UNDERSTANDING THE NEEDS, EXPERIENCE, AND INFLUENCE OF FAMILY CAREGIVERS IN THE BLACK COMMUNITY ACROSS THE PROSTATE CANCER CONTINUUM OF CARE

By

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To my parents, Altagrace & Verilus Piervil, who faithfully planted seeds of possibility and persistently watered them to reality; my siblings Venel Piervil, Anne Piervil, and Abigail Piervil for lifting me up and always reminding me why I came And to the participants, families, staff, and community advocates that helped make this project possible
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<td>CaP</td>
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UNDERSTANDING THE NEEDS, EXPERIENCE, AND INFLUENCE OF FAMILY CAREGIVERS IN THE BLACK COMMUNITY ACROSS THE PROSTATE CANCER CONTINUUM OF CARE

By

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This study sought to better understand the caregiving experience of family caregivers in the Black community across the prostate cancer (CaP) continuum of care. In the United States, CaP is the most frequently diagnosed non-skin cancer and the second most common cause of cancer deaths among men. Notably, Black men endure a disproportionate burden of morbidity and mortality related to CaP. Compounding this issue, family members are increasingly assuming the role of providing care and support to family members with chronic illness or disability. Further, research indicates there is an association between caregiving and negative health outcomes, increasing the disproportionate burden of disease and hardship in the Black community. Thus, the primary goals of this project were: 1) to explore the role and function of informal CaP caregivers across the continuum of care; 2) to identify the specific needs and support preferences of CaP caregivers at various stages of caregiving; 3) to identify perceived barriers to seeking support among prostate cancer caregivers in the Black community; and 4.) to investigate existing literature related to psychoeducational and support interventions addressing needs of prostate cancer caregivers in the Black community.
Guided by grounded theory methodology, participants were self-referred individuals meeting all inclusion criteria including 1) 18 years of age or older and 2) identifying as a CaP caregiver for a Black male. Results from this project indicate caregivers have a significant impact on the lifestyle and health seeking behaviors of men in the Black community. As a part of the hard-to-reach population of caregivers at-risk for several negative health outcomes related to caregiving, this group may benefit from participating in culturally tailored interventions addressing the specific needs identified in the current analysis. In addition, findings demonstrate caregivers in this community have substantial needs and encounter several barriers to seeking support throughout the CaP caregiving process that can have a substantial impact on the health of the caregivers, as well as, the patients in this vulnerable community. Results of this project can help inform the development of health promotion programs designed to improve health outcomes and care experiences of caregivers and patients experiencing various forms of chronic disease across the continuum of care.
CHAPTER 1
INTRODUCTION

Epidemiology of Prostate Cancer and Family Caregiving

The most recent global appraisals of prostate cancer, indicate an estimated 1.1 million men were diagnosed with prostate cancer (CaP) in 2012, accounting for approximately 15 percent of all cancers diagnosed in men (Ferlay, et. al., 2013; Bray, Ren, Masuyer, & Ferlay, 2013). In 2017, there will be an estimated 161,360 new cases of CaP representing 9.6 percent of all new cancer cases in the United States. Prostate cancer is the most frequently diagnosed cancer and the second deadliest cancer among all males in the United States (Jemal et al., 2017). In 2016, there were an estimated 26,120 deaths related to CaP, accounting for approximately 8 percent of all cancer deaths in men in the United States (Siegel et al., 2016). In 2017, the number of deaths related to prostate cancer is estimated to reach 26,730 deaths. Approximately 11.6 percent of men will be diagnosed with prostate cancer during their lifetime. The 5-year relative survival rate for patients diagnosed with prostate cancer from 2007-2013 is 98.6 percent overall. However, this rate varies by stage of diagnosis. The 5-year relative survival rate for prostate cancer is 100 percent at the Localized (i.e., cancer is located in the part of the body where it originated with no evidence of spreading) and Regional (i.e., cancer has spread to regional lymph nodes or tissues) stage of diagnosis. In contrast, the survival rate at the Distant stage of diagnosis (i.e., cancer is metastatic or has spread to other distant parts of the body) decreases significantly with a 29.8 percent rate of relative survival (Siegel et al., 2016).
Disparities across the Prostate Cancer Care Continuum

A review of relevant literature indicates prostate cancer is experienced at various stages (prevention, detection, diagnosis, treatment, and survivorship), often referred to as the prostate cancer continuum of care. Further review illustrates substantial evidence of disparities that exist across the CaP continuum of care. While prostate cancer is the most frequently diagnosed cancer among men of all races and ethnicities in the United States, when compared to their non-Black counterparts, Black men suffer a disproportionate burden of morbidity and mortality related to CaP across the continuum of care (Oliver, 2007; Jemal et al., 2017). National data reports indicate the age-adjusted CaP incidence rate for Black men is 154.1 per 100,000 compared to 86.9, 79.9, 49.5, and 45.5 per 100,000 for men identified as White, Hispanic, American Indian/Alaskan Native, and Asian/Pacific Islander respectively (U.S. Cancer Statistics Working Group, 2017; Jemal, et al., 2017). African American men are also more likely to have advanced disease when diagnosed (Ries et al., 2003; Drake et al., 2006; Li et al., 2016). When compared to their non-Hispanic White counterparts, African American men are twice as likely to die of CaP (American Cancer Society, 2016). African American men are also more likely to have advanced disease when diagnosed (Ries et al., 2000; Li et al., 2016). Compared to the state of Florida as a whole, the age-adjusted death rate of all cancers is approximately 28 percent higher in North Central Florida (North Central Florida Cancer Report, 2013). The age adjusted prostate cancer incidence from 2011-2013 among all races was 133.8 in Alachua County compared to 108.7 per 100,000 in the state of Florida. For black men the age-adjusted prostate cancer incidence from 2011-2013 was 200.7 in Alachua County; 336.8 in Duval County; 309.5 in Hillsborough County; 259.7 in Orange County; and 330.0 in Osceola County.
compared to 231.1 per 100,000 in the state of Florida. These rates indicate that in addition to the disparities that exist between races and ethnicities in North Central Florida, the region itself is experiencing disproportionate incidences of prostate cancer when compared to the state as a whole (State Cancer Profiles, 2013).

**Caregiving and Cultural Diversity**

Family caregivers, also referred to as informal caregivers, are generally defined as individuals that provide unpaid care to a relative for an extended period of time. More specifically, Schulz and Quittner (1998), defined caregiving as “extraordinary care (i.e., tasks that exceed the bounds of what is normative or usual for a parental, sibling, or spousal relationship) involving significant expenditures of time and energy often for months or years, requiring the performance of tasks that may be physically demanding and unpleasant” (Schulz & Quittner, 1998). An estimated 65 million Americans age 18 and older provide care to a chronically ill, disabled, or chronically ill family member, representing 29 percent of the US population (National Alliance for Caregiving & AARP, 2015). Of the 438,712 participants included in the 2009–2010 BRFSS, 111,156 self-identified as caregivers and on average, caregivers were 55 years old and female (Trivedi, 2014). Caregiving outcomes vary by gender as well, women were more likely to report providing 20 hours of care or more to a family member and women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income.

Rates of Caregiving and caregiver outcomes vary by ethnicity as well (Aranda and Knight, 1997; Ho et. al., 2009; Pharr, Francis, Terry, & Clark, 2014). In a national sample of elderly adults 44 percent of Latino respondents and 34 percent of Black respondents were reported to have received home based family caregiving compared to
25 percent of non-Hispanic White respondents (Weis et al, 2005). Country of origin and associated cultural factors also influence the caregiving process and experience for individuals in the United States. Compared to non-Hispanic White respondents, ethnic minorities had lower socioeconomic status and were more likely to receive care from family and friends. While African American caregivers had lower levels of caregiver burden and depression, caregivers in this group reported worse physical health than White caregivers in the sample.

**Economic Value and Impact of Caregiver Support**

The economic value of family caregivers has continued to grow overtime. In 2009, family caregivers in the United States provided an estimated $450 billion of unpaid labor each year and the amount of time spent providing care for a family member on average was 20 hours per week (National Family Caregivers Association & Family Caregiver Alliance, 2009; Feinberg, Reinhard, Houser & Choula, 2011). In 2016, 78 percent of caregivers incurred out-of-pocket expenses as a result of caregiving. Across race and ethnicity, financial strain measured by out-of-pocket spending was highest among Hispanic/Latino and African American caregivers; spending 44 percent and 34 percent of their income as a result of caregiving activities respectively, compared to 14 percent of out-of-pocket spending among White caregivers (AARP, 2016). Evidence from the academic literature suggests that caregiver support is a key element in cancer survivorship and engagement with healthcare systems (Blanchard et al, 2005; Webb et al., 2006; Halbert et al., 2009; Lepore et al., 2012). However, a substantial volume of evidence has also indicated that there is an association between caregiving and negative health outcomes (National Alliance for Caregiving & AARP, 2004; National Family Caregivers Association & Family Caregiver Alliance, 2006;
Pinquart and Sörensen, 2011). Research also indicates that most caregivers reported feeling ill-prepared to provide care for individuals with chronic disease (National Alliance for Caregiving & AARP, 2004). At the intersection of providing care and experiencing negative health outcomes, research has shown that participation in programs focused on education and support can have a positive impact on caregiver health (Zarit, Gaugler & Jarrott, 1999).

The Present Study

Prostate cancer in the Black community is a serious public health issue. Recent advances in technology and the impetus to increase early detection of CaP in older Black men has contributed to significant increases in rates of survival among this vulnerable population. As survival rates increase, the duration of caregiving also increases. Further, evidence indicates the provision of informal, unpaid care and support for prolonged periods of time can have significant consequences for the caregiver (Schulz and Beach, 1999; Schulz, & Sherwood, 2008). While there is considerable evidence to show that caregiver support is linked to increased strain and burden, few studies have focused on the specific needs of CaP caregivers in the Black community. Current investigations on the experience of spouses, partners, and significant others of Black men diagnosed with prostate cancer fail to identify culturally specific needs of caregivers and strategies for integrating caregivers as trained and supported caregiving advocates in the current model of health promotion. As informal family caregiving increases among adults in this community it is necessary to assess the public health outcomes of caregivers. Given these points, this project sought to better understand the caregiving experience of family caregivers in the Black community across the prostate cancer (CaP) continuum of care, with the goal of identifying needs,
barriers, and preferences of family caregivers towards the development of culturally specific behavioral health promotion programs, interventions and community resources.

**Research Design and Approach**

Creswell (2014) details three primary research approaches: qualitative, quantitative, and mixed methods. In general qualitative research is an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem; while quantitative research is generally an approach for testing objective theories by examining the relationship among variables; lastly mixed methods research, which is an approach to inquiry involving collecting and integrating both qualitative and quantitative data and using distinct designs to provide a diverse understanding of a research problem (Creswell, 2014). Concerned with how and why CaP disparities persist and influence the incidence and prevalence of caregiving burden in the Black community, this study elected to use a qualitative research approach to explore poorly understood phenomena related to the CaP caregiving experience across the CaP continuum of care in the Black community. Unlike quantitative methods of research which tend to be linear in design, focused on testing hypotheses, guided by existing theories, and generally culminating with results presented as descriptive statistics and trends; qualitative approaches tend to be more bidirectional in design and attempt to explain processes and patterns of human behavior, generally culminating with results presented as themes and concepts (Bryman, 2012). While quantitative research has historically been seen as a superior mode of conducting scientific research due to its ability to manipulate and control data allowing researchers to infer causation, in the context of social research involving human subjects, specifically vulnerable populations, this process of manipulation is rarely possible and often
unethical (gamble, 1997; Creswell, 2013). Further, it can be difficult to measure certain constructs related to the human experience and proxy constructs often fail to provide accurate measures of the concepts of interest related to a specific phenomenon or problem. Conversely, qualitative research can provide rich sources of contextual knowledge that can be used to explain and address specific problems that occur naturally in the world (Bryman, 2012). Furthermore, a key strength of the qualitative approach is its ability to provide a voice for special populations and its potential to aid in the dissemination of data related to the lived experiences and marginalized perspectives of disenfranchised groups whose needs are often excluded from academic literature (Creswell, 2013).

While the two approaches differ in overall purpose and technique, they can be used as complementary agents informing, explaining, and building more complete understandings of patterns and phenomena occurring in the world. Qualitative research can be especially useful as a research approach used to understand how social practices, cultural norms, access to care, and patterns in health care systems combine to influence social phenomena and further help generate meaning and help researchers to capture and better understand the experience of vulnerable and/or hard to reach populations (Foley & Timounen, 2015). Therefore, this study used a qualitative approach to explore lived experiences and better understand phenomena indicated by results of quantitative data pertaining to CaP disparities and the disproportionate burden of CaP caregiving in the Black community.

Methodology

Creswell (2013, 2014) outlines five types of qualitative research design: narrative research, phenomenology, grounded theory, ethnography, and case study. Guided by
the constructivist worldview, this study used a grounded theory design to explore the caregiving process and experience among family caregivers across the prostate cancer care continuum in the Black community. Characterized by an iterative process for developing meaning and generating theory, grounded theory methodology is a systematic approach used to identify concepts and develop theory that is grounded in data (Strauss and Corbin, 1994; Charmaz, 2006). Since its inception in 1967, the grounded theory approach has undergone several developmental deviations and currently exists in five main types (Glaser & Strauss, 1967; Charmaz, 2006; Corbin and Strauss, 2008; Bowers and Schatzman, 2009; Sbaraini, Carter, Evans, & Blinkhorn, 2011). This project was informed primarily by aspects of the ‘constructivist grounded theory’ process as defined by Kathy Charmaz in her work, Constructing Grounded Theory: A practical guide through qualitative analysis.

Across the various types of grounded theory, the fundamental components of a grounded theory study are Openness (research problem, question and reflexivity), purposive sampling, memo writing, concurrent analysis and data collection, coding and sorting, theoretical sampling, theoretical saturation, and production of a substantive theory (Charmaz, 2006; Morse et. al., 2009; Sbaraini, Carter, Evans, & Blinkhorn, 2011). For this primary study qualitative interviews were conducted with twelve self-identified prostate cancer caregivers. When possible this study aimed to establish both rigor and credibility of interviews by adhering to the 32-item, COREQ: consolidated criteria for reporting qualitative research in order to promote complete and transparent reporting (Tong et al, 2007). A brief reflexivity statement and detailed report of study activities is provided below.
Reflexivity statement

Personal reflexivity. As a Black, Haitian-American, female researcher, I have a special interest in addressing the disproportionate suffering related to chronic disease in the Black community. The disproportionate rate of morbidity and mortality related to prostate cancer among Black men and the resulting increase in family caregiving is especially disconcerting from a personal perspective, given that I self-identify as the daughter, sister, and niece of multiple Black men. Having served as a family caregiver myself, I interpret this problem to be an issue that is detrimental to the ethnic minority community as a whole, increasing economic challenges and other hardships already experienced at disproportionate rates in this community. In addition, having successfully matriculated through public health programs focused on health education, behavioral science, community health, and health policy and management, I have a fundamental understanding of social and behavioral theories related to health and health promotion. As a researcher, I bring this theoretical knowledge, in addition to my own personal lived experience, to my identification and understanding of social phenomena.

Epistemological reflexivity. Epistemology Ontology, commonly referred to as the philosophical worldview, is the basic set of beliefs that guide research choices and actions throughout the research process. My personal reflections related to the assumptions about the nature of the world and the various ways of knowing and understanding phenomena in society lead me to approach problems from the constructivist worldview which asserts that meanings and ways of understanding are constructed from multiple participant perspectives, in conjunction with that of the investigator conducting the research. The current qualitative research design and
grounded theory methodology were selected based on this understanding. In addition, throughout the research process questions were modified to reflect participant understandings of the various phenomena related to the CaP caregiving experience across the continuum of care. For example, a key area of interest during the developmental phase of this research was related to cultural preferences related to racial concordance of providers and support facilitators. However, as the participant interviews were conducted in the population of interest, it became clear that cultural preferences for support related to the CaP caregiving experience were more nuanced and thus, the topic area was broadened to include more variables related to past caregiving experience, religious concordance, and cultural understandings related to caregiving norms in the Black community. Sampling activities also reflected insights gained from interactions with participants. Thus, theoretical sampling was employed to gain a comprehensive understanding of the experience shared by a diverse group of caregivers in the Black community.

Taken together, the ultimate goal of my research is to identify key aspects—as defined by and with significant input from the community impacted—of intervention designs necessary to optimize health promotion programs for vulnerable, ethnic minority populations towards improved health outcomes and well-being overall in this community. Based on this research goal, it is likely that in future projects related to this research, my philosophical worldview may experience a paradigm shift towards a more action-based transformative, advocacy and participatory worldview with an emphasis on change oriented research focused on marginalized and disenfranchised groups.
Primary research

Rapport was established with the population of interest as a result of continued participation in activities and events associated with the Florida Minority Cancer Research and Training (MiCaRT) Center. In 2016 a series of informal focus groups were conducted at the MiCaRT community town hall forum with a purposive sample of self-identified CaP advocates who reported providing care for a family member diagnosed with CaP in the past 7 years. Initial research questions sought to understand key concepts that were central to the caregiving experience in the Black community. Sample questions included: What is the role of the caregiver in the CaP process? How has the CaP experience impacted your well-being? Were you prepared to be a caregiver? Memos and notes from the focus groups were coded to reveal key themes that were used to inform topic areas for the development of a population specific semi-structured interview guide for use among informal CaP caregivers during individual face-to-face interview sessions in the north- north central region of Florida. From June 2017 – September 2017, telephone and face-to-face interviews were conducted with twelve self-identified prostate cancer caregivers in central, north central, and north Florida. The IRB- approved semi structured interview guide consisted of 26 items initially and was modified throughout the study process (Appendix A). Facilitation of interviews was guided by Kvale’s interview criteria and therefore sought to create the most conducive setting for participants to feel comfortable to respond and share their understanding of the CaP experience based on their own perspectives and lived experiences (kvale, 1996). Initially, the study used purposive sampling techniques to gather information from individuals most knowledgeable about this community. Theoretical sampling techniques were used during later stages of research to gather
information related to caregivers that identified as adult children to address gaps identified in the data. Recruitment took place through a variety of community venues, such as UF Health Shands, Health Street, local churches, the Florida MiCaRT center, and other community advocacy organizations in the north-north central region of Florida. Inclusion criteria for participants was as follows: 1.) self-identified as an informal caregiver of a Black man with history of CaP and 2.) 18 years of age or older.

Data collection and analysis were conducted concurrently. Theoretical sampling was employed during the study to modify questions, refine participant recruitment and clarify uncertainties in the analysis. Recruitment ended when saturation was reached (i.e. nothing new emerged from subsequent participant interviews). Interviews were audio recorded and transcribed by a professional transcription service. To ensure accuracy, transcripts were verified by the first author who conducting each interview. NVivo software was used to code transcripts and organize codes into larger themes. Emerging themes and constructs were used to develop a substantive theory to inform a model of the critical aspects of CaP caregiving in the Black community. Study activities are outlined in Figure 1-1.

Secondary analysis

This analysis was supported by the assertion that findings from both secondary and primary qualitative data can be used to provide contextual and supplementary understandings and support of quantitative findings (Dale, Arber, & Proctor 1988; Bryman, 2012; Grbich, 2013). Primary data used in this analysis were derived from a multi-phased transformative, sequential mixed methods research study, which used both qualitative and quantitative research activities, guided by an overarching theoretical perspective with a specific focus on the experience and perspective of the
target population (Creswell, 2003; Creswell, 2009). A key strength of this strategy is its ability to provide a voice for special populations that are often left out of the academic literature (Cozby, 2011; Creswell, 2011).

Quantitative data from all black men diagnosed with prostate cancer from 2006 to 2010 (N=10,818) were obtained and examined from the Florida Cancer Data System. Next, qualitative data were collected using constructivists grounded theory methods to explore the experience of prostate cancer diagnosis, treatment, and survivorship from the perspective of Black men. Extensive bodies of literature have indicated that interviews have been widely accepted as a technique for use among community informants that have access to shielded information about a specific topic or area of expertise (Glaser & Straus, 1967; Patton, 2002; Cozby & Bates, 2011; Creswell, 2013). Thus, open-ended interviews were conducted with 32 men (18 US-born, 13 Caribbean-born, 1 African-born) diagnosed with prostate cancer in 2010. Interviews were facilitated by a trained and racially concordant community health worker. Interviews were audio recorded and transcribed by a professional transcription service. Transcripts were verified for accuracy by the community health worker responsible for conducting the interviews. NVivo software was used to code transcripts and organize emerging themes. A multidisciplinary research team participated in continuous open coding and iterative analysis as part of the grounded theory process.

Primary data were reviewed to assess ‘fit for inclusion’, whether the data could provide relevant information to address the new line of inquiry (Stewart, 1984; Dale & Procter, 1988), in this analysis. Having been significantly involved and acutely familiar with the original dataset, there was very little risk of potential misinterpretation or
misrepresentation of data collected from the primary dataset during the re-analysis process (Thorne, 1990). Summaries of relevant content related to the role and influence of family caregivers were created for each interview. Data were analyzed and sorted using thematic analysis (Patton, 2002). Findings within each code were used to generate thematic categories presented as emergent themes in the analysis.

**Specific Aims**

Together the aims of this dissertation study sought to understand the experience of caregivers in the Black community to better inform culturally specific interventions designed to improve both patient and caregiver outcomes. Specific aim 1 was to explore the role and function of informal CaP caregivers across the continuum of care. Specific aim 2 was to identify the specific needs and support preferences of CaP caregivers at various stages of caregiving. Specific Aim 3 was to identify perceived barriers to seeking support among prostate cancer caregivers in the Black community. To conclude, Specific aim 4 was to investigate existing literature related to psychoeducational and support interventions addressing needs of prostate cancer caregivers in the Black community.

**Summary of Chapters**

This dissertation consisted of a three key components: a secondary analysis, a primary research study, and a review of the literature. A number of research activities for each component of this dissertation were carried out concurrently. Thus study decisions were influenced by multiple inputs throughout the progression of the project. For instance, during the initial planning of this project the review of relevant literature was listed as the first objective, however, as emerging themes began to develop, it became necessary to refine the parameters of the review even further. For that reason,
the review of interventions addressing the specific needs of CaP caregivers in the Black community was undertaken after other study activities were underway and should be viewed as a part of theoretical sampling activities informing final recommendations and conclusions related to the theory or model of caregiving generated from this study.

Chapter 2 addressed specific aim 1, in which I explore the role and influence of informal caregivers as perceived by the CaP survivor across the prostate cancer continuum of care. Results indicated the role of the family caregiver is complex but an essential aspect of survivorship as described by CaP survivors. Men in this group viewed caregivers in this community as drivers of behavior modification and normalizing agents across the care continuum. Chapter 3 addressed Specific aim 2 in which I identify the specific needs and support preferences of CaP caregivers at various stages of caregiving. Findings revealed four categories related to caregiver needs and support preferences: 1) population specific programming; 2) counseling services; 3) support with daily activities/housekeeping and 4) culturally appropriate educational resources.

Chapter 4 addressed Specific Aim 3 in which I describe perceived barriers to seeking support among prostate cancer caregivers in the Black community. Perceived barriers to support were identified as: 1) lack of knowledge 2) lack of access; 3) lack of cultural and religious concordance; and 4) contextual protective factors. And lastly, Chapter 5 addressed Specific aim 4 in which I investigate existing literature related to psychoeducational and support interventions addressing specific needs of prostate cancer caregivers in the Black community. Four publications met eligibility criteria and are included in the review.
Family caregiving and resulting negative health outcomes related to prostate cancer in the Black community are significant public health issues that warrant further investigation and identification of cultural factors and other population specific predictors of caregiver strain and burden. This study aimed to better understand the caregiving experience of family caregivers in the Black community across the prostate cancer (CaP) continuum of care. More specifically, this project aimed to understand the specific support needs, barriers to support, and overall role and influence of the caregiver throughout the CaP experience from the perspective of both the caregiver and the care receiver.
Figure 1-1. Study Design

Opening Research Questions

Informal formative Focus Groups

Instrument Development

IRB Ethics Approval

Initial Purposive sampling
(4 participants)

Individual Interviews
(Notes During and Memo writing after each interview)

Data Analysis

Instrument Development
(Modification to content and sequence)

Theoretical sampling
5 participants (iteration1)
3 participants (iteration 2)

Individual Interviews
(Notes During and Memo writing after each interview)

Data Analysis

Mapping Concepts and theoretical memo writing
CHAPTER 2
ROLE AND INFLUENCE OF PROSTATE CANCER CAREGIVERS ACROSS THE CONTINUUM OF CARE: A QUALITATIVE SECONDARY ANALYSIS OF THE FLORIDA PROSTATE CANCER CARE AND SURVIVORSHIP PROJECT

Black men endure a disproportionate burden of morbidity and mortality related to prostate cancer (CaP). Increasingly family members are assuming the role of providing care and support to family members with chronic disease. Understanding the role and influence of the caregiver from both the perspective of the care-giver and the care-receiver is an important part of developing resources to assist individuals learning to provide care, as well as, avoiding negative outcomes among CaP survivors and their caregivers. The analysis aimed to explore prostate cancer survivor’s perceptions of the role and influence of family caregivers to better understand existing opportunities for: influencing behavior modification, improving experiences and outcomes for both the patient and the caregiver, and increasing sustainable CaP advocacy in the Black community. Secondary analysis of qualitative interview transcripts. Data were analyzed to explore new inquiries related to CaP survivors’ perceptions of family caregivers role and influence at each stage of care. Analysis used a thematic approach. Data included qualitative interview transcripts with 32 prostate cancer survivors from the Florida Prostate Cancer Care and Survivorship Project. The role of the family caregiver is complex. Caregivers in this community seem to have a significant influence on behavior modification and cues to action for Black men with prostate cancer. According to the men in this group, caregivers functioned as normalizing agents, coordinating care and creating a new normal, throughout the various stages of care and survivorship. Findings inform areas for future research to develop culturally tailored
psychoeducational programs addressing the needs of both the family caregiver and the care receiver across the care continuum from prevention to survivorship.

**Background**

Prostate cancer (CaP) is a significant issue in the Black community. While CaP is the most frequently diagnosed cancer among men of all races and ethnicities in the United States, when compared to their non-Black counterparts, Black men suffer a disproportionate burden of morbidity and mortality related to CaP (Oliver, 2007; Jemal et al., 2017). National data reports indicate the age-adjusted CaP incidence rate for Black men is 154.1 per 100,000 compared to 86.9, 79.9, 49.5, and 45.5 per 100,000 for men identified as White, Hispanic, American Indian/Alaskan Native, and Asian/Pacific Islander respectively (U.S. Cancer Statistics Working Group, 2017; Jemal, et al., 2017). Compounding this finding, African American men are also more likely to have advanced disease when diagnosed (Ries et al., 2003; Drake et al., 2006; Li et al., 2016) and twice as likely to die of CaP (American Cancer Society, 2016). Physical and psychological symptoms and side effects related to the CaP experience across the continuum of care (screening, diagnosis, treatment, and survivorship) have been reported as being traumatic, gruesome, emasculating, and frequently associated with cancer fatalism in Black men and the Black community as a whole (Allen, Kennedy, Wilson-Glover, & Gilligan, 2007; Purnell et al., 2011). Common post-surgery treatment related side effects include urinary incontinence, chronic erectile dysfunction, and increased reports of perceived and posttraumatic stress levels (Stanford et al., 2000; Purnell et al., 2011).

Increasingly family members are assuming the role of providing care and support to family members with chronic disease. Evidence from the academic literature suggests that family support, specifically spousal support is a key element in cancer
survivorship (Webb et al., 2006; Halbert et al., 2009). Thus, the CaP experience can have a significant impact on the health of both the patient and the family caregiver resulting in increased burdens for the Black community overall. In a qualitative study of Black women, ninety-seven percent of married women reported having some influence over the health care decisions of their spouses (Blanchard et al, 2005). The presence or absence of spouses at consultations was also shown to have implications for men’s engagement with healthcare systems (Halbert et al., 2009). A qualitative study which conducted separate focus groups with men and their significant others found that female significant others were seen as key motivators for men to be screened (Webb et al., 2006). Similar to these findings, Giarelli et al., (2003) found that spouses were also an important part of the prostate cancer experience for men in regards to decision making and positive outlook after surgery. There is a lack of evidence addressing the educational needs and support preferences of CaP caregivers and the role that they play in preventing late diagnosis, aiding in treatment decision making, providing care after treatment, and facilitating coping and satisfaction with quality of life during survivorship. These findings, compounded with a relative survival rate of 97.8 percent among Black men age 00-64 years, suggest that the role and influence of the caregiver may be relevant in understanding the needs of caregivers (educational and supportive) and the potential opportunities for interventions that address the needs and best practices for improved quality of life for both the caregiver and the CaP survivor.

These findings illuminate the need to better understand the role and experience of the family caregiver in an attempt to better identify specific areas for targeted need-based training and support in this vulnerable population. Understanding the role and
experience of the caregiver from both the perspective of the care-giver and the care-
receiver is an important part of developing resources to assist individuals learning to
provide care.

This analysis examined preexisting interviews from the Department of Defense
funded project (PCRP Health Disparity Award), Development of a Model of Prostate
Cancer Care and Survivorship (CaPCaS) for Black Men: A Grounded Theory Study of
Ethnically Diverse Black Men. Family caregivers of Black men with prostate cancer are
increasingly assuming the role of providing care to family member diagnosed with
prostate cancer. While there is evidence to indicate family caregivers have some impact
on health outcomes among men, there are gaps related to the specific role and
influence of family caregivers among Black men. The current analysis aimed to explore
the role and influence of family caregivers as reported by Black prostate cancer
survivors throughout the prostate cancer continuum of care towards a better
understanding of opportunities to influence behavior modification and improve health
outcomes, and increase CaP advocacy in this community.

Methods

Secondary analysis maximizes the potential for data extrapolation and further
informs implications of linkages found in existing primary data (Stewart, 1984; Dale,
Arber, & Proctor 1988). Qualitative secondary analysis involves the process of
thematically re-analyzing pre-existing primary data for the purpose of exploring new
lines of inquiry (Corti, Foster, & Thompson, 1995; Szabo and Strang, 1997; Johnston,
2014). Quality and credibility of this type of analysis are directly related to the
appropriateness of the research design and the rigor of the methodological approach
used to guide the collection of primary data in the initial study (Poland, 1995; Patton, 1999, Tong, Sainsbury, & Craig, 2007).

Primary data used in this analysis were derived from a multi-phased transformative, sequential mixed methods research study, which used both qualitative and quantitative research activities, guided by an overarching theoretical perspective with a specific focus on the experience and perspective of the target population (Creswell, 2003; Creswell, 2009). A key strength of this strategy is its ability to provide a voice for special populations that are often left out of the academic literature (Cozby, 2011; Creswell, 2011). Moreover this analysis is supported by the assertion that findings from both secondary and primary qualitative data can be used to provide contextual and supplementary understandings and support of quantitative findings (Dale, Arber, & Proctor 1988; Bryman, 2012; Grbich, 2013).

Quantitative data from all black men diagnosed with prostate cancer from 2006 to 2010 (N=10,818) were examined from the Florida Cancer Data System. Qualitative data were collected using constructivists grounded theory methods to explore the experience of prostate cancer diagnosis, treatment, and survivorship from the perspective of black men. Interviews have been accepted as a data collection technique used extensively with community informants that have access to shielded information about a specific topic or area of expertise (Glaser & Straus, 1967; Patton, 2002; Cozby & Bates, 2011; Creswell, 2013). Thus, open-ended interviews were conducted with 32 men (18 US-born, 13 Caribbean-born, 1 African-born) diagnosed with prostate cancer in 2010. Interviews were facilitated by a trained and racially concordant community health worker. Interviews were audio recorded and transcribed by a professional transcription
service. Transcripts were verified for accuracy by the community health worker responsible for conducting the interviews. NVivo software was used to code transcripts and organize emerging themes. A multidisciplinary research team participated in continuous open coding and iterative analysis as part of the grounded theory process.

Primary data were reviewed to assess ‘fit for inclusion’, whether the data could provide relevant information to address the new line of inquiry (Stewart, 1984; Dale & Procter, 1988), in this analysis. The second author of the present article served as the principal investigator of the primary dataset. Additionally, the first and third authors of the present article were also both significantly involved and acutely familiar with the original dataset. This proximity to the original dataset works to reduce the risk of misrepresenting and/or misinterpreting data from the primary dataset during the re-analysis process (Thorne, 1990).

Summaries of relevant content related to the role and influence of family caregivers were created for each interview. Data were analyzed and sorted using thematic analysis (Patton, 2002). The first author applied initial codes to the data. Findings within each code were used to generate thematic categories presented as emergent themes in the following section.

**Results**

Table 2-1 presents caregiver data reported by prostate cancer survivors in the sample with comparisons by country of origin and relation to the survivor. Prostate cancer survivors identified caregiver(s) as: spouses (14); adult children (10); siblings (1); a combination of a spouse and child (2); and/or a medical provider (2). Two survivors reported having no family caregiver. One survivor indicated an aversion to needing a caregiver and thus, declined to respond. Participants offered various
 rationales for why each caregiver was identified as their primary caregiver (medical experience, nature and longevity of the relationship, and access to social support).

**Rationale for Caregiver(s) Identified**

**Medical experience.**

My daughter, who is a surgeon here in _____, was primarily involved in sort of guiding and shepherding me through the decision-making process. Of course, my eldest son who lives in _____, who together with my Medic daughter, my wife, and my other son, we all discussed the options and discussed the situation with the Urologist and agreed to what the course of action should be.

Actually, I didn’t know anyone that have prostate cancer, you know, and, uh, because my son is in the medical field, you know, we talk about it and— and he tell me—he suggest that I go to the doctor and—“

**Nature and longevity of the relationship (familiarity/trust).**

Yes, of course, because we’ve lived long enough, and I have all my confidence and trust in her, after living with each other for 43 years. It is a considerable time.

Well, as I’ve said, my wife is a nurse, so she knows about it. When they told me—and from right there from doctor’s office, I call her.

With my wife, I’m comfortable discussing anything with her.

**Access to social support.**

I ain’t got no family here in _____ with me, so I ‘pend on my—on my—my doctor, which I had ever since I had—I been going to this doctor ever since I’ve been here for 15 years cuz, you know, we close, and he always—you know, if somethin’ come up, he always tell me, you know, "Let's go and check this out," or "Go—let's see what this is about" or—you know. And I go ahead and do it.

Emerging themes were categorized into one of two domains related to the role of the caregiver or the influence of the caregiver across the continuum. Figure 2-2 illustrates CaP survivors’ general perception of the caregiver role, influence, and related activities across the continuum. Themes with in each domain combined to create two larger constructs related to the role and influence of CaP caregivers. Caregivers where
identified as: 1) normalizing agents and 2) drivers of sustained behavior modification (Table 2-4). Emerging themes from each construct will be discussed in detail below.

**Normalizing Agents across the Continuum of Care**

Participants in the sample revealed that caregivers are connected to the CaP experience in several meaningful ways and function as normalizing agents across the various stages of care; as they are also, significantly impacted by the CaP experience in the Black community. One individual stated:

It [prostate cancer] only affects men, physically, but it's a family disease.

Another participant mentioned the benefits of having an ally during the CaP journey, stating:

[it's] always good to have somebody in your corner.

Respondents generally indicated that the role of the caregiver was to support, encourage, listen, and ultimately create a sense of normalcy throughout the Cap experience.

**Support at Point of diagnosis.** Several participants reported feeling overwhelmed and fatalistic at the point of diagnosis. In one example, a survivor shared that after receiving his CaP diagnosis, in a particularly brief and jarring manner from his physician, he was left feeling overwhelmed and in a particularly dangerous mindset, stating:

...I was in a daze just listening to cancer… I went to my car and sat a while. It could've been dangerous. And I felt, and 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 make sure they're all right before they walk out of the office.
Another survivor stated that he reached out to his spouse and caregiver at the point of diagnosis, seeking guidance as to how he should navigate the rest of the visit.

My wife is a nurse, so she knows about it. When they told me—and from right there from doctor's office, I call her.

Participants expressed that some form of support should be in place at the point of diagnosis to attenuate dangerous situations.

**Research before treatment.** Participants mentioned that they frequently relied on their caregivers to facilitate or guide research activities when the caregiver possessed medical training or health related expertise. One respondent stated:

And um, my wife, who is a retired medical technologist, she does um a lot of that reading and um, kind of uh guided me about all of that.

However, one participant indicated that while he relied on his spouse for medical guidance, he was also very involved in the information seeking phase, and stated that having current knowledge influenced self-efficacy for him during the CaP experience:

One thing with me is I will read about it. I know what is current about it, so when I go to my next visit, I will talk like an intelligent person with my doctor. No doctor is going to rattle me because myself, I'm prepared for the doctor. That's the advantage of being educated.

Another participant reported, being divorced, he trusted his adult children to do most of the information seeking related to treatment options that would have minimal side effects:

My two daughters started researching the best way to get it [treatment]... Going on the computer and looking and the feeling that would be the safest and the easiest way and it would leave me whole.

Participants that identified a spouse as their caregiver acknowledged that some of the side effects associated with CaP treatment would affect the spouse as well,
prompting them to encourage/accept the spouse’s participation during the ‘information seeking/treatment decision making’ stage of the CaP experience. One survivor stated:

In that paper they say ___ is the side affects you can get when they start to make the treatment for you …after the treatment…you can't see well…You can get vomit, dizzies…you can't make sex with your wife anymore. And then… I say to my wife, "You’re supposed to read this because I have to take a decision about that."

**Involvement in treatment decision making.** Respondents expressed using a family approach during treatment decision making. One participant indicated that he might have taken a different route with possibly more potential for risk. However, he took a safer route based on his spouse’s involvement and opinion.

My wife plays a part once I discuss it with her, but I had the final decision. But she, you know, led me, it’s best to take the safest route and the quickest route. Get it over with so you can get it over with and go back to life as normal.

Another participant stated that his entire family, led by the medical professional of the family, together with his actual physician contributed to the final decision.

My daughter, who is a surgeon here in _____, was primarily involved in sort of guiding and shepherding me through the decision-making process. Of course, my eldest son,… together with my Medic daughter, my wife, and my other son, we all discussed the options and discussed the situation with the Urologist and agreed to what the course of action should be.

**Support during treatment.** Participants reported that one of the key roles of the family caregiver throughout the CaP process, specifically during treatment was the provision of support and positive thinking. One participant stated:

My daughter say when [I went for treatment], “Daddy when you go just put a good smile on your face and the Almighty will carry you through,” and that’s what I did.

Another participant mentioned that his wife was empathetic and offered an outlet for him to discuss the CaP treatment experience.
My wife, uh, she listened. I would tell her what I had to go through.

Another survivor further illustrated the supportive role of the caregiver throughout the CaP experience and especially during treatment stating:

Very good. Very, very, very—she was very supportive. And, like I said, she attended the sessions with me, she went with me for the treatments and was there. And, you know, whatever I needed, if I needed something, she was there.

Respondents generally expressed that caregiver support provided hope and encouragement in contrast to their own feelings of fatalism.

**Sexual functioning and self-esteem.** Participants in this sample recognized the ability of the spousal caregiver to create a new sense of normalcy related to sexual activity and intimacy. Participants mentioned that caregivers played a major role in the survivor’s adjustment to erectile dysfunction and other related side effects of CaP treatment during survivorship. Caregivers were also cited as a contributing factor to the survivor’s self-esteem related to masculinity and sexual functioning. One survivor mentioned the ability of the spousal caregiver to influence survivor’s perspectives related to masculinity and erectile dysfunction.

Prostate affects our manhood. You know, the ED [erectile dysfunction]... Women discuss this. We—men, it's like—it's like you less than a man if your Johnson don't work, but let me explain it to you in a—in a different way.

In another example, one survivor cited his spouse’s response at the point of diagnosis which helped to reframe his outlook on diagnosis, treatment, and survivorship, stating:

And she said, "Okay. You have to go through treatment. All what I'm praying is that you are alive for me and the children. I'm not worried about sex. I just want you to be there for me and for the children."
Another participant mentioned the role the caregiver played on creating a new normal during intimacy, stating:

But I can get an erection. I can still ejaculate and so on, and I am all right. I—my wife is accommodating, and she is happy with me.

One survivor indicated that the changes related to sexual functioning impacted spousal caregivers in a significant way requiring significant adjustment from both the care receiver and the caregiver.

Sex life. It's going to affect it. If you have not been using Cialis or, uh, Viagra before, you'll probably have to use it. Um, I don't like too many medication, so I use erectile pump. You know? And not all woman like it. Uh, my wife didn't like it initially, but now she's kind of receptive to it.

In another example, one participant expressed feeling it was the spousal caregiver's role to be available and encouraging during times of optimal functioning stating:

So have a good health and a good lady, too, because if you want to make sex and then the lady doesn't understand you too, and make you down, if you want to caress your wife and then your wife is not disposed, not correspond with you automatically, you—you're going to lose...And don't put me down when I want to make sex with you." I say that always to her.

Participants in this sample recognized the ability of the spousal caregiver to create a new sense of normalcy related to sexual activity and intimacy across the CaP Continuum of care.

Life balance and leisure activity in survivorship. Participants shared that caregivers were important factors in helping them achieve and maintain life balance after treatment. One respondent expressed:

I'm just constantly busy doing so much with my son's school...In between stuff that I do with church and work, and, other community service of mentoring kids, I'm constantly busy. My wife is the one to have to drag me. "Calm down. Relax, take it easy. Do this,"
Participants also stated that caregiver’s were an important part of reintroducing leisure activity after the CaP treatment. One participant stated:

I like to play volleyball…with my family, my wife’s family. We get together, like, every other weekend, go in the backyard, you know, volleyball. Very competitive

Another participant stated that he and his wife continued their tradition of attending football games with family:

My wife and I have, uh, season tickets [to Jaguars games]. And we been season ticket holders for 20 years.

In another example, one participant described exploring new venues and types of entertainment with his adult child, stating:

I love the arts… sometimes my son, believe it or not. He would go with me [to art and music events].

While another survivor expressed enjoying simple entertainment at home with his spouse.

I’m into—I like boxin’, too, so me and my wife, we’ll sit and we’ll order Mayweather, and my wife sit right here and we watch it.

Participants expressed that after going through the life altering journey of beating CaP, the caregivers played an important role in assimilating back to life without treatment and embracing life activities outside of the context of being a man with CaP.

**Drivers of Sustained Behavior Modification**

Participants revealed that caregivers functioned as drivers of sustained behavior modification across the CaP care continuum from increasing screenings and regular check-ups to coordinating appointments, monitoring medication schedules, and improving the family diet and exercise routines. One participant stated:
Well, now that I’m married, my wife…, she makes sure you eat right. So, she gonna feed you right, so you know—and I’m also just goin’ to get regular checkups, you know, makin’ sure.

**Screening and awareness.** Participants indicated that caregivers had a significant influence on screening and follow-up behavior. One survivor stated:

> My wife encouraged me to do that, but it's important to have an annual checkup.

Another participant echoed that sentiment, adding that persistence was an effective approach contributing to health related behavior changes, stating:

> She stayed on my case.

Participants expressed that caregivers were vital to raising awareness and increasing advocacy in the Black community. One participant referenced the unique and powerful influence of the spousal caregiver and cited the need for care receivers to use their caregivers as a resource for accountability, in conjunction with individual knowledge, empowerment, and self-efficacy, stating:

> I just gotta believe once you get the ladies on board, that gets the men on board…and not be ashamed to say, "Hey, we need somebody on our back."

**Diet, nutrition and physical activity.** Participants stated that caregivers were able to alter survivors’ diets, considerably reducing their consumption of fatty fast food, while increasing consumption of fresh food prepared with less fat. Participants also mentioned that in addition to altering food consumed by the care receiver, caregivers were also able to influence care receiver’s food preferences. One participant stated:

> I’d go to McDonald’s, you know, those places out there, do a lot of fast-food. Now, she—we bake fish and eat salmon and, you know, a lot of vegetables. I love vegetables, love, love it-love it. Yeah.

Echoing that sentiment another participant expanded saying:
I mean, she—we definitely gonna have more vegetables and, you know, less this and less that. We gonna cook with, um, olive oil and stuff like that. Mm-hmm.

Another survivor illustrated the power of the caregiver to influence the removal of certain items from his diet completely, stating:

Since meeting her, I’ve cut out red meat. I don’t eat red meat.

Respondents also shared that caregivers had an influence on regular physical activity. One participant expressed that he was most likely to exercise when his wife was with him:

Uh, when I go with my wife, she’ll walk and I’ll kind of slow jog with her, but, um, sports, uh—that’s my, um, form of exercise

Participants commonly referred to the caregiver as the driver of behavior modification related to screening behaviors diet and exercise.

**Discussion**

The purpose of this study was to explore the role and influence of family caregivers across the prostate cancer continuum of care in the Black community. Consistent with findings from a national profile of family and unpaid caregivers who assist older adults with health care activities, most caregivers (80.4 percent) were identified as spouses and adult children (Wolff, Spillman, Freedman, & Kasper, 2016). In our sample spouses and adult children accounted for 76 percent of reported caregivers in this sample (44 and 32 percent respectively) figure 1. This analysis found that in this sample the role and influence of the caregiver varied based on relationship to the care receiver. When identified as an adult child the role of the caregiver was significant for the care receiver, however, it was limited to research and information seeking related to side effects of treatment, treatment decision making, and support
during treatment. While adult children were identified as significant sources of support throughout the care continuum; they were not generally identified as primary sources of support during survivorship. In contrast, when identified as a spouse, the role and influence of the caregiver was more extensive, consisting of providing support across the continuum from diagnosis to survivorship. Spouses were also more frequently identified as drivers of sustained behavior modification in this group. This singularity may be due to the nature of the side effects common in CaP survivorship. Survivors may feel uncomfortable receiving support or sharing information about erectile dysfunction, urinary incontinence, and other related side effects with their adult children. Future research should be conducted to identify difference in caregiver roles in order to better understand variation of caregiver needs between groups.

While individual explanatory models such as the health belief model and the theory of planned behavior highlight the concept of self-efficacy to influence or predict behavior change in individuals, this analysis begins to highlight, a conceptual gap related to the dynamic role and critical influence that social support may have among Black men in their actual lived reality with CaP. Specifically, this analysis depicts the potential for social support and caregiver advocacy to function as a vital driver of behavior modification associated with CaP awareness and screening among Black men. Similar to assertions from Gamble 2005, perspectives shared by men in this analysis demonstrate that due to historical trauma and persistent systems of inequality, the Black community has several reasons to mistrust and avoid public health systems (Gamble, 1997). The application of community-based interventions, grounded in theories that are derived directly from the Black community have great potential to be
effective in this community (Woods, Montgomery, & Herring, 2004; Abernathy et al., 2005). The data also corresponded with several studies have found that African American men do not have adequate knowledge about prostate cancer (Smith, DeHaven, Grundig, & Wilson, 1997; Odedina, Scrivens, Emanuel, LaRose-Pierre, Brown, Nash, 2004; Ogunsanya et al., 2017), underscoring the need for educational programs and CaP advocacy in the Black community in order to raise awareness. The cost of recruiting and training culturally sensitive community health workers can be a barrier to successful program implementation. This analysis highlights an existing avenue for the delivery of CaP information to Black men, specifically, the opportunity to utilize informal caregivers as advocates and community health educators in the Black community. Based on this analysis, within the Black community, family caregivers seem to be seated in a fitting position, in which they could easily transition to community CaP advocates operating much like community health workers (CHWs) to educate and inform Black men and the community as a whole about prostate cancer.

Limitations. This study had minor limitations. Among them, this study aimed to explore factors associated with prostate cancer disparities that exist in the Black community thus, the unique nature of the sample limited generalizability to a larger population. In addition, the selection of participants from various parts of Florida, do not necessarily reflect the experience of Black men from other regions. Additionally, while the sample of all Black men was sufficient for data saturation; when disintegrated by country of origin, the sample was slightly uneven. Finally, although the authors of the current analysis were especially familiar with data considered for this secondary
analysis, the data was limited by the questions and context of data collection that were employed during primary data collection.

In conclusion, prostate cancer in the Black community is a serious public health issue. Findings from this analysis indicate caregivers, specifically spouses and adult children, have significant influence over behavior modification and may serve as effective community advocates for increased CaP knowledge and screening in the Black community. Evidence also suggests that caregivers may be an ideal target population for organized CaP advocacy training, however, due to the link between decreased health status and identification as a family caregiver, more research is necessary to identify areas for support and best practices for the implementation of caregiver and advocate support initiatives in the Black community. In addition, to decrease negative health outcomes in both caregivers and care receivers, further research is necessary to determine technical preparedness needs and experiences associated with providing care to a family member for the caregiver and coping with receiving care from a family member for the care receiver. Future research should also examine how to best meet the needs of caregivers, with an emphasis on specific needs identified by caregivers in the Black community.
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<thead>
<tr>
<th>Categories</th>
<th>Sample Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
<td>Who do you consider to be your primary caregiver(s)? That is the person people who would help you if you needed assistance or would help you make decisions about your health care. How do people in your cultural or your ethnic group [can substitute the name cultural group] perceive or think about prostate cancer?</td>
</tr>
<tr>
<td><strong>Screening &amp; Diagnosis History</strong></td>
<td>Who else was with you during your diagnosis?</td>
</tr>
<tr>
<td></td>
<td>What was the first thing that came to your mind when you were diagnosed with prostate cancer?</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td>What was the level of involvement of your family or significant other(s) in choosing your treatment?</td>
</tr>
<tr>
<td></td>
<td>Who did you talk to prior to making your treatment decision? How did that person help you (or not help you) make your decision?</td>
</tr>
<tr>
<td><strong>Survivorship</strong></td>
<td>What made you feel comfortable or uncomfortable in your conversation with family and friends?</td>
</tr>
<tr>
<td><strong>Acculturation</strong></td>
<td>Tell me about your diet.</td>
</tr>
<tr>
<td><strong>Advocacy</strong></td>
<td>How would you describe your willingness to discuss your problems with other people?</td>
</tr>
<tr>
<td></td>
<td>Did anyone outside of your medical providers advocate to you about prostate cancer during your experience?</td>
</tr>
</tbody>
</table>
### Table 2-2 Frequency Table. Caregiver Relationship to Prostate Cancer Survivor

<table>
<thead>
<tr>
<th>Caregiver Identified</th>
<th>African-born</th>
<th>Caribbean-born</th>
<th>Native-born</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>1</td>
<td>6</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Adult Child</td>
<td>0</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Sibling</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Family (wife + children equally)</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>No Family Caregiver</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Medical Provider</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>No Response</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>13</td>
<td>18</td>
<td>32</td>
</tr>
</tbody>
</table>
Table 2-3. Rationale for Caregiver(s) Identified

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sample Quote(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Experience</td>
<td>My daughter, who is a surgeon here in ______, was primarily involved in sort of guiding and shepherding me through the decision-making process. Of course, my eldest son who lives in ______, who together with my Medic daughter, my wife, and my other son, we all discussed the options and discussed the situation with the Urologist and agreed to what the course of action should be. Actually, I didn’t know anyone that have prostate cancer, you know, and, uh, because my son is in the medical field, you know, we talk about it and- and he tell me—he suggest that I go to the doctor…my wife is a nurse, so she knows about it. When they told me—and from right there from doctor’s office, I call her.</td>
</tr>
<tr>
<td>Nature/Longevity of relationship</td>
<td>…we’ve lived long enough, and I have all my confidence and trust in her, after living with each other for ___ years. It is a considerable time.</td>
</tr>
<tr>
<td>Access to Social Support</td>
<td>I ain’t got no family here in ______ with me, so I ‘pend on my—on my—my doctor, which I had ever since I had—I been going to this doctor ever since I’ve been here for 15 years cuz, you know, we close, and he always—you know, if somethin' come up, he always tell me, you know, “Let's go and check this out,” or &quot;Go—let's see what this is about” or—you know. And I go ahead and do it.</td>
</tr>
</tbody>
</table>
Table 2-4. Emerging Themes

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Thematic Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role of the Caregiver:</td>
<td></td>
</tr>
<tr>
<td>Normalizing Agents across the Continuum of Care</td>
<td></td>
</tr>
<tr>
<td>Guidance at point of diagnosis</td>
<td></td>
</tr>
<tr>
<td>Research before treatment</td>
<td></td>
</tr>
<tr>
<td>Involvement with treatment decision making</td>
<td></td>
</tr>
<tr>
<td>Support during treatment.</td>
<td></td>
</tr>
<tr>
<td>Sexual functioning and self-esteem</td>
<td></td>
</tr>
<tr>
<td>Life balance &amp; leisure activity in survivorship</td>
<td></td>
</tr>
<tr>
<td>Influence of the Caregiver:</td>
<td></td>
</tr>
<tr>
<td>Drivers of sustained behavior modification</td>
<td></td>
</tr>
<tr>
<td>Screening and awareness</td>
<td></td>
</tr>
<tr>
<td>Diet, nutrition and physical activity</td>
<td></td>
</tr>
</tbody>
</table>
Figure 2-1. Caregiver relationships
Figure 2-2. Understanding the role and influence of the caregiver
In the United States, prostate cancer is the most frequently diagnosed non-skin cancer among men. Black men have the highest incidence of prostate cancer in the world. While there is considerable evidence to show that caregiver support is a key element of survivorship among men, there are significant gaps related to informal caregiver support. Family members are assuming the role of providing care and support to family members with chronic illness more and more each year. Understanding the needs and support preferences of family caregivers is an essential part of developing effective resources to assist caregivers and optimizing the role of the caregiver in health promotion initiatives. Qualitative interviews were conducted with twelve self-identified prostate cancer caregivers. Guided by grounded theory methodology data were collected analyzed using an inductive approach. Thematic analysis was used to code and categorize data into primary emerging themes. Data related to needs and support preferences were categorized into three primary themes: 1) population specific programming; 2) accessible support services; and 3) educational resources. Findings indicate family caregivers in this sample relied on informal and faith based support networks throughout the continuum of care. Additionally, support was better received when it was offered from entities that possessed direct experience providing care as informal CaP caregivers. Future research should focus on the development of culturally tailored programs addressing the specific needs of caregivers as a crucial component of the treatment process in order to optimize the role of the caregiver and improve health outcomes for both the caregiver and the care receiver.
Background

In the United States, prostate cancer (CaP) is the most commonly diagnosed non-skin cancer among men of all races and ethnicities (CDC, 2016). When compared to their non-Black counterparts, the Black community suffers a disproportionate burden of morbidity and mortality related to CaP (Oliver, 2007; Jemal et al., 2017; U.S. Cancer Statistics Working Group, 2017). Compounding this finding, African American men are also more likely to have advanced disease when diagnosed (Ries et al., 2003; Drake et al., 2006; Li et al., 2016) and twice as likely (68.1 vs. 27.7 per 100,000) to die of CaP compared to White men (American Cancer Society, 2016). The CaP experience, from diagnosis to survivorship, can be traumatic and life altering, causing several severe side effects (i.e. urinary incontinence) and implications for both the patient and immediate family networks (Stanford et al., 2000; Allen, Kennedy, Wilson-Glover, & Gilligan, 2007; Purnell et al., 2011; Purnell et al., 2011; Cobran et al., 2014). Notably, family caregivers are being identified as an essential part of the care process for patients diagnosed with chronic illness at an increasing rate. While a growing body of literature has shown that family caregiving can have a negative impact on caregiver health and wellbeing (Webb et al., 2006; Halbert et al., 2009), there is evidence to support the benefits of participating in programs that focus on education and support (Gallagher-Thompson, et al, 2000). Due to their social proximity and the existence of life long connections, family caregivers have a unique influence on the CaP experience for men throughout the continuum and play a significant role in addressing the needs of men with CaP from prevention through survivorship. While there is a substantial volume of literature related to men with CaP, there are gaps related to the specific needs and support preferences of family caregivers in this population. The current analysis aimed to explore the needs
Methods

Qualitative data were collected using constructivists grounded theory methodology to explore the CaP caregiving experience in the Black community. To ensure quality and rigor, this study aimed to incorporate a dimension of reflexivity throughout the research process (Koch & Harrington, 1998) and report on the fundamental components of a grounded theory study (Sbaraini, Carter, Wendell, Evans, & Blinkhorn, 2011). The current study sought to identify and describe the needs and support preferences of CaP caregivers across the CaP continuum of care. In 2016 two informal focus groups were conducted with a purposive sample of self-identified CaP advocates who reported providing care for a family member diagnosed with CaP in the past 7 years. Memos and notes from the focus groups were coded to reveal key themes that were used to inform topic areas for the development of a population specific semi-structured interview guide for use among CaP caregivers providing care for Black men. From June 2017 – September 2017, interviews were conducted with twelve self-identified prostate cancer caregivers in Florida. Sample questions from the IRB-approved interview guide are listed in Table 1. Interviews were facilitated by the first author after establishing rapport with gatekeepers in the population of interest. Data collection and analysis were conducted concurrently. Theoretical sampling was employed during the study to modify questions and refine participant recruitment and clarify uncertainties in the analysis. Recruitment ended when saturation was reached, that is nothing new emerged from subsequent participant interviews. Interviews were audio recorded and transcribed by a professional transcription service. To ensure
accuracy transcripts were verified by the first author who conducting each interview.

NVivo software was used to code transcripts and organize codes into larger themes. Major emerging themes are reported below.

**Results**

Participant ages in this sample ranged from 47 to 71 years of age. Caregiver self-identified as: spouses, adult children, and/or other family relative. Two caregivers had experienced being a CaP caregiver for multiple family members and was able to provide insights related to caregiver dynamics based on the varying dynamics of each relationship. Data related to needs and support preferences were categorized into three primary themes: 1) population specific programming; 2) accessible support services; and 3) educational resources.

**Population Specific Programming**

Participants in this group indicated there was a need for culturally sensitive programming that takes into account caregiver support preferences related to facilitation of services in order to increase credibility and trustworthiness. Further, participants specified the importance of integrating faith based components throughout support programs offered for this community. In addition to support preferences and faith-based components participants also mentioned the need for age appropriate and relationship specific support programs.

**Support preferences**

**Caregiver narratives.** Participants in this sample indicated that facilitation of support programs by individuals with firsthand experience was essential to establishing trust and building rapport in this community. One participant stated:
Probably someone that have experience, because if you have not experienced it how can you come before someone and tell someone you should do this and this when you haven’t lived through it. So it will be someone that can give things, information that they have actually, it’s not that what they did will work for me but it would definitely — I can use whatever they give to fit my situation. So it would have to be someone that have already experienced, that have that knowledge; and not coming from a book perspective where they read all this information in a book and now, they can share. It would have to be someone that really knows about being a caregiver.

Another participant echoed this sentiment with even more emphasis, recalling the frustration experienced after receiving sympathy instead of empathy and having to listen to blasé words of encouragement, stating:

Cause people say ‘I understand’, but “_____ no, you don’t understand” … don’t tell me you understand, because, unless you’ve been there when he was puking and the pain, and all these meds, and cleaning them up and trying to build on this man, that you’ve invested a life... “You don’t understand a _____ thing! don’t tell me you understand.”

Cultural concordance. Race and Ethnic match was also cited as a preference for facilitators of caregiver support groups. Participants indicated that it was easier to gain rapport with someone that shared a similar cultural background however, in the case of prostate cancer, having firsthand experience was view as a more vital facilitator characteristic. One participant stated:

Yes. Race would be second on the list for me.

While not as significant as first-hand experience as a caregiver, cultural aspects were still an important support need and preference. One participant mentioned:

The doctors, the few doctors that we were referred to for various stages and everything that he was going through none of them looked like us.

Unbiased or nonmedical providers. In addition to caregiver narratives and racial/ethnic concordance caregivers also mentioned a preference for non-medically
trained facilitators, again citing the significance of first-hand experience. When probed about facilitator preferences, one caregiver responded:

Not the physician. Maybe another person that has gone through it, with some questions to ask, to kind of help them to see the way they need to be thinking…So that people can see that this is not a doctor, it’s not somebody that works for the drug company or whatever

**Faith-based components**

The integration of faith based components into support programs, in combination with scientifically sound information or evidence based recommendations was also a theme that emerged repeatedly in the data. One participant shared:

I’m so glad now that the churches are becoming more involved, but I think we need tools for them.

Another participant stated the importance of the church in everyday life stating:

When we in trouble… the church is our first refuge. I don’t know about you. But the people I know and the circles I run, when something happens we get on the phone and we call out pastors.

**Age appropriate and relationship specific components**

Caregivers in this sample indicated the need for support programming that was age appropriate. Participants shared that the process of providing care occurred at various stages in life and their needs changed based on age and relationship to the person they were providing care to. Related older caregivers indicated the need for support that was catered to children as a means of helping children in the family understand what was happening in terms that they could understand. One caregiver stated:

We tried to shield our girls as much as possible but I just don’t feel it’s the way to do that either. I think, now knowing what I know today, I think we would have incorporated them more…maybe found material that were related on a child level, that they can understand.
In addition to age appropriate material, caregivers stated that there was a need for support programming that offered relationship specific components, as the experience would be different for an adult child as opposed to the experience of a spouse.

**Accessible Support Services**

The need for counseling services was mentioned repeatedly throughout the interviews. Caregivers reported feeling forgotten and perceived support services to be provided as an afterthought. One participant stated:

> Nobody seems to really care about the caregiver, to tell you the truth. They care about the patient, but not about the caregiver.

Caregivers are felt that support programs should incorporate support programs design to help caregivers and patients navigate the process of sharing the CaP diagnosis with family and friends. In addition to sharing the diagnosis, caregivers indicated a need for professional counseling service in addition to the spiritual support that was offered by the church. One participant stated:

> Yeah, I would go to him and say, “I’m so tired and I just don’t know how much I’m going to be able to take.” He didn’t get it. Like he’d say “you need to pray more. You need to lean on God more. You need to tell God”... and all of those things like I say are awesome. But the physical me, the mental me, not the spiritual me, needed somebody maybe with some counseling experience, to come and deal with that feeling of frustration, that feeling of coping, the need to cope I think a 1-800 number. I mean, that's a little impersonal, informal but just having that counselor, that person that you can go in and vent to, I think would have made the world [of difference] cause that would've been an outlet instead of having just to keep it all in and put on this face, we put on this look of “Oh, I'm fine. I'm great. Everything's gonna be fine.”

Cancer fatalism was also a major theme discussed by the caregivers in this group. Caregivers shared that men in the Black community were extremely intimidated and fearful of cancer. One participant stated:
I have to be honest. I think I was more in tune to what the doctor was saying than he was. He began to start talking about, “Who’s gonna walk my daughters down the aisle? Who’s gonna help my wife, you know care for our family?” Because, so he took on that macho persona and all I could share was, “Honey, this is about you. Right now it’s about you. We need you to be healthy and we will be fine.”

Conversely, another participant shared that cancer fatalism was a personal issue that caused additional stress, stating:

The first thing I thought of was “I don’t wanna lose him…cause you know when they say the big ‘C’, then the big ‘D’ coming, as they say.

**Educational resources**

Educational needs were also reported to be a significant need in this sample of caregivers. Participants mentioned receiving subpar information and explanations from doctors and other medical staff. One participant stated:

Considering that, “Oh, I got a booklet.” I think one of the doctors gave me a trifold that just explained where the prostate gland was.” I’m like, “Really?” But nothing really, besides the little note, you know when you go up to the hospital and they print out the paper when they discharging you.

Participants also emphasized the need for digestible information about all aspects of care and potential negative side-affects or common occurrences across the CaP care continuum. In addition participants also indicated the need for materials provided in various platforms.

[It would be better] If the material can be tailored, in such a way that it gives enough information but they’re not overloaded like the internet does.

Other respondent echoed this sentiment and expressed the need for information in an express format targeting key points for the caregiver related to expectations.

Maybe they need to have, like – and I don’t know if it’s already there – once they have – they have patient pamphlets or whatever, what will happen, what the patient is to expect. Then they have to have a section, “As a caregiver, this is how you can help this patient.”
Training related to physical aspects of caregiving was also a theme identified by caregivers in this group. Caregivers indicated that they were not prepared to provide care and typically it was incumbent upon them to make sense of medical devices and other clinical aspects of providing care. One participant stated:

No. I wasn't prepared. I just learned on my own from day to day just to do it. I mean it just come natural… It wasn’t anyone there to say well be on the lookout for these symptoms, or you know what you can do just in case this occur. I really wasn't prepared for it, it just happened.

Participants also stated that when support related to the physical aspects of caregiving were provided, the training was brief and generally offered after the caregiver had been providing care for a significant amount of time.

I would say that I had already been lifting him like for a year, eight months or a year before somebody noticed that I wasn’t doing it correctly. And said “Let me show you a better way… and bend your knees.”

**Discussion**

The purpose of this study was to explore the needs and support preferences of CaP family caregivers in the Black community to better understand issues that were relevant throughout the caregiving process for this community. Research indicates that caregiver are generally identified as female and on average 55 years of age (Wolff, Spillman, Freedman, & Kasper, 2016). The sample in this study was similar to the average characteristics defined in literature, with sample consisting of an all-female sample of women age 47 to 71 years of age. Future research should be conducted to identify within group variations in caregiver needs and support preferences in order to better understand specific needs of caregivers from different ethnic backgrounds. The economic value of family caregivers has continued to grow overtime. In 2009, family caregivers in the United States provided an estimated $450 billion of unpaid labor each
year and the amount of time spent providing care for a family member on average was 20 hours per week (National Family Caregivers Association & Family Caregiver Alliance, 2009; Feinberg, Reinhard, Houser & Choula, 2011). In 2016, 78 percent of caregivers incurred out-of-pocket expenses as a result of caregiving. Across race and ethnicity, financial strain measured by out-of-pocket spending was highest among Hispanic/Latino and African American caregivers; spending 44 percent and 34 percent of their income as a result of caregiving activities respectively, compared to 14 percent of out-of-pocket spending among White caregivers (AARP, 2016).

This study had minor limitations. Among them, small sample size and the unique nature of the sample limited generalizability to a larger population. Additionally, while the research team attempted to adhere to quality qualitative research techniques, results from this study are open to interpretation and the broader emerging theory is dependent on contextual factors.

In conclusion, this study sought to explore the needs and support preferences of CaP family caregivers in the Black community. Findings revealed issues that were relevant throughout the caregiving process for this community and will aid in the development of programs and future research designed to address how most effectively improve the CaP caregiving experience using culturally sensitive and population specific support programs. The disproportionate exposure to CaP in the Black community may result in more negative health consequences for caregivers in this population. The findings of this study illuminate the need to better understand the perceived barriers to seeking support services and accessing resources in addition to further examining how to best meet the needs of caregivers in this vulnerable population. Future research
should focus on finding evidence based best practices for incorporating the caregiver in the health care system. Due to the link between decreased health status and identification as a family caregiver, more research in necessary to identify areas for support and best practices for the implementation of caregiver and advocate support initiatives in the Black community.

**Compliance with Ethical Standards**

Research reported in this publication was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number UL1TR001427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

**Ethics.** This study was approved by the University of Florida Institution Review Board.

**Conflict of Interest.** The authors declare there are no conflicts of interest to disclose.
In the Black community, prostate cancer is a significant issue that can have negative impacts on both the caregiver and the care receiver. Understanding the perceived barriers to support among family caregivers is an essential part of developing effective resources and interventions designed to improve health outcomes and health care experiences in this community. This analysis sought to identify perceived barriers to seeking support among prostate cancer caregivers in the Black community in an effort to better understand existing needs and culturally appropriate opportunities in this community. Interviews were conducted with twelve self-identified prostate cancer caregivers. A grounded theory approach was used to help develop an IRB-approved, semi-structured interview guide informed by results from two informal focus groups. Thematic analysis was used to code and categorize data inductively. Perceived barriers to support fell into four categories: 1) lack of knowledge 2) lack of access; 3) lack of cultural and religious concordance; and 4) contextual protective factors.

Findings suggest there is a need for culturally tailored programs and resources designed to address the unique and complex needs of family caregivers in the Black community. Findings also suggest that caregiver support using digital health platforms may be effective in this community.

**Background**

Prostate cancer (CaP) is a serious public health issue in the Black community. Disparities related to the incidence and prevalence of morbidity and mortality related to CaP in this community have been well documented (Ries et al., 2000; Oliver, 2007; American Cancer Society, 2016; Li et al., 2016; Jemal et al., 2017; U.S. Cancer
As a result there has been a recent push to increase early detection of CaP in older Black men. Combined with recent advances in technology the push for awareness and early detection has contributed to significant increases in rates of survival among this vulnerable population. Unfortunately, as survival rates increase, the incidence and duration of family caregiving also increase.

Family caregivers, also referred to as informal caregivers, are generally defined as individuals that provide unpaid care to a relative for an extended period of time (Schulz and Quittner, 1998). In the United States, an estimated 65 million Americans age 18 and older provide care to a chronically ill, disabled, or chronically ill family member, representing 29 percent of the US population (National Alliance for Caregiving & AARP, 2015). Further, evidence indicates the provision of informal, unpaid care and support for prolonged periods of time can have significant consequences for the caregiver and negatively impact outcomes for the care receiver (Schulz and Beach, 1999; National Alliance for Caregiving & AARP, 2004; National Family Caregivers Association & Family Caregiver Alliance, 2006; Schulz, & Sherwood, 2008; Pinquart and Sörensen, 2011). Research also indicates that most caregivers reported feeling ill-prepared to provide care for individuals with chronic disease (National Alliance for Caregiving & AARP, 2004). This phenomena is even more significant in minority communities as rates of care-giving and caregiver outcomes vary by ethnicity as well (Aranda and Knight, 1997; Ho et. al., 2009; Pharr, Francis, Terry, & Clark, 2014). In a national sample of elderly adults, 44 percent of Latino respondents and 34 percent of Black respondents were reported to have received home based family caregiving compared to 25 percent of non-Hispanic White respondents (Weis et al, 2005). Further,
compared to non-Hispanic White respondents, ethnic minorities had lower socioeconomic status and were more likely to receive care from family and friends. While African American caregivers had lower levels of caregiver burden and depression, caregivers in this group reported worse physical health than White caregivers in the sample.

Reports on caregiving from the national alliance on caregiving indicate caregivers are generally willingly to provide care for relatives and derive satisfaction from providing care and support unfortunately, this natural gesture of goodwill results in caregivers that would not immediately describing themselves as caregivers; and thus results in caregivers that do not seek needed support. While there is considerable evidence to show that caregiving is linked to increased strain and burden, few studies have focused on the specific needs of caregivers and the barriers to CaP support in the Black community.

At the intersection of providing care and experiencing negative health outcomes, research has shown that participation in programs focused on education and support can have a positive impact on caregiver health (Zarit, Gaugler & Jarrott, 1999). Given these points, this project sought better understand barriers to seeking support among family caregivers in the Black community across the prostate cancer (CaP) continuum of care.

Methods

Rapport was established with the population of interest as a result of continued participation in activities and events associated with the Florida Minority Cancer Research and Training (MiCaRT) Center. In 2016 a series of informal focus groups were conducted at the MiCaRT community town hall forum with a purposive sample of
self-identified CaP advocates who reported providing care for a family member diagnosed with CaP in the past 7 years. Memos and notes from the focus groups were coded to reveal key themes that were used to inform topic areas for the development of a population specific semi-structured interview guide for use among informal CaP caregivers during individual face-to-face interview sessions in the north- north central region of Florida. Sample interview questions are listed in table 1. From June 2017 – September 2017, telephone and face-to-face interviews were conducted with twelve self-identified prostate cancer caregivers in central, north central, and north Florida. The IRB- approved semi structured interview guide consisted of 26 items initially and was modified throughout the study process (Appendix A). Facilitation of interviews was guided by Kvale’s interview criteria and therefore sought to create the most conducive setting for participants to feel comfortable to respond and share their understanding of the CaP experience based on their own perspectives and lived experiences (kvale, 1996). Initially, the study used purposive sampling techniques to gather information from individuals most knowledgeable about this community. Theoretical sampling techniques were used during later stages of research to gather information related to caregivers that identified as adult children to address gaps identified in the data. Recruitment took place through a variety of community venues, such as UF Health Shands, Health Street, local churches, the Florida Minority Cancer Research and Training (MiCaRT) center, the Black Male Prostate Cancer Coalition (BMPCC), and other community advocacy organizations in the north-north central region of Florida. Inclusion criteria for participants was as follows: 1.) self-identified as an informal caregiver of a Black man with history of CaP and 2.) 18 years of age or older.
Data collection and analysis were conducted concurrently. Theoretical sampling was employed during the study to modify questions, refine participant recruitment and clarify uncertainties in the analysis. Recruitment ended when saturation was reached (i.e. nothing new emerged from subsequent participant interviews). Interviews were audio recorded and transcribed by a professional transcription service. To ensure accuracy, transcripts were verified by the first author who conducting each interview. NVivo software was used to code transcripts and organize codes into larger themes. Emerging themes and constructs were used to develop a substantive theory to inform a model of the critical aspects of CaP caregiving in the Black community. Major emerging themes are reported below.

**Results**

Caregiver self-identified as: spouses, adult children, and/or other family relative. Caregiver ages in this group ranged from 47-71 years of age. Two caregivers had experienced being a CaP caregiver for multiple family members and was able to provide insights related to caregiver dynamics based on the varying dynamics of each relationship. Perceived barriers to support fell into four categories: 1) lack of knowledge 2) lack of access; 3) lack of cultural and religious concordance; and 4) contextual protective factors.

**Lack of Knowledge**

Caregivers identified a general lack of knowledge related to the presence of local support programs as a barrier to seeking support. One participant stated

But it wasn’t really no place here that I can go to. Well I probably was here but I didn’t seek it out cause I didn’t know about it.
Lack of Access

In addition to a lack of general knowledge related to support programs, transportation was also reported as a persistent issue in this community. Schedule conflicts also limited access to support for this group of caregivers. Caregivers expressed that support groups and other programs offered in their immediate area were generally offered during weekdays or work hours. One participant stated:

Transportation. Because I’ve been advised not to drive, so that has been a hindrance to me to get more involved.

Related to schedule conflicts, another participant indicated that the offerings were limited, expressing:

I think just the time that it was being held just wasn’t feasible for me to make that particular night.

Lack of Cultural and Religious Components

Participants in this group indicated that the content of the support programs could sometimes serve as a barrier to seeking support. Caregivers indicated that cultural differences in the way individuals grieved, in addition to misunderstandings related to spiritual activities and other cultural norms could also serve as barriers to seeking support. One participant stated:

To me it [support] was limited. I just can’t think of a better word right now for it. The information that was available for black families and I know I keep going back to that, but that’s what really resonates in my head that the conversations I had with them. They couldn’t understand my beliefs in God, and my hope that god’s going to heal it.” and I’m like, “Well, God needs a little bit of help.” and so talking to a white physician about the correlation between faith and health, they didn’t get it.

Contextual Protective Factors

Caregivers identified several barriers to seeking support that could also be identified as beneficial contextual factors that served to protect against negative health
outcomes. Contextual factor were identified as stage of diagnosis, past life experience with hardship, past experience providing care, culture of caregiving, personal attitude and religious faith. One participant expressed how her professional training had allowed her to assess the circumstance of her relative’s diagnosis and move forward efficiently, stating:

And I guess ’cause I'm a licensed clinical social worker as well…that sort of comes in to my training.

Another participant expressed being grounded in faith and having a personal connection to something larger than the diagnosis was a source of comfort negating the need to reach out to other individuals or seek support service. She stated:

It’s like I can guess console myself in my own prayer and talking to God in my own way and stuff like that.

Related another respondent indicated that faith allowed the family to be optimistic and hope for a favorable outcome, thus seeking support was not a priority.

Because we just realized it’s a point in time. And because we’re people of faith, I pulled on the faith for me to help, to lift our spirits up and encourage and stuff.

Experience with other illness was also cited as a protective factor. One participant indicated that having experienced similar hardship related to health in the past the CaP diagnosis was not as shocking or overwhelming.

Well, I mean, because I’ve gone through with multiple myeloma, when the prostate came, it wasn’t – the toll wasn’t too much.

Discussion

The purpose of this study was to explore barrier to seeking support in the Black community. Consistent with findings from previous research, most were identified as spouses or adult children, were female and on average between 49 and 55 years old
(Trivedi, 2014; Wolff, Spillman, Freedman, & Kasper, 2016). This analysis found that barriers to seeking support did not vary based on relationship to the care receiver. Future research should be conducted to identify difference in caregiver roles in order to better understand variation of caregiver needs between groups.

A recent study conducted with CaP caregivers in north central Florida reported four key areas related to needs identified by CaP caregivers in the Black community (Piervil et. al., 2017). Development of programs to address the barriers identified in this study could potentially reduce the prevalence of unmet needs in this community. The application of community-based interventions, grounded in theories that are derived directly from the Black community have great potential to be effective in this community (Woods, Montgomery, & Herring, 2004; Abernathy et al., 2005). While protective factors such as faith and community support are beneficial, it is important to ensure caregivers in this population are aware of the other resources that are available to them should they require more support or diversified support in the future. The data also corresponded with several studies have found that African American men do not have adequate knowledge about prostate cancer (Smith, DeHaven, Grundig, & Wilson, 1997; Odedina, Scrivens, Emanuel, LaRose-Pierre, Brown, Nash, 2004; Ogunsanya et al., 2017), underscoring the need for educational programs and CaP advocacy in the Black community in order to raise awareness.

Limitations. This study had minor limitations. Among them, this study aimed to explore factors associated with prostate cancer disparities that exist in the Black community thus, the unique nature of the sample limited generalizability to a larger population. In addition, the selection of participants from various parts of Florida, do not
necessarily reflect the experience of Black men from other regions. Additionally, while the sample of all Black men was sufficient for data saturation; when disintegrated by country of origin, the sample was slightly uneven. Finally, although the authors of the current analysis were especially familiar with data considered for this secondary analysis, the data was limited by the questions and context of data collection that were employed during primary data collection.

In conclusion, prostate cancer in the Black community is a serious public health issue. Findings suggest there is a need for culturally tailored programs and resources that take population specific barriers into account when making decisions about location, time, and scope of services. In addition, to decrease negative health outcomes in both caregivers and care receivers, further research is necessary to determine technical preparedness needs and experiences associated with providing care to a family member for the caregiver and coping with receiving care from a family member for the care receiver. Future research should also examine how to best meet the needs of caregivers, with an emphasis on specific needs identified by caregivers in the Black community. Findings suggest there is a need for culturally tailored programs and resources designed to address the unique and complex needs of family caregivers in the Black community. Findings also suggest that caregiver support using digital health platforms may be effective in this community.

**Compliance with Ethical Standards**

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Ethics. This study was approved by the University of Florida Institution Review Board.

Conflict of Interest. The authors declare there are no conflicts of interest to disclose.
Prostate cancer is a disease of increasing significance worldwide. In the United States prostate cancer is the most frequently diagnosed cancer among men and the second most common cause of cancer deaths among men. Black men endure a disproportionate burden of morbidity and mortality related to prostate cancer. Which has resulted in an increased population of unpaid family caregivers. Increasingly family members are assuming the role of providing care and support to family members with chronic disease. Research has identified specific needs related to the experience of caregiving in this community. Recent studies have also identified a number of barriers that may prevent caregivers from seeking support or engaging necessary health services. The current review sought to systematically evaluate the literature on the availability and influence of psychoeducational and support interventions designed for unpaid family caregivers in the Black community. This review aimed to adhere to the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines. An electronic literature search of CINAHL, Psychinfo, Pubmed, and Web of Science was conducted to obtain relevant studies. Interventions demonstrated increased ability to cope with stress and improved perceptions of social support. Self-efficacy and Perceived control were also factors identified with health seeking behavior. Gaps in the scientific literature indicate that more work is needed in order to better understand health seeking behavior and resources necessary for effective social support. Additionally, there is a need for the development of culturally tailored health interventions messages, materials, and initiatives for effective use among ethnically
diverse populations of Black men and their spouses. Findings will also help identify culturally acceptable methods for accessing vulnerable populations.

**Background**

Prostate cancer is a disease of increasing significance worldwide. In the United States prostate cancer is the most frequently diagnosed cancer among men and the second most common cause of cancer deaths among men. Black men endure a disproportionate burden of morbidity and mortality related to prostate cancer. Which has resulted in an increased population of unpaid family caregivers. Increasingly family members are assuming the role of providing care and support to family members with chronic disease. Research has identified specific needs related to the experience of caregiving in this community in addition to a number of barriers that may prevent caregivers from seeking support or engaging necessary health services. The current review sought to systematically evaluate the literature on the availability and influence of psychoeducational and support interventions designed for unpaid family caregivers in the Black community. This review aimed to adhere to the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines. An electronic search of four databases (CINAHL, Psychinfo, Pubmed, and Web of Science) was conducted to obtain relevant studies. Interventions demonstrated increased ability to cope with stress and improved perceptions of social support. Gaps in the scientific literature indicate that more work is needed in order to better understand health seeking behavior and resources necessary for effective social support in this community. Additionally, there is a need for the development of culturally tailored health messaging and initiatives for effective use among ethnically diverse populations of Black men and their caregivers.
Few studies have focused on the specific needs of spouses, partners, and other informal caregivers of Black men diagnosed with prostate cancer (CaP). While there is considerable evidence to show that caregiver support is a key element of survivorship among men, there are very significant gaps concerning informal caregiver support of Black men related to CaP. Further, rural communities experience significant disparities related to prostate cancer; with a 28 percent higher age-adjusted death rate for all cancers in the North Central Florida Region, relative to the state of Florida; there is a significant need for efforts to reduce the mortality rate related to CaP in this region. The age-adjusted prostate cancer incidence rate for black men from 2011-2013 was 231.1 in Alachua compared to 200.7 per 100,000 in the state of Florida. For white men the age-adjusted prostate cancer incidence from 2011-2013 was 79.5 in Alachua compared to 64.5 per 100,000 in the state of Florida (State Cancer Profiles, 2013). Thus there is evidence that there are both geographical and ethnic/racial disparities related to CaP. This review will provide insightful information about existing interventions designed to address prostate cancer and spousal/partner/informal caregiver support. Results will be used to provide recommendation for the development of interventions and resources designed to improve the health and well-being of Black men and their spouses, partners, and significant others acting as informal caregivers.

**Methods**

This review aimed to adhere to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Moher, 2009). A combination of Medical Subject Headings (MeSH) and keywords were used to identify relevant publications on psychoeducational interventions and support programs addressing CaP family caregiving in the Black community. Four electronic databases (CINAHL,
Psychinfo, Pubmed, and Web of Science) were searched from April to May 2017 using Boolean connections (i.e. ‘OR’ and ‘AND’) and variations of MeSH headings and the following search terms: prostate cancer, prostatic neoplasm, African ancestry, African American, Black, family caregiving, spousal support, care giver intervention. Additional publications were identified based on an examination of references in retrieved papers. Publications were filtered by title, abstract and appropriateness of review goal. The current review included all eligible studies that fit the definition of a randomized control trial (RCT) as defined by the National Cancer Institute (2015), “a study in which participants are randomly assigned to receive one of the several pharmacotherapies and/or behavioral interventions.” The following inclusion criteria were utilized to sort identified articles: include a RCT design, report results of peer reviewed primary research (reviews and secondary analysis were excluded), published in English, conducted in the United States, published between 1990 and 2016, assess measurable outcome(s), and report caregiver outcome(s). Reasons for exclusion were as follows: duplicate articles, intervention did not include psychoeducational or support components, interventions did not report caregiver outcomes.

Results

The electronic database search yielded a total of 1412 publications. A total of 948 publications were eliminated based on study duplication, title, and abstract. Twenty-one abstracts met eligibility criteria and were retrieved for full-text review. After full review, an additional seventeen articles were excluded due to an insufficient number of Black participants and/or failure to report caregiver outcomes. Thus, a total of four articles that addressed issues central to caregiver experiences in the Black community and were relevant to specific study goals were included in the current review.
All articles were published within the last fifteen years (Campbell et al., 2005; Giarelli et al., 2003; Manne et al., 2004; Northouse et al., 2007). Only one study focused only on Black caregivers as the population of interest and reported using culturally sensitive techniques for recruitment of African American participants (Campbell et al., 2005). Three of the four studies did not include a balanced sample of participants and Black participants were under-sampled (Giarelli et al., 2003; Manne et al., 2004; Northouse et al., 2007). One study was in the pilot phase (Campbell et al., 2005). All articles used a randomized controlled trial design. Table 5-1 presents a summary of study characteristics.

Campbell et al. (2005) was a pilot study designed to explore the feasibility and efficacy of a coping skills training (CST) intervention to enhance coping with treatment side effects in a sample of African American prostate survivors and their intimate partners. The study was the only study to use a homogenous sample of African American participants. The intervention group received six 1-hour sessions via telephone based intervention format designed to facilitate participation and increase retention. Partners that received the intervention reported less caregiver strain, depression, and fatigue.

Giarelli et al, (2003) was a randomized controlled trial designed to test the effects of a standardized nursing intervention protocol (SNIP). Partners were randomly assigned to usual care or usual care with intervention (8 weeks of biweekly sessions consisting of 1 telephone call and 1 home visit. The intervention tested the effects of SNIP on quality of life outcome variables for patients and caregiving spouses at 3 and 6 months after surgery. This study sample was unbalanced in terms of racial makeup.
(White participants 87 percent; African American participants 12 percent; Asian American participants 1 percent), however, group sizes were comparable (n=53 control; n=57 intervention). Caregiving partners in both the control and intervention group reported increases in perceived preparedness to provided physical and emotional support for their husbands at 3 and 6 month follow-up.

Manne et al, (2004) was a psychoeducational group intervention that used a block design with block sizes of 14. The intervention was designed to address distress, coping, personal growth and marital communication. The intervention consisted of six weekly sessions covering medical information about CaP, nutrition, stress management and coping skills training, communication, intimacy and sexual concerns, and survivorship issues. Outcome measures evaluated were distress, coping, post traumatic growth inventory, and cancer specific marital interactions. This study sample was unbalanced in terms of racial makeup (White participants 84 percent; African American participants 12.5 percent; Hispanic participants 1.8 percent; other 1.8 percent). Participants in the intervention group reported increases in the use of positive reappraisal coping and decreases in denial coping.

Northouse et al., 2007) was an intervention developed to improve couples’ communication, coping, hope, uncertainty, and symptom management. The family-based intervention known as the FOCUS program, was a supportive-educative intervention modified from a previous intervention used among patients with breast cancer. The program consisted of three home visits (90 min sessions) and two telephone meetings (30 min sessions) spaces 2 weeks apart and delivered between baseline and 4 month follow-up. The Study was designed to represent 5 core areas:
family involvement, optimistic attitude coping effectiveness uncertainty reduction, and symptom management. This study sample was unbalanced in terms of racial makeup (White participants 84 percent; African American participants 14 percent; Other 2 percent), however, group sizes were comparable (n=123 control; n=112 intervention). Caregiving partners in the intervention group reported higher quality of life, better communication, and fewer negative appraisals of caregiving and uncertainty. Conversely, patients in the intervention group reported less uncertainty and better communication, however no other effects were observed.

Discussion

The purpose of this review was to evaluate current interventions addressing the specific needs and barriers identified among CaP caregivers in the Black community. Although family caregivers are frequently reported as long-term providers of support and care for men diagnosed with CaP, the literature reveals that very few programs have tailored interventions or support programs to address their needs. This review illuminated a major gap in the literature on caregiver outcomes. Several studies that included caregivers failed to report caregiver outcomes indicating a lack of interest or focus on this group (Geisler et al., 2005; Holt et al., 2015). Further, this review reaffirms research findings stating that the Black community has been significantly under-represented in research evaluating feasibility and efficacy of psychosocial interventions designed to improve cancer experiences (Whitehead and Hearn, 2015; Smith et al., 1997; Allen et al., 2007; Gamble, 1997). Gaps in the literature indicate there is a need to further examine methods for which psychoeducational and support interventions can be optimized to improve outcomes for both the caregiver and the care receiver in the Black community.
Similar to findings of a meta-analytic review of tailored print health behavior change interventions, findings of the current review suggest there is a need for culturally tailored programs and resources that take population specific barriers into account when making decisions about location time, and scope of services (Noar, Benac, & Harris, 2007). Results from Campbell et al., (2005) found telephone-based educational interventions to be effective as a solution to several barriers associated with transportation costs attrition associated with travel and location issues such as parking. In addition several studies indicated that for individuals in the Black community telephone interventions may serve as a solution to cultural stigmas associated with seeing a therapist or seeking mental health services (Glajchen & Moul, 1996; Campbell et al., 2005). Findings also suggest that caregiver support using digital health platforms may be effective in this community. In addition, to decrease negative health outcomes in both caregivers and care receivers, further research is necessary to determine technical preparedness needs and experiences associated with providing care to a family member for the caregiver and coping with receiving care from a family member for the care receiver. Future research should also examine how to best meet the needs of caregivers, with an emphasis on specific needs identified by caregivers in the Black community. Findings suggest there is a need for culturally tailored programs and resources designed to address the unique and complex needs of family caregivers in the Black community. Findings also suggest that caregiver support using digital health platforms may be effective in this community. Lastly, due to the serious lack of interventions that include Black participants, more work is needed to help identify culturally acceptable methods for accessing vulnerable and hard to reach populations.
<table>
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<tr>
<th>Study</th>
<th>Study Design</th>
<th>Intervention</th>
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<th>Outcome measures</th>
<th>Results</th>
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<td>Giarelli et. al., (2003)</td>
<td>RCT</td>
<td>Standardized nursing intervention protocol (SNIP) designed to facilitate post-operative recovery, problem solving for patient and family caregiver dyads after discharge from the hospital</td>
<td>N=110 spousal dyads</td>
<td>Usual care</td>
<td>Caregiver preparedness (Preparedness for Caregiving Scale)</td>
<td>Intervention group felt better prepared to care for emotional needs of husbands at 3 month follow-up</td>
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<td>Coping (acceptance, positive reappraisal and growth, and denial subscales; 4-items of emotional approach to coping scale)</td>
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<td>Campbell et al., (2005)</td>
<td>RCT (Pilot Study) 6-session, culturally sensitive protocol (weekly, 1 hour telephone sessions)</td>
<td>Coping skills training (CST) intervention developed to enhance coping with treatment side effects</td>
<td>N=40 couple dyads Homogenous sample: African American prostate cancer survivors and their spouses</td>
<td>Usual care</td>
<td>Patient: Quality of Life (disease specific &amp; global), Self-efficacy, Partner: Caregiver Strain, Self-efficacy,</td>
<td>Patient: Moderate to large treatment effects for disease specific QoL in CST group Partner: less caregiver stress in CST group</td>
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<td>Northouse et al., 2007</td>
<td>RCT 5-session family intervention 3 home visits (90 min sessions) and 2 telephone meetings (30 min sessions)</td>
<td>FOCUS Family Intervention developed to improve couples’ communication, coping, hope, uncertainty, and symptom management</td>
<td>N=263 couple dyads Mixed sample: White (84%) African American (14%) Other (2%)</td>
<td>Standard care</td>
<td>Quality of life (medical outcomes 12-item short form MOS SF-12; Functional Assessment of Cancer Treatment FACT-G) Coping Strategies (28-item Brief coping Orientation to problems experiences scale) Self-efficacy (17-item Lewis Cancer self-efficacy scale)</td>
<td>Patient: intervention group reported less uncertainty and better communication Partner: Intervention group reported higher QoL, better communication, less negative appraisals of caregiving and uncertainty</td>
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CHAPTER 6
CONCLUSION

Public Health Impact

Demonstrated by the identification of target populations in order to reach national health goals, public health programs are inherently focused on population health. As defined by Winslow (1920), public health is “the science and art of preventing disease, prolonging life and promoting physical health and efficiency through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organization of medical and nursing service for the early diagnosis and preventive treatment of disease, and the development of the social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health” (Winslow, 1920). Similarly, but slightly more focused, population health is a term commonly used to describe “the health outcomes of a group of individuals, including the distribution of such outcomes within the group” (Kindig and Stoddart, 2003). Population health outcomes include general measures of mortality and morbidity, in addition to other more specific outcome measures related to social constructs or operationalized latent variables. While the two terms are similar, the distinction is important. Findings of this study will help inform the development of future interventions designed to improve outcomes in the Black community, raising average levels of the country’s health and reducing health equity gaps; impacting public health overall.
National Health Initiatives

Healthy People 2020

Administered by the United States Department of Health and Human Services (HHS) every 10 years, Healthy People is a set of goals and objectives designed to guide national health promotion and disease prevention in the United States. Targets of the initiative are revisited each decade to assess progress and modify the list of aims as needed based relevant problems, issues, or needs in the population and on the health status of the nation as a whole (Healthy People 2020). The Department of Health and Human Services designated the topics of “Cancer” and “Older Adults” as a topics of interest in Healthy People 2020. Several of the Healthy People objectives outlined within these topics were addressed in this study.

“Cancer” was designated as a topic of interest with the goal of reducing the number of new cancer cases as well as, illness, disability, and death caused by cancer. Several objectives outlined within this topic were addressed in this dissertation study. Objective C-7 to reduce the prostate cancer death rate, was one of the overarching goals of this research. The literature cites early detection as a key aspect of survival. This study found that both caregivers and care receivers identified caregivers as drivers of health seeking behaviors in this population and thus well suited to serve as trained advocates to raise awareness in this community. A related objective was C-19 to Increase the proportion of men who have discussed the advantages and disadvantages of the prostate-specific antigen test to screen for CaP with their health care provider. This study found that men reported being more likely to follow through with doctor visits and health care engagement of any kind if their caregivers encouraged them to. Relatedly, objective C-13 to increase the proportion of cancer survivors who are living 5
years or longer after diagnosis was also explored in this study. Caregivers identified cancer fatalism among men as a major theme in this population. This study found that in addition to increasing awareness and screening, survival was also dependent on attitudes and perceptions of cancer before the treatment decision making stage and during treatment. Both CaP caregivers and CaP survivors identified the need for counseling or coping resources at the point of diagnosis to combat cancer fatalism.

“Older Adults” was also designated as a topic of interest in Healthy People 2020. Of significance, the topic of “Older Adults” is listed as a new reference, indicating that it is a topic that was not included in Healthy People 2010, and is thus, an area of rising significance with serious implications for the population in the United States. Objective OA-9, to reduce the proportion of unpaid caregivers of older adults with disabilities with unmet need for caregiver support services was one of the primary overarching goals of this research. This study found that CaP caregivers in the Black community have specific support needs and barriers to seeking support. Needs identified were related to education and support programs. Barriers identified by caregivers in this study were cultural beliefs and cultural norms, access to support services related to transportation and lack of community resources, time, and lack of knowledge. By identifying specific needs and barriers to seeking support in this community health promotion teams can begin to address issues and develop culturally specific resources.

National Cancer Institute Center to Reduce Cancer Health Disparities

The National Cancer Institute (NCI), Center to Reduce Cancer Health Disparities (CRCHD) was established in 2001 in an effort to reduce the unequal burden of cancer in the United States. The multimodal collaborative aimed to strengthen the NCI cancer research portfolio in basic, clinical, translational, and population-based research to
address cancer health disparities. In addition, the CRCHD also aimed to advise and lead efforts in workforce diversity through the training of competitive researchers from diverse backgrounds. Formerly known as the Minority Institution Cancer Center Partnership (MI/CCP), the Partnerships to Advance Cancer Health Equity (PACHE) was one of the initial programs designed by the NCI, CRCHD to enable institutions serving underserved populations to train scientists from diverse backgrounds in cancer research and increase delivery of effective cancer advances to underserved communities. Similarly, the Continuing Umbrella of Research Experiences (Cure) program was also established by the NCI, CRCHD to offer unique training, outreach, and career development opportunities to enhance and increase diversity in the cancer and cancer health disparities research workforce by supporting-- via funding and competitive research opportunities-- promising candidates from middle school through the junior investigator levels.

This dissertation found the experience of providing care to a CaP survivor in the Black community to be a complex and understudied phenomena resulting in underused preventive services, increased likelihood of negative health outcomes, and a lack of resources, funding opportunities, and research interventions designed for this specific underserved and underrepresented population. Barriers to engaging health systems and participating in preventive care and/or community research were identified by caregivers and survivors in this study as a lack of population specific resources, influence of cultural beliefs and cultural norms, access to support services related to transportation and lack of community resources, time, and lack of knowledge. By identifying specific barriers to engaging health systems and participating in research in
this community, health promotion initiatives can begin to better allocate resources and funding opportunities for specific population in need of culturally specific resource to improve health outcomes via improved community outreach, training, and advocacy.

**National Cancer Moonshot Initiative**

The 21st Century Cures Act was signed into law by President Barack Obama in December 2016. The act provides funding for three scientific initiatives (21st Century Cures Act of 2016). The National Cancer Moonshot Initiative, also known as, the Beau Biden Cancer Moonshot Initiative was one of three initiatives launched to double the rate of progress in the fight against cancer, making more therapies available to more patients, while also improving our ability to detect and prevent cancer (Hudson and Collins, 2017). This study aimed to better understand the experience of CaP caregivers, as well as the role and influence of CaP caregivers in order to better understand and even further optimize the role and influence of the caregiver in an efficient way. This project aimed to use findings from this study to develop resources that can be used to increase awareness of available services and utilization of the health care system across the CaP continuum.

**Development of a Model for Health Promotion among Caregivers in the Black Community**

Healthy people 2020 identifies the “social determinants of health” as a designated topic area guided by a goal to create social and physical environments that promote good health for all. The social determinants of health posit that health is determined in part by the environmental, social, economic and cultural factors that shape individual behavior. In essence, the conditions in which individuals live can be used to explain why some Americans have better or worse health outcomes and health
related quality of life when compared to others. (Secretary’s Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020). Findings from this study were used to develop a model of health promotion for CaP caregivers in the Black community. Figure 6-1 was used to illustrate the relationship between specific needs and barriers identified as relevant themes throughout the caregiving experience in addition to other contextual factors that may influence caregiver outcomes. External factors illustrated in this model incorporate concepts described in the social determinants of health to account for external factors that may influence health outcomes for caregivers.

**Framework for Implementation of Health Promotion Interventions**

The Social Ecological Model (SEM) is a Multi-level approach that can be used as a comprehensive framework to guide program implementation at each level of influence for sustained behavior change in vulnerable and hard to reach populations, emphasizing the interaction between, and interdependence of, various factors within and across various levels of prostate cancer related experiences and outcomes (Glanz & Rimer, 2005). SEM approaches to health suggest that health outcomes and health seeking behaviors can be predicted based on a combination of several factors, such as: genetic predisposition, social relationships, communal interactions, local economics, and other environmental influences (Brofennbrenner 1977; McLeroy, Bibeau, Steckler, & Glanz, 1988). More specific, in addition to positing that behavior can be affected by factors from multiple levels of influence, this approach further emphasizes the significance of the various interactions that take place between the factors across the different levels of influence. Several organizations have used the framework to guide program development and a review of literature indicates five key levels of influence
most often cited in this approach: Individual, Interpersonal, organizational, Community, and Policy (Glanz, 2005; CDC, 2016). Thus, this research adopted the social ecological model of health promotion to represent the proposed multi-level approach for a dual prostate cancer prevention and family caregiver support program. At the individual level, interventions would focus on the individual’s knowledge of prostate cancer, beliefs about screening, and focus on educating and increasing prevention behaviors in the Black community, in conjunction with efforts to increase utilization of support services among caregivers. Potential activities might include creating culturally sensitive, educational brochures etc. At the interpersonal level, interventions would focus on interpersonal relationships between providers, caregivers, and care-receivers. Activities might include implementing the use of nurse navigators, provider recommendations for screening and support services for caregiver, and spouses and advocates encouraging screening behavior. The organizational level is concerned with institutional influence on the individual. For example, interventions would focus on instituting provider-patient reminders for screening, a health center adopting policy changes that incorporate caregiver health needs as a part of the CaP care protocol, or the installation of Community Health centers in minority communities. At the Community Level, interventions focus on collaborations among different entities like community advocacy coalitions, academic university research teams, and churches to influence particular communities, impacting the individual. Policy level interventions are intended to impact the individual through policy and law. Interventions and initiative take the form of guidelines, the tracking of trends in at-risk populations, taxation, etc. Examples of policy level interventions are taxing of cigarettes to reduce cancer incidence (increasing the
cost to the user, theoretically reducing ability or desire to continue the negative behavior of smoking), or aims of healthy people 2020.

**Study Limitations**

This project had minor limitations. First, the small sample size and the unique nature of the sample limited generalizability to a larger population. Related there is a need for caution in generalizing findings to all Black caregivers, as this population is diverse and within group differences may be observed based on country of origin, socioeconomic status, religious affiliation and any number of other confounding factors that may impact experiences and the process of creating meaning. Additionally, while the research team attempted to adhere to quality qualitative research techniques, results from this study are based on an attempt to capture the caregivers makes sense of their caregiving experience, thus the results reported in this dissertation are open to interpretation and the broader emerging theory is dependent on contextual factors.

**Recommendations for Future Research**

This study explored the CaP caregiving experience in the Black community to better understand phenomena that can have a direct impact on population health and consequently public health as well. A key strength of this study is its focus on population specific needs of caregivers. By allowing caregivers to share their experiences and voice concerns about issues that are most significant from their perspective, taking into account their positionality in the health care system, as well as, within the larger social context of their lived realities, researchers can begin to incorporate meaningful components in the development of future research and health promotion interventions within the health care system. Similarly, while the focus of theory generation was population specific, future research should aim to capture and compare perspectives
from a more ethnically disintegrated sample of caregivers to explore cultural differences in caregiving by country of origin and conceivably explore the influence of acculturation. Related, research comparing geographical outcomes and experiences should also be conducted to highlight differences in barriers and needs between rural and urban populations.

This study was guided by constructivist worldview, concerned with creating meaning based on the shared views of the population of interest and the interpretation of the researcher to develop a context and culture specific pattern of meaning. Future research should incorporate aspects of the transformative worldview which holds that research inquiry should be connected to advocacy and incorporate politics and/or a political change agenda (Creswell, 2014). Given the findings of this research and overwhelming evidence of health inequity in this community, future research should aim to include an action agenda intended to positively improve or influence participants’ wellbeing simply as a result of participating in the research. In the same vein, future research should seek to empower communities and address issues related to oppression and inequality. Thus there is a need for community based research that engages the community of caregivers in the research design and throughout the research process to ensure the representative voice of the community is echoed in all aspects of the research. Next steps of the research should also include population specific instrument development and testing to measure constructs identified by the population and/or validation of existing instruments that were not specifically designed for use within this population. In addition to instrument development, future research should also seek to develop educational resources using various mediums and
platforms to meet needs of caregivers and address barriers to accessing support (i.e. video segments, apps, e-health, m-health).

In conclusion, the purpose of this dissertation study was to gain a better understanding of the caregiving experience for family caregivers in the Black community across the prostate cancer (CaP) continuum of care, towards the development of targeted, ethnically sensitive approaches designed to eliminate disparities by improving caregiving experiences, increasing the use of support services, and improving health outcomes for both caregivers and care receivers across the CaP continuum of care. Findings from this analysis indicate caregivers, specifically spouses and adult children, have significant influence over behavior modification and may serve as effective community advocates for increased CaP knowledge and screening in the Black community. Evidence also suggests that caregivers may be an ideal target population for organized CaP advocacy training. Given this information it was important to investigate needs and barriers identified by caregivers in this community in order to betters support caregivers as advocates and integral additions to the health promotion framework in the health care system. By gaining a better understanding of the role of the caregiver, in addition to the support needs and barriers identified in this community, we can begin to better understand how to develop and implement initiatives at multiple levels of the ecological model towards improved outcomes for both the caregiver and the care receiver.
Figure 6-1. Model of Prostate Cancer Family Caregiving and Health Promotion.
APPENDIX A
INFORMED CONSENT FORM

Study ID: IRB 201701265  Date Approved: 5/18/2017  Expiration Date: 5/18/2018

INTRODUCTION

Protocol Title: Exploring experiences, needs, and perceived influence, of informal caregivers of Black men across the prostate cancer continuum of care

Name of person seeking your permission: Esther Piervi

Place of employment and position: University of Florida, Doctoral Candidate/Student Researcher

Please read this form which describes the study in some detail. A member of the research team will describe this study to you and answer all of your questions. Your participation is entirely voluntary. If you choose to participate you can change your mind at any time and withdraw from the study. You will not be penalized in any way or lose any benefits to which you would otherwise be entitled if you choose not to participate in this study or to withdraw. If you have questions about your rights as a research subject, please call the University of Florida Institutional Review Board (IRB) office at (352)-392-0433.

GENERAL INFORMATION ABOUT THE STUDY

Name of Participant: ________________________________

Purpose of the research study:
The goal of this research is to explore the social support experiences, needs, and perceived influence of caregivers of Black men at every stage of the prostate cancer (CaP) experience. This research aims to identify perceived barriers to Prostate cancer care as reported by spouses, partners, relatives, and significant others of Black men. You are being asked to be in this study because you have identified yourself as a caregiver age 18 years or older.

What you will be asked to do in the study:
You will be asked to participate in an audio recorded interview about your experience as a caregiver of a Black man with prostate cancer.

Time required:
Approximately 60 – 90 minutes.

Compensation:
Refreshments will also be provided.
Voluntary Participation:
Your participation in this study is completely voluntary. You can decline to answer any question at any point during the interview. There is no penalty for declining to participate in this study.

Right to withdraw from the study:
You have the right to withdraw from the study at any time without consequence.

Confidentiality:
Your identity will be kept anonymous. This study will not identify any comments made during the interview session as specific to any member of the group. No private health information or personal identifiers will be collected. Files will only be stored on researcher's password encrypted computer.

Risks and Benefits:
There is very small risk of embarrassment or discomfort associated with speaking to someone about health-related issues. Participation is completely voluntary and interviews will be guided by a trained research professional. Interviews will be recorded. Individuals will not be identified directly. No PHI will be sought in the interviews and identifiers will not be connected with participant responses. Interviews will be recorded and professionally transcribed. The principle investigator (Esther Piervil) will de-identify transcripts in Microsoft Word document format for accuracy and delete any identifiers that may be present. Data collected will be used as the collective voice of the group. Many safeguards in data collection and analysis will be implemented to allow for secure and confidential research process.

There are no direct benefits associated with participation in this study. If you choose to participate in this study, you will be helping researchers learn more about the experience and needs of prostate cancer caregivers of Black men. What we learn from this study could help create additional resources to improve the experience of caregivers.

Whom to contact if you have questions about the study:

Principal Investigator: Esther V. Piervil, MPH, College of Public Health and Health Professions, Department of Behavioral Sciences and Community Health, esthervp@phhp.ufl.edu

Faculty Supervisor: Mary Ellen Young, Ph.D., College of Public Health and Health Professions, Department of Occupational Therapy meyoung@phhp.ufl.edu

Whom to contact about your rights as a participant in this study:
IRB02 Office, PO Box 112250, University of Florida, Gainesville, FL 32611-2250; phone 352-392-0433

SIGNATURES

As an investigator, I have explained the possible benefits and the risks of this research study, as well as the alternative to being in this study

______________________________ ______________________________
Signature of Person Obtaining Consent / Study Staff Signature Date

Initial next the statement below in the box provided if you understand and agree to participate in this study. Sign and date your full name below.
I recognize that I was given a clear explanation and I understand what it is that I am agreeing to do. I understand the risks and the benefit to participating. I have been able to ask questions. I understand that the information I share with the investigator will be kept for this study.

Signature of Person Consenting / Participant Signature

Date
DO YOU CARE FOR A FAMILY MEMBER THAT HAS BEEN DIAGNOSED WITH PROSTATE CANCER?

We would like to hear about your experience as a caregiver.

Seeking Volunteers to participate in a study about the caregiving experience

Study participants will:
• Participate in one face-to-face or telephone interview

Time Commitment
• The interview will take about 60 - 90 minutes.
• Light refreshments will be provided.

To participate, you must:
• Identify as a caregiver of a Black Man
• Be 18 years or older

Location
The interview can be completed at any University of Florida affiliated facility or HealthStreet location.

Contact: Esther Piervil, MPH. (Phone: 352-800-9812)
LIST OF REFERENCES


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BIOGRAPHICAL SKETCH

Esther Vita Piervil was born in 1989, to parents Altagrace and Verilus Piervil. Originally, from Mount Dora Florida, she graduated from Mount Dora High School in 2007 with high honors and was a recipient of the prestigious Gates Millennium Scholarship (funded by a grant from the Bill & Melinda Gates Foundation). Esther obtained her Bachelor of Science degree from the University of Florida, College of Health and Human Performance in 2011. She received her Master of Public Health degree, concentrated in Health Policy and Management, from the Rollins School of Public Health of Emory University in 2013. After earning her graduate degree, Esther proudly served as an Americorp, City Year corps member in Pine Hills, Florida where she mentored and served as tutor and attendance coordinator for at-risk students enrolled at Evans Maynard High School. In 2014, Esther enrolled in the University of Florida, College of Public Health and health Professions, Behavioral Science and Community Health Doctoral Program as both a McKnight Doctoral Fellow and a Dean’s Office Grinter Fellow in the Social and Behavioral Sciences Program. In 2017, Esther Vita Piervil received her doctorate degree having earned the title, Doctor of Philosophy in Public Health. As a Black, Haitian American, first generation female scholar, Esther is passionate about public health and community level health promotion. She has participated in chronic disease prevention research projects related to tobacco use, diabetes, obesity, sexually transmitted diseases, and cancer outcomes. Esther is a proud big sister to Anne and Abigail Piervil, and the humble little sister of Venel ‘Jason’ Piervil. Through research and community leadership she hopes to begin a legacy dedicated to the promotion of health equity and scholastic achievement, encouraging community empowerment and financial freedom in disenfranchised communities.