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An Intergenerational Approach to Prostate Cancer Education: Findings from a Pilot Project in the Southeastern United States

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Abstract

African Americans (AA) are more likely to develop and die from cancer than any other racial or ethnic group. This study assessed older and younger/middle-age African-American (AA) men's (1) knowledge and attitudes about prostate cancer (PrCA) and PrCA screening, (2) participation in clinical research, and (3) health and cancer-related decision making. Twenty-eight AA men (14 older, mean age 59.8; 14 younger/middle age, mean age 30.4) received a PrCA education program and completed pre/post education program surveys, as well as qualitative post education interviews. Younger/middle-age men were more knowledgeable about PrCA and PrCA screening than older males. Older men reported being invited to participate in a clinical trial more often than younger males but were more likely to report that participation in clinical trials was risky and they did not plan to participate in medical research in the future. Younger/middle-age males were more willing to participate in a clinical trial in the future and reported fewer barriers to participation in clinical research. There is potential for using intergenerational communication strategies with older/younger AA male dyads in PrCA interventions.

Keywords

prostate cancer; intergenerational communication; health disparities; cancer education; African-American men

Introduction

African Americans (AA) are more likely to develop and die from cancer than any other racial or ethnic group [1, 2]. Ethnicity is a significant predictor of the stage at which cancers are diagnosed, with increased rates of later-stage cancers among ethnic groups due to limited prevention practices and poor access to cancer information and appropriate health care resources [1]. While AAs are more likely to develop and die from cancer than all other racial/ethnic groups [2], AAs also have low rates of participation in cancer research, particularly in clinical trials [3]. The two largest prostate cancer (PrCA) clinical trials to date included few or no AA men [4, 5]. The results from these two studies showed that screening using the prostate-specific antigen (PSA) test had no substantial effect on reducing the PrCA mortality rate (or at least not large enough to counteract the negative consequence of treatment side effects). These results, along with other scientific evidence, have led to the U.S Preventive Services Task Force to recommend against routine PSA screening [6]. The American Cancer Society (ACS), however, recommends that men make an informed decision with their doctor about whether or not to screen for PrCa [7]. Participation in education programs about cancer and medical research (e.g., clinical trials) can help patients make more informed decisions by gaining knowledge about screening and treatment options [3].

Health promotion experts have attempted to reduce cancer disparities through prevention programs that are tailored to the AA community. Most notably, these efforts include incorporating culturally targeted messages and images into educational materials [8–11], instituting faith-based initiatives [12, 13], and delivering educational programs in non-traditional venues such as barber shops [14], beauty salons [15, 16], and at health parties (i.e., home gatherings where AA women learn about breast cancer and receive small gifts) [17]. One element that unites these efforts is recognition that communication plays an integral role within the AA community. In particular, AA southern culture is steeped in intergenerational communication, with roots tracing back to slavery [18].

Knowledge is typically passed between generations from an older family member to a younger family member [18]. This “downstream” flow of information reflects the desire of parents and grandparents to transmit culture and teach their children based on their own lived experiences. From a public health perspective, however, it is likely that the younger generation is exposed to more health and medical information in their daily lives, namely through exposure to more dynamic and interactive environments (e.g., school, Internet, social media, etc.). As such, public health interventions have increasingly used a dyad approach, where younger members of the community or family are paired with and educate older members of the family about particular health topics (“upstream” flow of information) [19–26].

Mosavel has used this “upstream” approach to educate women about cervical cancer [20]. In her work, she found that daughters are willing to share cervical cancer information with their mothers and in most cases mothers were accepting of the information because they saw their daughters as informational gatekeepers and educated about health [21]. Furthermore, results from research conducted by Washington and colleagues with adult daughter and mother

dyads showed that daughters influenced their mothers' ability to navigate the health care system and contributed to health-related decision making and breast cancer screening behaviors [26]. Additionally, an intergenerational sharing of health knowledge and health-related decision making utilizing both “downstream” and “upstream” approaches has been shown effective in studies with adult children and parents that both have hypertension [25] and with parents that have overweight or obese children involved in energy balance interventions [24]. Downstream approaches have been effective in parent-based tobacco use prevention for youth [19] and substance use prevention in adolescent girls [23].

Formative research with AA males and females found that both younger/middle-age and older AA men were considered hardest to reach for PrCA education programs [10]. Given this, our study assessed AA older and younger/middle-age men's (1) knowledge and attitudes about PrCA and PrCA screening, (2) their participation in clinical research, and (3) their health and cancer-related decision making.

Methods

Education Intervention

This pilot education intervention was based on information gained from previous research with AA men and women [9, 10, 27]. Education sessions were administered to a total of 28 participants (14 older men, mean age 59.8 and 14 younger/middle-age men, mean age 30.4; recruited in dyads from the community, churches, and cancer center using flyers and word-of-mouth) over four weeks at a local cancer center auditorium in a southeastern state. The majority of participants did not have a personal history of cancer, however, because the focus of this pilot study was on communication about cancer within families, some PrCA survivors were included given the potentially important role of personal testimonials in motivating other men to engage in health- and cancer-related decision making.

See Table 1 for additional participant demographics. Education topics covered included:

- PrCA risk factors and symptoms,
- PrCA screening guidelines,
- Clinical trials and informed consent, and
- Overcoming barriers to discussing cancer.

Prior to and following the education sessions, participants also were asked to complete a 75-item survey to assess their change in PrCA and clinical trials related perceptions, knowledge, behavior and cancer decision making. Sample items included: “The prostate is one of the male sex glands” (True/False) and “How often do you have enough information to make a decision about your health care?” (All of the time/ most of the time/some of the time/none of the time). All participants completed both the pre- and post-test surveys. Participants received a monetary incentive following the completion of the pre-test and an additional incentive following the post-test.

Participant Qualitative Interviews

Following the education sessions, 10 telephone interviews were conducted with five older and five younger/middle-age participants. These 10 participants (five older and five younger/middle-age) were selected randomly from the original list of 28 participants who agreed to be contacted following the completion of the pilot intervention. The interview guide, which contained 10 qualitative questions adapted from existing instruments [28, 29], was conducted to improve understanding of how the education program was received by participants and how the program could be improved for future delivery. Qualitative items included: “What was your favorite part of this PrCA education program” and “How do you think this program would be helpful to other men in your community?”

Analysis

The education intervention was assessed using a pre- and post-test measure. Non-parametric statistical tests (e.g., Wilcoxon rank sum test) and rates (e.g., frequencies / percentages) were used to examine quantitative survey results. Due to the small sample size (N=28), significance, at the traditional p value of .05 was not achieved for most items, but results demonstrating the greatest changes from pre- to post-test are discussed. Analyses were conducted using SPSS® 18.0 [30]. Participant telephone interviews were audio recorded to ensure important information from participants was captured. Qualitative responses were transcribed and examined for common themes [31].

Results

Pre/Post Education Survey Results

The reported results are based on those items that showed the greatest change from pre- to post-test (See Tables 2 and 3). The results thematically fall within four categories: (1) PrCA knowledge, (2) conversations with a doctor about PrCA, (3) clinical trials participation, and (4) health and cancer-related decision making.

Prostate Cancer Knowledge—Overall, knowledge about the prostate and PrCA increased from pre- to post-test. The largest increases in knowledge were related to prostate anatomy, the PSA, and digital rectal exam (DRE), and PrCA symptoms. Overall, the younger/middle-age men showed more notable increases in knowledge than older men following the intervention. Current ACS guidelines about PrCA suggest that AA men begin discussions about PrCA screening with their doctor at age 45 [7] and at pre-test 12% of all men correctly identified age 45 for when AAs begin PrCA screening discussions; at post-test this correct response increased to 31% (NS). At pre-test, 23.1% of older men incorrectly answered 50 as the age that AA men should begin discussions about PrCA screening with their doctor and at post-test 0% (NS) of older men listed this response. At pre-test, 7.7% of younger/middle-age men correctly identified age 45 as the age for beginning discussions about PrCA screening with their doctor; this correct response increased to 30.8% at post-test (NS).

Conversations with a Doctor about Prostate Cancer—During the education sessions the importance of discussing PrCA and PrCA screening with a doctor was

emphasized. When asked whether, “My doctor told me about the advantages of PrCA screening” and “My doctor told me about the disadvantages of PrCA screening,” older men reported talking about the advantages and disadvantages of PrCA at pre- and post-test more often than younger/middle-age men.

Clinical Trials Participation—The benefits of clinical trials and health-related research were discussed in the education program and at pre- and post-test older men reported being invited to participate in a clinical trial in the past and participated more often than younger/middle-age males. However, older males were more likely to report that participation in clinical trials was risky. The largest barrier reported by all men for why they had not participated in a clinical trial was time/schedule fit, followed by transportation and difficulty understanding the consent forms. Overall, younger/middle-aged men reported fewer barriers to clinical trials participation at post-test compared to older men. Although many barriers to participation were reported by the participants, particularly by older men, both older and younger/middle-age males were still willing to participate in a clinical trial in the future. At pre-test, 68% of all participants reported planning on participating in clinical trials in the future; at post-test, the intention to participate increased to 74% (not significant).

Health and Cancer-related Decision Making—Finally we assessed how older and younger/middle-age men make health and cancer-related decisions. When participants were asked, “What role do you play in making your own health care decisions?” most reported that their doctor discussed options with them and then together they came to a decision with their doctor. However, older men were more likely to report making a decision together with their doctor compared with younger/middle-age men.

Qualitative Interview Results

Ten out of 28 participants (five older and five younger/middle age) participated in the qualitative interviews. Overall, interview participants shared positive experiences about the program. Findings were grouped into four main categories: (1) education program evaluation, (2) comfort level discussing PrCA, (3) suggestions for future education sessions, and (4) PrCA knowledge.

Education Program Evaluation—When asked, “What was your favorite part of this PrCA education program?” participants described gaining more general knowledge about PrCA, learning about healthy eating habits, and the relaxed nature of the educational sessions. Specifically, participants said, “Learning that you need to be tested,” and “The information about prostate and prostate cancer, and the food you eat.” Participants felt comfortable expressing what they enjoyed about the program, but not so comfortable discussing their least favorite aspects. Many participants simply stated that all components of the program were useful. An older male said, “I don’t have anything negative, everything was helpful.” Another older participant mentioned that he did not enjoy learning about the DRE, but he did explain that the discussion and the test were necessary. Participants felt it equally as difficult to provide suggestions for improvement of the education program. When participants did suggest improvements, most were logistical in nature. One younger/middle-age male said, “I would have liked three days all at once, instead of spreading it out.” Every

older male had at least one suggestion for improvement. Recommendations included: removing the income question from the survey, adding additional classes so that more in-depth information could be provided, discussing the importance of diet, stressing to younger men the importance of getting checked early, community and church participation and partnering, including medical doctors in the program, and making more men aware through advertisements or television commercials.

Comfort Level With Talking about Prostate Cancer—During the participant interviews we deemed it important to understand if the educational content led to some behavior change or intention to change behavior. When asked, “Do you feel that this program made you more confident about speaking to a doctor about PrCA screening or treatment? Why or why not?” every participant reported being more confident and comfortable speaking to a doctor about PrCA screening and/or treatment. A younger/middle age male reported, “Now I can feel more comfortable about what he is going to tell me, and “I can know what I need to think about for the future.”

Suggestions for Future Education Sessions—The education program was developed with the guidance of community partners and during the telephone interviews it was important to understand if the participants thought the program would be helpful to other men in their communities. All participants thought the program could be helpful to other men and they gave suggestions on how to get more men involved. Participants suggested: going into churches to make presentations, using word of mouth, and going into barbershops to recruit additional men for an education program. Furthermore we wanted to understand what types of incentives might motivate other men to participate in cancer education programs in the future. Most participants agreed that incentives were necessary to garner support from the community. Money and food were the most commonly suggested incentives.

Knowledge about Prostate Cancer—Finally, we wanted to know what new information or skills the participants gained as a result of the education program. Participants reported being more aware of PrCA, understanding that AA men are more affected by PrCA, knowing when to talk to their doctors about PrCA screening, and learning about various treatment options. Overall, both older and younger/middle-age participants reported learning at least one new piece of information as a result of their participation in the program.

Discussion

Our study assessed AA older and younger/middle-age men's (1) knowledge and attitudes about PrCA and PrCA screening, (2) participation in clinical research, and (3) health and cancer-related decision making. This is one of few studies to use a variety of methods to explore PrCA, PrCA screening, and research participation among older and younger/middle-age AA men.

Our findings revealed differences in older and younger/middle-age men's knowledge and attitudes about PrCA and PrCA screening, differences in their clinical research participation,

as well as differences in their health and cancer-related decision making. Younger/middle-age men were shown to be more knowledgeable about PrCA and PrCA screening than older males. Given this, younger males can help to educate older males about PrCA and PrCA screening based on their greater knowledge. Prior research has shown that older generations often see younger generations as a trusted informational source and therefore older males may be accepting of health knowledge from younger men [21]. This sharing of trusted and valued health information from generation to generation highlights an approach that researchers, clinicians, and families can use to promote awareness about PrCA and PrCA screening.

Our study also revealed that older men reported being invited to participate in a clinical trial or a health-related research study in the past and actually participated more often than younger/middle-age males, but were more likely to report that participation in clinical trials was risky. Younger/middle-age males, conversely, were less likely to report being invited to participate in a clinical trial, but were more likely to be willing to participate in a clinical trial in the future and report fewer barriers to participation in clinical research. Given this difference in perspective, younger males can aid in facilitating discussions around clinical research participation and may help to change the opinion of older males about medical research participation and older males can use their experience with clinical trials to help younger males navigate clinical trials participation. This approach would entail utilizing both an “upstream” and “downstream” approach, both of which have been shown to be successful in other health interventions [19–26].

Finally, our study also found that older males were much more likely to report discussing the advantages and disadvantages of PrCA screening with their doctors than younger/middle-age males. In addition, older men were more likely to report making a decision together with their doctor about their health compared with younger/middle-age men. Given that the American Cancer Society (ACS) encourages informed decision making about PrCA screening [7], it is encouraging to know that more than half of all men, regardless of age, reported their doctor discussing the clinical options and then coming to a joint decision together (pre-test 56%, post-test 60%).

Limitations

This mixed-methods study has limitations. The sample consisted of a small number of AA men from one county in the southeastern United States. While the results indicated relatively large intervention effects, few were actually statistically significant. Even if the sample size were larger, the results may not be generalizable to AA men with or without PrCA across the state or to other parts of the U.S. In addition, the results cannot be generalized to other racial and ethnic groups. Despite these limitations, this study provided valuable information that can contribute to the future development of both culturally and age appropriate strategies to educate both older and younger/middle-age AA men about PrCA and cancer-related research. The mixed methods approach greatly strengthened the study design because it allowed us to use data from the pre- and post-test surveys and from the qualitative interviews. The interviews helped obtain more in-depth information about the success of the education program and how programs like it can be used in the future to educate other AA

populations about PrCA and health-related research. In addition, including both older men and younger/middle-age men in our study provided us with an age perspective that can be used to tailor future education interventions or messages to different segments of the AA male population.

Conclusions

Not only do the results of the PrCA education program show promise for utilizing intergenerational communication strategies; both upstream [20] and downstream [18], the thematic differences highlighted in the interviews also showed insight into how both older and younger generations can educate one another about health. Most notably, older males reported already talking to their doctors about PrCA screening and treatment and being highly comfortable. On the contrary, younger/middle-age males reported being willing to talk with their doctors in the future given their participation in the program. This shows that older males have experience talking about PrCA screening with a doctor but younger males can use that older male experience to know how to talk with a doctor in the future.

The research presented here shows the potential for using both upstream and downstream intergenerational communication strategies to effectively relay health and cancer-related information (with a focus on PrCA) between older men and younger men. Given that PrCA incidence and mortality are significantly higher in AA men compared with European-American men [1, 2] and that in general AAs are more likely to develop and die from cancer than any other racial or ethnic group [2], sharing important information about PrCA, PrCA screening, clinical trials participation, and health and cancer-related decision making from generation to generation is an important strategy for addressing the cancer prevention and control needs of AA men.

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Table 1

Education Intervention Participant Demographics (N=28)

GENDER	Older Men (N =14)	Younger/Middle-Age Men (N=14)
AGE (years)	59.8 ± 8.9	30.4 ± 9.2

MARITAL STATUS	Freq[*]/Percent	Freq[*]/Percent
Single	2(14.3%)	10(71.4%)
Married	7(50.0%)	3(21.4%)
Separated	3(21.4%)	0(0%)
Divorced	2(14.3%)	0(0%)
Widowed	0 (0%)	0(0%)
Other	0(0%)	1(7.1%)
EMPLOYMENT STATUS		
Full-Time	5(35.7%)	6(42.9%)
Part-Time	0(0%)	6(42.9%)
Retired	6(42.9%)	0(0%)
Not Employed	3(21.4%)	2(14.3%)
INCOME LEVEL		
<20,000/year	2(15.4%)	5(35.7%)
\$20,000 to \$39,999	4(30.8%)	1(7.1%)
\$40,000 to \$59,999	2(15.4%)	3(21.4%)
\$60,000 to \$79,999	2(15.4%)	1(7.1%)
\$80,000 to \$99,999	2(15.4%)	2(14.3%)
Over 100,000	1(7.7%)	2(14.3%)
HIGHEST EDUCATION LEVEL		
Less than high school	1(7.75%)	0(0%)
High School/GED	5(38.5%)	3(21.4%)
Some college	7(53.8%)	9(64.3%)
Bachelor's Degree	0(0%)	1(7.1%)
Advanced/Graduate Degree	0(0%)	1(7.1%)

* Totals in each section vary due to missing responses

Pre/Post Education Survey Results

Table 2

Prostate Cancer Knowledge							
Item	All Participants n=28		Older Men n=14		Younger/Middle-Age Men n=14		
	Pre-Test	Post-Test	Pre-Test	Post-Test	Pre-Test	Post-Test	
The prostate is the size of a walnut. (TRUE)	75.0%	96.0% *	71.4%	92.9%	78.6%	100%	
The PSA and DRE screenings may have false-positive or false-negative results. (TRUE)	43.0%	75.0% *	42.9%	71.4%	42.9%	78.6% *	
Pain or burning when passing urine is a symptom of prostate cancer. (TRUE)	59.0%	89.0% *	57.1%	78.6%	57.1%	100% *	

Conversations with a Doctor about Prostate Cancer							
Item	All Participants n =28		Older Men n=14		Younger/Middle-Age Men n=14		
	Pre-Test	Post-Test	Pre-Test	Post-Test	Pre-Test	Post-Test	
My doctor told me about the advantages of prostate cancer screening (STRONGLY AGREE or AGREE)	58.0%	64.0%	85.7%	85.7%	21.4%	42.8% *	
My doctor told me about the disadvantages of prostate cancer screening (STRONGLY AGREE or AGREE)	40.0%	48.0%	64.3%	50.0%	14.2%	42.8% *	

Clinical Trials Participation							
Item	All Participants n=28		Older Men n=14		Younger/Middle-Age Men n=14		
	Pre-Test	Post-Test	Pre-Test	Post-Test	Pre-Test	Post-Test	
Have you ever been invited to participate in a clinical trial or a health-related research study? (YES)	18.0%	29.0%	21.4%	35.7%	14.3%	21.4%	
Have you ever participated in a clinical trial or a health-related research study? (YES)	14.0%	30.0%	28.6%	35.7%	0%	21.4%	
Do you plan on participating in clinical trials in the future? (YES)	68.0%	74.0%	71.4%	71.4%	78.6%	71.4%	
Participation in clinical research is risky. (YES)	4.0%	25.0%	0%	42.9% *	7.1%	7.1%	

Health and Cancer-Related Decision-Making							
Item: What role do you play in making your own health care decisions?	All Participants n=28		Older Men n=14		Younger/Middle-Age Men n=14		
	Pre-Test	Post-Test	Pre-Test	Post-Test	Pre-Test	Post-Test	
Response: My doctor keeps me informed but makes decisions based on what is best for me.	30.0%	12.0%	23.1%	7.7%	35.7%	16.7%	
Response: My doctor discusses options with me and then we come to a decision together.	56.0%	60.0%	61.5%	69.2%	50.0%	50.0%	
Response: My doctor tells me my pros and cons and then I decide what to do.	14.0%	28.0%	15.4%	23.1%	14.3%	33.3%	

* p = <.05

Table 3

Barriers to Participation in Clinical Trials Research

BARRIERS*	All Participants (N=28)		Older Men (N=14)		Younger/ Middle-Age Men (N=14)	
	Pre-Test**	Post Test**	Pre-Test**	Post Test**	Pre-Test**	Post Test**
The time of the clinical trial did not fit my schedule	36.0%	22.0%	35.7%	35.7%	21.4%	0%
I did not have transportation to attend	14.0%	5.0%***	14.3%	7.1%***	7.1%	0%
I did not trust the researcher	9.0%	5.0%	14.3%	7.1%	7.1%	0%
Researchers pressured me	0%	0%	0%	0%	0%	0%
The informed consent was too complicated	7.1%	7.1%	7.1%	7.1%	7.1%	7.1%

* Participants were asked to provide multiple answers if applicable

** Totals in each section vary due to missing responses and multiple selections

p = < .05