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Building Capacity in a Rural North Carolina Community to Address Prostate Health Using a Lay Health Advisor Model

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Abstract

Background—Prostate cancer is a critical concern for African Americans in North Carolina (NC), and innovative strategies are needed to help rural African American men maximize their prostate health. Engaging the community in research affords opportunities to build capacity for teaching and raising awareness.

Approach and Strategies—A community steering committee of academicians, community partners, religious leaders, and other stakeholders modified a curriculum on prostate health and screening to include interactive knowledge- and skill-building activities. This curriculum was then used to train 15 African American lay health advisors, dubbed Prostate Cancer Ambassadors, in a rural NC community. Over the 2-day training, Ambassadors achieved statistically significant improvements in knowledge of prostate health and maintained confidence in teaching. The Ambassadors, in turn, used their personal networks to share their knowledge with over 1,000 individuals in their community. Finally, the Ambassadors became researchers, implementing a prostate health survey in local churches.

Discussion and Conclusions—It is feasible to use community engagement models for raising awareness of prostate health in NC African American communities. Mobilizing community coalitions to develop curricula ensures that the curricula meet the communities' needs, and training lay health advisors to deliver curricula helps secure community buy-in for the information.

Keywords

Prostate cancer; African American; lay health advisors; community engagement

Introduction

According to National Cancer Institute (NCI; 2014) data, prostate cancer (PCa) deaths have decreased markedly in recent years for all men, yet African American men still bear a disproportionate burden of PCa incidence and mortality compared to men from other racial

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or ethnic groups. There is a statistically significant disparity in age at diagnosis for African American compared to Caucasian men, with African Americans being diagnosed at an earlier age on average (Parker et al., 2011; Shao et al., 2009). African American men diagnosed with PCa also tend to have higher prostate-specific antigen levels and Gleason scores than Caucasian men do (Shao et al., 2009). PCas diagnosed in African American men are, on average, more aggressive than those removed from Caucasian men (Amling et al., 2004; Powell, Bock, Ruterbusch, & Sakr, 2010; Shao et al., 2009). Some studies have found that African American men are diagnosed with PCa at more advanced stages than Caucasian men (Jayadevappa, Malkowicz, Chhatre, Gallo, & Schwartz, 2010; B. A. Jones et al., 2008; Marlow, Halpern, Pavluck, Ward, & Chen, 2010).

Geography-related PCa disparities also exist and may even explain some of the disparities by race. Among urban men, PCa incidence is higher than that for rural men, but mortality is higher among rural men (Obertova, Brown, Holmes, & Lawrenson, 2012). Reasons for this gap include scarcity of screening and diagnostic services in rural communities (Obertova et al., 2012); inaccessibility of screening, physicians, and/or health care (R. A. Jones, Underwood, & Rivers, 2007; Oliver, Grindel, DeCoster, Ford, & Martin, 2011); limited resources for transportation (Stamatiou & Skolarikos, 2009); and limited PCa knowledge (R. A. Jones et al., 2007; Obertova et al., 2012; Pruthi et al., 2006; Stamatiou & Skolarikos, 2009).

The Importance of Community Engagement

Novel, creative interventions and community engagement are needed to address these challenges for rural African American men. Community engagement in research positively affects health through numerous conduits, including empowerment of community members and groups, increasing access to information, and enhancing community capacity (Wallerstein & Duran, 2006). Through collaborations between organizations and research institutions, programs can effectively and sustainably be implemented; such collaborations can be achieved through fostering leadership in health among community members and stakeholders (Foster & Louie, 2010; Lasker & Weiss, 2003). In turn, community participation promotes community ownership of programs, which facilitates sustainability and program pride (Foster & Louie, 2010). Through this process, partners can build trust, promote colearning, and ease power dynamics (Belone et al., 2014). Engaging the community in the research process not only builds community capacity for research but also can increase knowledge of and ability to take action to address health disparities (Coats, Stafford, Thompson, Javois, & Goodman, 2014).

A recent study by Gwede et al. (2013) used community-based participatory research (CBPR) strategies to develop and implement a training curriculum for cancer lay health advisors (LHAs). The program involved community stakeholders at each of the stages of their curriculum development process and focused on improving education about cancer prevention and screening among underserved populations. Their training included modules that covered the duties of LHAs, health disparities, basic information about cancer, research, and clinical trials. LHAs also received supervised field training. This program was seminal to PCa research because it demonstrated the utility of an LHA network for engaging the

community using principles of CBPR to address racial and ethnic cancer health disparities using an LHA network that extends beyond acting solely as peer educators (Gwede et al., 2013).

CBPR remains a critical strategy for targeting cancer disparities in underserved groups, such as African American communities. Gehlert and Coleman (2010) used focus groups to engage the African American community in South Side Chicago to gauge a lay working understanding of the social factors that can lead to breast cancer disparities between African American and Caucasian women. Findings from the focus groups led to the invocation of CBPR principles and the formation of a community steering committee for leading the charge and, later, a task force for forging ahead with its mission, which mobilized the community and concerned organizations to fight breast cancer disparities.

The Utility of LHAs

A recent article concisely summarized the utility of LHAs as an effective approach to reducing health disparities and delivering community-based interventions. LHAs are generally members of the community where the research intervention is being implemented, and they share health information and/or link others in their community to health services and resources (Sun et al., 2014). The effectiveness of the LHA model is primarily due to the LHAs' very intimate knowledge of the social networks from which they come, ability to communicate with individuals within those networks, and unique propensity to incorporate culture into health promotion efforts (Sun et al., 2014).

The LHA model has been used widely with growing use to educate African American communities about different types of cancer. As part of a community-academic partnership to improve PCa screening among African Americans in Tennessee, LHAs served as implementers of an intervention to educate community members about PCa using a brochure developed in tandem with the community (Patel et al., 2013). This intervention proved successful at improving screening rates among participants and, correspondingly, increasing knowledge about PCa among those who were screened. In an earlier study, LHAs were used to increase awareness and usage of mammography among African American women in North Carolina; the intervention featuring the LHAs was associated with a 6% increase in mammography usage compared to those in other counties (Earp et al., 2002).

Purpose of the Present Article

This article will describe the feasibility of using an LHA model to engage a rural, economically distressed African American community in North Carolina (NC) about prostate health and to build their capacity to be active members of the research team. The outcomes of this research demonstrate an extension of an LHA role from one that entails primarily peer education to becoming part of the research enterprise. Specifically, it will detail the cooperative establishment of the research agenda, the formation and mobilization of a community coalition to enhance an existing prostate health curriculum, the implementation of that curriculum to train 15 LHAs (called Ambassadors), and the engagement of those Ambassadors in both sharing information about prostate health and

collecting survey data. As such, the article will illustrate the building of community capacity for research and health education.

The goals of the Ambassadors project, set by the academic partners in consort with the community, were to (1) develop a community steering committee for better rural men's prostate health; (2) identify and train community members to be PCa Ambassadors by educating them and, in turn, have them educate other community members in their network about prostate health; and (3) expose community members to the research process through training on research ethics and the administration of a survey collecting cancer health data within the faith-based community. The community identified PCa as a topic of interest and need, thus driving the formation of the project.

Approach, Strategies, And Results

Theoretical Considerations

The appeal of LHAs, to the project team, was that a new innovation or piece of information shared with key members of a community can filter down to other members of the community. This movement is best explained by diffusion of innovations theory (Rogers, 2003), which describes the communication process through which new concepts or "innovations" are passed over time through members of a social system (Oldenburg & Glanz, 2008). LHAs share information and practices and help develop norms within their own social networks, which tend to be extensive because LHAs are often chosen by the community as being well connected and influential (Altpeter, Earp, Bishop, & Eng, 1999). The LHAs' contacts, ostensibly, then share the innovation with people in their own social networks, both actively and passively, with the goal of adoption and implementation of the concept or practice.

Primary Community–Academic Partnership

The current project aims to build community capacity for research and education among an impoverished, largely African American, community in rural North Carolina and, as such, is rooted firmly in partnerships between academicians and community stakeholders. The community–academic partnership began in 2006 when health disparity researchers and a community health educator (CHE) from an academic medical center began working with a local Baptist association of African American leaders and churches to conduct a cancer needs assessment of their community. The goal of this assessment was to identify community challenges and priorities as part of an NCI health disparities initiative. As the university gained knowledge of its partners' interests in solving cancer-related disparities in the state, the Baptist association became a natural partner in leveraging funding from the university's School of Government Community–Campus Partnership program because of its previously expressed concern with PCa among rural African American men. Likewise, the program was concerned about the health and economy of Tier 1 counties in the state. These expressed needs, and the goals of the partnership drove the present program.

Community Steering Committee

The project team, including the Community Health Educator, formed a community steering committee of key stakeholders within or affiliated with the community to ensure that the voice of the community at large was heard and considered in every stage from planning to implementation and evaluation. Two community academic research partners were invited to participate on the committee based on their vested interest in and dedication to prostate health. The first partner had already developed a PCa LHA training curriculum, and the second partner was a native of the county and had established relationships with the local faith-based community. The committee also included a health educator from the local health department, a representative from the Baptist Association, and two local health care providers.

The committee was integral in leading the research process, developing training and survey materials, and disseminating results. Specifically, the members provided guidance on proposed methods and helped design research materials for the community. Members also guided the application process and determined selection criteria for Ambassadors. The committee offered guidance regarding disseminating project findings and using project results to inform the development of future research projects and/or community action. Ambassadors' enrollment and outcomes data were shared with committee members along with other information pertinent to the success of the project. The committee convened locally on a monthly basis to discuss the materials and assess the project's progress.

Curriculum Refinement

The research project team developed a 2-day training session in preparation for PCa educational outreach using a modified version of the *On the Ground Prostate Cancer Ambassador* training curriculum (not publically available) previously developed by one of the community-academic research partners who was on the project's community steering committee member. In 2008, the *On the Ground Prostate Cancer Ambassador* training curriculum was developed to provide lay leaders with the knowledge and skills needed to communicate information about PCa to men and their families. The development process was an iterative one of refinement by the research project team and community steering community over a 15-month period. The refinement process served to ensure that the curriculum could be easily understood by the priority population while providing a thorough understanding of PCa with a focus on prostate anatomy and physiology.

For the purpose of the current project, the steering committee tailored the curriculum for use in the rural county by including county-specific data regarding the incidence and mortality associated with PCa, adding Web-based resources on PCa and cancer disparities (e.g., the National Library of Medicine), inserting interactive exercises, and changing the format from a singleday training to a 2-day session with reinforcement activities. The training curriculum was also expanded to include a section on prostate health in general (vs. having a cancer-specific focus) to reflect the broader area of diseases of the prostate.

Recruitment and Selection of PCa Ambassadors

Applications were solicited with the goal of forming a group of 20 to 25 African American participants to become PCa Ambassadors in the rural, economically distressed county. Churches affiliated with the Baptist Association each received a packet that included flyers advertising the project, informational letters, and applications for those interested in becoming Ambassadors. The letters explained the expectations of an Ambassador, which included participation in a 2-day training, conducting at least three outreach/educational activities following training, and administering a church health survey to members in their congregation.

Applications were distributed over a 2-month period to 24 churches affiliated with the Baptist association in the county, who in turn distributed them to interested members. Completed applications were returned to the project's Community Health Educator (CHE). In addition to demographic factors, the research team assessed the applicant's completion of prior educational trainings related to PCa or other health conditions and their current level of involvement in the community. The criteria for selecting Ambassadors were individuals who possessed a strong interest in improving prostate health and a history of community involvement.

The institutional review board at the university provided oversight and human subjects protection for the entire program. Prior to the start of the first training session, the CHE obtained informed consent from all training participants.

The project resulted in the successful training of 15 Ambassadors. There were 17 applications received; all of them came from African Americans in NC, and all were accepted. The 17 applicants began training, but 3 applicants did not complete the training, leaving 14 Ambassadors. One steering committee member also completed the training, yielding the 15 Ambassadors. While this number fell short of the goal of 20 to 25 owing largely to difficulties contacting some church leaders, all partners felt satisfied with this result. Of the Ambassadors, about half had at least a college degree, the majority were women, and one participant had prior health-related training (Table 1). All Ambassadors came from the targeted community.

Ambassador Training

With the modifications of the curriculum, one community partner (ANR) served as the training facilitator for both sessions, working in tandem with the CHE. In preparation for the training, the partner assisted the team with finalizing and packaging the training and outreach materials as well as the pre- and postsession assessments.

The goal of the first training day (approximately 4 hours) was to increase knowledge of the prostate, symptoms of PCa and other diseases of the prostate, PCa screening recommendations from the American Cancer Society (ACS), and treatment options. Special emphasis was placed on understanding risks and benefits of PCa screening as described by the ACS and making an informed decision. The first training module covered four sections of the curriculum: Introduction to the Ambassador Model; Public Health and Prostate Cancer Trends; Prostate Health: Anatomy and Physiology; and Screening.

The second training day (4 hours) consisted of the remaining curriculum sections on PCa treatment, resources, and promoting PCa awareness in the community. The second day's training session emphasized effective strategies for sharing information with others in the community. The Ambassadors were taught how to develop their own script for speaking about prostate health and had an opportunity to practice responding to questions from others through role-play. The training facilitator demonstrated the use of the National Library of Medicine as a reliable source for obtaining information related to PCa and prostate health in general, compared to obtaining information from often unreliable online sources. "Teach back" sessions were incorporated at the end of each training module on both training days to reinforce key points.

Training sessions were based on adult learning theory, which emphasizes the need and desire for experiential and self-directed discovery (Merriam, 2001). Examples given in the classes were tailored to situations that could happen in real life, and learners were given opportunities to practice and gain practical skills through problem-solving such situations. Moreover, Ambassador candidates set their own goals for the training, used practical tools, and valued the input that was given to them in their training.

Knowledge Assessments

The Ambassadors completed pre- and postsession assessments to determine changes in general knowledge related to prostate health. Additionally, changes in the Ambassadors' confidence self-ratings for selecting and sharing appropriate PCa educational literature and referring individuals to appropriate health resources were measured. An overall satisfaction survey was administered at the end of the second training session. Survey data were analyzed using SAS software Version 9.2 (SAS Institute, Cary, NC), and changes in knowledge and confidence were evaluated using Student's paired *t* test statistic.

Training Successes

The training proved successful for increasing knowledge about PCa (Table 2) and for maintaining confidence about presenting information. Prior to completing the training sessions, on average, the Ambassadors had a high level of knowledge about PCa and health (Table 2); the mean knowledge score was 6.4 out of a possible 8 points (*SD* = 0.63). On completing the trainings, Ambassadors improved their knowledge of PCa; the mean knowledge score rose to 7.7 out of 8 points (*SD* = 0.61). This increase in knowledge was statistically significant; $t(13) = -4.69, p = .0004$. Approximately 84% of Ambassadors stated that training provided them with a greater understanding of PCa disparities in North Carolina. All of them agreed that they had a greater understanding of the ACS screening guidelines for PCa, and about 92% reported improved comfort with sharing information about PCa (data not shown).

Pledge of Service

Following training, all Ambassadors signed a pledge and created outreach plans to guide the completion of at least three outreach/educational activities within the subsequent 6 months. The Ambassadors received a tool kit that included prostate health educational literature, a specially designed tabletop chart describing the anatomy of the prostate and prostate-related

diseases, a local PCa resource guide, and other cancer-related giveaway items. The academic Community Health Educator made monthly calls to the Ambassadors to document the number of outreach activities, the number of individuals reached, the types of information shared, the type of educational tool(s) used, and anecdotes shared by the Ambassadors; she also helped troubleshoot outreach challenges. Following the monthly calls, all information was immediately entered into an Excel database for maintenance and analysis.

Two thirds of the Ambassadors completed three educational activities within 6 months following the training. Outreach activities included group presentations, bulletins/displays, health fair exhibits, and one-on-one conversations with family members and friends. While approximately half of the outreach occurred in faith-based settings, Ambassadors also targeted places of employment, social organizations, community agencies, and family, friends, and neighbors (Figure 1). In total, the Ambassadors reached over 1,000 individuals through their efforts over 6 months.

Ambassador Training in Research Ethics and Data Collection

A third goal of the project was to expose the Ambassadors to the research process so they would be better able to participate in potential research partnerships. To build their research capacity, the research team provided training to enhance knowledge and skills in research ethics and survey data collection. Following the initial Ambassador training, 12 of the Ambassadors completed a 1.5-hour research ethics training that had been previously approved by the university as an alternative human subjects research training program for community members who work with investigators to conduct research. The research ethics training consisted of a training module that covered topics on the ethical principles of human subjects research, rights and protections of human research participants, and informed consent. The module also addressed the definitions of “research” and “research participants” and the institutional review board’s role and function.

Completion of the human subjects training enabled Ambassadors to conduct a health survey in their church communities. The CHE met with the Ambassadors to review the survey and provided specific instructions for administering the survey, which included instructions on obtaining informed consent from participants. The Ambassadors were provided a script to guide them throughout the process of administering the survey to participants. The purpose of the survey was to identify opportunities for further research based on the level of cancer health knowledge and health needs in the faith community of the county. The survey included items about screening behaviors for breast, prostate, and colorectal cancers; cancer risk factors; survivorship; participation in cancer clinical trials; and comfort level regarding participation in health research.

Some of the Ambassadors worked in pairs to coordinate the administration of the survey. While some Ambassadors were mainly responsible for coordinating logistics and recruiting participants to take part in the survey (known as “coordinators”), the other Ambassadors (known as “administrators”) were responsible for obtaining informed consent from participants, providing survey instructions, and collecting surveys from the participants. This process demonstrated the Ambassadors’ capacity to conduct data collection and their leadership in the field. Together, the Ambassadors were able to collect and return 129

surveys, completed in whole or in part, to the research team out of the 200 distributed to participating churches (65% return rate).

Maintaining Communication

At the conclusion of the project, efforts were made to keep the Ambassadors, steering committee, and participating churches apprised of the study's progress. A community newsletter was created to share project findings with the Ambassadors, church participants, and the steering committee. The newsletter provided information about the Ambassadors trained, community members reached via outreach efforts, and key survey findings about cancer, its risk factors, and community participation in research. Each participating church received a plaque expressing the Ambassadors' continued commitment to improving the health of their community. The plaque included the names of the Ambassadors affiliated with each church, and a group photo.

Discussion

The Ambassador training program was one of the first to employ community engagement techniques (i.e., building research capacity, use of an LHA program model, and involvement of community partners at every stage in the research process) to develop and implement a curriculum for PCa LHA training in a rural, economically distressed African American community in North Carolina. The community steering committee helped refine the research agenda and provided essential input on the process from recruitment of participants to be trained as Ambassadors to the implementation of the health survey.

LHA programs for cancer are often considered ideal practices in community cancer health education (Gwede et al., 2013). They mobilize community members to educate their peers rather than relying on outside researchers or clinicians, and they empower the community to address its own health challenges. Use of the LHA model in this project contributed to community research capacity building by training community members to communicate current information on prostate health using a tool kit based on reliable sources of information. The training also allowed the Ambassadors to gain the necessary knowledge and skills to assess the cancer health needs of their community.

Some aspects of the program's format were very successful and should be retained in future programs. For instance, having a 2-day session worked well for Ambassadors because they were able to remember more material than they might have if the sessions were combined into a single day. The 2-day format afforded the opportunity to synthesize the material before learning something new. Furthermore, Ambassadors enjoyed the community-academic partner who facilitated and related to him extraordinarily well. Not only did they feel that this facilitator was interesting and engaging, but also they believed he had credibility in delivering health information based on his history of training community members across the state as Ambassadors. Finally, the partners trained Ambassadors of both genders, as the community believed women play an important role in helping their partners obtain care and make screening and other health care decisions.

The program was not without weaknesses. First, results may not be generalizable to the African American population as a whole. The sample of participants came from one county in North Carolina, and the participants self-selected into the study by applying to become Ambassadors. As such, they may not be representative of their community and of African Americans in the state or country. The knowledge survey taken by the Ambassadors consisted of only 8 questions and was only administered to 15 individuals, and the results may have had a ceiling effect. However, finding an effect on this more diminutive scale suggests evidence for a significant effect on a grander one. The Ambassadors self-nominated to receive training, though the project team did approve them; as such, they might not have been the people who would naturally emerge should the community itself nominate lay helpers. Finally, there are no data for differences in PCa knowledge or prostate-specific antigen screening rates among community members with and without (or before and after) Ambassador contact.

A lesson learned was to keep training sessions as interactive as possible. Participants very much enjoyed the activities throughout the sessions. However, having more regular activities and points of discussion in each training module and taking advantage of more “teach back” sessions would enable the project team to glean greater feedback about how well the Ambassadors were able to comprehend the material presented. Because a number of the Ambassadors had personal experiences with PCa, making the training more interactive might allow the project team to observe how the Ambassadors were able to apply their knowledge to real-life situations. Yet this approach would need to be carefully devised such that those with a personal PCa experience share only information based on factual sources.

Moreover, engaging and building relationships with community champions facilitated the involvement and participation of other community leaders in research efforts and optimized chances for success. The idea for the project came from discussions with the community; PCa was an area they identified as having critical need. Furthermore, the four churches that participated may have done so because of a highly committed steering committee member who was also a full-time pastor and active member of the Baptist Association with ties to those churches. The steering committee itself was instrumental in the project’s success by guiding the research team in developing the instructional material, identifying people who might be interested in participating, and granting their approval for evaluation documents. Also, the fact that the facilitator of the PCa training sessions had ties to the community afforded him credence as a legitimate source of health information and made him relatable to the Ambassadors. Having the Ambassadors, as members of the community, conduct surveys with their peers may have led to the high success rate in the completion of surveys.

Conclusions

The integration of theory with models of intervention and the CBPR approach for engaging community partners, leaders, and stakeholders to educate the community about prostate health is a program that can be replicated in any community or context. Practitioners desiring to implement such a program should consider using an interactive format delivered over multiple days and involving community members of both genders. The community was engaged from the onset of this project such that they assisted in the adaptation of the

intervention for use specifically in their community. By facilitating community engagement throughout the research process, community buy-in was maintained continuously throughout the project, research capacity was built, and the beginnings of community empowerment were witnessed. The sizeable reach by the Ambassadors, over 1,000 individuals, is very encouraging.

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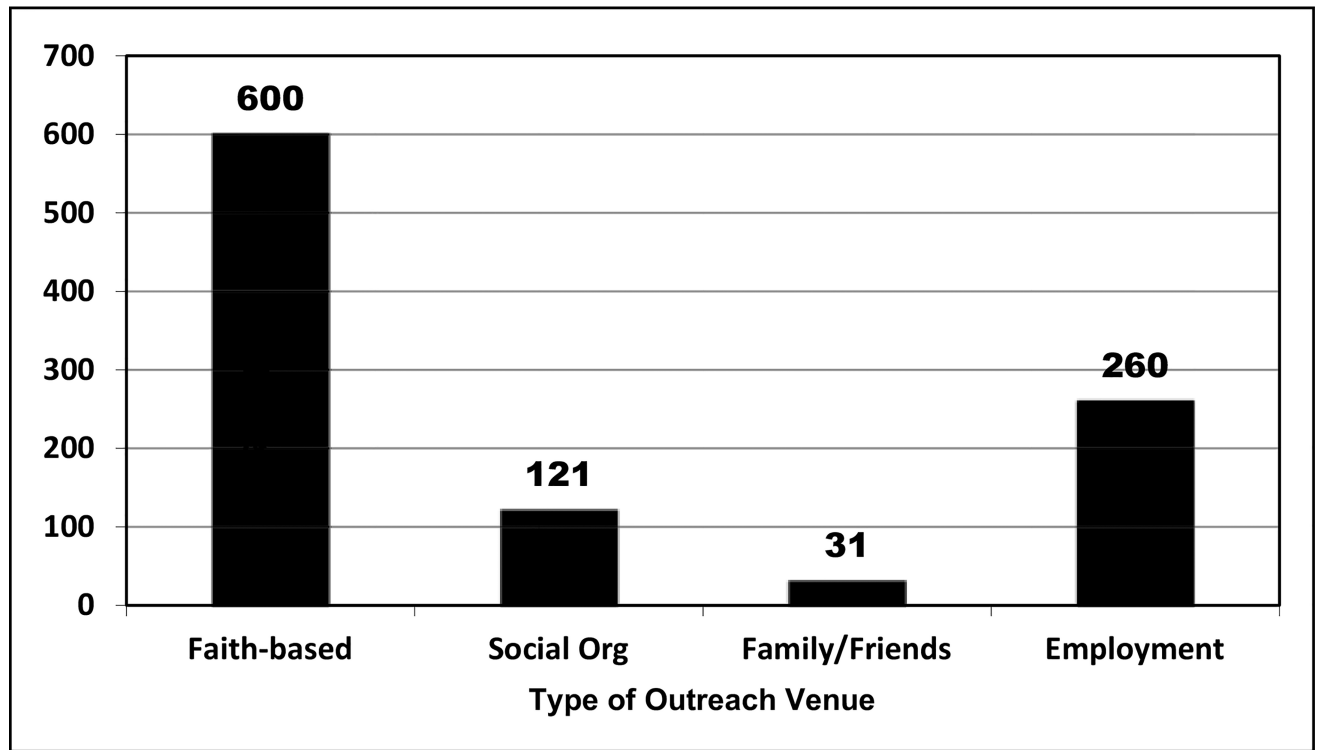


Figure 1.
Number of People Reached by Ambassadors During Educational Outreach

Table 1Demographic Characteristics of the Prostate Cancer Ambassadors ($n = 15$)

Characteristics	No. of Ambassadors (%)
Age range (years)	
48–53	2 (13.3)
54–59	3 (20)
60–65	4 (26.7)
65+	3 (20)
Unknown	3 (20)
Gender	
Female	9 (60)
Male	6 (40)
Education	
High school (or equivalent)	3 (20)
Community college/associate	2 (13.3)
College/undergraduate/graduate	7 (46.7)
Unknown	3 (20)
Employment	
Full-time	4 (26.7)
Part-time	1 (6.7)
Retired	5 (33.3)
Unemployed	2 (13.3)
Unknown	3 (20)
Previous health education training	
Yes	1 (6.6)
No	14 (93.4)

Table 2Knowledge Assessment Among Ambassadors, Pre- and Posttraining ($n = 15$)

Statement Type	% (No.) Correct	
	Pre	Post
1. Prostate cancer Ambassadors are persons to whom individuals go to naturally for information, and they share information in natural settings.	100 (15)	100 (15)
2. African American men are more likely to develop and die from prostate cancer than Caucasian men.	100 (15)	100 (15)
3. A full prostate cancer screening includes both a PSA blood test and a digital rectal exam.	87 (13)	100 (14), Missing (1)
4. The prostate screening test, PSA, stands for prostate-specific antigen.	87 (13)	100 (14), Missing (1)
5. The prostate is a gland located just below the bladder.	86 (12)	100 (14), Missing (1)
6. Cancer is the only disease that can affect the prostate.	79 (11)	87 (13)
7. There are many factors that can increase one's chance of getting prostate cancer.	93 (14)	87 (13)
8. Working with a physician to address common prostate health issues is important in keeping the prostate healthy.	100 (15)	100 (15)

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