

# Prostate Cancer Survivors as Community Health Educators: Implications for Informed Decision Making and Cancer Communication

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**Abstract** Recent evidence questioning the effectiveness of prostate-specific antigen testing leave community-based prostate cancer (CaP) outreach programs with a dilemma between promoting screening and highlighting screening risks. CaP survivors are uniquely positioned to address this problem by drawing upon real-life experiences to share nuanced information and perspectives. While CaP survivors have historically been incorporated into outreach programs, little is known about their impact on psychosocial outcomes and their effectiveness compared to professional health educators. This study addressed these gaps through a quasi-experimental design where African American men attended a CaP screening session conducted by a health educator (HE) or survivor educator (SV). The presentation included prostate cancer statistics, CaP information, and descriptions of CaP screening tests. SV were encouraged to bolster their presentations with personal stories whereas HE maintained fidelity to the curriculum content. All participants completed pre- and post-test questionnaires. Our sample comprised a total of 63 participants (HE group=32; SV group=31) with an age range of 40–70 years. Decision

self-efficacy increased significantly in the SV group ( $p=0.01$ ) whereas perceived screening risks reduced significantly in the HE group ( $p<0.001$ ). No significant changes were found in knowledge, subjective norms, outcome expectancies, and screening benefits. Survivor educators were found to have significantly greater appeal ( $p=0.03$ ), identification with audience ( $p=0.01$ ), and liking ( $p=0.03$ ). Training CaP survivors as health educators might be a viable strategy for community-based cancer communication efforts confronted by the CaP screening controversy. We discuss conceptual and programmatic implications of our findings and present directions for future research.

**Keywords** Prostate cancer · Screening · Survivors · Communication · CBPR

## Background

Prostate cancer (CaP) remains the most frequently diagnosed cancer and the second leading cause of cancer deaths in men; in its latest report, the American Cancer Society (ACS) [2] has estimated 241,720 cases and 28,170 deaths due to CaP in 2012. For reasons still undetermined, African American (AA) men continue to be disproportionately affected by CaP, accounting for the highest mortality rate of any racial or ethnic group in the USA (54.2 per 100,000) and 2.4 times the mortality rate for white men [1].

Prostate cancer prevention through community education, however, is a tricky proposition as randomized trials have found no benefit for annual primary screening using the prostate-specific antigen (PSA) test [3]. Consequently, medical and community organizations are locked in a controversy regarding screening promotion. On the one hand, organizations like the US Preventive Services Task Force take caution from scientific evidence to recommend that patients make an informed decision about screening after weighing risks and

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benefits with their physicians [9]. In contrast, community organizations prefer straightforward screening promotion as it reaches more audiences and contributes to cancer prevention [28]. Their reluctance to adopt the informed decision making (IDM) frame is premised on the fact that the contradictory evidence might add ambivalence to the screening choices of men at risk. Consequently, this debate has affected community outreach programs that are caught in a dilemma between promoting screening to prevent cancer or heeding medical experts and policymakers to prevent possible unnecessary treatment.

Cancer survivors as health educators: many community-based prostate cancer interventions have utilized trained health educators to create awareness about CaP, risk factors, screening, diagnosis and treatment, and to promote informed decision making [6, 26]. However, the PSA debate has infused uncertainties into the community health education sphere that is now grappling with the need for new strategies to effectively communicate complicated issues (such as screening risks) in an already fraught topic. A 2009 St. Louis, Missouri study [27] conducted to identify opportunities for improving CaP communication in African American communities found evidence suggesting the potential for CaP survivors to enhance the success of educational outreach programs. Survivors were perceived as credible and compelling sources of information that could be readily accepted and understood by groups of people. Survivor discussions got the full attention of participants, fostered sharing of information and stories from the participants, and allowed the participants to ask questions during and after the discussions about prostate cancer symptoms, risk factors, and treatment options. A discussion participant said, “*It reinforces the need for men to talk more openly about this problem.*”

These findings corroborated past successes of cancer survivors as educators providing information and support in the prevention and early diagnosis of cancer. Among the foremost proponents of incorporating cancer survivors in health education programs was Kaur [17] who, after studying cancer issues among Native American communities noted that “Cancer survivors...can be invaluable resources to educate others, raise cancer awareness, and most importantly prove that cancer is not always fatal”. Historically, studies have suggested that survivors can successfully mobilize participation by being the main source of initial information about the program, and can enhance programs with their ability to “share stories” [10]. Face-to-face interactions with healthy male prostate cancer survivor role models normalize the cancer experience and alleviate the feeling of isolation [25]. Involvement by prostate cancer survivors in the process of designing intervention content has proven productive in increasing knowledge and self-efficacy levels among participants [5]. The word “survivor” itself is perceived as positive—a perception that can only

facilitate the internalizing of survivor educators’ optimistic attitude and affirmative advice [15].

Studies have also documented the role of survivors in outreach and their cognitive and social benefits in the case of other cancers and among different populations. For instance, a breast and cervical cancer education project initiated by the Southwest Oncology Group found that Hispanic cancer survivors can not only be trained as health educators, but information provided by them can successfully prompt women to adopt screening tests such as mammography and pap smears [14]. Among Native Americans, cancer survivors have contributed to the content and design of culturally relevant educational materials, and offered crucial insights into quality-of-life issues that inform programmatic work [7]. The internationally known Promotora programs have shown the effectiveness of incorporating survivors along with culturally sensitive materials as they create awareness while sharing their everyday life experiences with family, friends, and community members [13, 18]. Recent examples of survivors being used in health education and advocacy include the National Coalition for Cancer Survivorship (<http://www.canceradvocacy.org/resources/>), the ACS’s Man-to-Man program (<http://www.cancer.org/Treatment/SupportProgramsServices/MantoMan/index>), and the LUNgevity Foundation (<http://www.lungevity.org>). A critical differentiator between cancer survivors and health educators lies in the ability of the former to narrate personal life stories about their cancer journeys. Communication scientists have used narrative theory to shed light on how storytelling by prostate cancer [4] and breast cancer survivors [19] can provide unique insights into their management of stress and family relationships during the cancer experience.

Despite these disparate bodies of evidence, surprisingly, little is known about the exact nature and extent of survivors’ contributions to knowledge and decision making about CaP screening, diagnosis, and treatment. Though survivors have been incorporated into cancer outreach programs for years—the ACS’s Reach to Recovery started in 1952 [24]—the examination of their precise impact and strengths are rare [29]. In addition, programmatic support of survivors in CaP outreach is ad hoc, and further research is required to better understand how to systematically make the most of survivors’ experience in an educational setting, for maximum impact, at reasonable cost. There is a need to assess how survivors’ experience with screening, diagnostic and treatment decisions may inform community-based decision support programs.

*Study Aims* Our study set out to examine whether CaP survivors are indeed more effective communicators of screening-related messages as compared to trained, professional health educators in a community setting catering to AA men. Specifically, our research was guided by two overarching research questions:

RQ1: Which type of presenter—health educator (HE) or survivor educator (SV)—enhances knowledge, beliefs, and screening intention related to prostate cancer, to a greater extent?

RQ2: Which type of presenter—health educator or survivor educator—has better appeal among African American men?

## Methodology

We employed a quasi-experimental pre-test–post-test approach to study the comparative effects of health educators (HE) and survivor educators (SV) on knowledge, beliefs, intention to screen, and presenter appeal. Survivor and health educators were affiliated with collaborating community organizations, including both health departments and health advocacy organizations that were already involved in CaP outreach education. All educators (HE and SV) were African American. Survivor educators were male and middle aged; health educators were younger and both male and female.

*Conceptual Framework* Two theoretical approaches—from behavioral science and communication—informed the study. The Integrative Model of Behavioral Prediction [12] suggests that intentions (readiness to engage) are the best predictors of performing a particular behavior. The model assumes three determinants of intentions, namely attitudes (attitude towards performing the behavior in question); norms (the amount of social pressure one feels vis-à-vis the behavior); and self-efficacy (one's sense of personal agency with respect to performing the behavior). Attitudes are shaped by beliefs about the behavior and a psychological evaluation of its outcomes; norms, influenced by perceptions about what the majority feel about an issue, and what is usually done; and self-efficacy is shaped by beliefs about one's control and power to perform a certain behavior.

To examine the differential effects of survivors, educators on attitudes, norms, and self-efficacy, we use the narrative communication framework for cancer prevention [20]. According to this framework, narrative communication uses a “representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit or explicit messages about the topic being addressed.” In contrast, non-narrative communication includes “expository and didactic styles of communication in the form of reasons and evidence supporting a claim.” We examine the effects of each presenter type (survivors vs. health educators) by focusing on specific characteristics of their communication styles. For example, whether the audience identifies with the speaker, the level of engagement he generates, and ability to effectively communicate the subject matter.

*Measures* Demographic variables included age, education, marital status, employment status, insurance coverage, income, and screening history. Knowledge [adapted from [23]] was captured using a 7-item scale with statements such as “If you have an abnormal PSA test, your doctor may recommend that you have a biopsy.” Decision self-efficacy [adapted from [16]], operationalized as an individual's confidence to make an informed decision about screening, was measured using a 4-item scale comprising statements such as: “I have enough information about prostate cancer.” Subjective norms were measured using a 2-item scale with statements such as “My family expects me to get screened for prostate cancer.” Outcome expectancies, explained as beliefs about the results of performing a certain behavior, were measured using a 3-item scale with statements such as: “Getting a prostate-specific antigen (PSA) test done early is essential to prevent the risk of getting prostate cancer.”

In light of the debate surrounding the PSA test and IDM, we measured the effects of presenter type on perceived benefits and barriers related to screening. Screening benefits were measured using a 2-item scale with statements such as: “Getting screened for prostate cancer will give me the information I need to make my own health decisions.” Screening risks and barriers were measured using a 4-item scale and comprised statements such as: “I don't know if I can handle knowing I have cancer.”

The post-test questionnaire was identical to the pre-test questionnaire with the exception that it comprised additional questions related to presenter's attributes and presentation skills. The presenters' narrative appeal was measured through a composite 15-item 5-point Likert scale (Chronbach's  $\alpha = 0.86$ ) comprising a variety of constructs; Perceived expertise of the presenter (command over subject), trust in the presenter, identification with the presenter, ease of understanding (how easy it was to comprehend the educators' presentation), and negative reactions elicited by the presenter [19, 21]. Pre- and post-test questionnaires are available on request.

*Analysis* We measured reliability of psychosocial scales using Chronbach's  $\alpha$ : knowledge ( $\alpha = 0.78$ ), subjective norms ( $\alpha = 0.79$ ), benefits ( $\alpha = 0.81$ ), risks and barriers ( $\alpha = 0.81$ ), and decision self-efficacy ( $\alpha = 0.62$ ). Knowledge scores were computed by recoding incorrect and don't know as 0 and correct as 1, followed by summing the scores for all the items. We tested for equivalence between respondents in the HE group and the SV group using chi-squares. We compared mean pre–post scores for participants in both groups using paired sample *t* tests. We compared the perceived appropriateness and appeal of the presenter between the two groups using one-way ANOVA. Data were analyzed using SPSS version 17.

*Participant Profile* Participants in both HE and SV groups were comparable across all demographic characteristics and prostate cancer history. Overall, our sample comprised 63

participants (HE group=32, SV group=31). Participants were between 40 and 70 years old. One half of the participants in the SV group (50 %) received high school education in contrast to the HE group where about half (46.9 %) were college educated. An equal number of participants in both groups were married (18) and employed (20) in either fulltime, part-time, or freelance jobs. Nearly a third of participants from both groups (HV=34.4 %, SV=34.5 %) belonged to the \$20,000–40,000 income bracket and about half (HV=59.4 %, SV=48.4 %) were covered by employee insurance. A majority of the participants across both groups (HE=81.2 %, SV=72.4 %) did not report a family history of prostate cancer.

## Procedure

*Sample Recruitment* AA men and presenters were recruited at outreach events organized by collaborating partners in community settings such as health fairs in local churches. We arranged sessions with HE or SV in a manner that would enable an equal number of AA men to be exposed to each presenter type. All participants received study incentives in the form of \$10. The Institutional Review Board at a Mid-western US university approved the study.

*Intervention* Small groups of African American men attended a talk presented by either a health educator or a cancer survivor. The presentations lasted between 15 and 30 min and included topics such as prostate cancer statistics, information about prostate cancer, benefits and risks of screening tests, and a Q&A session (detailed outline available in Appendix 3). The presenters used either a flipchart or a PowerPoint slideshow depending on the size of the audience. Survivor educators were encouraged to bolster their presentations with personal stories, anecdotes, and insights from their experiences with screening and diagnosis and dealing with emotional and psychological issues. Health educators maintained fidelity to the curriculum content. The primary aim of the curriculum was to improve knowledge about prostate cancer and to increase self-efficacy to make an informed decision about CaP screening. Participants completed pre- and post-test questionnaires before and after the presentation respectively.

## Findings

### *Knowledge Beliefs and Intention to Screen (Table 1)*

We observed increments in knowledge, subjective norms, and outcome expectancies across both groups but these shifts were not statistically significant at the  $p < 0.05$  level. Decision

self-efficacy enhanced significantly in the SV group, but only marginally in the HE group.

Positive perceptions about screening benefits were enhanced among participants in the HE group, but dropped among those in the SV group. Perceptions about screening risks and barriers reduced across both groups, but the shift in the HE group was statistically significant. We observed marginal increases across both groups for the dichotomous (yes/no) variable capturing screening intention at pre-test and received a universal yes response at post-test.

### *Feedback on Presenter Type (Table 2)*

While appeal for both survivor and health educators was high, participants in the SV group found their presenter significantly more appealing, identifiable, and likeable as opposed to their counterparts in the HE group. In terms of being perceived as experts, and bearing a similarity to the audience, the survivor educators were rated more highly than the health educators with the differences approaching statistical significance. Survivor educators were also found to be more trustworthy, and more engaged with the audience.

## Discussion

As the prostate cancer screening debate rages on among medical researchers and policymakers, the prevention community finds itself stuck between a rock and a hard place in terms of creating educational strategies that can best communicate this conundrum to the general public. The importance of our study in this scenario is that it examines one such strategy—prostate cancer survivors as educators—that has been previously employed, but whose efficacy has seldom been systematically evaluated.

Overall, our results offer new insights for cancer educators and points for deliberation among the community-based participatory research (CBPR) community. Our analysis of change in psychosocial factors related to cancer screening demonstrated that by and large, the magnitude of change (captured in the columns titled “Diff”) in the intended direction was greater among the survivor educator group than the health educator group. The uniqueness arose from two statistically significant findings. One, both types of educators successfully reduced perceptions about screening risks and barriers but the reduction was more pronounced among the health educator group. Consistent with results from our previous study, this suggests that health educators might be advocating or promoting screening by addressing its barriers more persuasively or emphatically as opposed to survivor educators. The corollary to this finding is that survivors possibly promote screening by downplaying risks and barriers, as a result of

**Table 1** Comparison of psychosocial variables by presenter type

Variables	Health educator group (N=32)			Survivor educator group (N=31)		
	Pre	Post	Diff	Pre	Post	Diff
Knowledge (max score 7)	4.10	4.30	0.20	4.55	4.83	0.28
Beliefs (max score 5)						
Subjective norms	4.26	4.38	0.12	4.28	4.34	0.06
Decision self-efficacy	3.33	3.52	0.19	3.44	3.75	0.31*
Outcome expectancies	4.39	4.40	0.01	4.30	4.41	0.11
Screening benefits	4.23	4.32	0.09	4.36	4.31	-0.05
Screening risks and barriers	2.54	2.22	-0.32*	2.49	2.28	-0.21
Intention to screen						
Yes/no	0.96	1.00	0.04	0.97	1.00	0.03

Paired *t* tests used to examine mean differences

\*Significance at *p* < 0.05 level

their positive life experience (of surviving cancer) where screening has indeed been beneficial. This may be a cause for concern given the controversy about screening.

Two, we found that decision self-efficacy increased significantly among the survivor group but only marginally among the health educator group. When considered, in light of changes in other variables, these findings suggest that survivor educators might be providing a realistic, balanced perspective on the screening issue by enhancing knowledge, communicating benefits and barriers, and resulting, most importantly, in an increased confidence among men to make informed decisions on their own. Discussion of intention to screen merits less attention because of the ceiling effect whereby participants already reported high intention to screen at baseline.

The results for presenter appeal were unanimous in favor of survivor educators. These findings may be attributed to the ability of survivors to connect on an emotional level with the audience by narrating their life experiences and emboldening them with personal perspectives on issues beyond just the

mechanics of screening. These include communicating with one’s family, managing gender identity, and emotional coping. In sum, survivors are able to introduce personal experiences to the CaP screening discussion and the dilemma facing African American men, thereby enhancing their reception as educators in community settings. The generalizability of our findings is limited by our sample size, a drawback that is common to studies recruiting African American men from under-resourced settings [11]. Consistent with Darcy et al.’s recommendation to mitigate this issue, we employed a CBPR approach by collaborating with a local community-based prostate cancer advocacy group to recruit educators and participants, and manage the logistics of the study. We suggest, however, that future studies examine the efficacy of survivor educators on larger samples and preferably with a randomized sample that might ensure greater representativeness and generalizability.

This study has implications for conceptual and programmatic challenges confronting prostate cancer prevention efforts. From a conceptual standpoint, in light of the controversy about CaP screening, professional associations have argued for an IDM approach that equally communicates screening benefits and risks and places the onus upon the individual to make a decision based on such information. This approach has received limited buy-in from community-based organizations for whom equivocation about screening recommendations is seen as a confusing and complicated message to impart to community members. It is imperative that community-based agencies train survivor educators adequately before conducting educational sessions, as care should be taken to ensure accurate presentation of scientific details about risks of screening, biopsy, and treatment for CaP. Properly trained survivor educators might provide a viable solution, as they can draw upon their life stories to tread this conceptual tightrope and successfully communicate the desired message.

The programmatic challenge pertains to the recruitment and management of cancer survivors in community-based programs. In our experience, this process can be as inspiring

**Table 2** Comparison of feedback on presenter appeal and narrative power

Feedback (max score 5)	N=63			
	Health educator	Survivor	<i>F</i>	<i>p</i> Value
Appeal	3.61	3.88	5.03	0.03*
Expertise	4.23	4.48	2.90	0.09
Trust	4.18	4.40	2.53	0.12
Identification	3.68	4.19	6.86	0.01*
Liking	3.98	4.34	5.21	0.03*
Similarity	3.26	3.55	3.07	0.09
Ease of understanding	2.04	2.07	0.02	0.89
Engagement with audience	4.07	4.34	1.81	0.18
Negative reaction	1.93	1.90	0.02	0.89

\*Significance at *p* < 0.05 level

One-way ANOVA used to examine mean differences

as it can be sensitive. Some cancer survivors draw strength from their life experience and might find it an empowering experience to be able to share their story with others [22]. For others, it is possible that repeatedly narrating their real stories compels them to revisit unpleasant memories, causing emotional and psychological distress as has been reported previously [8]. A potential strategy to preempt undesired effects might lie in designing recruitment programs that strengthen existing social support structures for survivors and continue their process of rehabilitation. Formalized incentive schemes, monetary or otherwise, might also help in promoting and institutionalizing this educational strategy among survivors of not just prostate cancer, but also other cancer types such as breast and cervical.

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