

Needs of Black Men at the Point of Prostate Cancer Diagnosis (PPCD): The Florida CaPCaS Study

Odedina, F.T^{1*}, Young, M.E², Pereira, D², Williams³, Nguyen, J¹, Dagne, G⁴

¹College of Pharmacy, University of Florida Research and Academic Center, Orlando, FL, USA

²College of Public Health and Health Professions, University of Florida, Gainesville, FL, USA

³College of Medicine, University of Florida, Jacksonville, FL, USA

⁴College of Public Health, University of South Florida, Tampa, FL, USA

***Corresponding author:** Folakemi Odedina, College of Pharmacy and Medicine, University of Florida Research and Academic Center, Orlando, FL 32827, Tel: 407-313-7112; E-mail: fodedina@cop.ufl.edu

Abstract

Black men are disproportionately affected by prostate cancer (CaP) and continue to experience disparities across the CaP care continuum. The care received at the point of CaP diagnosis (PPCD) is extremely important to help Black men cope with CaP. The Florida Prostate Cancer Care and Survivorship (CaPCaS) study focuses on developing a theoretical framework that explains the CaPCaS experiences of Black men. This particular study focuses on the needs of Black men at the PPCD. Driven by grounded theory, study included interviews from 31 Black men, 17 US born Black men and 13 Caribbean born Black men. PPCD needs expressed by Black men included having physicians make them comfortable, time to come to terms with the diagnosis, and psycho-oncology/emotional support. The developed framework provides information that can be used by physicians to prepare for their PPCD consultation with Black men. Providing Black men with immediate support to cope with the diagnosis may make a significant difference in effective treatment choices and eliminating treatment decisional regrets.

Keywords: Black men; Grounded theory; Prostate cancer diagnosis; Prostate cancer survivorship

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Introduction

Disparities in prostate cancer (CaP) continue to be a major problem, especially for Black men. The American Cancer Society estimates the risk of CaP to be 70% higher in Black men compared to non-Hispanic Whites^[1]. Black men are also more likely to die from the disease compared to any other racial/ethnic group. According to the Institute of Medicine's report, potential sources of the CaP disparities seen in Black men can be at individual (personal or provider), institutional or health systems level^[2]. Several published articles have also documented potential reasons for the CaP disparities experienced by Black men within the last two decades^[3-13]. Some of the reasons include biological differences, higher testosterone level compared to other ethnic groups, poor CaP survival rate, late stage presentation,

high grade of CaP, aggressiveness of the disease in Blacks, inadequate knowledge, economic factors, limited health care access, lack of trust for the health care system and inappropriate diet.

About 30,000 Black men will hear the words, "you have prostate cancer" in 2016^[1]. Hearing the devastating news of CaP diagnosis can lead to several emotions. As expected, Black men's reaction to initial CaP diagnosis varies, from being shocked when notified of their initial CaP diagnosis to the perception of getting a "death sentence"^[14,15]. Relative to treatment decisions, while some Black men indicated that the information received from physicians decreased their anxiety^[16], other Black men's experiences included not being given adequate information to make a decision by a physician^[17]. Some patients reported that they were not given options for treatment or were in shock



and could not provide input. Patients have also reported that they felt as though they were not knowledgeable enough to ask questions concerning treatment options and preferred for the physician to make the choice for them^[18]. Unfortunately, decisional regret is now a common observation among men who are not involved in making treatment decisions^[15].

For Black men who find themselves at the Point of Prostate Cancer Diagnosis (PPCD), it is important to understand their needs and help them cope effectively as they navigate the CaP survivorship continuum. Overall, not many studies have been conducted to comprehensively understand the needs of Black CaP survivors. In line with our research program's goal of ensuring quality cancer care for Black men, the primary objective of this study was to explore the needs of Black men at the PPCD. This study is part of a large scale study that focuses on developing a model of CaP care and survivorship (CaPCaS model) using grounded theory to study ethnically-diverse Black CaP survivors.

Materials and Methods

Research design and population

The study design was a prospective, grounded theory study that involved one-on-one in-depth interviews of 31 CaP patients on their CaP care and survivorship (CaPCaS) experiences. Based on the principles of community engagement research and guided by open-ended questions, one-on-one in-depth interviews were conducted with each participant in their home or at a convenient location in the community. Qualitative research was the methodology of choice because we were exploring research areas where relatively little is known about the PPCD needs of Black men. Specifically, 17 native-born US Black men (NBBM) and 14 Caribbean-born Black men (CBBM) were enrolled in the project.

The study setting was Florida. The inclusion criteria were Black men; personal history of CaP; ability to complete two separate interviews with each one expected to last 2 - 3 hours; and flexibility to meet interviewers at a convenient community site for the interviews. Participants were identified through the Florida Cancer Data System (FCDS)^[19] (Florida Department of Health, 2007) database. The Florida Department of Health (DOH) Bureau of Epidemiology published standard procedure for the FCDS (Florida Department of Health, 2007) was employed to recruit participants.

Data collection and analyses

The data collection was conducted by a trained Community Health Worker (CHW) using semi-structured interview process. The interview guide was constructed by the research team and the study community advisory board (CAB) members to ensure language appropriateness, understanding and cultural sensitivity. The interview questions focused on participants' background information and diagnosis history, including: participants' personal story of diagnosis, feelings, emotions, reactions, regrets and level of personal/family/physician involvement in diagnosis.

The study dataset included interview transcripts and field notes of the CHW interviewer describing his insights about the interviews. The data analyses included preparing and verifying the narrative data, coding data, and abstracting the themes

that evolved on the needs of Black men at the PPCD.

Results

Seventeen native-born US Black men (NBBM) and 14 Caribbean-born Black men (CBBM) were selected to participate in the current study. The majority of the participants were between 50 and 69 years (74.19%), did not have college degree (64.52%), and were currently married (61.29%).

Reflecting back on their experiences, the men identified clear needs at the PPCD. One of the needs identified by the men is *having a physician they are comfortable with* to discuss their diagnosis. For example, Participant 1594 (NBBM) expressed his comfort with a physician who shares the same racial background with him.

I didn't know who to talk to.... And it was this doctor—not calling any name—that I ran into, and he was of color, like I was....I'm saying, lots of time, we don't know who to talk to. There's no one to talk to, so we're embarrassed. But I just happened to know this doctor—....and we became friends.

Another need shared by participants is the *need for a second opinion*. Participant 1594 (NBBM) advised that it was important for Black men to take control by requesting for a second opinion.

Just because one doctor said, "We need to give you some treatment," that don't mean you need to do that. Get a second opinion because doctors are not God. They're practicing. And so I'm so glad, um, that I did this because it wasn't that severe.

Another important need was *emotional support at the PPCD*. Participant 1594 (NBBM) expressed a need for empathy:

But I finally went to the, um—they got me a room where I could wait on the doctor. I sat there, and the lights were dim. I guess that's to make you relax. Uh, but one thing that was most disturbing to me was when the doctor came in the room. He just asked me when was I ready—what treatment I wanted. And I looked at him crazy because he had not identified himself. He hadn't said good morning. And I said, "Look. Let me think on this." I said, "Because you haven't said good morning or nothing. You're just asking me when I want to start the treatment." I came, went back to the car, and I knew I had to do something. So I said, I need to talk to someone.

Participant 2024 (CBBM) made a strong case for emotional support, especially for men who are not accompanied during diagnosis.

When the doctor told me, and, um, you know, and this was where I think—the medical profession could be improved, um, in term—he-he came to me, he was very matter of fact. He said, um, "The-the-the treatment method which we can discuss. Thank you very much." And I was in a daze just listening to cancer, you know. I-I went to my car and sat a while because I was not, um, in the-in the mind to-to drive. I could've been dangerous. And I felt, and I-I've said this to several people, I didn't expect the doctor to remain there holding my hands. He had other patients to see. But I feel that in the doctor, uh, urologist office there should be someone after someone is given that diagnosis to sit with them and chat with them and-and make sure they're-they're all right before they walk out of the office. So I felt, uh, I felt that—I felt in some way that was lacking.

In addition, Participant 2024's (CBBM) reflections underscores the fact that the PPCD may not be an ideal place or time to discuss treatment options. With the range of emotions that the men go through at the PPCD, it is difficult to comprehend any follow up discussions after the words "you have CaP".

Participant 2024 (CBBM) also strongly expressed that men *need time to deal with the diagnosis* at the PPCD.

And, again, he wasn't rude. He was—he was—he just told me what to do, and said, "Okay, um, um, I gotta go." You know, he gotta go. Of course, he had other patients in the—in the office waiting. And I had—and I had—it took me a good half an hour to recover, get myself together before taking off.

—and I just feel that, um, maybe not everyone takes it like me, but I feel that, um, there should be something there to—in terms of, um, helping people transition. Even, "Are you all right to go home? Are you all right to get in your car?" Because getting into a weapon.

Another participant expressed a strong desire for *immediate action* (Participant 975, CBBM):

Then I se—go there. Then, uh, when they start to do the test thing like that, then, uh, they tell me, "Yes, definitely you have." I-I say, "How big? How fast is it?" They say, "Well, is not that sudden on you." But, uh, they're goin' look at it, and at three months a level, uh-uh, how fast is-is grow. And I say, "Well, no matter what's fast it go in the defeating, you got to do what I want to do. I want to take it out."

Discussion

A significant contribution of this study is the identification of the needs of Black men at the PPCD as eloquently expressed by Participant 2024 (CBBM).

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In addition to having physicians make them comfortable at PPCD, the PPCD needs expressed by participants included time to come to terms with the diagnosis, psycho-oncology/emotional support. Anyone who has just received a diagnosis of cancer cannot be expected to immediately continue to function as he was prior to the PPCD. This is especially difficult for men who are alone at the PPCD. Nevertheless, it is expected that the men will listen attentively and understand subsequent consultation by the physician, leave the consultation room almost immediately and may have to drive home or back to work right after CaP diagnosis. There seems to be a support gap that needs to be closed at the PPCD. Providing the men with immediate support to cope with the diagnosis may make a significant difference in effective treatment choices and eliminating treatment decisional regrets.

Conclusion

The primary goal of this study was to develop a framework that explains the experiences and needs of Black men at the PPCD. The PPCD interpretative framework describes the status of Black men at the PPCD, their experiences during the PPCD and their needs at the PPCD. The framework provides

information that can be used by physicians to prepare for their PPCD consultation with Black men as well as develop a support system for Black men at the PPCD.

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