

# COMMENTARY: BUILDING AN EVIDENCE BASE FOR PROMOTING INFORMED PROSTATE CANCER SCREENING DECISIONS: AN OVERVIEW OF A CANCER PREVENTION AND CONTROL PROGRAM

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African American (AA) men have significantly higher mortality rates from prostate cancer (PrCA) than other racial groups. Therefore, there is a critical need to identify strategies for promoting informed PrCA screening decisions among this population. This article details the community-driven, social and behavioral research being implemented by a Statewide Cancer Prevention and Control Program (CPCP) to support the development of person-to-person and technological interventions to improve the dissemination of PrCA information to AA men and their families. This article concludes with four recommendations to advance future research and practice related to the use of interventions for promoting informed PrCA decision-making among AAs. These recommendations include: 1) informing men about controversial screening recommendations; 2) including families in educational interventions about PrCA; 3) using technology as a modality for disseminating PrCA information when appropriate; and 4) aiming to create interventions that can be translated into community and clinical settings. *Ethn Dis.* 2017; 27(1):55-62; doi:10.18865/ed.27.1.55.

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## BACKGROUND

Despite advances in urologic practice and the steady decrease in prostate cancer (PrCA)-related mortality, PrCA remains the leading cancer among American men.<sup>1</sup> There exists a pronounced PrCA disparity between African American (AA) and European American (EA) men, with AA men having much higher incidence, survival, and mortality-to-incidence ratios.<sup>1,2</sup>

Mixed evidence about the efficacy of prostate-specific antigen (PSA) screening has led to a fervent debate among researchers and practitioners regarding whether or not PSA screening should be offered as an option for early PrCA detection.<sup>3</sup> In 2011, the United States Preventive Services Task Force (USPSTF) made a research-informed recommendation that no healthy man receive routine PSA-based screening for PrCA.<sup>4</sup> However, some researchers have been concerned that the evidence upon which the USPSTF based their screening recommendation has major flaws.<sup>5,6</sup> In-

deed, if one examines the Globocan maps produced by the International Agency for Research in Cancer, it is clear that the United States has the highest PrCA incidence rate; however, it has a relatively low (second lowest quintile) PrCA-related mortality rate.<sup>7</sup> These apparently conflicting data are inconsistent with the notion that PSA-based screening is universally bad (as it is well-documented that the large increases in PrCA incidence observed in the United States over the past 25 years are largely due to widespread use of PSA screening).

One deficiency in currently available research findings is that AA men, who are diagnosed with more aggressive forms of PrCA at younger ages, are poorly represented in the largest of the US clinical trials conducted to investigate PSA efficacy.<sup>8</sup> Other organizations, such as the American Cancer Society (ACS), have not stated their recommendations as emphatically as the USPSTF; instead, they place the onus of PrCA screening decisions on men and their health care providers. Specifically, the ACS recommends that men make informed decisions with their doctors only after learning about the risks, benefits, and uncertainties of screening.<sup>9</sup> These risks and uncertainties include, but are not limited to, the

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sensitivity of the PSA exams, which can lead to false positives, or the detection of indolent cancers, which constitute more than 80% of all PrCAs.<sup>9</sup>

In response to the PrCA screening recommendations by the ACS, the Statewide Cancer Prevention and Control Program (CPCP) at the University of South Carolina has developed a pipeline of research to guide interventions that promote informed PrCA decisions. The CPCP, founded in 2003, aims to reduce cancer-related health disparities through an interdis-

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ciplinary and community-driven approach. The core and affiliate faculty expertise within the CPCP is diverse and an established network of academic, clinical, and community partners further strengthens core resources.<sup>10</sup> This article details our evolving efforts to assess knowledge and perceptions about PrCA screening among AA men and their families and create interven-

tions that can empower them to make informed PrCA screening decisions.

The CPCP emphasizes interdisciplinary or transdisciplinary research. Interdisciplinary research is supported by a conceptual model that “integrates theoretical frameworks from those disciplines, requires the use of perspectives and skills of the involved disciplines throughout multiple phases of the research process.”<sup>11</sup> Transdisciplinary research involves “mutual learning” between the discipline that leads to theory development. Ideas conceived in this new cross-cutting, “intellectual space” can then be used to solve a given challenge.<sup>12</sup> The cross-fertilization also can lead to acquiring new knowledge and skills among all representatives in the collaborative (eg, health promotion expert learns to build basic algorithms).<sup>13</sup>

In Figure 1, we acknowledge the need for incremental change in knowledge and the capacity for all perspectives (especially those of the community) to influence fundamental change in research direction and scope. In our process, which includes four main phases, the community is the focal point of our innovation and we therefore employ principles of community-based participatory research (CBPR) in all of our work. During the discovery phase (formative research and conceptualization period), we commonly involve the community through the convening of a community advisory board that consists of key stakeholders who have formal (eg, president of small PrCA support group) and informal (PrCA survivor) roles in a given community. Similarly, during the development (ie, intervention creation), delivery (ie, implementation),

and dissemination (ie, diffusion of innovation) phases, we involve and engage the community in the research. In addition, the arrows in the model denote the iterative nature of CPCP research. This allows us to revisit one or more of the earlier phases regardless of the phase in the research process (development to dissemination). Our overall goal is to produce the most effective and sustainable solutions for ameliorating the cancer burden among disadvantaged populations.

## RESEARCH FOCUS AREAS

### Assessing Communities' Communication and Information Needs

Some of the earliest work performed under the auspices of the CPCP focused on identifying the incidence, prevalence, and other salient patterns of PrCA in the Southeastern United States, with a special focus on South Carolina. During this discovery phase, multiple analyses demonstrated that PrCA is a much more dangerous disease among AA men in the Southeast than nationally.<sup>2</sup> By late 2009, researchers within the CPCP had a clearer understanding of PrCA from an epidemiological perspective. However, understanding about the attitudes and behaviors of AAs related to PrCA screening lagged behind. Therefore, Friedman et al (2009) conducted in-depth qualitative research to explore PrCA communication and health literacy among a small group of AA men.<sup>14,15</sup> Findings revealed multiple barriers to PrCA communication among participants, including limited communication

## THE SC CPCP RECURRING LOOP MODEL<sup>©</sup>

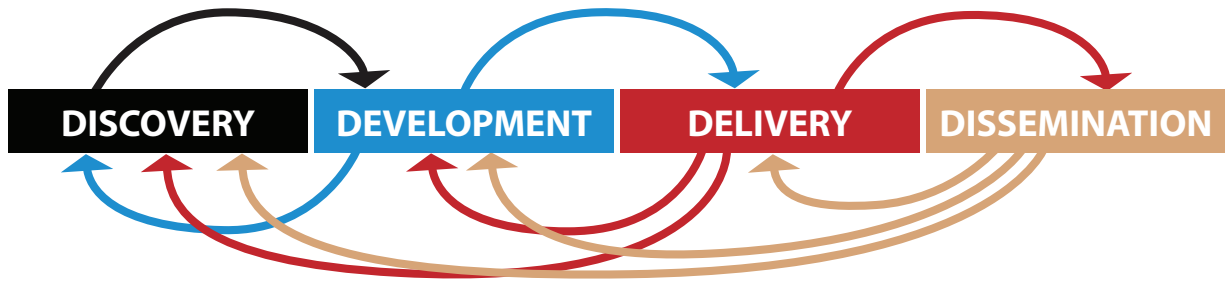


Figure 1. SC CPCP Recurring Loop Model

within families, lack of access to culturally appropriate health information, and fear of PrCA.<sup>15</sup> Participants also had limited understanding and various misconceptions about PrCA screening.<sup>14</sup> These findings suggested the need for a strategy targeted at overcoming barriers to participants' PrCA information needs. Community members indicated they needed targeted PrCA messaging dispersed by opinion leaders, such as pastors, PrCA survivors, and AA women.<sup>14,15</sup> Based on these findings, a larger study that included both AA men and women was implemented to gain the information necessary to develop and deliver a targeted PrCA intervention.

Emerging literature indicates that women are the source for health information within AA households.<sup>14</sup> It also is well-documented that AAs' spiritual needs play a pivotal role in influencing their participation in research.<sup>16,17</sup> However, there had been no previous study on PrCA education and informed decision-making in South Carolina that included AA men and women. Therefore, in 2010, the CPCP developed and evaluated a PrCA education intervention as

part of a National Cancer Institute (NCI)-funded cancer disparities network grant (U54 CA153461). The specific aims of this mixed methods research were to assess, among AAs in a faith-based setting: 1) the current knowledge and attitudes regarding PrCA prevention and screening, and participation in PrCA research (ie, discovery); 2) changes in knowledge and attitudes about research participation following a pilot education program developed based on informational needs (ie, development and delivery); and 3) culturally appropriate strategies for promoting cancer research among AAs in a faith-based community (ie, dissemination).<sup>18,19</sup> We discovered that AA men and women had limited knowledge about PrCA and limited experience participating in research. AA men and women had similar views on the barriers that limited PrCA communication (eg, fear), but had slightly different perspectives on which barriers had greater impact on AA men's informed decision-making about PrCA screening.<sup>20</sup> AA men also reported that their health care providers were often the principal influencers on their PrCA

screening decisions.<sup>20</sup> Based on this information, we developed a comprehensive in-person education program that covered information on PrCA and medical participation. The program was delivered through four, one-hour, in-person sessions. Knowledge and perceptions regarding research participation were evaluated through surveys administered pre- and post-program.

Our survey findings showed that AA men and women experienced moderate increases in their PrCA knowledge and were more open to future participation in research.<sup>20</sup> However, there was a noteworthy difference between AA men's and women's perceptions about whether younger or older men would be harder to reach through PrCA communication efforts. Women overwhelmingly agreed that older men would be the hardest to reach. By contrast, men expressed that younger men would be harder to reach.<sup>20</sup> Based on this finding, we delivered and evaluated our PrCA education program with dyads of younger (aged <40 years) and older (aged ≥40 years) men. Through this study, we discovered that younger AA men had greater gains in knowl-

edge between pre-and post-tests and were more open to participating in research than were older AA men.<sup>21</sup> Therefore, we concluded that delivering our PrCA education program to younger and middle-aged AA men together could facilitate an exchange of information that may make informed decisions about PrCA screening easier for older men. This research has important implications for AA men given that they tend to be diagnosed with more aggressive disease at younger ages than EA men.

### **Technology for Assessing and Aiding Health Decision-Making Behavior**

Beginning in 2010, we began exploring technology as a means to: 1) enhance the communication between researchers and participants (ie, discovery); 2) extend the reach of our educational program and potentially make it more sustainable (ie, delivery and dissemination); and 3) facilitate informed decision-making between a health care provider and a patient. The first two projects detailed below (ie, Photovoice and Teleconference) were completed as a part of the larger NCI-funded pilot project.<sup>18</sup> The third and fourth projects (ie, Decision Aid & Algorithm) were implemented as independent studies.

### **Health Decision-Making Through Their Lens**

The goal of our first technology-related project was to test the feasibility of using Photovoice, an innovative qualitative methodology, to enhance communication between AA men/women and researchers about general health and PrCA decision-making.<sup>22</sup>

Therefore, we trained this population to use digital cameras to capture aspects of their environment that influence their decision-making. Though participants were generally guided by a set of questions, we allowed them enough flexibility for themes to emerge organically from the data. We found that Photovoice was an effective means of enhancing participant/researcher communication about their health decision-making (based on the richness of the data collected). We also discovered that using Photovoice in conjunction with short audio-recorded narratives provided even richer context about participant health decision-making.<sup>22</sup> Through emerging themes, we found that participants were largely aware of the practices needed to remain healthy, but communicated several barriers that hindered them from engaging in healthy behaviors such as lack of access to care and lack of time to engage in healthy habits (eg, exercise).<sup>22</sup> These findings emphasized the efficacy of Photovoice for illuminating barriers to health and serving as a basis for creating future health programs. Our findings also underscore the need for researchers to understand the many factors influencing health decision-making. Based on the Photovoice project, we developed a booklet with participants' pictures taken during the project along with their direct quotes. The printed booklet was then distributed to study participants, partners, and community leaders.

### **Expanding the Reach of our PrCA Education Program through Videoconferencing**

Immediately following the NCI project, the research team sought to

evaluate and further refine our materials with assistance from study participants and funding from the South Carolina Cancer Alliance. Therefore, we moved from the delivery/dissemination phases (see loop model, Figure 1), back to the development phase. Materials were evaluated through a mailed survey to 32 participants and a community forum with 38 additional participants. The research team received positive feedback with some recommended improvements,<sup>23</sup> including clarifying technical terms, enlarging text and images, and including more of the latest statistics on PrCA. The education program (presented by physicians, researchers, and PrCA survivors) was then disseminated to participants via broadcast at three academic and community institutions across the state.<sup>23</sup> Videoconference attendees (25 men; 3 women) reported being empowered to communicate with their health care providers and/or others about PrCA.<sup>23</sup> Participants also expressed satisfaction with receiving information through a videoconference modality.<sup>23</sup> The videoconferences were also made available online so that other organizations and individuals across the state could access them for informational purposes.

### **Development and Testing of a Computer-based PrCA Decision Aid**

In 2012, the CPCP began investigating innovative technological methods for empowering AA men to make informed decisions about PrCA screening. Based on an extensive literature search, which demonstrated the effectiveness of decision aids and the paucity of literature on the use of em-

bodied conversational agents in PrCA interventions, Owens et al conducted research to develop an ideal modality for educating AA men.<sup>24</sup> The goals of the study were to assess whether a computer-based decision aid (CBDA) for PrCA screening would be appropriate for middle-aged and older AA men in South Carolina. More specifically, the exploratory study examined: 1) PrCA risk and screening knowledge; 2) decision-making processes for PrCA screening; and 3) use of, attitudes toward, and access to interactive communication technologies

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(eg, computers).<sup>25</sup> Based on discoveries made during this phase, Owens et al developed an agent-led education program that built on our original PrCA education program, but also included an interactive component to better prepare men for a conversation with their physician. In addition, the perceived usability and acceptability of the CBDA also was assessed among participants and expert reviewers.<sup>25</sup>

We discovered that AAs were mostly knowledgeable about PrCA; however, few engaged in informed decision-

making, and few were informed about the risks and uncertainties of PrCA screening. Most participants used interactive communication technologies on a daily basis for various purposes, including health information seeking.<sup>24</sup> They also were open to using this system if it were easy to use and the embodied conversational agents were culturally appropriate.<sup>24</sup> With regard to the usability, both participants and expert reviewers were accepting of the CBDA, but suggested minor changes (eg, making text larger).<sup>25</sup> Research is ongoing to assess the impact of the CBDA on the actual knowledge and PrCA screening behaviors of AA men through the delivery and evaluation of the program to a robust sample of AA men. Plans to disseminate the CBDA following the evaluation are also ongoing, but include possibilities such as integrating the CBDA into existing electronic health records and working with larger hospitals to make the CBDA available on tablet computers at all PrCA screening events.

### **Toward Prediction and PrCA Decision-Making**

Within the past two years, there has been increasing attention within CPCP on the use of predictive analytics to determine if there is a specific PSA pattern change among men with high-risk, virulent cancers and those with low-risk/no PrCA.<sup>26,27</sup> Identifying such an algorithm could be very important for predicting with high probability whether we can use a repeat PSA method to determine which cancers warrant treatment and which cancers can afford to be watched or surveilled over time. Initial research on pattern differences in PSAs of men

with high-risk and low-risk cancers was performed using PSA measures from >20,000 men enrolled in the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial.<sup>26</sup> Findings from our group show that the PSA change patterns over time are innately different in men with high-risk PrCA when compared with men with low-risk PrCA.<sup>26</sup> However, further research is needed to validate the algorithm used to detect these patterns, particularly among AA men because most of the large public datasets include scarce numbers of AA men (≈4% in the PLCO). A next step in this research is to create a cohort of AA men willing to receive annual PSA screenings. This cohort would provide results that are broadly analogous to the PLCO, but much more robust with respect to AA representation (eg, in the VAMCs the percentage of African Americans is close to 40%).

## **DISCUSSION**

### **Considerations for Promoting Informed Prostate Cancer Screening Decisions**

Based on the findings of our multifaceted research efforts on promoting informed decision-making about PrCA screening, we have four key recommendations for academic and clinical stakeholders.

#### *Recommendation 1: Communicate the Controversy*

For decades, there has been controversy over the efficacy of the PSA exam, but these debates have become more frequent following the 2011 PrCA

screening recommendation from the United States Preventive Services Task Force.<sup>28,29</sup> For example, Richard Ab- lin, one of the scientists credited with the discovery of the antigen measured through the PSA test, has expressed being fervently against the test as a routine predictor for PrCA.<sup>30</sup> His apprehensiveness about the exam is linked to the fact that it is not capable of detecting the PrCA or its virulence. Conversely, other organizations, such as the ACS, recommend informed decision-making. Despite the controversy, millions of men continue to receive routine screening.<sup>31</sup> Therefore, it is critical that men be prepared to make an informed PrCA screening decision with their health care provider as recommended by ACS. In addition to knowing about the risks, benefits, and uncertainties of the PrCA screening, being “informed” also means having knowledge about the existence of, and reasons for, the current PrCA screening controversy. Men should be aware that because of the controversy, their health care provider’s perspective on PrCA screening could be highly influenced by one organization’s recommendation over another. Many of our study participants had no knowledge of the PrCA screening controversy, the disadvantages of PSA screening, or how the controversy may have influenced their health care providers’ recommendations.<sup>32</sup> Having knowledge about the screening controversy could ensure that PrCA screening decisions are ultimately consistent with a man’s values. In addition, a man needs to understand how they will use the information and eventual treatment decisions, or decision not to treat, in the case of a positive find-

ing. Therefore, understanding PrCA treatment options also is essential to decisions about PrCA screening.<sup>26</sup>

### *Recommendation 2: Recognize that PrCA Decisions are a Family Affair*

Decisions about PrCA screening are most often made by a man and, usually, his health care provider.<sup>33</sup> However, in many cases a family member is involved indirectly by making a man more aware of PrCA or encouraging him to visit his provider.<sup>34</sup> Family members also have been shown to be more trustworthy sources of information among AAs<sup>35</sup> and may be preferred over other members of their social circle.<sup>35,36</sup> In addition, the social support provided through an individual’s family member (eg, spouse) increases the likelihood that a man will “act” on the health information that they receive.<sup>35</sup> Therefore, involving both female and younger male family members in PrCA education efforts could be advantageous to ensure that AA men acquire timely and trusted PrCA information and use this information to engage in informed decision-making with their health care provider. For example, having an intergenerational, dyadic approach to delivering PrCA education could be effective for both younger and older AA men.<sup>21</sup> Younger men in our study were in their 20s and 30s, which account for some of the greatest users of technology.<sup>21</sup> Therefore, by having a better understanding of the disease and informational needs through a formalized PrCA education program, younger men may be able not only to encourage their older relatives to visit their providers to have a con-

versation about PrCA, but to keep them and their relative informed about the most up-to-date PrCA information online. On the other hand, older men who have been through the informed decision-making process can help to prepare younger men to make a PrCA screening decision. Also, by having open dialogue about PrCA, older men may feel more comfortable informing younger men if PrCA is discovered. Subsequently, a younger man with a family history of PrCA can decide how early he would like to start having conversations with his provider about whether or not to receive PrCA screening at all.

### *Recommendation 3: Use Technology When It Is Appropriate*

CPCP researchers have had great success with using technology for health behavior assessments, promoting PrCA education and decision-making, and predicting the virulence of PrCA.<sup>22,24-27</sup> The first two scenarios of technology use are the most salient to this section. Prior to deploying technology in either of these groups, the research team investigated the prior use of similar technologies among comparable groups of people. Furthermore, training was available to participants (eg, Photovoice training), and all study activities were voluntary. Overall, many of our participants had some level of familiarity and comfort with using technology and were open to using technology for informing us about their health decision-making or learning about PrCA. In some cases, technology use may not be as appropriate based on acceptance of and access to the technology by the target population.

*Recommendation 4: Aim to Create Interventions with Community and Clinical Translation*

One goal that is central to CPCP is the notion that the work should have high-value to the scientific community and be translated in ways to sustainably benefit community and clinical partners. Much of our recent work may have a high probability of being used by health care providers to guide patient care. The CBDA, for example, can be incorporated into existing tablet-based check-in systems or their appointment sent to patient phones through an electronic medical record system. Therefore, patients are ready to make informed decisions about PrCA screening with their providers at the times that they choose. The repeat PSA algorithm can be used by medical teams as an in-clinic computer application to assist the patient and his health care provider with making decisions about PrCA treatment. By creating interventions with the goal of improving clinical translation, researchers have a better chance to expose practitioners to the scientific innovations that we have investigated. This will ensure that we will have an impact far beyond the waves we create in our own scientific communities. Plans for disseminating research innovation in a way that is translatable should be explored during the conceptualization of the research, though this can happen at a stage during our conceptual model. Therefore, individuals who are key to the translation process (eg, EMR companies, physicians, technology transfer office), should be involved as early as possible as they may have suggestions for increasing the odds that your technology can be

transformed into a sustainable tool for your target market. Our center is currently engaging in these discussions about the CBDA, which is at the dissemination stage, and the repeat PSA algorithm, which is at the discovery stage, with guidance from attorneys in our technology transfer office.

**CONCLUSION**

Informed decision-making as it relates to preventing unnecessary PrCA deaths is not just one decision, but a series of decisions. If a man receives screening and his results are indicative of PrCA, he and his health care provider then need to decide whether or not he should have a biopsy and then consider further treatment options. Because of the various screening outcomes, men may need to be informed about next steps given each outcome. This knowledge will be especially important for AA men for whom PrCA is typically more aggressive,<sup>37</sup> more likely to be diagnosed in later stages, and be diagnosed at an earlier age than in their EA counterparts.<sup>38</sup>

Therefore, CPCP researchers will continue working in partnership with community and clinical stakeholders to better understand this complicated decision-making process and continue to develop community-driven interventions that will empower men, their families, and vast communities to make informed PrCA decisions.

**ACKNOWLEDGMENTS**

Our research was approved by the University of South Carolina institutional review board (IRB) and all procedures followed were in accordance with the ethical standards of the IRB and the Helsinki Declaration of 1975, as revised in 2000. Accordingly,

participants in all studies mentioned in this article consented to participation prior to their involvement.

**CONFLICT OF INTEREST**

No conflicts of interest to report.

**AUTHOR CONTRIBUTIONS**

Research concept and design: Owens, Friedman, Hébert; Acquisition of data: Owens; Data analysis and interpretation: Owens; Manuscript draft: Owens, Friedman; Statistical expertise: Owens; Acquisition of funding: Owens; Administrative: Friedman, Hébert

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