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Prostate Cancer Ambassadors: Enhancing a Theory-Informed Training Program for Informed Decision-Making

Anissa I. Vines¹, Jaimie C. Hunter², Veronica A. Carlisle², and Alan N. Richmond³

¹Department of Epidemiology, Gillings School of Global Public Health, The University of North Carolina at Chapel Hill, CB #7435, Chapel Hill, NC 27599, USA

²Lineberger Comprehensive Cancer Center, The University of North Carolina at Chapel Hill, CB #7435, Chapel Hill, NC 27599, USA

³Campus-Community Partnerships for Health, P.O. Box 12124, Raleigh, NC 27605, USA

Abstract

Despite the high burden of prostate cancer in African American communities, there is a paucity of knowledge about prostate health. This paper describes the enhancement of a curriculum for training lay health advisors, called prostate cancer ambassadors, on informed decision-making for prostate cancer screening. Adult learning theory informed the structuring of the training sessions to be interactive, self-directed, and engaging. Trainings were developed in a manner that made the material relevant to the learners and encouraged co-learning. The research team developed strategies, such as using discussions and interactive activities, to help community members weigh the pros and cons of prostate-specific antigen (PSA) screening and to make an informed decision about screening. Furthermore, activities were developed to bolster four social cognitive theory constructs: observational learning, self-efficacy for presenting information to the community and for making an informed decision themselves, collective efficacy for presenting information to the community, and outcome expectations from those presentations. Games, discussions, and debates were included to make learning fun and encourage discovery. Practice sessions and team-building activities were designed to build self-efficacy for sharing information about informed decision-making. Topics added to the original curriculum included updates on prostate cancer screening, informed decision-making for screening, skills for being a lay health advisor, and ethics. This dynamic model and approach to lay health advisor (ambassador) training is flexible: while it was tailored for use with prostate cancer education, it can be adjusted for use with other types of cancer and even other diseases.

Keywords

African American; Prostate cancer; Lay health advisor; Informed decision-making; Social cognitive theory; Adult learning theory

Introduction

In the USA, the incidence rate of prostate cancer is higher for African American men than for Caucasians and African Americans with prostate cancer have more than twice the mortality rate of Caucasians [1]. Research has revealed that the disparity may be driven by a significant lack of knowledge of prostate health factors among African American men [2], especially those with low levels of formal education [3]. This gap in knowledge could impede men's abilities to engage in discussions with their healthcare providers and, ultimately, to make informed decisions about prostate cancer screening.

Researchers have explored the possibility of using lay health advisors (LHAs) to help disseminate information about prostate health to African American men. LHAs are native members of a community who are viewed as natural leaders, caring and good advice-givers, providers of advice in a way that is often spontaneous and informal, and having large social networks over which to share information [4]. They are trained to share health-related information with others in their community. These characteristics are all strengths of LHAs that contribute to their ability to facilitate the transfer of educational information throughout the community.

The feasibility of developing an LHA training curriculum for prostate cancer education has already been demonstrated. Recent research has featured trained lay health advisors, called "barber health advisers" [5, 6]. During regular visits with their clients, the advisers shared information on how to make informed decisions about screening for prostate cancer. Post-encounter client surveys indicated statistically significant improvements in prostate cancer knowledge and likelihood of having a discussion with their doctor about screening [5]. Another study using community-based participatory research (CBPR) strategies successfully trained paid LHAs using a seven-module curriculum over four sessions [7].

Background of the Present Study

The Carolina Community Network for Reducing Cancer Health Disparities at the University of North Carolina at Chapel Hill is a National Cancer Institute-funded health equity center dedicated to eliminating cancer-related disparities among African Americans in North Carolina. During a 2010 needs assessment, the center's community partners identified knowledge of prostate cancer and access to health education resources as significant needs for African Americans in their communities. State statistics underscore the need for an intervention, indicating that deaths from prostate cancer occurred at more than 2.5 times the rate for African Americans (52.5 per 100,000 population) than for Caucasians (18.9 per 100,000 population) [8]. In response, the center worked with two of its community partners to update the "On the Ground Prostate Cancer Ambassadors for Caswell County," an LHA-based prostate health education program [9].

One update to the On the Ground Prostate Cancer Ambassadors curriculum that was necessary was to deemphasize prostate-specific antigen (PSA) screening for prostate cancer. In May of 2012, the US Preventive Services Task Force (USPSTF) recommended against PSA screening for asymptomatic men of any age [10]. The USPSTF's decision was not without controversy; critics noted serious methodological flaws in the studies upon which

the recommendation was built. For instance, the studies were not sufficiently powered for African American men [11]. Owing to this shift in understanding and the uncertainty that continues to surround PSA screening, it was prudent to update the curriculum to include informed decision-making which is “an individual’s overall process of gathering relevant health information from both [a] clinician and from other clinical and nonclinical sources, with or without independent clarification of values” [12] (p. 59).

The goal of this manuscript is to detail the process of enhancing the On the Ground Prostate Cancer Ambassadors program to include informed decision-making in the curriculum using an interactive learning framework guided by social cognitive theory and adult learning theory. Adult learning theorists laud the development of learning activities that meet the styles and needs of adult learners—that is, activities that are interactive, engaging, and self-directed—to promote maximum learning and material retention [13]. This research study was reviewed and approved by the Institutional Review Board at the University of North Carolina at Chapel Hill.

Enhancing the “On the Ground” Curriculum

Overview of Changes to the Curriculum

The original On the Ground Prostate Cancer Ambassadors training program included six units that covered the roles of the ambassador; the milestones in public health regarding prostate cancer and related statistics; prostate health, including the anatomy and physiology of the prostate, screening, and prostate cancer risk factors; treatment of prostate cancer; promotion of prostate cancer awareness in terms of barriers to healthcare, patient privacy, when having conversations about prostate health, and cultural competence; and the provision of prostate cancer resources such as local advocacy programs and support groups. This training, implemented over 2 days, served as a good building block for the current research owing to its base in science and emphasis on interactivity. Since none of the original units focused on informed decision-making, especially in light of the controversy sparked by the USPSTF’s position statement against prostate-specific antigen (PSA) screening for prostate cancer for any man, regardless of age [10], the enhanced version of the curriculum was reorganized and infused with the criteria and steps for making an informed decision about PSA screening.

The USPSTF’s informed decision-making (IDM) guidelines were also used in a toolkit that included a PowerPoint presentation with information about making an informed decision, a wallet-sized informational card outlining the steps of informed decision-making, and a table-top flip chart for use in explaining prostate health, screening, and decision-making information. IDM content was infused in the materials to include information on how to guide community members in assessing their risk for prostate cancer; understanding the risks, benefits, and alternatives to screening; participating in making the decision to be screened; and making a decision that is consistent with their own values and desires [14].

It was also important to optimize interactivity and learning within the modules, given that adults were the targeted training group. To this end, theory-informed, interactive learning strategies were implemented throughout the program to enhance the uptake of information

by the trainees and, ostensibly, bolster their delivery of information to individuals in their respective communities or social networks. Trainers went above and beyond token interactions, such as simply calling on people to participate during class, to develop games, debates, realistic scenarios, and mock presentations for the ambassadors to deliver.

There were other additions to the curriculum. For one, the curriculum acknowledged the role of women in helping their loved ones make decisions about prostate health by making the training material inclusive along with the provision of practical skills training for being a female ambassador. This addition followed a lesson learned from formative work, in which focus group participants identified women as important vehicles for helping convince the men in their lives to go to the doctor and care for their health [15]. The curriculum trained individuals to identify the limitations of PSA screening and then provided them with guidance for speaking with others in their community about the informed decision-making process without pressuring those community members to make a specific or predefined choice. Participants received guidance in setting personal beliefs and values aside to focus on explaining the facts as presented in the training sessions to others. Time was also devoted to explaining the importance of delivering the information with fidelity to avoid potential harm by not introducing personal views or judgments. A final enhancement to the curriculum was the addition of a unit to give trainees hands-on practice with the toolkit that they later received following their completion of the training program.

The approach to enhancing the curriculum was guided by a set of core competencies from the original iteration of the curriculum and the new content, such as mastery of informed decision-making. These *competencies* were grouped and used to define the topic of each unit in the curriculum. For each topic, objectives were developed based on the key skills needed for each trainee/ambassador to be considered competent in the area. Finally, teaching strategies were identified, informed largely by adult learning theory and social cognitive theory, to help the ambassadors solidify their new knowledge.

The final curriculum reflects how topics, objectives, and strategies were integrated to create a cohesive product (Table 1). The goal was to use theory not only to determine how to incorporate informed decision-making for prostate cancer screening into the curriculum but also to guide the delivery of that information using interactive learning strategies to improve self-efficacy for delivering the information and to maximize retention.

Social Cognitive Theory

Social cognitive theory (SCT) [16], which evolved from social learning theory, emphasizes the myriad ways a person learns a specific behavior from others in his or her environment. A key principle of SCT is reciprocal determinism, which recognizes that people interact with their environment, being changed by it, but also exerting their own influence upon it [17]. This paradigm is critical to interactive training sessions because the trainees co-learn with one another and determine the manners in which they are going to influence their own environment when they commence with their outreach efforts. SCT acknowledges the critical relationship between the ambassador trainees and the communities of which they are members and helps make the training relevant and useful through the modeling of delivery strategies. While SCT is usually associated with changes in health behaviors directly, the

present study focused on improving awareness and knowledge that could lead to effective communication of prostate cancer information to others and, ultimately, influence healthcare decisions. This curriculum emphasizes four constructs from social cognitive theory: observational learning, self-efficacy for delivering information and making an informed decision, collective efficacy for delivering information, and social outcome expectations.

Observational learning, often called modeling, describes the acquisition of knowledge to perform a specific behavior through social influences or relationships [17]. The sessions were designed to provide opportunities for modeling, both from trainers and from other ambassador trainees. The study team, which included community partners, modeled the process of giving a presentation and sharing the information and gave the ambassador trainees opportunities to demonstrate the skills for one another and receive feedback.

Self-efficacy is a complex construct that refers to “a person’s beliefs about [his or her] capacity to influence the quality of functioning and the events that affect [his or her] life” [17] (p. 202). *Teach-back* sessions were designed to build self-efficacy for delivering information and educating on how to make an informed decision by helping participants practice new skills. Positive reinforcement was also used to boost self-efficacy.

To develop *collective efficacy*—that is, beliefs about the group’s collective ability to act as prostate cancer ambassadors [17]—trainers helped participants construct plans to support one another in their community. Options shared included guiding the trainees in giving group presentations and working in *tag teams* in which partners or group members presented complementary information so that everyone got to present the material with which they felt most comfortable. Formative work indicated that the option of group/partnered delivery of information was preferable to individual presentation, as each partner or member of the group had his or her own strengths.

Outcome expectations refer to consequences, both good and bad, that the participant expects to occur if he or she performs the behavior [17]. In the present study, it was expected that the dynamicity and interactivity of the class would improve self-confidence and, thus, improve outcome expectations for presenting the information in the community. For example, hearing success stories from others who work in the community was expected to improve outcome expectations. Thus, activities such as group discussions, debates, and mock presentations were designed to boost engagement and help participants feel confident about the material, which is also a key component of adult learning theory.

Adult Learning Theory

In addition to SCT, principles of adult learning theory (ALT) [13] were used to enhance the implementation of the prostate cancer curriculum. ALT respects the unique, multimodal learning needs that adults have. ALT posits that people learn best when the material is relevant to them [13]. Hence, following the advice of community partners, local- and state-level prostate cancer statistics were included in the lessons to make them more relevant to African Americans living in North Carolina. For all units, more graphics and charts were added to facilitate interaction during the presentation and to make the data more user-friendly. The anatomy of the prostate and other *academic* lessons were interactive and

engaging, weaving opportunities for experiential learning into the curriculum, as indicated by ALT. Many opportunities for interaction emerged, including games and debates to engage the participants with the material more fully. To maximize comprehension and recall, there were frequent reviews of the content; some of these occurred in a fun *pop quiz* format in which trainees answered questions in teams. Current misconceptions about prostate cancer and its diagnosis and treatment were addressed through the provision of opportunities for trainees to share their prior knowledge.

The length of delivery of the curriculum was maintained to occur ideally over 2 days with a total time of 12 hours.

Assessment

Questionnaires were developed to assess knowledge acquisition and changes in SCT constructs. Knowledge was assessed with 25 true/false pre-/post-session questions based on the learning objectives underlying the curriculum (Table 1). Outcome expectations were assessed through Likert scale items that queried what people felt their experiences would be like as an ambassador delivering the information one-on-one or in a small audience presentation (7 items) and personal changes and feelings that they expected to experience from their work as ambassadors (5 items).

Self-efficacy for information delivery and making an informed decision was worded as *confidence* for simplicity, despite the fact that the two constructs are distinct. As noted by Bandura [18], confidence considers the strength of a belief but, unlike self-efficacy, does not indicate what the targeted behavior or object of that confidence is (i.e., “self-efficacy for talking to my doctor about my prostate health”). To address self-efficacy, then, one must assess both what a person believes he or she can do and how strong that belief is [18]. To assess the strength of self-efficacy in several dimensions of making an informed decision (or, for women, helping a loved one make an informed decision) and performing outreach work, responses to the 12 items were rated on a scale of 0 to 2, where 2 is the highest. Collective efficacy for delivering prostate health information was measured in a similar manner but with emphasis placed on anticipated group performance.

Discussion

The On the Ground training curriculum was enhanced to be engaging and interactive and gave trainees ample opportunities to co-learn and practice their new skills. The ability of the study team to leverage support from its community partners to assist in identifying strategies for trainees to use in approaching community members and working with other ambassadors to give presentations is a strength of the program. This support meant that someone who knew the communities intimately could ensure that the values and standards of the community were upheld in the trainings. Further, the original On the Ground curriculum was developed with a community advisory board and the details of that process have been described elsewhere [9].

While lay health advisor’s initiatives are not new or innovative, the way in which this curriculum was developed is different from others in the literature. The curriculum is among

the first to incorporate skills for men and women to teach others informed decision-making for prostate cancer screening using an LHA training model. A point of pride was the use of two well-respected theories to inform the enhancements to the training curriculum. The SCT and ALT were used throughout the process. Recognizing the role of women was an important contribution to the curriculum since they are viewed as key conduits for getting information to their husbands and other family members [15]. Further, the team provided the ambassadors with a multimodal toolkit containing teaching tools that are appropriate for different types of presentations: a wallet card for one-on-one conversations, a table-top flip chart for small group discussions, and a set of slides for larger presentations.

The process for developing an informed decision-making-enriched curriculum has significant implications for cancer education. Our model of using theory to inform the modification of an LHA program for prostate health holds promise for maximizing topic-related educational attainment for the trainees. This model is readily modifiable such that it can be applied in other contexts, with other diseases, or populations and would be especially germane for other cancers for which screening may be controversial. In the end, the enhanced On the Ground Prostate Cancer Ambassadors curriculum is a helpful tool for bringing cancer education to the community and it relies on strong teaching/learning principles and builds self-efficacy for informed decision-making.

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Table 1

On the Ground Prostate Cancer Ambassador training curriculum enhanced with informed decision-making

Unit no.	Topic	Objectives	Teaching and learning strategies		
1	Introduction to the lay health advisor (LHA) model	1	Describe the role of a prostate cancer ambassador (LHA)	1	Trainees share their own stories of times when they worked to address health with their community.
		2	Explicate the benefits of using the LHA model to share information about health with the community	2	Trainees discuss what they already know about prostate cancer.
				3	Trainers lead group discussion about what the role and benefits of the LHA model are.
				4	Trainees complete a “pop quiz” about LHA roles
2	Prostate cancer statistical trends and incidence	1	Identify the top causes of death in the state and state where prostate cancer (PCa) falls	1	Trainees rank top 5 causes of death among African American men and compare their ideas against trainers’ presentation.
		2	Present incidence, prevalence, and mortality data for PCa	2	Trainers present updated statistics, making them relevant to the trainees by making them specific to age, place, and race.
		3	Discuss the increased risk of PCa for African American men		
		4	Define “disparity” and describe how it relates to the topic of PCa	3	Trainees discuss determinants of racial health disparities in PCa and other conditions and relate them to their own knowledge and experiences
3	Biology of the prostate	1	Describe the prostate’s anatomy	1	Trainees work through “teach-back” problems in which they present information back to the trainers and the larger group to demonstrate mastery and confidence.
		2	State the function of the prostate		
		3	Explain 3 conditions that can affect prostate functioning	2	Trainees play games to help solidify understanding of difficult concepts.
		4	Detail PCa origins and staging	3	Trainees discuss current knowledge and myths about PCa
4	PCa treatment and risk reduction	1	Describe treatments for prostate cancer, including prostatectomy, radiation, chemotherapy, immunotherapy, and cryotherapy	1	Trainees problem-solve challenging scenarios and “what-if”s with their team members.
		2	Present health behaviors that may reduce cancer risk	2	Trainees present information about treatment during teach-back session.
		3	Discuss prognosis for PCa	3	Trainees practice “how-to” start a conversation about PCa with someone in the community
5	Screening for PCa	1	Define “screening” and describe why it is done	1	Trainees share what they already know about PSA testing, including the controversy surrounding it.
		2	Present some pros and cons of screening for PCa	2	Trainees divide into two teams and debate controversial PCa topics.
		3	State the US Preventive Services Task Force (USPSTF)’s recommendation about prostate-specific antigen (PSA) screening	3	Trainees work in teams to present a list of the pros and cons of PCa screening.
		4	Describe reasons for dissenting opinions stemming from the USPSTF’s recommendation	4	Trainees practice ways to encourage informed decision-making (things they could say, what encouragement would “look like,” conversation starters)

Unit no.	Topic	Objectives	Teaching and learning strategies
		5	Outline the steps for informed decision-making
6	Practical skills for being an ambassador	1	Describe some skills that all LHAs should have
		2	Explain ways in which ethics are important when working as an LHA
			1 Trainees identify and describe additional skills they think will be needed to be successful as an ambassador.
			2 Trainees and trainers openly discuss implications of not working ethically to deliver PCa information.
			3 Trainees choose the best ways to approach different challenging scenarios
7	Toolkit practice	1	Reiterate the goals of the project, especially the fact that the overall goal is to present information to the community so that members can make decisions appropriate for them
		2	Demonstrate ways to use the tools and information contained in the toolkit
			1 Trainers give mock presentation in front of trainees and ask them to critique their delivery of the information.
			2 Trainers divide into teams and practice giving presentations to one another and to the larger group, obtaining feedback along the way.
			3 Trainees identify and list general presentation "turn-offs," such as not making eye contact
8	Healthcare utilization and the role of women	1	Identify and describe some barriers that can keep African American men from going to the doctor
		2	Explain the role of LHAs in helping overcome barriers
			1 Trainees list barriers to prostate health that they think are most critical for African American men.
			2 Trainees problem-solve scenarios in which someone may not want to go to the doctor to get his prostate checked and provide some ideas for how (or when) to intervene.
			3 Trainers challenge the trainees to think of ways in which women (e.g., wife) can be involved in prostate health
9	Project logistics	1	Outline plan for reaching community members with the LHAs' message
		2	Identify ways in which LHAs can work together to support each other
		3	Describe how to document and report contacts with community members
			1 Trainees set goals for their LHA work.
			2 Trainees network with one another to identify potential partners and plan their approach for outreach.
			3 Trainers encourage trainees to work together as needed.
			4 Trainers review project forms and explain the purpose of documentation as well as how to do complete them