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Developing Partnerships and Recruiting Dyads for a Prostate Cancer Informed Decision Making Program: Lessons Learned From a Community-Academic-Clinical Team

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Abstract

Prostate cancer (PrCA) is the most commonly diagnosed non-skin cancer among men. PrCA mortality in African-American (AA) men in South Carolina is ~50% higher than for AAs in the U.S as a whole. AA men also have low rates of participation in cancer research. This paper describes partnership development and recruitment efforts of a Community-Academic-Clinical research team for a PrCA education intervention with AA men and women that was designed to address the discordance between high rates of PrCA mortality and limited participation in cancer research. Guided by Vesey's framework on recruitment and retention of minority groups in research, recruitment strategies were selected and implemented following multiple brainstorming sessions with partners having established community relationships. Based on findings from these sessions culturally appropriate strategies are recommended for recruiting AA men and women for PrCA education research. Community-based research recruitment challenges and lessons learned are presented.

Keywords

African-American men and women; Community-based participatory research; Research partnerships; Recruitment; Cancer communication; Multi-media

Introduction

Prostate cancer (PrCA) is the most commonly diagnosed non-skin cancer among men. Both incidence and mortality from prostate cancer are significantly higher in African-American (AA) men compared with European-American (EA) men. In South Carolina this cancer disparity is 50% more extreme than in the country as a whole (i.e., about 80% higher in AA than EA South Carolinians) [1]. There is significant controversy surrounding PrCA screening [2, 3]. Much of this controversy derives from the prostate-specific antigen (PSA) test's detection of cancers that grow too slowly to be a health threat [4]. Over-diagnosing indolent disease and under-treating virulent disease can lead to serious adverse consequences. The incidence of virulent PrCA in AA men is significantly higher than in EA men [1]. The American Cancer Society strongly recommends shared decision making between healthcare providers and patients regarding the decision to screen [3].

The most recent statement of the U.S. Preventive Services Task force indicates that PSA screening results in small to no reduction in PrCA mortality that is more than counterbalanced by the adverse consequences of screening [5]. Despite the relevant evidence supporting its position to not recommend PSA testing, AA communities continue to express a desire to undergo regular PrCA screening [6, 7]. The evidence against PrCA screening is based on studies that involve little active participation by AA men [8, 9].

Research to explore and understand PrCA research participation by minority and disadvantaged groups is needed [10]. While AAs are more likely to develop and die from

cancer than all other racial/ethnic groups [3], they have low rates of participation in cancer research, particularly in clinical trials [11]. Despite federal mandates to include both women and racial/ethnic minorities in clinical trials research [12], AAs have generally represented less than 10% of participants in NCI-sponsored cancer prevention [13] and treatment [14] trials in the U.S. The Selenium and Vitamin Cancer Prevention Trial (SELECT) reported the highest proportion of AA male participants to date at 15%, and attributed this accomplishment largely to intensive recruitment efforts, which included active involvement of leaders from national AA organizations and targeting sites with high potential for AA recruitment, including South Carolina [15].

Barriers to participation in cancer research by AA and other underserved groups have been documented at the patient, provider, and systems levels. At the patient level barriers include mistrust of the medical system and of research [16], strict study eligibility criteria [17], low-socioeconomic status [18], lack of health insurance coverage [19], and limited awareness or education about trials [20]. Providers' limited awareness or lack of referral to clinical trials also serve as barriers [21]. There also has been evidence of institutional [22] and structural [23] barriers to AA recruitment and participation. AA women play a key role in health and cancer decision making of AA men and prior research suggests the importance of including both AA men and women in research to examine knowledge and perceptions about PrCA screening and barriers and facilitators of AA men's participation in cancer research [24, 25]. Our understanding of strategies for engaging AA communities' participation in healthy behaviors is often based on programs conducted with AA women [26].

This pilot research assessed the knowledge and attitudes of AA men and women regarding participation in NCI-sponsored research, specifically pertaining to PrCA. Napoles and Chadiha [27] recommend that investigators incorporate and evaluate multiple recruitment methods in their studies in order to advance the science on effective recruiting and retaining of racially and ethnically diverse groups into health-related research.

Community-Academic-Clinical Partnership Development for Pilot Research

The Community Networks Program Centers (CNPC), which are funded by the National Cancer Institute's Center to Reduce Cancer Health Disparities as U54 cooperative agreements (2011–2015), are designed to reduce cancer-related health disparities through high-quality intervention research. CNP Centers have three main goals: (1) to increase the knowledge, access, and use of prevention and treatment options to reduce cancer disparities in target populations; (2) to perform community-based participatory research (CBPR) interventions examining the best ways to promote prevention and treatment; and (3) to train qualified health disparities researchers in CBPR and promote cancer development (<http://crchd.cancer.gov/research/cnpc/overview.html>). There are 23 CNPCs in the U.S. Each focuses on a specific population(s): 9 on African Americans; 6 on Hispanics/Latinos; 3 on American Indian/Alaskan Natives; 2 on Native Hawaiian/Pacific Islanders; 2 on Asians; and 4 on other underserved groups (e.g., rural populations).

According to the U54 Request for Applications (RFA-CA-09-032), CNP Center applicants were required to propose a research program of innovative and evidence-based clinical research adhering to the principles of CBPR for two research projects: one full research project for a controlled intervention and one pilot educational research project to be directed by a new or early-stage investigator. This paper describes partnership development and recruitment efforts of a Community-Academic-Clinical research team for the South Carolina Cancer Disparities Community Network's pilot project – a PrCA education intervention with AA men and women that was designed to address the discordance between high rates of PrCA mortality and limited participation in cancer research. Additional requirements for the

pilot project included: an assessment of and changes in knowledge, attitudes, and/or behaviors of racial/ethnic and underserved populations regarding participating in NCI-sponsored clinical trials, collaborations with other NCI-sponsored resources/programs [e.g., the NCI Community Clinical Oncology Program (CCOP), the NCI Community Cancer Centers Program (NCCCP)], and promoting the role of racial/ethnic and other underserved populations in research.

In keeping with CBPR principles [28], a community advisory panel of AA men and women was established at the outset to help guide all recruitment and project implementation and evaluation activities. Panel members were contacted by telephone and/or email invitation. They included UsTOO® Chapter Leaders, community cancer educators, members of the statewide Cancer Alliance, PrCA survivor, and local AA author and radio host. The academic and clinical teams' roles also were established early on and subcommittees were created. A recruitment coordinator was put in place at both university and clinical setting, a community project promotion team was formed, and education session leaders and assistants were identified based on expertise and availability. Finally, a research advisory panel was established to ensure accurate education and evaluation (survey and focus group protocol) content about PrCA screening and clinical trials participation. The research advisory panel comprised the medical director / principal investigator (PI) of the CCOP and NCCCP, the U54 PI, and the Research, Community Outreach, and Training Core Leaders of the U54.

Specific Aims of this pilot project, developed collaboratively by the community-academic-clinical team, were to assess among AAs, (1) current knowledge and attitudes regarding PrCA prevention and screening and participation in PrCA research, (2) changes in knowledge and attitudes about research participation following a pilot education program, and (3) culturally appropriate strategies for promoting cancer research among AA communities. Based on study findings, a preliminary framework on PrCA research communication with AA communities will be developed employing best practice recruitment strategies and communication principles to encourage high-risk, minority populations' increased knowledge and participation in cancer prevention research.

Research Setting and Participant Eligibility

Based on grant requirements we developed a partnership with the NCCCP and CCOP and selected to work within counties in the Northwest corner of the state of SC to allow for this collaboration. Mortality-to-incidence ratios (MIRs) for PrCA in the region are significantly higher in AA men than in their EA counterparts; i.e., 58% higher for PrCA [29]. Eligible participants were AA men (without history of PrCA) 40 years of age and AA women 21 years of age with spouse or male relative 40 years, with English as a first language.

Program Components

Phase 1: Formative Focus Groups

Participants were invited to participate in a focus group discussion and to complete a brief questionnaire eliciting descriptive information (e.g., gender, age, education, personal health and cancer information-seeking and screening behaviors). A 19-item focus group protocol with open-ended questions was developed in collaboration with the NCCCP and community advisory panel. Topic domains included: current practices and comfort level in PrCA communications with healthcare providers and family members; barriers to discussing PrCA within AA families and with providers; perceptions of and barriers to participation in cancer research and clinical trials; and recommended strategies for doctor-patient and family communication about making informed decisions for PrCA screening. Focus groups ranged in length from 90 to 120 minutes and were audio-recorded. A total of 22 focus groups, 11

with AA men and 11 with AA women, were conducted with a total of 81 participants (43 men with mean age of 51.0 years, 38 women with mean age of 50.3 years) at a local public library.

The team conducted each focus group with one moderator and one note taker. Moderators were race- and/or gender-matched to participants (e.g., African-American male moderator for focus groups with AA men). Participants were informed in writing and orally of the purpose of the focus groups. Moderators used comprehensive probes to obtain and clarify participants' responses to focus group questions. Culturally sensitive and appropriate language was used to describe the research process and conduct the focus group sessions. At the end of the focus groups, participants received an incentive in appreciation for their time and participation. The community advisory panel, research advisory panel, and NCCCP partners contributed to the interpretation of focus group findings.

Phase 2 Pilot Education Intervention

Fifty-six of the 81 focus group participants (69.1%) agreed to participate in Phase 2 of the project - a four-week, four-module pilot education program for both AA men and women. Participants were asked to complete a pre/post education survey with Likert-type questions. A total of 49 participants (26 men and 23 women) completed both pre- and post-tests. Survey topics included the function and anatomy of the prostate, PrCA risk, and PrCA screening; clinical trials and research participation; health care decision making; and patient-provider communication. Each of the modules was offered multiple times to enable a personalized and relaxed training environment with an optimal number of participants per session. The curriculum, developed by the community-academic-clinical team, was based on previous formative work [30]. Session topics included: What is the prostate? What is prostate cancer? What are risk factors and symptoms? Dispelling myths about prostate cancer (Week 1); Prostate Cancer Screening Guidelines: Should I get screened for prostate cancer? (Week 2); What are clinical trials? What is informed consent? (Week 3); Talking about Prostate Cancer: Overcoming barriers to discussing cancer (Week 4). Between sessions, participants also received education messages about the previous week's session by postcard, email, or text message. Participants received a monetary incentive during week 2 and following completion of the post-survey.

Recruitment Framework

Guided by Vesey's framework [31] on recruitment and retention of minority groups in research, recruitment strategies were selected and implemented following multiple brainstorming sessions with partners with established community relationships. Strategies included conceptualization, planning, and development of the recruitment plan and promotional materials in collaboration with community partners; recruitment of study sample with community partners; developing and conducting culturally appropriate education sessions and pre/post-education assessments; and reporting of findings to the community and engaging the community and community partners in planning for future research.

Recruitment Strategies

Recruitment occurred between January and April 2011. A multi-faceted, culturally appropriate approach to recruitment was employed. Main recruitment strategies included partnering with a prostate nurse navigator; multi-media promotion, and word of mouth.

Working with Prostate Nurse Navigator—The National Coalition of Oncology Nurse Navigators defines an *Oncology Nurse Navigator* as “a professional whose clinical nursing expertise guides patients, families and their caregivers to informed decision-making; collaborating with a multi-disciplinary team to allow for timely cancer screening, diagnosis,

treatment, and increased supportive care across the cancer continuum. By accompanying the patient through every aspect of their cancer journey, the ONN is able to ensure access to the information necessary to make the best possible decision about treatment choices, secure the best therapies and provide counsel and advice to improve the patient's quality of life" [32]. The NCCCP-based nurse navigator who partnered with us on this project educates cancer patients and non-patients going through the PrCA screening process and patients undergoing surgery and/or treatment; guides them in clinic appointments, and provides the support and expertise for individuals and family members [33]. Supporting and navigating each patient is done by reinforcing education and coordinating information and care with a team of physicians and allied healthcare professionals. With her experience and expertise in facilitating support groups and programs and referring patients to appropriate cancer support programs and resources and her established relationships in their community, the ONN played a key role in the recruitment process. She and the NCCCP community project promotion team were invited to speak about the project at churches, community centers, and hospital departments (e.g., environmental and food services). They also partnered with the local UsTOO® support group on recruitment through formal and informal seminars and word of mouth.

Multi-Media Approach—We worked with a variety of media outlets in order to promote and recruit AA men and women for this study. Because radio was found to be a recommended strategy for reaching AA communities in previous qualitative work across the state [34], the team taped one audio segment on a radio station with large AA listenership and conducted a live radio segment on one of the community advisory panel member's radio show intended for older AA men and women. During focus groups with both men and women, participants stated that they believed radio could be an effective strategy to promote PrCA education. One male participant stated that radio was a good way to reach AAs "*cause a lot of people do listen to the radio.*" Similarly, another male participant, speaking about the effectiveness of radio messages, stated, "*They talk without the prostate on there....And that's what you need, some venue like that, something this big that can get through the mass of people.*"

Promotional messages also were posted on community event websites and community partner organization and healthcare websites and list serves. Flyers were distributed in the local newspaper and at local businesses, library, churches, barbershops, health fairs, and door to door. Furthermore, in-person education and promotion about the study was conducted by the community outreach team at health fairs, churches, community meetings (e.g., UsTOO®), and medical appointments by NCCCP partners.

Word of Mouth—Previous research with AA men and diverse populations demonstrates participants' consistent recommendations for word-of-mouth and social networking as effective methods for recruiting minority groups into health and cancer education research [35, 36]. Participants said that talking with others about PrCA and finding out about screening practices through "word-of-mouth" were most effective strategies for reaching AA men with PrCA prevention messages. In one of the focus groups, a male participant discussing the importance of in-person communication said, "Three of us are in here right now, two of us are gonna go out and talk to somebody and touch somebody, and they're gonna believe what we say." Similarly, one female participant, who said she got involved in the project because a friend told her about it, said to other participants, "But, see, now you are the grapevine. You coming to get educated and then you pass it on along." While not required of participants, they were asked to recruit friends and family members when they signed up for the study. This type of snowball sampling has been used in other qualitative research on PrCA with minority populations [37].

Logistics

Recruitment of participants was accomplished through a team effort by the community-academic-clinical team. Clinical partners with the community outreach team typically collected the names, ages, and phone numbers of potential participants from various faith and community-based settings. These names were then entered into a spreadsheet and shared with the academic research team through Google Docs™, a web-based program that allows individuals to securely share and edit documents with other users in real-time. It is a free service and accessible to anyone with an email account hosted by Google™.

Using the Google Docs™ spreadsheet, the academic team members called each potential participant and asked a series of questions to ensure that each met eligibility criteria. Following this process, eligible participants were offered dates of upcoming focus groups and their dates of availability were recorded on the spreadsheet. Clinical partners were asked to contact those individuals who did not respond after three calls to verify their participation eligibility. One to two days prior to their scheduled focus group, each participant received a reminder call from either a clinical or academic team member regarding their scheduled appointment. The Google Docs™ system enabled both teams to denote which participants had been called and if they were still available to attend their scheduled session. Changes to the spreadsheet were reflected immediately to all users with access to the spreadsheet. Therefore, no duplicate reminder calls were made and all team members knew if participant was not expected to be in attendance at a focus group session. A similar use of Google Docs™ was employed to schedule participants for the four PrCA education session offered throughout the course of this pilot project.

Recruitment Challenges

Scheduling—Recruiting dyads (i.e., AA men and women) was quite challenging. Male and female-participants were asked to attend separate two-hour focus groups on the same day at the same time and attend four one-hour education sessions over four weeks on the same day at the same time. In total we held over 20 focus group sessions and 16 education sessions in order to accommodate people's schedules and availability; however, it remained challenging to schedule both men and women at the same time. While 76 couples and 37 singles ($n = 189$) were originally recruited for our study, only 22 couples and 37 singles ($n = 81$) were available to participate in focus group sessions. In addition, 18 couples and 13 singles ($n = 49$) completed all aspects of the study. Single participants were paired up to attend the same sessions if possible. Previous research has explored the costs of recruiting dyads for health-focused studies [38, 39]. Voils and colleagues [39] recently published relevant recommendations for researchers conducting partner-based programs, including minimizing travel to the study site; budgeting more for participant incentives and staff effort; and limiting exclusion criteria.

Recruiting from Afar—The university team was located two hours from the study location. Thus, many recruitment calls were made to participants from a long-distance telephone number and participants may have chosen not to respond to those calls. In order to minimize recruitment issues that could have resulted from following up with interested participants in this way, telephone numbers from both academic (not local) and clinical (local) partners were listed on the recruitment flyer, newspaper insert, and radio announcements. Clinical partners set up a voice mail message specifically for the project and assisted with telephone follow up in order to keep participants engaged in the program.

Other Health Priorities of Participants—During focus group and education sessions, several participants mentioned having chronic conditions including diabetes, hypertension, asthma, and cancers other than PrCA. Female participants shared their experiences with

colon, cervical, and breast cancer as well as other chronic illnesses. Male participants also talked openly about their current health concerns, most of which included hypertension, diabetes, and hypercholesterolemia. It is likely that individuals with more immediate health concerns would devote less time to education projects focused on health concerns that did not directly impact their day-to-day lives. One couple did drop out of the study because of serious health issues of one of the individuals.

For many participants, their involvement in the project's education sessions was the first time they had learned about PrCA and its prevalence among AA men. This may have made recruitment more difficult simply because people in the community may have been less aware about PrCA. The individuals participating in the study, however, did seem to be concerned with cancer in general. When asked about the types of clinical trials that would help their community, participants often mentioned cancer. However, more participants stated that hypertension and diabetes were their biggest health concerns. One male participant said, "Heart disease and high blood pressure would be one, diabetes another. I mean it's running rampant in our community." Another male participant stated, "One of the other diseases that is plaguing the African American, both male and female is diabetes, and sugar, you know." Participants may have been more likely to participate in education programs focusing on these other health concerns that they perceived to be the largest threat to the health and well-being of their communities.

Lessons Learned and Recruitment Recommendations

Start Recruitment Early and Be Flexible—Throughout the recruitment period, we learned to be flexible with scheduling and implementation while still conducting high-quality research. We made minor adjustments to the targeted age-range, expanding it to include both older and younger participants than originally desired. We also held focus groups regardless of how many people attended; thus, three of the focus groups had only one or two people in attendance. Because of the low attendance at the originally scheduled focus groups, we held four additional focus groups to gain additional participant perspectives. We were less flexible regarding our decision to have male and female participants attend focus groups on the same day. Initially, we felt that it was necessary to have men and women attend focus groups on the same day to avoid biasing the data. We expected that if either a male or female participant was involved on a different day, they could potentially inform their counterpart about the details of the focus group discussion or the survey questions. However, this may not have been necessary as males and females were in separate groups and this requirement only made scheduling more difficult. To accommodate the varying schedules of participants during our four-week education program and to maintain good overall study retention, we allowed couples to sign up for different dates or times for the education as long as they both attended during the same week of the education program. Because scheduling was such a huge challenge throughout the education portion of the program, we probably could have combined education modules to reduce the number of times participants had to attend sessions. We will attempt this strategy during the next phase of study recruitment.

Promote Finale from the start—Promoting the participant celebration early on in the study was one strategy we used to retain participants throughout the extended project period. At our first focus group, we began distributing "save the date" flyers promoting a celebration that would honor program graduates at project's end with a dinner. We asked participants to provide us with dates and times, allowing us to schedule the celebration during a time when most participants could attend. We reminded participants about the celebration throughout the project period at education sessions and through telephone reminders. Nearly all participants attended the final celebration, demonstrating people's

interest in gathering with other participants to reflect with others on the program and their accomplishments. Several community, legislature, and hospital spokespeople were in attendance served as keynote speakers at the event. Because these special guests were invited to the celebration mid-project, we did not promote their attendance to participants. In the future, we will plan in advance so that we can promote guests and speakers and their support of our project as a strategy to recruit and retain participants.

Engage Community Advisors using Formalized Process: Moving toward an Advisory Council—Although members of the community advisory panel were engaged in every aspect of the study from development and recruitment to dissemination, with such a large project team, we recommend a more formalized approach to engaging community in research. For future recruitment for cancer education programs our team has developed an advisory council form that specifies time and participation requirements. This will include attending one in-person advisory council planning meeting (2 hours); participating in three telephone meetings; supporting the development of the education program; distributing at least 20 flyers about the program and track where flyers distributed; recruiting eight participants for the program; completing survey about the advisory council process; attending first education program session to introduce yourself; and sharing insights with others.

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