

Point of prostate cancer diagnosis experiences and needs of black men: the Florida CaPCaS study

Folakemi Odedina, PhD,^a Mary Ellen Young, PhD,^b Deidre Pereira, PhD,^c Christopher Williams, MD,^d Jeniffer Nguyen, PhD,^a and Getachew Dagne, PhD^e

^aDepartment of Pharmacotherapy and Translational Research, College of Pharmacy, University of Florida Research and Academic Center, Orlando; Departments of ^bOccupational Therapy and ^cClinical and Health Psychology, College of Public Health and Health Professions, University of Florida, Gainesville; ^dDivision of Urology, College of Medicine, University of Florida, Jacksonville; and ^eDepartment of Epidemiology and Biostatistics, College of Public Health, University of South Florida, Tampa

Background Black men are disproportionately affected by prostate cancer and little is known about their experiences at the point of prostate cancer diagnosis (PPCD). Men who self-identify as black are commonly treated in a singular cohort even though they may be of diverse ethnic origin. This is especially important given the increasing number of foreign-born blacks in the United States.

Objective To examine the experiences and needs of ethnically diverse black men at the PPCD to develop an interpretative framework.

Method The research population was black men who had been diagnosed with prostate cancer during 2006-2010. We used a qualitative research design based on grounded theory principles. Using a semistructured interview guide, a trained interviewer collected data on the participants' PPCD experiences. The data analyses included verifying the narrative data, coding data, and developing an interpretative framework.

Results From an initial sample of 212 black men, data were collected from 31 participants. The interpretative framework that emerged from the study describes the status of black men at the PPCD, experiences of black men at the PPCD, and emotional reactions of black men at the PPCD. Of note is the need among men at the PPCD for psycho-oncology support, emotional support, and time to reflect on the diagnosis.

Limitations Men with different experiences may have chosen not to respond to recruitment efforts or refused participation in the study.

Conclusion The framework provides information that physicians can use to help their patients cope at the PPCD.

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As of 2016, Florida ranks second among all states in the United States in estimated new cases of prostate cancer and second in estimated deaths from prostate cancer.¹ Disparities in diagnosis, mortality rates, and access to cancer care also continue to be a major problem in Florida, especially for black men. For example, black men were the only racial/ethnic group that did not meet the Healthy People (HP) 2010 objective to reduce the prostate cancer death rate to 28.2 per 100,000 men and that has not met the HP 2020 objective to reduce the prostate cancer death rate to 21.2 per 100,000 men (Table 1). Based on the 2013 prostate cancer mortality rates for Florida,² the death rate for black men is almost twice the HP 2020 goal (37.49 per 100,000).

A diagnosis of prostate cancer is a life chang-

ing event for a man. In particular, there is limited research on the experiences and coping mechanisms of black men at diagnosis. This limited body of research indicates that black men's reactions to their initial diagnoses varied, from being shocked when notified of their initial diagnosis of prostate cancer,³ to perceiving that they had received a "death sentence".⁴ In regard to having to make decisions about their treatment options, some black men indicated that the information about treatment that they received from physicians decreased their anxiety,⁵ whereas others noted that they had not been given adequate information by a physician to make a decision.⁶ 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 treatment

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TABLE 1 Florida prostate cancer burden by racial/ethnic groups (per 100,000 men)

Year	Hispanics	Non-Hispanic white	Non-Hispanic black	Healthy People 2020 Goal
2012	55.81	51.60	96.91	21.2
2013	17.09	15.16	37.49	

choice for them.⁶ Decisional regret is now a common observation among men who are not involved in making decisions about their treatment.³

According to the American Cancer Society, about 30,000 black men were diagnosed with prostate cancer in 2016.⁷ It is important to understand these men's needs and help them cope effectively as they navigate the survivorship continuum. 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 experiences and needs of black men at the point of prostate cancer diagnosis (PPCD). Specifically, we developed an interpretative framework for black men's experiences at the PPCD, focusing on United States or native-born black men (NBBM) and Caribbean-born black men (CBBM). African-born black men were not included in this study because of the low sample size for that ethnicity. This study is part of a large-scale study that focuses on developing a model of prostate cancer care and survivorship (CaPCaS model) using grounded theory to study black, ethnically diverse prostate cancer survivors.

Methods

The study aims to close the prostate health disparity gap for black men in Florida through community engaged research in partnership with survivors of prostate cancer and their advocates. The current study was a prospective, grounded theory study that involved one-on-one, in-depth interviews with 31 prostate cancer patients about their care and survivorship experiences. Specifically, 17 NBBM and 14 CBBM were enrolled in the project. Appropriate human subjects review and approval were obtained from the University of Florida, the Florida Department of Health, and the Department of Defense.

Research design

This is a qualitative research study. Based on the principles of community engaged research and using a rigorous qualitative research methodology, we recruited NBBM and CBBM with a personal history of prostate cancer. Guided by open-ended questions developed by the team, one-on-one in-depth interviews were conducted with each participant in their home or at a convenient location in the community. Our primary focus was on the participants' care and survivorship experiences, with primary focus on their prostate cancer diagnosis. Qualitative research was our methodology of choice because little is known about the PPCD experi-

ences of black men.⁸ With qualitative research, we were able to get our participants to "relive" their experiences in the presence of a culturally competent, well-trained interviewer and elicit the information about their care and survivorship experiences based on their interpretation. In addition, we were able to capture the dynamic processes associated with their experiences, documenting sequential patterns and change through both verbal and nonverbal communications, because the participants were interviewed twice.

Research population and recruitment

The study setting was Florida. The inclusion criteria were: black men, personal history of prostate cancer, 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)⁹ database. At the time of the study, the most recent FCDS database was for 2010. The FCDS has collected the number of new cancer cancers diagnosed in the state of Florida annually since 1981. It is a comprehensive incidence-only registry and does not extract data on patients with a death certificate. All investigators are bounded by the confidential pledge required for the use of the FCDS data.

We used the Florida Department of Health's (DoH's) Bureau of Epidemiology standard procedure for the FCDS⁹ to recruit participants. Our recruitment strategies included: initial patient contact by written correspondence; second mailing that included a telephone opt-out card after 3 weeks for nonrespondents (the telephone opt-out card explained to the patient that if no response was received, the study investigator would attempt a telephone call to introduce the study); and a telephone call by a study staff to introduce the study for nonrespondents. As per the Florida DoH standard procedure, we did not disclose on the cover of the study mailings that the patient was being contacted for a study specific to cancer. Efforts to recruit a patient stopped immediately if a patient indicated that he did not wish to participate. All of the study staff making participant contact were extensively trained to provide a clear and accurate description of cancer registration in Florida. In addition, to assist the study staff in providing clear and accurate responses, responses to frequently asked questions were made available to the study staff. During the participant recruitment phase, anyone who seemed to be upset when contacted was reported immedi-

ately (within 24 hours) to the DoH cancer epidemiologist. In addition, the name of anyone who stated that he did not wish to be contacted again was given to the DoH so that the person would not be re-contacted.

Prescreening of participants for eligibility

All eligible participants who agreed to participate in the study comprised the pool of potential study participants. For those who agreed to participate, the following information was obtained by telephone interview using REDCap software:¹⁰ name and contact information, country of birth, age, marital status, and education level. The demographic information facilitated a purposeful systematic selection of black men of diverse age groups (younger than 50 years or older than 50 years), marital status (single, including divorced or separated, or married/in a relationship), and educational level (college degree or not college educated). An incentive of a \$5 gift card was provided to all the men who participated in the screening phase. Using systematic sampling to ensure demographically diverse participants, 40 participants (20 NBBM, 20 CBBM) were selected from the initial pool of participants to participate in the study.

Data collection

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 members to ensure language appropriateness, understanding and cultural sensitivity. For this study, 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. For the CBBM, we also obtained information on the age at which they immigrated to the United States. The CHW interviewer was trained to question participants and encourage them to elaborate on areas of importance to their experience.

A total time of about 5-6 hours was scheduled for the data collection per participant, which is sufficient for gathering in-depth perspectives. We scheduled two interviews lasting not more than 3 hours at a time so as not to create burden for study participants. Participants had the choice to have the interviews completed in a single session or spread out over 2 days. The interviews were audio-recorded to provide ease of transcription and back-up of data. At the end of the interviews, participants were compensated for participating in the study.

Data management and analyses

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 develop-

ing an interpretative framework for black men's experiences at the PPCD. Interviews were transcribed verbatim by a professional transcription service that has policies in place for protected health information. Each transcript was then verified for accuracy by the CHW interviewer. The interview transcripts were imported directly into NVivo 11, a computer-assisted data analysis software that allows coding and modeling of complex narrative data. The data coding was conducted by our interdisciplinary team of clinicians, behavioral scientists, and social scientists. It is important to note that the NVivo 11 software was not used to analyze the data per se. However, it provided a sophisticated and systematic way to manage the following tasks for the analyses: organizing large quantities of narrative data, coding text, retrieving text by codes, querying the data, comparing sets of data interpretation between NBBM and CBBM; and developing analytic models. The study team members coded the data in weekly team meetings. The coding consisted of reading the data and identifying major themes, then assigning labels to and defining emerging categories.

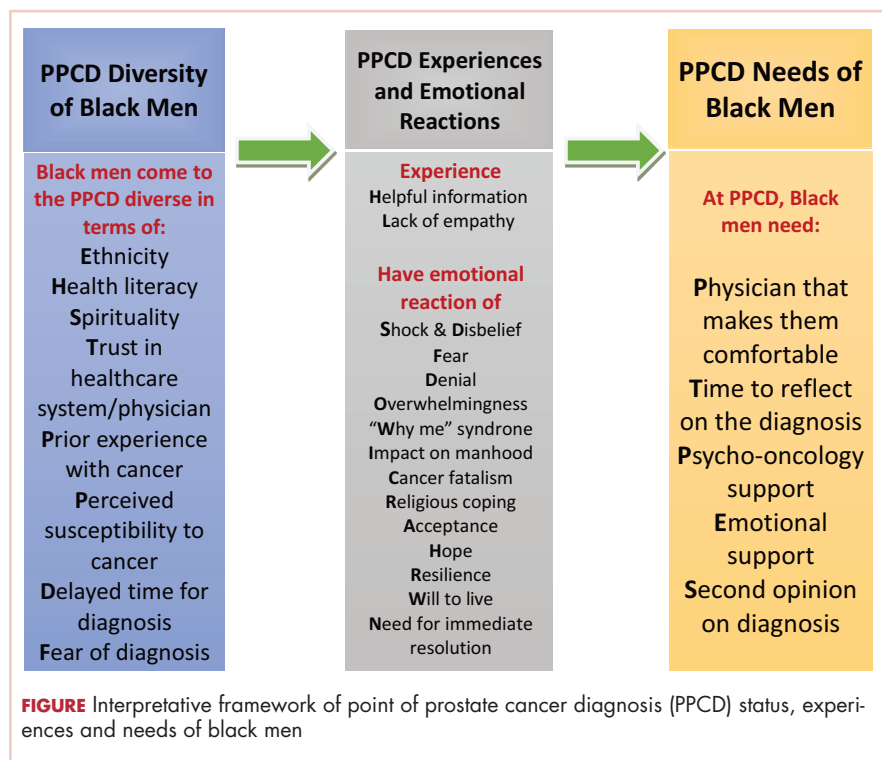
Two levels of coding were used. The first, open coding, refers to an approach to data with no preconceived ideas about what will be found; and the second, focused or axial coding, refers to reviewing data for the purpose of more richly coding on a particular theme.¹¹ We used dimensional analysis to ensure that each emerging concept was carefully defined. The study team went back and forth between the data and the emerging analytic framework, using constant comparison of new data with already coded data and new categories with previously analyzed text.¹²

To ensure trustworthiness and credibility,¹³ the study team maintained an audit trail that documented how and when analytic decisions were made. In addition, peer debriefing was conducted to ensure credibility, including the presentation of findings to the study community advisory board members as part of the community engaged research approach.

Results

Description of participants

The FCDS provided a database of 1,813 participants identified as black men diagnosed with prostate cancer in 2010. Because the FCDS does not extract data on patients with a death certificate, we found out during the pre-screening phase that a few of the men were deceased. In addition, there were a significant number of incorrect addresses. We obtained a total of 212 completed responses by phone during the prescreening phase. The majority of the participants were aged 60-69 years (48.2%), had a high school diploma only (26.1%), and were currently married (65.3%). Relative to ethnicity, 67% of participants classified themselves NBBM, 24% as CBBM, 3.5% as black men born in Africa, and 5.5% as Other/Don't know/Refused. For the CBBM, the most common countries of birth were Jamaica, Haiti, and Guyana, respectively.



In all, 40 participants (20 NBBM and 20 CBBM) were selected from the 212 participants to participate in the study. Selection was conducted systematically to ensure representation in terms of age, marital status, education, and geographical location. Data saturation was achieved with 17 NBBM and 14 CBBM, after which we ended data collection (Table 2). Data saturation is the standard for deciding that we are not finding anything different from the interviews first coded and last coded. Although we were specifically looking for differences between the two groups (NBBM and CBBM), no between-group differences emerged. Each man's experience was unique to him with some common themes emerging described hereinafter (Figure).

Moderating factors and experiences at PPCD

Some of the moderating factors that the study participants identified as affecting their reactions to the PPCD included health literacy, insurance status, spirituality, mistrust, prior experience with cancer, perceived susceptibility to cancer, and delay in diagnosis (Table 3, p. 15). Health literacy, defined as personal, cognitive, and social skills that determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health, was one of the moderating factors found in this study.¹³ Some of the black men came to the PPCD with a low level of health literacy, which had an impact on their understanding of the treatment options. For example, in the interview, participant 798 (NBBM) was confused about what tests had been done and was not able to accurately describe the treatments offered

to him. Participant 1263 (CBBM) struggled to express the purpose and procedures associated with diagnostic biopsy. However, there were participants with a high level of health literacy (eg, participant 449 [NBBM]), who decided to research the disease.

Another factor to consider is the insurance status of participants at the PPCD. The majority of the participants had good insurance coverage, but some were affected by poor insurance coverage. Participant 1881(NBBM) made his treatment decision primarily on the basis of the pending lapse of his insurance coverage rather than the best clinical option for him. Participant 1979 (CBBM) described both his confusion on the screening tests and the impact of not having insurance coverage. Upon obtaining insurance coverage, he sought treatment for his prostate cancer with an urgency

that he did not experience when he was first diagnosed when uninsured.

The spirituality of black men was another moderating factor at the PPCD. Participant 827 (NBBM) noted that he was unaffected when he received his diagnosis because he was a true believer. Some of the black men also came to the PPCD with lack of trust in the physician and/or the health care system and perceived a sense of contempt from the physician. Participant 1594 (NBBM) described mistrust based on the history of medical exploitation of black men as well as a perception of current discriminatory practices.

Another important PPCD status to note for black men is prior experience with cancer, including prior personal cancer history and/or prior cancer history of a family member. Participant 2024 (CBBM) described the meaning of cancer to him, while participant 798 (NBBM) echoed the despair of the cancer diagnosis based on experience with other cancers in the family. Sometimes there were multiple cancers in the family or even among the significant others of the participant, as was the case with Participant 1936 (CBBM).

Of greatest concern were men who delayed their diagnosis or treatment, perhaps resulting in their cancer being at a more advanced stage when they eventually did return for care. Finally, some of the men came to the PPCD appointment with a low expectation of receiving a diagnosis of prostate cancer, whereas others came to the PPCD fearful of the results of their testing.

In describing their experiences, participants expressed both positive and negative experiences: on the positive side,

TABLE 2 Participants' demographic characteristics (N = 31)

Characteristic	No. of patients (%)
Ethnicity	
Native-born black men	17 (54.84)
Caribbean-born black men	14 (45.16)
Age, y	
<50	1 (3.23)
50-69	23 (74.19)
≥70	7 (22.58)
Education	
Less than college degree	20 (64.52)
College degree or higher	11 (35.48)
Marital status	
Now married	19 (61.29)
Widowed	4 (12.90)
Divorced	4 (12.90)
Separated	1 (3.23)
Never married	3 (9.68)
Presence of family/friends at PPCD	
None	25 (83.33)
Wife only	5 (16.13)
Adult daughter only	1 (3.22)

PPCD, point of prostate cancer diagnosis

they found the information provided by the physician to be helpful; but on the negative side, the sterile or medically-focused encounter was perceived as a lack empathy on the part of the physician.

Cognitive, emotional, and behavioral coping experiences

As expected, there were ranges of emotions, including shock, disbelief and denial (Table 4, p. 17). Some of the men questioned why *this* (the cancer) was happening to them when they had done “nothing” to deserve it. *Doing nothing* in this case meant that they had lived a healthy lifestyle with no obvious apparent cause to have the cancer. Fear and cancer fatalism were experienced by a significant number of the men, with their thoughts immediately turning to death and dying. This was especially the case for men who had lost a loved one to cancer. Conversely, some of the men wanted immediate resolution, focusing instead on ways to beat the cancer and with a strong will to live.

Reliance on faith was a big part of coping at the PPCD. Some of the men drew strength from their faith to get them through their cancer journey. Others found a way to accept the diagnosis – one participant accepted the diagno-

sis and the fact that this could mean dying (after living a good life), whereas another participant accepted the diagnosis with the hope that he would find a cure. Hope was more realistic with the knowledge that other men had survived prostate cancer.

Reflecting back on their experiences, the men also identified clear needs at the PPCD. One of the needs they identified was having a physician they were comfortable with to discuss their diagnosis. Another need was for a second opinion. Participant 1594 (NBBM) advised that it was important for black men to take control by requesting a second opinion. Participant 2039 (NBBM) described a feeling of navigating blindly and trying to find answers that would be helpful to him in his cancer journey. However, his experience with a second opinion was not helpful because the second physician was at the same clinic as his primary physician. His recommendation was to get a second opinion at a different clinic or center. Another important need was emotional support at the PPCD. Participant 2024 (CBBM) made a strong case for emotional support, especially for men who are not accompanied during diagnosis. In addition, Participant 2024's (CBBM) reflections underscore 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 hearing the words “you have prostate cancer.” Participant 2024 (CBBM) also strongly expressed that men need time to deal with the diagnosis at the PPCD.

Discussion

The primary goal of this study was to develop an interpretative framework of black men's experiences at the PPCD. The Figure provides a pictorial summary of the framework. Study results indicated that black men come to the PPCD with different emotions and different experiences. Although the majority of the men were NBBM, there is a significantly increasing number of foreign-born black men receiving a diagnosis of prostate cancer in the United States. Given that black men carry a disproportionate burden of the disease, with a significantly higher incidence compared with any other racial group, it is important that tailored services are provided to black men at the PPCD.

We also found that black men came to the PPCD diverse in terms of their ethnicity, health literacy, spirituality, trust in health care system/physician, prior experience with cancer, perceived susceptibility to cancer, delayed time for diagnosis, and fear of diagnosis. Of importance for physicians is that the black race is not homogeneous. There is a significant number of foreign-born blacks at the PPCD, and they often have different cultural beliefs and values compared with NBBM. In addition, some of the foreign-born black men may not have English proficiency and may need a medical interpreter during the PPCD consultation. In addition, a patient's pre-existing lack of trust in the

TABLE 3 Moderating factors that affected the reactions/experiences of black men at PPCD

Identified factors	Participants' expressions
Health literacy	<p>Participant 798 (NBBM) Yeah, yeah. We, uh—I had—I had—I had two—I had two, uh—the options they gave me—they could go—they could do a—uh, like a surgery— ... and, uh—and they could do a—a—a—wow, man. I can't pronounce these big words. Uh, it's somethin' like a bop—bop—mmm. Well, anyway, it was between the surgery and, uh, the—the blaze—the blaze. It was, uh—it was—what you call it? It's, uh—it was a blazer treatment. It was like a—a blazer where you get—it's just—just what—they set—they lay you on this table, and then they turn this big machine, you know, and it go across your bodyThen it come back around cross your body, and then—then when they do that, then you get up. It's just like a blazer that goin' in there cuttin', you know, or—or burnin' the cells in—inside you.</p> <p>Participant 1263 (CBBM) They find out, my last test I have is when I have the um, the bionic shot. The 12 shots Yeah, 12 shots. That's—that shot is just like a test to you, they put the full light on, put you to sleep if you want to sleep, if you don't want to sleep the camera up in your bomsee and then it tests your 12 shots and send to test and come back—four come back positive, and the rest then came back normal The four positive was aggressive.</p> <p>Participant 449 (NBBM) I can say that for sure, and probably with my father as well. The reason that I started, um, monitoring my PSA was because, uh, my father finally talked to me about his prostate cancer. I did some research on it, and one of the first things that I, uh, read was that prostate cancer could be hereditary. With that in mind, I decided that I needed to do something to make sure that if I was going to get prostate cancer, that I knew about it as soon as possible.</p>
Insurance status	<p>Participant 1881(NBBM) And I think—but I was guided—I think I was led that way by—by options that were not viable, that were not given to me with the—once again, it was the policy beginning to lapse, not bein' renewed, not knowin' whether or not I'm gonna be able to get insurance to—to follow through on that. And so there's an urgency situation here as well. I gotta get up under this before that policy lapse and get this done.</p> <p>Participant 1979 (CBBM) Uh, I learned, uh, eh, I had prostate cancer—when I get prostate cancer, and I—uh, no. First time, before, I don't—I don't have, uh, insurance. I go to the clinic that gives me—they put me in their program, but the doctor one day told me, "_____, you're supposed to make a test, a digital test."... its name PCS—S—PSA, I think so—to check if you, uh, negative about that, but I scared because I know on the first time they do that for me, eh, I don't like it. And then I—I'm—I am a little bit, eh—I'm a little bit, eh, shame about that. You know? ... but one day—when I got insurance from—in—insurance, I—I went, eh, to the doctor. The doctor, my primary doctor, the same. "_____, you have to take—you have to take a decision right now.'</p>
Spirituality	<p>Participant 827 (NBBM) You know what? It—for some strange reason, it did not—it did not affect me mentally because I'm a true believer that all things work for the ... good. And I believe in the man upstairs, and ... it just ... didn't affect me. So I got prostate cancer. Let's treat it. You could get rid of it and move on.</p>
Mistrust	<p>Participant 1594 (NBBM) And as black men—and I think one—and I can attest to this—we don't trust doctors because of the Tuskegee experiment and other things that they do They are sometimes—uh, white doctors, they look down or they don't want to touch you. And just, um, to point that out.</p>
Prior experience	<p>Participant 2024 (CBBM) Because, um, although I knew that prostate cancer, um, had the best chance of being cured of all the cancers, when the doctor told me I had prostate cancer, I did not hear prostate, I heard cancer. The big C. And my brother, um, my younger brother died, um, back in 2006 from, um, colon cancer, so that was—it was that close to me because I was diagnosed most about five years ago. So it was that close to me, the memory of him, I only heard cancer.</p> <p>Participant 798 (NBBM) First thing that came to my mind there, I said, "Oh, Lord, don't tell me that I got cancer." And I'm—I'm just seein' one of, my sister just died with cancer. And it just—the thing that started runnin' through my mind, the people I know that died with cancer, and I'm sayin', "Don't tell me I got this here." You know? And I—you know, and, uh—and I didn't never see, you know, uh—like, I wasn't never there, but I never seen nobody tell me they went to the doctor and all this here, and I said, "I don't wanna—I don't wanna be caught up in like that."</p> <p>Participant 1936 (CBBM) I mean, I was—I—I just was thinkin' of my dad and thinkin' of—um, well, at the time I had a—um, a fiancée. She also passed with—um, um, with cancer, was the—uh, I forget the one that what it's call, but she had that, you know. Then I also thought of my mom. My mom passed away with lung cancer in—uh, in her 90s.</p> <p>Participant 329 (NBBM) Here we go again. No, I—the—the process of having cancer.</p>
Perceived susceptibility	<p>Participant 2039 (NBBM) Prior to that—to—prior to that prostate cancer was foreign to me. It—it was somethin' that happens to everybody else and not me.</p>
Delay in diagnosis or treatment	<p>Participant 915 (NBBM) You know? Not like swollen. It just felt rough or somethin', I guess. Um, a year later he checked it again and said, you know, "It just feels strange." He'd like to take a picture of it. And then they took pictures, and he saw, uh, where it was discolored and, you know, deformed, and thought that it was cancerous.</p>

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Fearful of testing **Participant 847 (NBBM)** Well, it was just—I guess it—it was about—it was time for me to get a check-up. I had been putting it off and was scared, and so I said, “Well, I’m getting pretty old and I need to go in and get this checked.” And that’s how I—that’s how it came about. And—and um—

Experiences at PPCD **Participant 449 (NBBM)** Um, based on, uh, the information that, uh, the doctor shared with me, I—I thought the— the diagnosis was accurate. Um, I didn’t really have any, um, other questions that he or the staff could answer that they didn’t answer. They were pretty—pretty thorough in answering most of my questions.

Participant 1594 (NBBM) 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 was 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 cuz he had not identified himself. He hadn’t said good morning. And I said, “Look. Let me think on this.” I said, “Cuz 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.

CBBM, Caribbean-born black man; NBBM, native-born black man; PPCD, point of prostate cancer diagnosis.

health care system may have a negative impact on the PPCD consultation. It is thus important that the physician takes the time to instill trust and make the men comfortable during the PPCD consultation.

For some of the men who had fear of a prostate cancer diagnosis and/or prior experience with cancer, cancer fatalism was experienced at the PPCD. Cancer fatalism, defined as an individual’s belief that death is bound to happen when diagnosed with cancer, has been documented as a major barrier to cancer detection and control.¹⁵ For example, fatalistic perspectives have been reported to affect cervical cancer,¹⁶ breast cancer,^{17,18} colorectal cancer,¹⁹ and prostate cancer^{20,21} among blacks. It is thus important to effectively address fatalistic beliefs when a man is diagnosed with prostate cancer.

Other emotions at the PPCD that may affect effective treatment decision making also need to be addressed immediately. For example, the emotions of fear, denial, and feeling overwhelmed are potential barriers to timely treatment decision making. Psycho-oncology interventions to appropriately deal with these emotions at PPCD or right after the diagnosis may be crucial for the men. In particular, a group-based psychosocial intervention focusing on: provision of education about treatment options for prostate cancer and their acute and late effects; negotiating treatment and treatment side effects; enhancing communication with treatment providers; managing distress; and engaging positive family- and community-based social support to optimize emotional, behavioral, social, and physical outcomes in black men with prostate cancer.

In addition to having physicians make them comfortable at PPCD, the PPCD needs expressed by participants included having time to come to terms with the diagnosis and receiving psycho-oncology/emotional support. Anyone who has just received a diagnosis of cancer cannot be expected to immediately continue to function as he did before the PPCD. This is especially difficult for men who are alone at the PPCD. Nevertheless, it is expected that they will listen attentively and understand subsequent consultation by the physician, then leave the consultation room almost immediately, and be able drive home or back to

work right after the 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.

Methodological rigor was established through purposeful sampling, extended time with participants, standardized procedures for data collection, management and analysis, multidisciplinary interpretation, and validation of results with the community advisory board. Because the research participants were purposefully selected from a statewide database of black men diagnosed with CaP, generalizability of findings to the two target groups of NBBM and CBBM can be assumed, with the caveat that men with different experiences may have chosen not to respond to recruitment efforts or refused participation. Black men who were not sufficiently fluent in English to be interviewed were also excluded and are not represented in these findings. Black men of other nativity (including African-born black men) and residing outside of Florida were also not represented.

In conclusion, the PPCD interpretative framework developed in this study, 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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TABLE 4 Cognitive, emotional, and behavioral/coping experiences of black men at PPCD

Identified factors	Participants' expressions
Cognitive	
Denial	Participant 1354 (NBBM) Uh, why me? And denial. That –what? I'm in good health. You know, I didn't do anything wrong. I don't smoke, never smoked. You know, how did I get this cancer and where did it come from?
Cancer fatalism	<p>Participant 2128 (CBBM) It was just a question of—I was just being fatalist about it you know. It's one of these things that happens and I was fortunate that it was immediately diagnosed and treatment could be organized.</p> <p>Participant 2024 (CBBM) Because, um, although I knew that prostate cancer, um, had the best chance of being cured of all the cancers, when the doctor told me I had prostate cancer, I did not hear prostate, I heard cancer. The big C. And my brother, um, my younger brother died, um, back in 2006 from, um, colon cancer, so that was—it was that close to me because I was diagnosed most about five years ago. So it was that close to me, the memory of him, I only heard cancer.</p> <p>Participant 1822 (NBBM) When they first said cancer that's my, that's how my wife died, from cancer. So you know when it hit me I said, "Oh, you know, I gotta go too now." But I've been holding on now for—she been dead now 15 years.</p> <p>Participant 2039 (NBBM) "Am I gonna die?" and pretty much with cancer.</p> <p>Participant 486 (NBBM) Death. I'm afraid to die. Yeah, that was the first thing and would it come back.</p> <p>Participant 1970 (NBBM) First thing that came to my mind is I have a sickness that probably gonna take my life.</p> <p>Participant 355 (NBBM) [Sigh] The first thing. I say, "Well, is death near?" I'll be honest with you. I was scared. I said, "Well, if this is the way God wants me to end it, that's fine."</p>
Disbelief	Participant 2039 (NBBM) "Why me?" You know, at such a young age. Uh, I got diagnosed at 54, and I pretty, uh—I said I was 53—53 [and a half] when I got diagnosed. And bein' that the ma—the person said, "Cancer," it just—you know, it—it—it rocks your world when you don't know—you—you don't know nothin' about it. You know?
Thoughts about impact on manhood	Participant 486 (NBBM) What effect it would have on me, from being a male, you know, I feared rumors that—I had heard rumors that it would take your manhood away from you and everything about it. That you would never be the same.
Questioning/ exploring reasons	<p>Participant 1261 (CBBM) Um, you know, I was—I was just curious, you know, "What is it? Is it something I ate? Is it—is it the environment?" Or, you know, just—just kind of started looking at my lifestyle. I know like—but I never—I mean, I don't drink alcohol. I don't smoke. Um, in fact, I used to—did not detest people who smoke, but hate being around smoke and all that kind of stuff, so—and alcohol and stuff like that. I—and I—I thought I ate pretty healthy, so I was curious. "Man, you know, how did—how did I get this?"</p> <p>Participant 1261 (CBBM) I was like, "I—I can't believe it." I'm always healthy, always, you know, try to eat healthy, and, you know, I—I just questioned, you know, "What—what is it? What caused it?" You know, that was like, you know—you know, "What—what—what caused this?" So that was the biggest thing for me. I'm—I'm healthy. I've always exercised. I ran all the time, played soccer. I'm always movin'.</p>
Emotional	
Shock	<p>Participant 1970 (NBBM) I'm gonna repeat the same thing as it was—it was like slap in the face, but, uh, again, the reality, do—which—what I'm gonna do about it. You know, I'm gonna take care of this problem.</p> <p>Participant 847 (NBBM) I was shocked, scared, worried, you know, all of that. It—it kind of—it kind of flipped me. I didn't know how—how bad it was or nothing, but he told me it wasn't that bad, but I need to go in and get rid of it.</p>
Hope	Participant 355 (NBBM) And I remember I read about _____, the _____, has prostate, and it was treated, and he's still living. Uh, _____ has prostate. He was treated and is—and is living. And I think, uh, _____, uh, uh, _____, _____, the black guy, has prostate. He was treated and is living. So that kind of gave me some confidence that if I get a very good treatment, the end has not come.
Fear	<p>Participant 1822 (NBBM) Oh, it scared me a little bit then. You know?</p> <p>Participant 2128 (CBBM) Well, initially, there was a feeling of trepidation, fear, and disbelief, not knowing what to expect. Not knowing what was involved in the treatment. As I said, the only information or evidence that I could draw on was what my wife experienced when she was going through chemo and radiation treatment and I just hoped that it would not be as severe, at least at the outset. That the treatment would not be as severe to me as it was to her. Unfortunately, that was not the case.</p> <p>Participant 2024 (CBBM) Um, and it was scary when I was told I had prostate cancer, quite frankly.</p> <p>Participant 1594 (NBBM) And, um—it was a cold moment, okay?</p>

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Fight/resilience

Participant 866 (CBBM) Well, the first thing that comes to one's mind when they hear the—the big letter C is that, "Oh, man. This is a journey. It's a journey that can either put you in the grave or it's a journey that you're just gonna have to fight vigorously, but your life is basically changed." And so I had to look at it—I'm a—as—as—if—if it's was gonna kill me, I gotta go down fightin' with it. But it does change your life.

Participant 1970 (NBBM) And I think the most important thing about it is reading, getting information. Knowledge about prostate was the thing that, um, kinda brought me around to, "I can beat this."

Participant 847 (NBBM) Well, they kind of had me worried there for a minute. I didn't know what to expect or what to do, but I still—I felt good. I mean, you know, it's—you know, it's—it was just—just like a normal life. I—but I just knew I had this cancer and I had to get it out.

Participant 449 (NBBM) Um, nothing negative. Uh, it—fear was not, um, an emotion that I experienced when I got the diagnosis. Um, my only, uh, thought, I think, was, uh, how do I—how do I take care of this? You know, how do I cure myself?

Participant 449 (NBBM) Um, I knew that there was nothing that I had done that caused the disease. You know, I—I—it just—I just happened to be the one that—that had the prostate cancer. Um, my only concern was, you know, uh, uh, curing. You know, how do I recover from this and—and live another 50 or 60 years?

Need for immediate action/urgency

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."

Acceptance

Participant 1887 (CBBM) Well, I am a person who would accept, you know, what life—whatever life chose. As y—I do, I accept it. I realize we are all right. I have had—had—had a good life, and if this is how I have to go, well, then it didn't bother me too much.

Participant 1979 (CBBM) No. I'm not sad. I'm relaxed because I know I—I expect I'm going to find a result about that. Yeah.

Religiosity/faith

Participant 1261 (CBBM) Well, when my doctor told me. I had to go to the office, and when he told me I had cancer, I—he said—all he said to me, he said, "You know, I'm sorry to tell you, you have, uh, prostate cancer." And I stood there, and I remember walking outside of his office, um, and I lifted my hand, and I said, "Lord, you said, in everything, give thanks, both for good and the bad," and I just said, "It is what it is."

Participant 827 (NBBM) You know what? It—for some strange reason, it did not—it did not affect me mentally because I'm a—I'm—I—I—I'm a true believer that all things work for the—for the—for the good. And I believe in the man upstairs, and it—it just—it—it didn't affect me. So I got prostate cancer. Let's treat it. You could get rid of it and move on.

Participant 1263 (CBBM) I didn't feel nothing. I didn't broke down nothing at all. I was have faith and I was going through with it.

Will to live

Participant 527 (NBBM) First thing that came to mind: I don't want it to cut my life short. I want to go ahead and live a full life. I wanted to go ahead on and be able to do the kinda things that I used to do and—and—and enjoy. Uh, I didn't wanna leave my wife, uh, you know, early. You know? If I go a natural death, then I can't do anything about that, but if I can prevent leaving early by taking care of myself and going and get the—the necessary, uh, uh, medication, the necessary, uh, uh, surgery, or the necessary treatment to prevent me from passing early. It—it gave me the long longevity that I—I—I expected to receive.

Behavior

Delay taking action

Participant 1594 (NBBM) But what happened when I was diagnosed, I said, okay. Um, I just couldn't believe it. And it took me maybe two or three months to go to the treatment center. And when I got to the treatment center, um, I saw on the sign, cancer, and I got back in the car before I went in the building. Okay. God. It's saying cancer. I finally got enough nerve to get up and go back in, and I sat there.

Expressed needs

Need to be comfortable with physician

Participant 1594 (NBBM) 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. So I came to the office and got on the computer and typed this in and said, "I need to talk to somebody." And this doctor said, "Well, you can come in and talk to me." He reserved two hours just for me and him to talk. And, um, he discussed—I—I got my own—I brought the—the medical record with me. I made sure. ... 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—to know this doctor— ... and we became friends. And he took me in and said, "Well, look, my aunt—my uncle had it. My brother have it, so don't be embarrassed." So he made me comfortable.

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Need for a second opinion

Participant 1594 (NBBM) And by—to sum it up, you should all—do a second choice. Just take control. And I learned from that. 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 cuz doctors are not God. They’re practicing. And so I’m so glad, um, that I did this because it wasn’t that severe.

Participant 2039 (NBBM) Prior to that—to—prior to that prostate cancer was foreign to me. It—it was somethin’ that happens to everybody else and not me, but when it happens to you, you know, you kinda sit back and just ask, “Where do we go?” After the initial shock and the scariness of, you know, this radiation. What is this radiation gonna do? What is the seeds gonna do? ... and pretty much it—without havin’ knowledge of someone else who had already experienced it, you pretty much navigatin’ this thing in the blind. You takin’ other people words and literature that’s been con—I would say the literature that’s been compiled on someone else success rate or someone else, uh, uh, dealin’ with the issue, you know, but you don’t have nothin’ to compare it with because that’s who you was referred to. So you—you don’t get—when you ask for a second opinion—in my case, I got a second opinion from one of the partners, and that’s not a good thing ... yes. I—I—I—I say I highly recommend it (second opinion) due to—due to some of the complications that occurred at this particular center, I feel—you know, I feel that, uh, I would’ve been best served if I went somewhere else because you never know what the—my thought was when they say, “Well, you talk to Joe Blow over here. He’s gonna look at what we find and give you a second opinion.” And some of them opinions, as we would discuss later—they actually created more problems than if I would’ve went somewhere else and got another person that wasn’t a partner in the establishment.

Need for emotional support time to reflect on diagnosis

Participant 2024 (CBBM) Again, um, as I said, my other brother who had just died a few years with colon cancer, so I was very ... hypersensitive towards cancer. 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.

CBBM, Caribbean-born black man; NBBM, native-born black man; PPCD, point of prostate cancer diagnosis.

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