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Implementing Community-based Prostate Cancer Education in Rural South Carolina: A Collaborative Approach through a Statewide Cancer Alliance

Catherine Troy^{1,2,3}, Ashley Brunson^{1,3}, Andrew Goldsmith^{2,3}, Samuel Noblet^{3,4}, Susan E. Steck^{4,5}, James R. Hebert^{4,5}, Johnny Payne⁶, Doug McCormick⁷, Daniela B. Friedman^{3,4}

¹College of Arts and Sciences, University of South Carolina, 1521 Greene Street, Columbia SC, 29208

²South Carolina Honors College, University of South Carolina, 1215 Blossom Street, Columbia SC, 29208

³Department of Health Promotion, Education, and Behavior, University of South Carolina, Arnold School of Public Health, 915 Greene Street, Columbia SC, 29208

⁴Statewide Cancer Prevention and Control Program, University of South Carolina, 915 Greene Street, Columbia SC, 29208

⁵Department of Epidemiology & Biostatistics, University of South Carolina, Arnold School of Public Health, 915 Greene Street, Columbia SC, 29208

⁶Upstate Prostate Cancer Alliance, 412 Perry Hill Road, Easley SC, 29640

⁷AID Upstate, 811 Pendleton Street, Suite 10, Greenville SC, 29601

Abstract

The purpose of this study was to evaluate the impact of implementing community-based prostate health education programs in rural communities. Prostate cancer (PrCA) remains one of the most common cancers among men, and a growing body of literature demonstrates that large interracial differences in PrCA incidence and mortality rates consistently disfavor African Americans in comparison to European Americans. It also is evident despite the overall decrease in cancer death rates in the United States in recent decades, rural areas are experiencing a reduction in death rates much more slowly. In this study, education session content focused on PrCA risk factors, symptoms, screening, healthy diet and exercise, treatment options, and provider communication strategies. Forty individuals participated and completed pre/post-education program surveys to assess changes in PrCA knowledge and cancer decision making. Participants showed improvements in education and awareness following the session and overall impressions of the program were consistently positive as exhibited by participants' answers on a satisfaction survey.

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Corresponding author: Daniela B. Friedman, PhD - dbfriedman@sc.edu; 803.576.5815.

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The findings demonstrate the real need both in terms of research to understand the underlying problem and to provide practical solutions that can be implemented to reverse the current situation. The results obtained support community-based education programs as an effective means of delivering PrCA prevention, screening, and treatment information to rural communities.

Keywords

community-based cancer education; rural communities; prostate cancer; prevention; train-the-trainer

Introduction

Prostate cancer (PrCA), one of the most common cancers among men, accounts for approximately 20% of all male cancer cases in the United States, and the risk for developing PrCA increases with age [1–3]. Nationally, PrCA incidence in African-American (AA) men is about 50% higher than in European-American (EA) men [4], and the differential is larger in South Carolina, with incidence approximately 80% higher [5]. Not only are incidence rates higher than in EAs, but the disease tends to be much more virulent in AAs, resulting in a mortality rate that is about two times higher than in EAs, with a differential that is even more extreme in South Carolina than for the United States as a whole [6]. Reasons for these disparities may be the result of differences in social, environmental, lifestyle, and genetic factors [6]. Despite the overall decrease in cancer death rates in the United States in recent decades, rural areas are experiencing a reduction in death rates much more slowly than in urban areas. Recent data from the Centers for Disease Control and Prevention demonstrate that rural America has a current cancer mortality decrease of 1.0% per year, while urban America has experienced a decrease of 1.6% per year [7]. Death rates remain higher in rural areas as there continues to be ethnic, racial, and socioeconomic disparities in cancer outcomes [8]. Rural communities face disadvantages, including higher poverty rates, lower educational attainment, and lack of access to health services, which lead to higher incidence and mortality rates for individuals and communities in these areas [9].

Limited education about PrCA serves as a barrier to effective cancer prevention and control [10]. Education programs can significantly increase prostate health knowledge among AA men [11–13]. Efficacious dissemination of information pertaining to PrCA via rural community-based education programs serves as a promising strategy for promoting early detection and treatment of cancer [14–16]. Education programs can promote primary prevention through healthy lifestyles as well as active engagement in secondary prevention such as early screening that can lead to earlier diagnosis and more effective treatment [15, 17]. The National Cancer Institute suggests that community-based and interpersonal communication channels that permit open discussion, may elicit more support and motivation than alternative forms of communication, and are the most effective strategy for educating communities about cancer [18]. Community-tailored programs can increase the investment of rural community members which in turn increases the efficacy of the prevention and control measures [19].

Over the past eight years, we have engaged with community partners, stakeholder organizations, and the statewide cancer alliance to develop collaboratively an evidence-based prostate cancer educational curriculum for AA communities across urban and rural counties. Holding focus groups and forums with AA men and family members (partners and younger male relatives) [20–23], pilot testing the curriculum [12, 13], conducting interviews/surveys with community partners and providers [11, 24], reviewing existing prostate cancer material and resources [25–27], and evaluating in-person and videoconference implementation of the program [12, 13, 28, 29] have all contributed to the development and continued refinement of our curriculum. This multi-faceted approach to our curriculum development is guided by principles of health and cancer communication [30, 31] that stress ongoing and rigorous evaluation of program messaging and co-creation of community-based recruitment strategies and programming [29, 32]. This paper describes the community-based offering we conducted specifically within rural counties in South Carolina.

Methods

AA men (and their partners/relatives) were recruited for a PrCA education program using flyers, radio and newspaper advertisements, professional listservs, and word-of-mouth. Forty-one individuals participated in one of three education sessions offered in three counties of the state (Barnwell, Darlington, and Florence counties). The education program has been continually updated and refined over time based on attendees' evaluations, review of existing materials and programs, and the state of the science. The current iteration of the program is overseen by the Prostate Cancer Workgroup of the South Carolina Cancer Alliance. Workgroup members include university researchers, community members, PrCA survivors, and clinicians. Content consists of evidence-based information reviewed and piloted in focus-group research with AA men and women [4, 13, 21] and with workgroup members. Education topics include: What is the prostate?, PrCA risk factors and symptoms, PrCA screening guidelines, healthy eating and physical activity guidelines, and tips for how to communicate effectively with providers about prostate symptoms and cancer. The education session is administered by multiple workgroup members. Presenters are a PrCA survivor (JP), registered dietitian (SES), physical activity experts (DM, SN), and cancer communication researcher (DBF). The education session lasted approximately 1 to 1.25 hours, with another 0.5 to 0.75 hours for a panel discussion and question and answer session with the participants and a local primary care provider.

Prior to and following the education sessions, participants were asked to complete a survey to assess changes in PrCA knowledge and cancer decision making. The survey consisted of 19 knowledge questions, 9 healthcare/cancer decision-making questions, and 11 demographic questions. All questions were close ended with response options on a Likert scale. Participants also completed a satisfaction survey following the education program which consisted of five questions - 3 close-ended and 2 open-ended examining participants' ratings of the session speakers and content as well as their plans as a result of participating in the education session (e.g., speak with their doctor, get screened for PrCA, etc.). Participants received a monetary incentive following the completion of the post-test and satisfaction survey.

Response differences in accuracy on the pre- and post-tests were analyzed using the McNemar test, and statistical significance was set at $\alpha=0.05$ (i.e., $p<.05$). All analyses were conducted using SPSS statistical software version 26.

Results

Key participant demographic information was obtained via the pre-survey form (see Table 1). AA was the most prevalent race among participants (92.3%), with the rest identifying as White, non-Hispanic. Most participants were married (60%) and not working (68% were retired and 16% were unemployed). One-fifth of respondents reported household income below \$10,000, while 32% reported income greater than \$50,000. Highest education level completed for most participants was “some college, technical, or vocational training” (42.3%) followed by a high school diploma or GED (26.9%).

Participants responded to questions about their access to healthcare and cancer screening decision making. The vast majority of participants (88.9%) acknowledged they had a regular, primary care provider. A minority of participants (37.0%) felt encouraged by their healthcare provider to look for health information. Approximately 68% reported that their provider spent an adequate amount of time with them at appointments. Conversely, 14.8% rarely or never felt like they had enough information to make decisions about their health. With regard to prostate health specifically, 56.5% said their healthcare provider had given them advice about reducing their risk for PrCA, but only 40.9% indicated they had discussed PrCA screening with their provider.

Table 2 presents the questions asked in both pre/post surveys, as well as participants' accuracy on each item expressed as a percentage. Improvement in accuracy was evident in 12 of 19 items, including a 36.3% increase in accuracy on item 7 (True or False: The PSA and DRE screenings may have false-positive or false-negative results.) and a 33.4% increase in accuracy on item 5 (True or False: Maintaining a healthy weight reduces your risk of prostate cancer). Accuracy decreased on items 1, 3, 6, 9, 10, and 17, though all instances of decrease were less than 10% except for item 6, which was administered only to participants in one of the three counties where the education program was implemented (item was improved following the first administration of the program). All items except items 6 and 3 (True or False: Decreased need to urinate is a symptom of prostate cancer) had a post-test accuracy percentage greater than or equal to 50%. Participants demonstrated increases in knowledge that were statistically significant for items 5, 7, and 11. The possibility of associations between knowledge scores and self-reported health literacy, race/ethnicity, and education also were examined; however, no statistically significant associations were found.

Discussion

Guided by community engagement and health communication principles, we developed a PrCA education program for rural communities encompassing information about PrCA risk factors, symptoms, screening, healthy diet and exercise, PrCA treatment options, and healthcare provider communication strategies. The program was developed in collaboration with the South Carolina Cancer Alliance Prostate Cancer Workgroup

representing community members, university-affiliated cancer researchers, and clinicians. This program was conducted against a background of working with the AA community, including on PrCA education [13, 25]. Previous work identified specific needs in terms of cancer education [21, 33, 34] and that previous community-engaged work has led to continuous refinement of our programming [28, 29].

This education program was administered by a PrCA survivor and health care professionals in three counties in South Carolina in 2018–2019 to 40 participants and included panel discussions with local health care providers following the educational session. Improvements in education and awareness were evidenced by increases in accuracy of responses on the majority of survey questions.

Overall impressions of the education program were consistently positive, exhibited by participants' answers on a satisfaction survey administered at the end of the session. All participants were "satisfied" or "more than satisfied" with the education session's presenters, content, opportunities to ask questions, and the class overall. Moreover, the satisfaction survey gauged how participants plan to advocate for their own prostate health following the education session and ways they envision prostate related healthcare can be improved. All participants indicated that they planned to take some form of action to reduce their risk of PrCA and increase PrCA awareness in their community. Just over 70% indicated they would talk to their healthcare provider about getting screened and 64.5% of participants planned on making an informed decision about whether or not to get screened. Furthermore, 61.3% planned to encourage others to talk to their provider about whether or not to get screened for PrCA. For recommendations on how to increase prostate health awareness among AA communities, "more advertisements" and "more informational sessions and meetings" were common suggestions.

Large interracial differences in PrCA incidence and, especially, mortality rates that consistently disfavor AAs in comparison to EAs have been evident in cancer registry data [35] since around the time that the War on Cancer was declared in 1971 [36, 37]. It also is evident that there are large differences in comparing rural with urban populations that have been resistant to attempts to create material improvements. As we describe in a recent paper describing differences in cancer mortality-to-incidence rates by US Congressional District, areas in the country that have high proportions of people living in rural areas or large numbers of AAs have particularly high mortality rates for given incidence [38]. They also tend to have high incidence in the first place [4]. South Carolina is an excellent example of this. South Carolina, like other places in the American South but unlike virtually any other part of the country, also has high AA representation in rural areas. The long-standing disparities that exist by rurality and race that are most evident in South Carolina have been refractory to efforts aimed at risk reduction over the past decades [39, 40]. This indicates a real need both in terms of research to understand the underlying problem and to provide real, practical solutions that can be implemented to reverse the current situation.

Community-based education programs can be effective means of delivering PrCA prevention, screening, and treatment information to rural communities. However, community-based education programs face many challenges such as low enrollment of

racial and ethnic minority groups, which is a concern for improving health outcomes in ethnically diverse rural areas [38]. Culturally appropriate and community-tailored education programs that address health disparities in rural communities are essential to cancer prevention and control efforts [19, 41]. Rural communities have cited recruitment via word of mouth through community communication channels and involving community schools and churches collaboration as effective recruitment strategies [42].

Barriers to enrollment into prostate health education programs can be addressed using community-engaged research approaches. Effective strategies include recognizing the distinct identity of the community; utilizing strengths and resources unique to the community; facilitating collaboration throughout all stages of research; commitment to a sustainable, long-term education process; achieving balance between research and intervention that is mutually beneficial for the community and researchers; and focusing on relevant community public health issues [29]. Adherence to these strategies in a manner that is mutually beneficial to both the researcher and the community has shown to yield higher enrollment and has the potential to improve outreach and impact on ethnic and racial minority groups living in rural communities [29].

Acknowledgments

We acknowledge that there are study limitations. The sample size is relatively small, and the data reported in this paper are from three separate educational sessions within one southern state. We cannot generalize findings to other rural counties or populations in our state or beyond. As we continue with the implementation and evaluation of prostate health education across the state, we plan to expand to additional rural counties and involve additional providers, including urologists. While participants demonstrated increased knowledge about topics related to screening, physical activity, and maintaining a healthy weight, there is a need and opportunity to incorporate more in-depth content about these topics through a multi-session educational intervention for AA communities.

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Table 1:

Participant demographic data (n=40)

Demographic Variables	Percentages
Average age (years)	62.4
Race/Ethnicity	
White, non-Hispanic	7.7%
African American, non-Hispanic	92.3%
Hispanic	0%
Other	0%
Marital status	
Single	28%
Married	60%
Separated	4%
Divorced	4%
Widowed	4%
Other	0%
Employment status	
Full time	8%
Part time	8%
Retired	68%
Not employed	16%
Household income	
Less than \$10,000	20%
\$10,000-\$19,999	8%
\$20,000-\$29,000	4%
\$30,000-\$39,000	20%
\$40,000-\$49,000	16%
Over \$50,000	32%
Highest level of education completed	
Less than high school	11.5%
High school graduate or GED	26.9%
Some college, technical, or vocational training	42.3%
Bachelor's degree	7.7%
Advanced Graduate Degree	11.5%

Table 2:

Results of Pre/Post Survey Knowledge Questions (n=40)

QUESTION #	PRE-TEST (% correct)	POST-TEST % (%correct) Change		P-value
True or False				
1. The prostate is a part of the male reproductive system.	84.9	75	-9.9	1.00
2. The prostate is normally the size of a walnut.	61.3	67.9	6.6	0.22
3. Decreased need to urinate is a symptom of prostate cancer.	35.5	28.6	-6.9	0.25
4. Pain or burning when passing urine can be a symptom of prostate cancer.	64.5	67.9	3.4	0.22
5. Maintaining a healthy weight reduces your risk of prostate cancer.	45.2	78.6	33.4	*0.004
6. Eating more energy-dense foods and less nutrient-dense foods can improve overall health	50.0	25.0	-25.0	0.50
7. The PSA and DRE screenings may have false-positive or false-negative results	38.7	75.0	36.3	*0.006
8. A man can have prostate cancer without having any pain or other symptoms	80.6	85.7	4.9	0.13
9. Prostate cancer only affects older men.	90.3	85.7	-4.6	1.00
10. Prostate cancer is a slow growing cancer so I don't need to worry about it.	74.2	67.9	-6.3	1.00
11. Both non-vigorous and vigorous activity lowered men's risk of death from any cause.	22.6	53.6	31.0	*0.01
12. Behavior changes are more difficult to accomplish with a partner	45.2	50.0	4.8	0.45
Multiple Choice				
13. Prostate cancer can be diagnosed by which of the following:	61.3	82.1	20.8	0.25
14. Which of the following lifestyle factors can increase your risk of prostate cancer?	41.9	53.6	11.7	0.63
15. Who do you think is more likely to get prostate cancer?	35.5	53.6	18.1	0.13
16. Individuals of which race are more commonly diagnosed with prostate cancer?	74.2	78.6	4.4	0.45
17. Which of the following is a benefit of physical activity?	87.1	78.6	-8.5	1.00
18. Which of the following is aerobic exercise?	41.9	53.6	11.7	0.22
19. Which of the following should you do before your doctor's appointment?	61.3	75.0	13.7	1.00

* Statistically significant at the $p < .05$ level; P-value is based on the McNemar test, with significance set at $\alpha = 0.05$ (i.e., $P < .05$).