finding a physician that they can feel comfortable with, and that they can … trust … many Black people are looking for a Black physician, a Black [oncologist], and a Black urologist, a Black family practitioner … across the board, people are looking for physicians who look like them, and can relate to their language, culture, and so on. (Government leader)

The informants relayed anecdotes of unnecessary/inappropriate surgery, doctors not following protocol because a patient did not fit the profile of a disease, and reports of racism and disrespect. To find a doctor with whom the men could feel comfortable, the consensus was that the men relied primarily on personal recommendations from trusted others.

> I had one of my brothers that wanted to know what doctors do I use. I said, "Well, my doctors … are all on the northern side. So you want to go?" He said, "No problem." So I gave him all my doctors … because if [he's] comfortable … he'll do something. (Community leader)

Related to the medical distrust, informants stressed the desire to find a physician with whom they can feel comfortable, and whom they can trust; they felt this was more difficult to accomplish with non–African American doctors. Across the board, people were looking for physicians who looked like them, and could relate to their language and culture (concordance), while noting frustrations and difficulties of locating physicians overall, and specialists in particular, by race.

Aim 2 Findings: Community Pathways to Health Care Empowerment

The second aim of the study was to move respondents beyond identifying problems to suggesting solutions. The emphasis was on the characteristics of their community that could serve as a foundation for creating effective health education programs. Many of the responses appeared on the surface to merely repeat the barriers identified above. However, deeper analysis showed that the new emphasis on constructive progress brought out a key underlying belief among community leaders: these communities depend on themselves and not outsiders. They clearly felt that outside education efforts will only be successful to the degree that the community members are involved and invested. One informant stated this clearly:

> I think the community should be bombarded with information. Education is so important and I think once that happens, and people become more aware of how this particular disease can be stopped or at least slow down, it has that impact on the community … you have people from the ivory tower taking a look down and say, "okay, we have our statistics. This particular population is not responding." It's not responding because it's a lack of contact, there's a disconnect… . So I think it's very important that we plug the people in. If you're trying to service them, plug them in, so that they [give] the input, and then this person, being a member of the community, will talk to other members of the community. And then you would tend to get more involvement because it's folks talking to each other. (Health care provider)

As other informants had already pointed out, however, a fundamental problem is packaging the information in a unique way to increase awareness and encourage people to "talk about" prostate cancer in the way the community had started a breast cancer dialogue. A particularly interesting finding was the widespread frustration about the ineffectiveness of running free prostate cancer screening programs; even with appointments, men routinely did not show up.

> Look at the women in my community … every October [the county holds programs for breast cancer awareness month] … [In contrast] [w]e have free prostate cancer screenings … trying to get [men] to come … is a big problem. Women talk about it all the time, and if we could get the men to just think about coming to these free screenings, [it] would be just wonderful. (Community leader)

> [I'm] at a loss because … [prostate cancer screening is offered at no cost with] monies that our legislator provides. [We] try to [schedule] appointments. [We] explain that … it's not time consuming. They could come in and it's very quick and they're out. (Community leader)

Health fairs, community events, or walks were mentioned as potential sources for disseminating health information. However, informants who already used these methods found them minimally effective in attracting men at increased risk for prostate cancer.

> There is an unusual amount of privacy [among men] … to the point of their own detriment. So women … we can talk. But I've also found that the men who will talk will come to [a female pastor] rather than go to the male pastor. Because if it appears to be a sign of weakness, they would rather look a little weaker with [a woman rather] than with another man. (Religious leader)

> A very, very few come and seek [a pastor's] advice about [prostate cancer], it's really so hush-hush. (Religious leader)

Informants saw group meetings lead by survivors that the audience would respect and identify with as having the greatest potential for success in educating men about prostate cancer. Again, from prior experience, informants stressed that meeting topics should be more broadly based, not singularly focusing on prostate cancer, or the turnout would be low. Several suggested co-sponsoring programs with a community-based African American/ Black institution. Though some named potential partners such as schools, Civic Associations, or local chapters of the National Association for the Advancement of Colored People (NAACP) or A Hundred Black Men, most named the church as the most trustworthy organization.

> The church has always been the community liaison to everything. People trust the church, and what the church has to offer. So if there's going to be any education … it's got to be through the churches, because they will not trust any organizations outside, because they feel that the government can intervene in some way, shape, or form. But the church where most of us had our roots, they will trust, and the pastor has to be supportive of it, along with the lay people, and realize this is us. …The church is where the heart is. (Religious leader)

In contrast, only a minority of church leaders reported church-sponsored health-related activities. A few noted the presence of a women's group or health ministry within the church that brought in speakers and involved the church in community health events. But again, informants noted, that even for the few health fairs and prostate screening programs that were conducted, they were not able to succeed in recruiting participants even when partnered with local public health agencies. Placing advertisements/announcements in church bulletins also proved ineffective for recruiting participants for non-church-sponsored health programs. From the pastors' perspective, spiritual rather than bodily health was the church priority, taking all the church's time and resources. Parishioners only appeared to seek health care help or advice when the family was in need of day-to-day end of life support.

When asked for solutions to this dilemma, the most common response was that the information should not be targeted at the private health needs of men; their ethic of privacy and putting themselves last will undermine the efforts. Reflecting on the success of the WPLI, informants noted the positive impact the program had on improving breast cancer knowledge, and screening practices in the African American community. The majority of participants felt that women more than men readily talked with one another, and with medical providers about health care issues. To effectively reach men, informants consistently suggested three changes to current health education practices: reaching out to women, bringing in trusted speakers, and broadening community programs to include additional community health concerns.

Reaching out to women in order to reach men was one of the most widely proffered solutions. Repeatedly informants told us that "women [are the ones who] talk about preventative care. We tell everything, you know. And share everything," and that "[women are] the ones who push their husbands … make appointments and so forth." Thus, men could be reached via the women in their lives. One informant reporting on one of the few effective events conducted, attributing much of its success to contacting women for participation and not men.

> We had … a seminar … on prostate cancer… . the key was to [recruit] women, to let them know we were going to have the forum, that we would do some screenings, and that we would discuss prostate cancer [treatment] … and we would try to dispel myths related to prostate cancer… . We had [a] large turnout. The women did their job. They brought the men … on a Saturday which normally would not occur. (Government leader)

Broadening programs to wider health issues facing the community was also suggested by multiple informants as a way of reducing the reactiveness of men. A heavily emphasized suggestion was to turn the health education program into a way for the community to get together and have fun: "[M]ake it a family event, have music and food—definitely food."

> [I]f you're looking at getting men and women together and youth together, especially African descent folk, there's one thing you must have that will attract them, but you make sure it's got to be both physical as well as intellectual. You've got to have food. (Religious leader)

> You have food, they will show up. You set a minimum fee, they will show up. Then you get a top notch speaker who can walk the walk and talk that talk. If you get someone up there who's a doctor, who's way up in the clouds … these folks down below ain't going to have no idea. So it's got to be someone who looks like them, who speaks like that, rap like them, talk like them, and guess what? And they say rap like that. (Religious leader)

> You don't want an event where people are just sitting down to the table, giving them information. It would be considered boring and people wouldn't come. But if you … you pack the event with different activities that requires moving around, activity, action, I think you'd tend to attract more. (Health care provider)

Making the event have attractions for kids and young people would make it something the whole family could come to for inexpensive entertainment. While health education might not be the main attraction to participants, exposure to information and raising awareness in a non-threatening environment is the first step for starting a dialogue.

Finally, in addition to bringing in women and taking the spotlight off of men's prostates, informants suggested that cancer information should come from voices that community members trust.

> The time I went up to the pulpit and let the whole church know what my problem was … right after that I had about six of the brothers coming over wanting to know what I'm going through. Once somebody's gone through it, you're able to bring others along with you, which is like getting on the train. You[r] going on the train, you know the way. So here you have somebody that never been there before, [you] say "get on the train with me." (Community leader)

> There … need to be folks who can give a testimony of survival, who have undergone it, and explain to [men] the process … that there's nothing to worry about, that this is the best way of saving you years of misery down the line. (Religious leader)

These three strategies—targeting men through women, sponsoring broad-based and enjoyable community health events, and providing trusted testimony—would improve attendance and increase the likelihood that prostate cancer information would be successfully disseminated.

Discussion

The purpose of this study was to identify facilitators and barriers to prostate cancer screening, work-up, and treatment among African American men through community engagement using principles of CBPR and qualitative research methods. This study was developed from requests by community residents to create a prostate cancer educational program modeled after the WPLI for breast health created through a community–campus partnership. Throughout the study, investigators partnered with residents of the two towns to develop interview scripts, recruit, interview, analyze, and synthesize study findings into an actionable program. The study mobilized two communities around a topic that was not publically discussed. Through the recruitment process, attending civic and fraternal organization meetings, religious functions, and meetings with government leaders, helped to raise awareness and start a dialogue about prostate cancer among African Americans in the region. Engaging these two towns in the data collection process further solidified their engagement for participation in a future program focused on prostate cancer. From prior collaborations, residents voiced their desire to keep programs within their own communities and were less likely to travel for health programs (unpublished communications).

Using key informant interviews, this study identified concerns, barriers, and possible facilitators to screening, diagnosis, and management of prostate cancer in two communities of African American residents. While the sample and case study methodology limits generalizability of specific findings, the emergent results suggest methods of building on community strengths which could have applicability to other diseases and other African American communities. A synthesis of key informant findings by our town hall meeting participants into actionable items are presented throughout this discussion. The barriers and facilitators to screening for prostate cancer among African American men identified in Aim 1 of this study were similar to other studies conducted within the United States and internationally. Common cross study themes included, fear and mistrust of the medical community, economics, competing events, machismo, and fatalistic beliefs about cancer (Blocker et al., 2006; Ford et al., 2006; Friedman, Johnson, et al., 2012; Friedman, Thomas, et al., 2012; Gamble, 1997; Halbert et al., 2009; Kennedy, Mathis, & Woods, 2007; Ng et al., 2013; Sanchez et al., 2007). Prior studies have similarly identified family and spousal support as valuable motivators and facilitators for African American men to seek and obtain prostate cancer screening, and make broad based health-related decisions (Blocker et al., 2006; Friedman, Johnson, et al., 2012; Friedman, Thomas, et al., 2012; Jones, Steeves, & Williams, 2009; Ng et al., 2013). This study confirmed the findings of Sanchez et al. (2007) that prostate cancer is a very private and personal issue and not one that African American men wish to speak about in public.

Aim 2 results suggest some constructive ways to move beyond the barriers identified. In particular, this study suggests an approach to health education built on church-sponsored, family-oriented, survivor-based, cross gender programs. These recommendations are in agreement with existing research while addressing many of the barriers such research identified. Study participants suggested that broadening cancer education programs beyond focusing on prostate cancer alone may increase the comfort level of participants while still disseminating the vital information men need about prostate cancer decisions from screening through treatment.

Prior studies identified the church as a comfortable place to obtain health information and the importance of the church and faith in the lives of African Americans (Blocker et al., 2006; Friedman, Johnson, et al., 2012; Holt et al., 2009; Husaini et al., 2008; Ng et al., 2013; Odulana et al., 2013; Rowland & Isaac-Savage, 2013). Unfortunately, key informants in this study noted the difficulties of using the church to engage men specifically, despite their success with cancer education programs for women (Erwin, Spatz, Stotts, Hollenberg, & Deloney, 1996; Schoenfeld et al., 2006). This contrast in program success may be explained by prior research showing a stronger relationship between religion and health among women than men (Holt et al., 2009). To overcome these gender differences, participants strongly encouraged creating an educational program that involved both genders. Town hall meeting participants added the idea of creating a survivor-based outreach, where African American cancer survivors (including both men's and women's cancers) are invited to speak at church events. These programs would provide a trustworthy source of information not currently available, but without needing a specialized effort to organize or attend a health fair. The precedence for using such a model is founded in the national success of the Witness Project for breast and cervical health among African American women and implemented in the study region (Erwin et al., 1996; Schoenfeld et al., 2006). This recommendation comes full circle to the reason for conducting this study, as the initial request to develop a prostate cancer awareness program came from an individual who himself a prostate cancer survivor achieved success in encouraging his fellow congregants to seek workup and treatment for prostate cancer by telling his personal story.

To achieve program success, key informants recommended that programs be conducted in partnership with a trusted community group or institution, such as churches or African American organizations. In addition, programs must be broad-based, addressing issues of concern for the entire family and community, not just for men. As African Americans were reported to shy away from hearing about such private matters directed at themselves, a forum that reaches the women in their lives (wives, daughters, mothers, sisters, granddaughters, significant others etc.) may disseminate information about men's health more effectively than targeted programs. As described by some informants, the events should provide free food at a minimum as well as potentially some source of entertainment or fun.

Finally, a key concern of study participants was how to help men decipher screening and treatment recommendations. For few health issues is this more of a problem than in prostate cancer where there is no consensus on work-up and treatment (American Cancer Society, 2012; Chou et al., 2011; Smith et al., 2009; Taylor et al., 2012; U.S. Preventive Services Task Force, 2012). Further complicating this decision process is the scarcity of African American physicians and urologic specialists in the region, an issue almost universally voiced by key informants. In the United States, only 47% of minority patients are seen by a minority physician (Simon, Marsteller, & Lin, 2013). Wray et al. (2009) similarly identified the scarcity of African American physicians as a barrier to prostate cancer care with recommendations for the training and hiring of additional community minority physicians.

In the absence of patient–physician concordance, the study pursued suggestions for developing other ways to address this issue in the African American community. Town hall meetings provided the forum for this discussion. Improved patient–physician communication skills were recommended by town hall meeting participants as a viable solution for the local region to help bridge this gap while the medical education system addresses increasing minority training. Helping residents create their medical histories to bring to their physician was discussed as one step in opening up patient–physician communications. Town hall meeting participants also recommended creating a community seminar series that encompasses preparing for a health care provider visit, speaking with the provider, and maintaining a personal health history as a way to create/strengthen the patient–provider partnership. The universal feeling was that having this information readily available would improve patient confidence when speaking with a health care provider, especially when seeing the provider for the first time.

The patient–physician communications literature provides empirical support for the utility of the ideas proposed by town hall participants. Research has identified concordance as key to overcoming the difficulties African Americans have with physician communications (Friedman, Thomas, et al., 2012). However, the quality of the patient–physician relationship among African American men was a stronger predictor of trust than concordance by race (Jones et al., 2009). Satisfaction, improved overall health and cancer screening rates, compliance, and informed decision making increased when patient–physician communications were improved or perceived as good (Blocker et al., 2006; Cegala, Marinelli, & Post, 2000; Francis, Bowman, Kypriotakis, & Rose, 2011; Katz et al., 2004; Lepore et al., 2012; Williams, Haskard, & DiMatteo, 2007). On-line information sharing vehicles such as patient portals and electronic personal health records may help address town hall participant recommendations to improve bi-directional physician–patient communications (Agarwal, Anderson, Zarate, & Ward, 2013; Meier, 2013). Prior research, therefore, lends credence to the intuitions of study participants. The crucial take away message from this study is that these lay recommendations represented what community leaders and community members thought would be effective for themselves and their neighbors.

Limitations

The study did have some challenges and limitations, many of which are inherent to the case study methodology. The sample was purposive and participants self-selected, so the views included may not be representative of all perspectives. However, the personal, unstructured nature of the material is not easily obtainable via survey; the exploratory nature of Aim 2 required a less structured format. As the key informant interviews showed, African American men do not feel comfortable speaking about health, and the amount of information available about prostate cancer is limited. These difficulties in recruitment were previously documented (Sanchez et al., 2007). This study overcame some of the discomfort issues by (a) expanding on the established WPLI network; (b) providing concordance between interviewer and informant; and (c) focusing questions on community health to relieve participants from having to discuss their own health, if they chose to. The prostate cancer knowledge gap is reflected in the number of persons declining to participate due to a lack of knowledge about the topic.

Conclusions

This study was effective in fostering community dialogue in two towns around a topic that otherwise was rarely discussed, and identified barriers and facilitators to improving medical care for African American men. The study was successful in garnering support, recruiting participants, and fostering a prostate cancer dialogue because of the strength of the community–campus partnership focused on the health of African Americans began more than a decade prior. Findings from this study reflect the perceptions of local leaders and residents in two key areas: (a) the needs of their community in terms of overcoming problems based on inadequate knowledge, inaccurate beliefs, and low priority health attitudes; and (b) the strengths of the local community on which an effective empowerment-oriented intervention can build. These strengths highlighted the importance of family and the church in supporting African American men in their health education and care decisions, and encouraged locally based events directed at families. Patient– physician concordance is also of importance to the local communities, but the limited availability of African American physicians in this region underscores the need to develop other options to break down patient–physician barriers. Improving patient-provider communications was a high priority identified to address lack of concordance by race. Of greatest importance, however, was the fact that the approach of this study has engaged key informants, town hall meeting participants, and stakeholders in the health issues of their local community.

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Table 1

Participant Demographics.

Demographic characteristic	***n***	**%**
Gender		
Male	27	69%
Age (years)		
Mean ± *SD*		55.3 ± 13.9
Range		29–89 years
Duration of residence in Suffolk County (years)		
mean ± *SD*		31.2 ± 14.6
Range		7–57 years
Race/ethnicity		
Black/African American	28	72%
Education		
College graduate/education beyond college	33	86%
Key informant group		
Community leaders	13	33%
Health care provider	9	23%
Religious leaders	9	23%
Government leaders	8	21%
Personal experience with cancer[a]		
Prostate cancer	23	59%
Other cancers	29	74%

[a] Defined as individual, family or friend with a history of cancer.