An Exploration of Precancer and Post-Cancer Diagnosis and Health Communication Among African American Prostate Cancer Survivors and Their Families

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Sabrina L. Dickey, PhD, MSN, RN¹, Caneisaya Matthews MS, BS², and Eugenia Millender, PhD, RN, PMHNP-BC, CDE¹

Abstract

Prostate cancer is the second most common cancer among American men, with Black men at the highest risk for the disease. Few studies have been published on how communication between Black prostate cancer survivors and their family members affect health outcomes and subsequent health communication. The purpose of this study was to understand cancer and health communication among Black prostate cancer survivors and their families before and after disclosing their diagnosis. Through a mixed method design, I I Black prostate cancer survivors participated from the Southeastern region of the United States, completed questionnaires, and took part in a focus group. The study utilized 4 focus groups of Black prostate cancer survivors ranging in age from 5 I to 76 years. Descriptive statistics revealed 91% (n=10) of participants indicated they could openly discuss health issues in their family and 82% (n=9) indicated a female relative as the person responsible for teaching about health. An analysis of the transcripts revealed four themes utilizing thematic network: (a) communication over the life course of the prostate cancer survivor, (b) parents' communication with family, (c) disclosing prostate cancer diagnosis, and (d) treatment options for prostate cancer. Results suggested the participants recognized the importance of discussing prostate cancer with their families to reduce fears and misconceptions about the disease. Through the exploration of cancer and health communication within Black families, solutions can be derived for increasing health behaviors and health knowledge among men.

Keywords

Prostate cancer, family communication, cancer communication, Black men, health disparity

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Background

In the United States, prostate cancer remains the second most common cancer among men and the second leading cause of cancer death in men (Gomella, 2017; Siegel et al., 2019). Since 1975, Black men have experienced higher prostate cancer incidence and mortality rates, approximately two times higher than those of White men in the United States. Prostate cancer clearly has a health disparity among Black men, compared to White men, despite a 5-year survival rate of 98% (National Cancer Institute, 2018). Data have identified multiple risk factors

including age, race, access to health care, and family history of the disease to account for the disparities (American Cancer Society, 2019; Centers for Disease Control and Prevention, 2019; Nettey et al., 2018). Men with a family

¹College of Nursing, Florida State University, Tallahassee, USA ²College of Medicine, Florida State University, Tallahassee, USA

Corresponding Author:

Sabrina L. Dickey, PhD, MSN, RN, College of Nursing, Florida State University, 98 Varsity Way, Tallahassee, FL 32306-4310, USA. Email: sldickey@fsu.edu

history of prostate cancer are two to three times more likely to receive a diagnosis of prostate cancer than men with no family history of prostate cancer (Centers for Disease Control and Prevention, 2019). In light of the familial risk of prostate cancer, sharing health information can be a vital aspect for bringing awareness of prostate cancer screening through the use of shared decision-making.

The varying guidelines/recommendations and lack thereof for prostate cancer screening further compound the health disparity of prostate cancer among Black men compared to White men. To address the prostate cancerscreening dilemma, shared decision-making is endorsed by leading health organizations such as the American Cancer Society and United States Preventive Task Force (Blackwelder & Chessman 2019; Ragsdale et al., 2014). The issue with using shared decision-making to receive a prostate cancer screening is that it requires men to be educated and willing to communicate about prostate cancer. Researchers observed that Black men were unaware of their increased risk for prostate cancer and had poor knowledge about the disease (Gwede et al., 2015; Jones et al., 2009; Lepore et al., 2017; Mofolo et al., 2015; Oliver et al., 2018).

To make an impact on the health disparity of prostate cancer among Black men, when compared to White men, research must be focused on cancer and health communication that occurs within their families. Given the known familial risk factors and need for shared decision-making for prostate cancer screening, an issue arises from a lack of research that examines factors during the formative years of the prostate cancer survivor's life, which influences the degree and manner in which health information is shared. Engaging in family discussions on cancer and health can alert immediate and distant family members to their risks of illnesses and the need for screening or engaging in healthy behaviors. In the context of the current study, immediate family members were comprised of parents, spouse, children, siblings, grandparents, and grandchildren, while distant family members consisted of aunts, uncles, and cousins. This manuscript explores the concept of cancer communication regarding prostate cancer and health among Black prostate cancer survivors and their families.

Cancer and Health Disclosure in Black Families

The study of cancer communication among prostate cancer survivors has focused heavily on communication between the physician and the patient to identify barriers to prostate cancer screenings and prostate cancer knowledge (Choi et al., 2018; Pedersen et al., 2012; Woods-Burnham et al., 2018). Studies indicated minimal health communication

regarding cancer and sexual function occurred among Black families (Friedman et al., 2012; Hovick et al., 2015; Thompson et al., 2015) due to lack of connection or closeness between family members, fear of gossip, stigmatization, and traditional views of health being a private topic (Bowen et al., 2017; Hovick et al., 2015; Thompson et al., 2015; Yamasaki & Hovick, 2015). Meanwhile, other common conditions such as hypertension were readily discussed within families and not considered taboo as cancer was (Bamidele et al., 2018; Hovick et al., 2015; Thompson et al., 2015; Wray et al., 2009). Studies indicated that decreased health communication in Black families resulted in decreased knowledge of family health history and health risk (Hovick et al., 2015).

Prostate cancer is considered a personal and sensitive issue due to the possible side effects from treatment or the disease itself, such as urinary and bowel incontinence and sexual dysfunction. Feelings of self-blame for not participating in routine medical checkups led men to feel shameful and embarrassed, causing them to keep their diagnosis a secret from others (Ettridge et al., 2018). Literature indicated the stigma surrounding cancer led to shame, embarrassment, and fear of social rejection, which prevented Black men from communicating their health conditions with relatives (Rivas et al., 2016). In Black families, it was undesirable for relatives to know about a diagnosis of the disease (Woods-Burnham et al., 2018). Other studies revealed health information was not shared among Black families and siblings and children were unaware of a family history of prostate cancer (Friedman et al., 2009a, 2009b, 2012; Yamasaki & Hovick, 2015). If a family history of prostate cancer is not shared or there is a significant delay in sharing the information among immediate and distant family members, the stigma and code of silence surrounding prostate cancer will be perpetuated. The silence may also lead to a late diagnosis among other family members at risk for prostate cancer, which may have been prevented if there had been communication regarding the risk and need to be screened. Moreover, fatalism has consistently been recognized in the literature as a concept that negatively impacts receiving a prostate cancer screening and a diagnosis of prostate cancer (Bustillo et al., 2017; Christman et al., 2014; Cobran et al., 2014; Conde et al., 2011; Powe, 1997; Powe & Johnson, 1995). In fact, Black men have a higher tendency to perpetuate the concept of fatalism due to cultural experiences, a history of slavery, economic instability, dismantling of the family, and a lack of knowledge, to name a few factors (Christman et al., 2014; Cobran et al., 2014; Powe & Johnson, 1995).

Bowen et al. (2017) identified family as an essential unit for the transmission of health information and cancer research through three steps. Step one, within the family, increased communication regarding cancer and cancer risk can be prompted by discussing the family cancer history.

Second, the family is viewed as a source of support to be utilized in times of sickness and health. Finally, the family is the primary source for learning cultural and health behaviors that may reduce the risk of and enhance one's knowledge of cancer. The literature reported family discussions on cancer have the potential to be therapeutic and healing for the cancer survivor as well as family members (Duvall et al., 2012). For family communication to be effective when discussing illnesses such as cancer, family members must be prepared to receive a cancer diagnosis or prognosis (Baider, 2008). Hence, if family members are not prepared to receive the illness information, there may not be an open and effective flow of cancer and health communication within the family. Individuals diagnosed with cancer or other illnesses may perceive a family member is not able to handle the information and choose not to share the information. Within each family unit there exists an intimate zone of family communication. If a family member frames an illness as their issue and problem, it results in the individual shutting down communication about his or health and experiencing it alone (Baider, 2008). When this occurs, there is a barrier to sharing essential cancer and health information that may impact the individual's own health and that of the immediate and distant family members.

An exploration of cancer and health communication among Black prostate cancer survivors and their families provides a different avenue for understanding barriers to and facilitators for communicating their diagnosis and additional pertinent health information with those who may be at risk. Through the dissemination of health information and specifically cancer within Black families, narratives on the importance of health screening and health risks can be promoted through the generations.

The literature lacks research that explores cancer and health communication among Black prostate cancer survivors and their immediate and distant family members. The current study is one of the first to explore cancer and health communication among Black prostate cancer survivors and their immediate and distant family members. Therefore, the study is deemed as a pilot study, which explores the concepts of cancer and health communication among Black prostate cancer survivors and all family members instead of the traditional dyadic research involving the prostate cancer survivor and his spouse. The purpose of this pilot study was to explore cancer and health communication within the families (i.e., immediate and distant family members) of Black prostate cancer survivors before and after disclosing their diagnosis. The study fills a gap in the literature for examining cancer and health communication among Black prostate cancer survivors and their families. The central research question for the current study is listed as follows: What is the extent of cancer and health communication among Black prostate cancer survivors and their families?

Methods

Design

A mixed methods design comprised of questionnaires and focus groups was implemented to explore the purpose of this pilot study. Through the quantification of data from the questionnaires, the study provided descriptive statistics regarding the participants' perception of cancer. Qualitative methodology provides a rich context for exploring the intricacies of health-care research. The use of focus groups extracts rich subjective data regarding patients' experience with prostate cancer and health communication within their family, which may not be obtained using questionnaires. The use of focus groups provides a context for participants to express their feelings, overcome embarrassment, and obtain and provide support for their feelings, which are inherent in their group but not necessarily seen within the dominant culture (Kitzinger, 1994, 1995). A concurrent triangulation method within the mixed methods design was implemented in the current study. Among the various types of mixed methods designs (e.g., sequential exploratory, sequential explanatory, concurrent nested), triangulation was selected due to the concurrent use of questionnaires and focus groups, which allows for conclusions based on a single phenomenon (Creswell et al., 2003; Greene et al., 1989). Therefore, the mixed methods design provides descriptive statistical and rich subjective data to explore the single phenomenon of cancer and health communication among Black prostate cancer survivors and their immediate and distant family members.

The Human Studies Committee at Florida State University provided ethical approval (Approval number 2018.25503) to conduct the study. The time frame for the study was from April 2018 to January 2019. Eligible participants completed questionnaires and participated in a focus group. Some focus groups were conducted both in person and audio recorded and some were conducted using Skype and only audio recorded. Informed consent was obtained electronically or in writing prior to the participants completing the questionnaires and participating in the focus group.

The focus group questions were developed after discussions with the research staff and a review of the literature focused on cancer and family communication, quality of life among Black prostate cancer survivors, qualitative methodology, and thematic network analysis. The research staff received prior training regarding qualitative methodology and conducting focus groups. A key aspect of the training centered on the avoidance of leading questions and refocus on participants who were not answering the questions.

Recruitment and Screening

Recruitment consisted of printed flyers at Florida State University and community health clinics and presentations at various organizations with predominantly Black members or patrons (e.g., Masonic and philanthropic organizations, churches, and barbershops). A Facebook advertisement for the study recruited Black men from Florida, Mississippi, Louisiana, Georgia, and Alabama. The various states were selected for recruitment due to the high concentration of Black men residing in the Southern states. The recruitment flyers and Facebook ad contained a phone number to register for the study along with a link to electronically register for the study.

A brief phone call was used to screen potential participants for eligibility in the study. Eligibility criteria consisted of (a) Black men over the age of 18 years with a current or past diagnosis of prostate cancer, (b) the ability to speak and understand English, (c) access and ability to use the internet, and (d) willingness to participate in a focus group online or in person. Participants were required to indicate the date of their prostate cancer diagnosis (month/year) and the name of their oncologist. The research team screened the information provided by potential participants and after eligibility was determined, the participants were provided the option to complete the questionnaires online or in person. A total of 42 individuals completed the online registration and after phone calls were screened, 11 were determined to be eligible. Despite the study being focused on cancer and health communication among Black prostate cancer survivors, over half of the 42 individuals were not eligible because they were not prostate cancer survivors. After determining eligibility, participants were provided with a link to complete the online questionnaire utilized in the study. During the screening calls, individuals provided their availability for participating either in an online or in-person focus group. Local participants selected an in-person focus group, while nonlocal participants participated via Skype using only audio. Skype was selected for use as a platform for conducting focus groups due to its history of use since 2003, compared to other more recent platforms such as Zoom and Google Hangouts.

Data Collection and Sample

The principal investigator, research assistant, and an African American prostate cancer survivor/advocate facilitated the focus groups. The African American prostate cancer survivor/advocate was present to provide a source of comfort and support to the participants along with sharing his experience of prostate cancer. However, the prostate cancer survivor/advocate did not participate in any of the focus group discussions with the men. The principal investigator also shared her narrative of assisting a family member diagnosed with prostate cancer and her 25 years of experience as a registered nurse to build trust and rapport among the participants.

Data collection consisted of the 11 participants completing the questionnaires and taking part in a focus group that was conducted online via Skype (via computer and phone) or in person. To maintain trustworthiness of the data, the protocols for data collection and other facets of the study were implemented identically in the face-toface and Skype focus groups. Participants shared similarities in the demographic and treatment experiences, which did not require the segmentation of individuals in focus groups. The use of only audio among the online Skype focus was the only difference in protocol between the in-person and Skype focus groups. Due to the lack of face-to-face contact with participants who were not local, audio-only Skype was utilized to provide comfort to participants sharing sensitive information. Prior to the onset of each focus group (in person and online), participants were informed of the benefits and possible risks of participation in the study. A question-and-answer segment was provided for participants to address any questions or concerns pertaining to the study during the screening process and prior to the focus group. Next, consent forms for participants to sign were provided in person or online. After participants signed the consent forms agreeing to participate, the principal investigator and research assistant provided each participant with a unique identifier that was not duplicated in the study. Hence, when addressing the participants, they were only referred to by their assigned patient identifier and when they spoke, they indicated their unique identifier. The participants utilizing Skype were able to speak freely utilizing their unique identifier whenever they responded to questions from the research team or to other participants in the focus group.

Most of the men who participated in the local focus groups knew one another, which assisted in building rapport among the group members. An interview guide composed of 22 open-ended questions was devised from the concepts of cancer and family communication, familial relationships, cancer survivorship, prostate cancer diagnosis and treatment, perceptions of prostate cancer disclosure, and comfort with health communication. Despite the number of questions in the focus groups, the participants provided adequate data in a succinct manner. Examples of the questions from the interview guide utilized in the focus groups were "When you were growing up, how did your family feel about people that were diagnosed with cancer?"; "What made you tell family members about your diagnosis of cancer?"; and "What was the hardest part of informing your family members you had prostate cancer?" Ample time was provided for responses and clarification as needed. Hence, an environment conducive for open discussions was created.

Focus groups were audio recorded using a digital recorder. The 11 participants were divided into two inperson focus groups held at a local community center and

two online focus groups conducted via Skype. The two in-person focus groups consisted of one group containing five participants and one group containing two participants. The literature reveals the size of a focus group can range from 3 to 15 participants, with the ideal size being from 4 to 8 (Holloway, 2005). However, due to the sensitive topic, the pilot status of the study, and the conflicting schedules of the participants, two of the focus groups contained less than three participants. The remaining two focus groups that participated via Skype contained two participants each. Research indicated the simultaneous use of online and in-person focus groups did not create a substantial discrepancy in the data (Woodyatt et al., 2016). Accordingly, results from the research indicated there were similar results in each group, while the only seeming difference was the online focus group being shorter in duration and the men sharing additional topics that were considered sensitive (Woodyatt et al., 2016). Within the current study, each focus group lasted between 45 and 60 min and notes were taken by the principal investigator and research assistant. The data obtained from the questionnaires and focus groups were maintained in accordance with HIPPA guidelines. Participants who completed the questionnaires and participated in a focus group were compensated with a \$50 gift card.

Quantitative Measures

The Family Cancer and Health Communication Questionnaire (FCHCQ) was developed by the researcher and designed to measure perception of the topics relating to cancer, comfort in communicating about cancer and health issues, and topic avoidance within families. The impetus for the development of the FCHCQ was based on the Family Avoidance of Communication About Cancer scale developed by Mallinger et al. (2006), which examined a woman's perception of her ability to openly discuss her cancer experience with her family. Due to the lack of questions in existing scales that addressed comfort in discussing cancer and health with immediate and distant family members, knowledge of family member's health histories, and specific topics of avoidance, the FCHCQ was developed. The FCHCQ originally consisted of 30 items and 6 subscales that examined perceptions of cancer, religion and spirituality, family communication, and cancer communication. Responses were scored using a Likert Scale, which ranged from 1 = strongly disagreeto 5 =strongly agree along with fill-in-the-blank responses. It was piloted among a population of undergraduate students at a public university in the Southeastern United States. Psychometrical properties of the family cancer and health communication items indicated a Cronbach's alpha of .645. The Cronbach's alpha for the perception

of cancer items was .64 (Dickey et al., 2019). The FCHCQ was revised and focused on the perception of cancer for use in the current study. Demographic questions were incorporated in the FCHCQ.

Qualitative Data Analysis

The thematic network analysis served as the framework for analyzing and developing the codes and themes from the qualitative data. Unlike deductive analysis, which is based on previous research and theory, thematic network analysis utilizes an inductive approach to code data without using a preexisting coding framework (Nowell et al., 2017). Therefore, the data guide the formation of themes and codes as opposed to a predetermined framework (Smith & Firth, 2011), The exploration of cancer and health communication among Black prostate cancer survivors and immediate and distant family members warrants this type of approach, which is not based on previous research, theories, or preconceived notions. Thematic network analysis has garnered support as an invaluable methodology in health-care research, which provided the impetus for its use in the current study (Smith & Firth, 2011). Thematic network analysis is an established qualitative methodology that examines textual data and formulates thematic networks through web-like illustrations. Thematic network analysis is comprised of developing (a) basic themes, (b) organizing themes, and (c) global themes (Attride-Stirling, 2001). The use of web-like illustrations for organizing themes and coding data from the text allows thematic network analysis to stand out as a robust methodology for systematically organizing and presenting the data (Attride-Stirling, 2001). At the core of thematic network analysis is a focus on understanding an issue within the text and presenting the data from lowest to highest order of premise (Attride-Stirling, 2001).

Trustworthiness, as indicated in the literature by the concepts of credibility, dependability, transferability, and conformity is an essential concept within qualitative research (Elo et al., 2014; Thomas & Magilvy, 2011) and was achieved through abiding by these concepts in the design and methodology of the study. Credibility refers to describing and identifying the experiences of individuals and how well the data is represented as a whole (Thomas & Magilvy, 2011). Through the use of audio recordings, two medical transcription services approved by the university institutional review board (IRB), notes, and transcription by the research team, the descriptions and experiences of the participants were accurately obtained. Therefore, credibility of the qualitative data was maintained. Dependability for the current study was achieved through the identification and description of the purpose, methods, analysis, and interpretation of the data, which are hallmark indicators of establishing dependability (Elo et al., 2014). In terms of transferability, the current study is a pilot, wherein the results will provide a foundation for implementing a larger study. Ultimately, the findings of a larger study can be generalized, which is a condition of transferability (Elo et al., 2014). The last concept, confirmability, was established by the research team's insight and reflection, which occurred after each focus group and review of the transcribed data and notes. Attributes of confirmability are identifying biases of the researcher and clarification of information provided by participants (Thomas & Magilvy, 2011).

The audio recording of each focus group was transcribed by two different professional transcription services. The transcribed text was entered into the qualitative and mixed methods program NVivo, which assisted with coding and the development of themes. To ensure reliability of the coded data, the principal investigator and the two research assistants independently reviewed the transcripts and coded the data. After the data was coded, the principal investigator and research assistants came to a consensus for the codes and themes identified from the data.

Quantitative Data Analysis

Participant responses from the FCHCQ produced descriptive frequencies from the subsections of participant responses regarding perception of cancer and family health history. The sample size in this pilot study did not allow for statistical analysis for significance of the results. Therefore, generalization of the results cannot be conferred.

Results

Quantitative

All participants identified as African American, non-Hispanic with a mean age of 66 years, the majority of whom had a 4-year degree (n = 8, 72%). Participants were primarily married (n = 8, 73%) and over half (n = 6, 54%)reported an income between \$50,000 and \$74,999. Most participants reported a religious background of Christianity (n = 10, 90%) and most had received a radical prostatectomy (n = 10, 55%). The month and year of the participants' diagnosis of prostate cancer were also collected. The majority of participants indicated they were diagnosed within 2 to 3 years of participating in the study (i.e., 2018 = 2, 2017 = 1, and 2016 = 2), while the remaining participants were diagnosed within 7 to 8 years of participating in the study (i.e., 2011 = 2 and 2012 = 1) and 11 to 15 years since diagnosis and participating in the study (i.e., 2007 = 2 and 2004 = 1). Results from the demographic data are presented in Table 1.

Table 1. Participant Demographics (N = 11).

Variable	Mean	N	%
Age	66		
Education			
Two-year college degree		- 1	10
Four-year college degree		8	72
Graduate degree		2	18
Income			
Income between \$10,000 and \$14,999		- 1	10
Income between \$50,000 and \$74,999		6	54
Income above \$75,000		4	36
Marital status			
Married		8	73
Not married		3	27
Religious background			
Christianity		10	90
Other		- 1	10
Treatment			
Surgery (prostatectomy)		10	55
Radiation		4	22
Still deciding		4	22

Note. N = number of participants.

Table 2. Location of Participants' State of Residence.

Participants' state of residence	Number of participants in each state
Florida	9
Georgia	1
Louisiana	I

Most participants were from Florida despite recruiting from various states in the South. Results are presented in Table 2. Descriptive statistics from the FCHCQ indicated that in response to perception of prostate cancer, participants expressed a sense of comfort while being around those with cancer with a mean of 4. Participants tended to select "disagree" for the question regarding cancer patients experiencing a decreased quality of life. The mean score for the question was 2.56. Participants were given a free response question to indicate their first reaction when thinking about cancer. Two recurring responses were "Death" and "Concern." Data for perceptions of cancer are presented in Table 3.

There were three questions pertaining to family health communication, for which participants indicated a family member who was open to discussing health issues and a family member with whom they were comfortable discussing health topics. Results revealed nearly all participants (n = 10, 91%) believed they could openly discuss health issues with their family members. Females were

Table 3. Descriptive Statistics Perceptions of Cancer.

Question	Mean	Min	Max	SD	Variance
Perceptions of cancer					
I'm comfortable around those with cancer	4	I	5	1.5	2.25
Cancer decreases quality of life	2.56	I	4	1	I
Cancer increases quality of life	2.69	I	5	0.92	0.84
Individuals with cancer have large financial obligations	3.38	I	5	0.92	0.84
Cancer is associated with death	3.31	I	5	1.45	2.09
People with cancer often experience pain	3.06	2	5	0.97	0.93
Depression is often associated with cancer	3.38	2	5	0.78	0.61
People with cancer are viewed differently by others	3.69	2	5	0.85	0.71
Cancer is a lifelong diagnosis	2.75	I	4	1.03	1.06
Family members struggle to cope with another family member's cancer diagnosis	3.63	2	5	0.78	0.61

Note. Minimum and maximum scores based on a Likert scale in which I = strongly disagree and S = strongly agree. SD = standard deviation; Min = minimum: Max = maximum.

Table 4. Mean Scores for Knowledge of Family Health History.

I know the health history of my	Mean	SD
father	3.81	1.54
mother	4	1.33
brother	4	1.22
sister	3.45	1.68
paternal grandfather	2.3	1.72
paternal grandmother	2	1.80
maternal grandfather	2	1.09
maternal grandmother	2.5	1.84

Notes. N = 16. Mean = average scores based on a Likert scale in which I = strongly disagree and S = strongly agree. SD = standard deviation.

the most selected (n=8,73%) for comfort in discussing topics in general. Similarly, results indicated female relatives (n=9,82%) were primarily responsible for teaching about health in the family. Participants were also asked to rank health topics in order from most avoided to least avoided as follows: (a) homosexuality, (b) sex and marriage, (c) relationships, (d) money/finances, (e) illness/sickness, and (f) death. The next section examined the participants' knowledge of their family members' health history yielded the highest mean at 4. Additional data for the participant's knowledge of family members' health history are presented in Table 4.

Qualitative

Utilizing the thematic network analysis, coding the data yielded nine basic themes that were derived from four main themes, three organizing themes and one global theme. The organizing themes included (a) parents' communication with family, (b) disclosing prostate cancer diagnosis, and (c) treatment options for prostate cancer, wherein the global theme for the data was identified as (d) communication over the life course of the prostate cancer survivor. Figure 1 depicts the web-like map derived after coding the textual data and deducing the information into basic, organizing, and global themes.

Parents' communication with family. One of the organizing themes was identified as the participants' communication within their family, which included communication within their household while growing up. Eight of the 11 participants reported there was little discussion about health topics among their family during their childhood. Furthermore, participants identified their mother as the primary person responsible for teaching about health. The focus group discussions indicated preventative health measures or health conditions experienced by their parents or other family members were seldom discussed. For example, when queried regarding their parents teaching or discussing the importance of annual physicals and other health behaviors during childhood, participants denied learning about preventive health behaviors. For example, a participant indicated:

"No, neither. You know, we learned those things later in life probably, yes.

Not so much when we were growing up." (76-year-old participant)

Similarly, another participant indicated health was not readily discussed in his family while growing up. However, now as parents, the participants indicated a desire to be forthright in sharing information. For example:

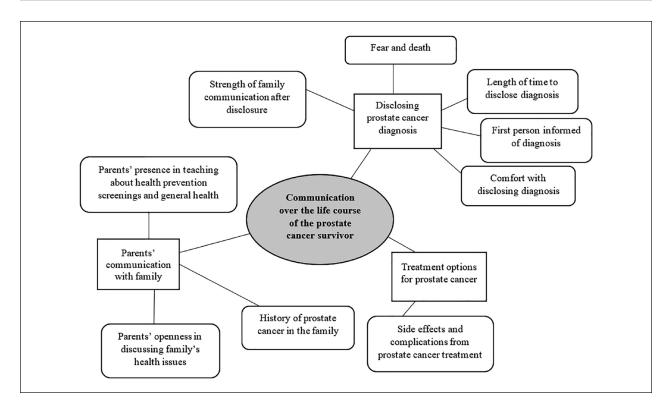


Figure 1. Thematic network analysis of qualitative data.

I don't know about other families, but I say as we grew up, we weren't the type of family. We were – knew we were loved, but we didn't discuss a lot of that. But we – as a parent now, we feel that those things that we didn't experience, my wife and I we try to do a little bit better as parents. (72-year-old participant)

Another participant shared his experience with discussing health issues within his family while growing up:

Growing up we had, I would say, probably as good a relationship as a father/son can have, but this was – health wise, this was something that was never ever discussed. (62-year-old participant)

For one participant, health was viewed as a topic that was not discussed with his father. Another participant recalled:

So, the communication was up on the level, but he didn't discuss his health problems or nothing, plus he died at an early age and we never knew he had heart problems, but he talked to us about our problems. He never discussed himself to us. (61-year-old participant)

There was a sentiment regarding the lack of knowledge of health topics as a cause for delay in seeking preventative health behaviors. A lack of knowledge for

engaging in preventative health behaviors was stated by one participant:

No, none of that. I went in the Army 18 right out of high school. So, you know when you get inducted into the Army you do a full physical and everything. And so, from that point on, I kind of took it upon myself to do that. (72-year-old participant)

The participant was responding to the question on knowledge of engaging in preventative health behaviors such as physicals, immunizations, and screenings. His response indicated he was not aware of the need to engage in preventative behaviors until he became an adult and received mandatory health screenings in the military. A lack of knowledge pertaining to preventative health behaviors was resolved upon the participant learning what is required to maintain one's health.

The use of natural remedies to treat illnesses was expressed by one of the participants. According to one of the participants, the use of natural remedies as opposed to seeking medical services from a health-care provider assisted in preventing some health issues. However, there should be a balance between the appropriateness of using natural remedies for an illness and using conventional medical services. The previously mentioned participant, seemed to exhibit a propensity to utilize natural remedies during childhood and once adulthood was reached, a

health-care provider was sought. This finding was based on the participant's following statement:

They dealt with most of the health problems themselves like giving us home remedies.

They believed in herbs. My grandmother believed in herbs and things like that. So, until I got to be an adult, I don't think I even really went to the doctor but maybe one or two times, a licensed doctor. (68-year-old participant)

Secrecy about the health of family members may have existed for one of the participants. It was assumed there were no health issues experienced by a participant's mother due to a lack of discussion about her health. However, the same participant could not confirm that his mother did not experience any health issues such as high blood pressure or diabetes when he was a child. One participant recalled:

I grew up in a house with nobody, but my mother and I was the only child. Unfortunately, I had a close cousin and we didn't – we talked about, I guess, health things very seldom because she didn't have any issues that I knew of. . . (61-year-old participant)

In some situations, the mother may have been the primary source of acquiring health information due to the absence of a father. The lack of a father or father figure to discuss male and health issues with may prove to be difficult for some males. Acquiring the information has the potential to evoke feelings of embarrassment, which was evident from the following statement by one participant:

Although because I didn't have a father, so it's like the females in my family, which is four, were always communicating to my mom about health issues, female issues, but for the males, I guess it was more or less embarrassing. (72-year-old participant)

In contrast, one participant noted that his mother actively emphasized health during his childhood. He reported that this experience in his younger years established the basis of health communication with his own family, allowing him to teach his children the importance of living a healthy life. The participant stated:

My mother, when I go back to her, she told me even as a young man she said, "The way you take care of yourself now gonna have a lot to do with how you're gonna live when you get older." She pushed that at our household, that health. (61-year-old participant)

Despite many participants disclosing limited health discussions within their families, participants seemed to be aware of a history of prostate cancer in their family. In fact, 7 of the 11 participants reported a family history of prostate cancer and 6 of the men reported a first-degree relative with prostate cancer. Although this knowledge of family history of prostate cancer was not necessarily always a topic of discussion, it was questioned after witnessing signs of sickness.

And I'm almost – I'm almost sure my father had prostate cancer because he was bedridden for about seven years and there were other factors. We never really talked about what exactly was wrong. I knew he had congestive heart failure, but I'm almost pretty sure he had prostate cancer too. (68-year-old participant)

Disclosing prostate cancer diagnosis. Participants' experiences of disclosing their prostate cancer diagnosis was the second organizing theme identified. Many participants agreed stigma and fear were associated with prostate cancer and posed as barriers in disclosing the diagnosis. However, as learned from later discussions, stigma and fear did not necessarily mean that all the participants succumbed to those feelings. Four of the 11 participants indicated fear was invoked by a diagnosis of prostate cancer. For example, a participant stated:

I thought it was a death sentence, so I didn't tell my wife until I was going into surgery. For one thing I came through the surgery okay, so I had to tell her. (69-year-old participant)

The concept of fear as a barrier to disclosing the diagnosis was also evident in the statement by another participant:

You know, I'm going to say probably fear and that may not make a lot of sense, but we probably would rather not know because – I don't know. It's just the fear of finding out that, you know, we're supposed to be tough, you know, and I don't know. (62-year-old participant)

Fear, along with thoughts of death, was also evident among other participants when one recalled:

My wife was with me on the day of surgery, but I did not – I didn't tell anybody 'cause I was scared. You know, like I said, this is my way out of here. (76-year-old participant)

Along with fear and death, despair was noted to accompany the diagnosis of prostate cancer. An additional participant shared his thoughts of being diagnosed with prostate cancer:

It was – After they did the biopsy and gave me the results, it was like a dark cloud came over me and I just, you know,

was like wow. And, you know, I thought about not giving up but, you know, I'm gonna die. (69-year-old participant)

Fear of death and illness were identified as reasons for not readily disclosing their diagnosis. The participants' fatalistic attitude after their prostate cancer diagnosis supports research that indicates a link between fatalism and prostate cancer (Couper et al., 2010; Dale et al., 1999; Hamilton et al., 2015; Miller et al., 2001; Pierce et al., 2003).

There was a general feeling of being uncomfortable with voluntarily sharing the diagnosis. These sentiments were evident from the following statements by two participants. One participant indicated:

What I did is I waited six months because my mom she had some health issues and I didn't want to tell anyone cause I knew eventually it would have got to her and because she was diagnosed with cancer and so I just wanted to wait until I told anyone. And so, after my mom past, that's when I shared it with my sister and my other sibling. (72-year-old participant)

The other participant indicated:

I had qualms about sharing my situation with anyone. I mean, if it came up, I discussed it. I didn't – I don't think I went and just said, hey, you know, I got prostate cancer, come up in a conversation, but they knew that I was gonna have surgery and I told them what the surgery was all about. (69-year-old participant)

Participants suggested increasing discussions within their families as a solution to eliminating communication barriers. Many believed progress had already been made and that men were becoming comfortable with talking about their health. Participants shared that opening up about their diagnosis increases knowledge about prostate cancer, which in turn decreases fears and misconceptions.

In contrast, 4 of 11 participants said it took less than a week to inform their family members of their prostate cancer diagnosis. It was evident that some participants needed time to accept their diagnosis and plan how to disclose the information to their family. For example, a participant recounted:

I think I may have taken a day or two just so I could prepare to tell my children and my brother knew because he called in on me just asking what was the results, how was things, and he knew. He knew immediately. I took a couple of days before I told my children, but it was more or less maybe two to three days. But I told everybody kind of around the same time the word began to get out, but it was afforded that – and my children are all adults, but I just wanted to make sure that they knew what I was dealing with especially with my son. (58-year-old participant)

Similarly, another participant indicated:

It didn't take long. I think it was like – it might have been the next day or the same day because at the time wasn't nobody home but my wife. And so, I told her. (61-year-old participant)

Three participants seemed to acknowledge a need to increase cancer and health communication with their sons. Participants stated the diagnosis of the disease created a realization for both father and son that knowledge of the health of the other is important for understanding the different health risks and the risk of death from diseases that have occurred in their family.

With my son I think it increased because for the first time – I think the first time in his life that I might pass away, so he became concerned about my health and he would – every time I went to the doctors or had a problem he would call. If I didn't give him an answer that he wanted to know, he would call my wife cause he know she would tell him. But our communication especially with disease increased because when I was diagnosed with cancer. (71-year-old participant)

Another participant noted:

With sons and the family. My communication has increased, particularly with the males asking them or telling them that, look, this is something that's in your family, particularly with my son and it's that you are third generation, your granddaddy had it, I got it, and you need to be checked. And also, with my nephews I'm telling them as well. (68-year-old participant)

Similarly, the communication between the participant and family members appeared to increase their concern and overall communication. This finding was evident as a participant recalled increased communication with his son when he stated:

I think it has strengthened my relationship and also communication with them because they often call. They call more than they would usually call, and I speak with them more and because, you know, they're – I wasn't overly concerned about my health. And after reassuring them that I'm healthy, I'm doing fine, you know, there's some issues with that but there's still more concern. (62-year-old participant)

Treatment options for prostate cancer. The final organizing theme identified was the treatment option for prostate cancer along with the side effects of the treatment. Participants seemed to enjoy discussing their treatment options. It was the sharing of treatment options that led to discussions on the side effects from the treatment. Even though discussions on treatment and side effects were not based on specific questions within the prepared focus group questions, the men seemed to gain comfort in

sharing their experiences and knowing that others encountered similar situations. Discussions on treatment options were initiated by participants in the online and in-person focus groups. For example, one participant stated:

And so, I had – like, I had mine removed altogether too. And like the last couple of years, I developed a hurting in the groin. (72-year-old participant)

Once the participants began sharing their choice of treatment, they began to disclose the side effects they experienced from the treatments. Even though the treatment options varied from surgery to radiation, the prominent side effect encountered seemed to be urinary leakage.

And even though I have severe leakage and I went through physical therapy for the leakage to no avail, I went through – I use the pads. I went through the acupuncture to no avail. Acupuncture helped for a short while. (76-year-old participant)

Discussion

This mixed methods study explored various cancer and health communication trends among Black prostate cancer survivors and their immediate and distant family members. Despite the lack of sufficient number of participants for implementing statistical analysis for significance, the descriptive statistics provide an insight into this cohort's perception of cancer and health communication among their family members. The qualitative and quantitative data provided two avenues to explore the gap in the literature regarding cancer and health communication among Black prostate cancer survivors and their immediate and distant family members. Furthermore, the mixed methods design provided data to address the study's research question "What is the extent of cancer and health communication among Black prostate cancer survivors and the families?" Data from the focus groups implied the participants gained a sense of responsibility to share their diagnosis with their sons, family members, and other males. The participants' willingness to do this could stem from the increased risk of prostate cancer among first-degree relatives and Black men in general. In fact, the participants' diagnosis seemed to assist in increased bonding with their sons. Three of the 11 participants indicated communication increased between father and son after the diagnosis. Nine of 11 survivors' responses indicated they understood that a solid line of communication with their family members would reduce misconceptions and emphasize the importance of preventative screenings for prostate cancer.

Although health was not commonly discussed in past generations of Black families, the focus group participants stated health communications have significantly increased in Black families and Black communities. These findings were consistent with the Yamasaki and Hovick (2015) study, which reported motivation to improve health communication within Black families resulted from past family experiences of health secrecy of parents. Using focus groups, the men gained insight into their communication experiences as children within their families and how those experiences shaped their perception and willingness to disclose their own diagnosis of prostate cancer. This knowledge can lead to the development of interventions focused on increasing family and cancer communication particularly in the high-risk group for prostate cancer, Black men.

Despite the results indicating open communication in Black families, the sensitive topic of sexuality was reported to be avoided in the quantitative portion of the study, which is consistent with previous studies (Bamidele et al., 2018; Hovick et al., 2015; Thompson et al., 2015; Wray et al., 2009). These findings could be based on the phenomenon reported by Friedman et al. (2012) and Vijaykumar et al. (2013) that Black men prefer to discuss sensitive topics such as prostate cancer with other Black men who have experienced the disease.

Another finding from the study that was consistent with those in the literature was the role women played as the main health communicators in the family. Studies by Bowen et al. (2017) and Friedman et al. (2012) emphasized the woman's role as that of health informant, health motivator, and family health history gatherer. Quantitative data within the current study revealed mothers as the primary persons responsible for health communications within the families. Data from the focus groups revealed mothers as the source of health information. Participants in the study recognized the importance of contributing to the health conversations and promoting health, while also desiring to be more involved in health conversations. This recognition could lead to improved health communications within vulnerable populations, thereby reducing fears of going to the doctor and increasing the use of preventive health behaviors.

Previous research reported that Black men diagnosed with prostate cancer did not communicate with family members after diagnosis, as they associated it with death and decreased masculinity (Cobran et al., 2018). While the focus group discussions did reveal feelings of fear, death, and hesitation with prostate cancer disclosure among some of the participants, several recalled a willingness and openness to disclose their diagnosis to family, friends, and the community. Qualitative data suggested that health communication increased between the survivors and their children, in particular their sons, after the diagnosis of prostate cancer. It appeared the participants

regarded their diagnosis as a wake-up call that Black men are highly susceptible to prostate cancer and their sons need to be informed about it. Increasing health communication between Black first-degree male relatives may be a large part of the solution to increasing prostate cancer knowledge and awareness and interest in their health. Furthermore, health-care providers are in a unique role to gather additional information regarding the Black prostate cancer survivors' familial history of cancer and health information disclosure. Research, such as the current study, is needed to uncover the topic of cancer and health information among Black prostate cancer survivors and their families, unlike the traditional studies that examined communication and quality of life among Black prostate cancer survivor and their spouse and/or significant other.

Limitations and Implications

While the pilot study provides insight into the cancer and health communication among Black prostate cancer survivors and their immediate and distant family members, there are limitations. Despite the FCHCQ recording Cronbach alpha scores of approximately .70 in a previous study among a convenience sample of college students, this was the first study to use the questionnaire format among Black prostate cancer survivors, which was a limitation. As previously stated, the study was a pilot in which results cannot be generalized to the population of Black prostate cancer survivors and their immediate and distant family members. Generalizing the results to the Black population is further complicated due to the majority of participants who identified as middle-class, college educated, and married. The characteristics of the participants could have resulted in them being more willing to share information. Additionally, the recall of information regarding the participants' family cancer communication and their own experience with prostate cancer may be a limitation. While some of the participants were diagnosed within 2 to 3 years of participating in the study, there were participants whose time of diagnosis to participation in the study was 7 to 15 years. Furthermore, the study as a pilot is a limitation of the study. The small sample size also prevented the use of statistical analysis for significance of results. Even though the prostate cancer survivor/advocate only shared his experiences as a prostate survivor at the onset of the study, prior to the participants responding to any of the focus group questions, and did not participate in the focus group discussions, this may have influenced some of the information shared by the participants. We would be remiss not to indicate this as a limitation of the study.

When caring for Black men at risk of or living with prostate cancer who may be skeptical of the health-care system, we must utilize communication and share

decision-making skills that include aspects of caring and trust to positively influence their health status (Millender et al., 2016). Through exploring and fostering communication among Black men, a precedence may be set to create a safe environment wherein they are comfortable to share their perceptions and/or fears of prostate screening and diagnosis of cancer with family members, friends, and health-care providers. To make a difference in supporting cancer and health communication among Black prostate cancer survivors, health-care providers must venture past the superficial question regarding who they've informed of the diagnosis and question their patients' familial histories of disclosing cancer and health information. Through focusing on the deeper issue of cancer and health information disclosure within families, health-care providers can identify potential psychosocial and psychological issues pertaining to sharing the diagnosis. The participants' comfort in sharing their most sensitive experiences with prostate cancer in the focus groups indicates the type of open communication that must exist to increase use of the health-care system by Black men. Ultimately, an increase in use of the health-care system may increase awareness of prostate cancer and thereby decrease the disparity between Black and White men.

While this study adds to the scarcity of literature regarding cancer and health communication among Black prostate cancer survivors and their families, further investigation into the impact of past family communications on disclosure of prostate cancer and health information is warranted. Through an exploration of incidence and communication practices within families, research can identify barriers to and facilitators of communication within families. Thus, cycles of closed communication among the group with the highest risk for prostate cancer (Black men) have an opportunity to be broken. The family is the central unit for acquiring communication and interaction skills among individuals. Therefore, research focused on family communication styles will lend to the examination of cancer and health disclosure.

This was one of the first studies to pilot the exploration of cancer and family communication among prostate cancer survivors and their immediate and distant family members. Previous research was limited to exploring Black prostate cancer survivors and/or their spouses (Friedman et al., 2009b, 2012; Wray et al., 2009). This study elucidates the impact that generational influences may have on cancer and health communication among a small cohort of Black prostate cancer survivors. An understanding of familial communication among Black prostate cancer survivors provides a foundation for the development of educational interventions focused on increasing awareness of prostate cancer risk factors and engaging in informed decision-making, and for health-care providers understanding possible barriers for Black men to utilizing

the medical system. Dispelling prostate cancer myths through open and honest communication among the highrisk groups for prostate cancer, (i.e., Black men and firstdegree relatives) provides an opportunity to decrease the stigmatization of testing and the diagnosis of prostate cancer. Additional research must explore the Black prostate cancer survivor's journey from childhood through adulthood to gain insight into the decreased utilization of medical services and engagement in preventive and healthy behaviors. Through future explorations of how Black men develop their ideation toward cancer and health communication and healthy behaviors, culturally tailored interventions can be developed to promote the importance of engaging in healthy behaviors and the regular use of a health-care provider. Despite the small sample, it still allowed for data saturation and provided a foundation to continue studies that incorporate quantitative and rich qualitative data to examine a topic that is lacking in the literature. Future studies will incorporate diverse racial/ ethnic prostate cancer survivors to compare their caner and health communication patterns.

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The authors want to indicate that the interchangeable use of African American and Black men within this integrative review is based on the usage of the terms within the articles in the review.

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ORCID iD

Sabrina L. Dickey (D) https://orcid.org/0000-0003-2889-4344

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