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## An Integrative Counseling Approach for African American Couples with Prostate Cancer

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## **An Integrative Counseling Approach for African American Couples with Prostate Cancer**

### **Keywords**

cancer, older adults, prostate, sexual functioning, identity

PRACTICE

# An Integrative Counseling Approach for African American Couples With Prostate Cancer

Andrew W. Wood, Jessica L. Martin, and Kaitlyn Bruns

*The experiences of African American couples facing prostate cancer include cancer concerns that intersect with sexuality, older age, and culture. We provide a review of concerns and counseling strategies and present an integrative approach through a case study. Future research on testing such approaches is encouraged.*

**Keywords:** cancer, older adults, prostate, sexual functioning, identity

Approximately 3 million individuals have been diagnosed with prostate cancer (PCa; American Cancer Society [ACS], 2020), a disease that affects mostly individuals over the age of 55 and is the most common cancer in the United States (Surveillance, Epidemiology, and End Result Program [SEER], n.d.). Trends in PCa diagnosis show that the disease affects one in seven men over the age of 70 (SEER, n.d.), with a lifetime potential of 15.9% (U.S. Preventive Services Task Force, 2018). However, PCa incidence and mortality rates have been declining over the past 20 years, with 98% of individuals diagnosed surviving for more than 5 years (SEER, n.d.). Although these numbers provide good news to those who have been diagnosed with PCa, health disparities continue to exist, and the incidence and mortality rates for African American men are disproportionally higher than those of other races (Taksler et al., 2012). These numbers tell many stories. However, one story that is not immediately apparent is the mental health needs of African Americans who have been diagnosed with PCa. Furthermore, examining contextual factors such as racial health disparities and considering other individuals who are affected by cancer, specifically the romantic partners of those diagnosed with cancer, may help broaden our understanding of the experiences of those facing cancer. Counselors have not typically been provided with information on how to address the mental health concerns of individuals with PCa; therefore, we aim to

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examine the counseling concerns of African American couples facing PCa, as well as provide a guide to integrating treatments.

The counseling field is just beginning its foray into cancer-related counseling issues, with sporadic publications over the years (e.g., Curtis & Juhnke, 2003). Since Curtis and Juhnke's (2003) publication 18 years ago, the field of PCa care has expanded considerably. In this article, we explore general information that counselors should know about PCa, including how it is traditionally diagnosed and treated; information about the impact that PCa has on the African American community; and counseling interventions for African American couples facing PCa, which we illustrate in a case study scenario.

## WHAT COUNSELORS SHOULD KNOW ABOUT PCA

The first question that counselors may ask is, "What exactly is prostate cancer?" PCa is a cancer located in the prostate, a small gland surrounding the urethra that plays a role in sperm protection and production (Walsh & Worthington, 2012). PCa is a sex-specific cancer, meaning that only individuals who are born with male sexual organs including a prostate will be at risk of developing the disease. It should be noted in the PCa literature that individuals with the disease are generally referred to as "men," but PCa does not exclude transgender women or nonbinary individuals (Ingham et al., 2018). PCa can develop for a variety of reasons, similar to those associated with the development of other types of cancer (e.g., exposure to carcinogens), but it tends to affect mostly older men (National Cancer Institute, 2019). Because of the prostate's place in the body, removal of and/or other treatments for PCa (e.g., internal [brachytherapy] or external radiation, hormone therapy) often result in temporary or lifelong urinary issues (e.g., incontinence) and sexual dysfunction (e.g., impotence; Hoffman et al., 2020). Because some of these issues encompass sexual dysfunction, men may report depression and anxiety-related symptoms during and after treatment due to a loss of intimacy with their partners (Albaugh et al., 2017). In addition to some of the side effects of treatment and the disease, information about the incidence and mortality of PCa may help counselors to better conceptualize the reach and effects of the disease.

Understanding PCa requires counselors to understand who is affected by the disease and how it affects the client physically and mentally. Given the advancements in new and more efficient methods of screening, PCa screening has become a regular activity for those over the age of 40 following the advice of most medical professionals (e.g., U.S. Preventive Services Task Force, 2018). Morbidity has decreased over time, from a 5-year survival rate of 66% in 1975 to 98% between 2009 and 2015. This leads many professionals to consider PCa as not necessarily a disease people die from, but rather, die with (Riihimäki et al., 2011). Most individuals who are diagnosed with PCa (71%) are between 55 and 74 years of age (Stangelberger et al., 2008). Rates of cancer recurrence

can differ depending on treatment, but a review at a median of 8 years post-radical prostatectomy (i.e., removal of prostate gland) found that 45% of the population had some form of recurrence or metastasis (Freedland et al., 2017). African American individuals have a 78% higher chance of being diagnosed with PCa than White individuals and a 21.7% higher chance of mortality (ACS, 2020; Taksler et al., 2012). African Americans have the highest death rates, with 38.9 deaths per 100,000, higher than the average of all races (19.2 deaths per 100,000). Furthermore, PCa accounts for the highest number of new cancer cases and the second highest number of cancer deaths among African Americans (ACS, 2020). Although these statistics are sobering, one factor that has been widely supported for helping to reduce mortality rates for PCa survivors is the role of screening.

The U.S. Preventive Services Task Force (2018) regularly publishes screening recommendations for PCa. For individuals who do not have additional risk factors (e.g., family history of PCa), it is recommended that screening begin as early as 55 years old. However, African American men have been found to develop the disease earlier compared with men from other racial groups, and as such, being African American is considered a risk factor (U.S. Preventive Services Task Force, 2018). Given increased rates of PCa for African American men, screening has become a crucial issue for researchers, with some studies pointing to the need for community-informed decision-making (Sandiford & D’Errico, 2016) and multiple studies examining the role of the partner in this process (e.g., Allen et al., 2018). Treatments can range from active surveillance to removal of the prostate, which all have unique health and psychosocial outcomes (Walsh & Worthington, 2012).

Health disparity issues caused by PCa largely concern African American men, with proposed need for screening guidelines specifically for this population (Shenoy et al., 2016) and developing new methods of sharing information within African American couples (Allen et al., 2018). The issues surrounding PCa, from initial screening to survivorship, are marred by health disparities for African American men—as evident from poorer treatment outcomes, more aggressive disease, higher incidence, and higher mortality—and are attributed to a mixture of genetic, behavioral, systemic, and socioeconomic factors (Z. L. Smith et al., 2017). Furthermore, the rate of cancer recurrence after different types of treatment (e.g., brachytherapy, radical prostatectomy) is higher for African American men as compared with men from other racial groups (e.g., Faisal et al., 2014; Yamoah et al., 2011). Some additional medical and psychosocial concerns exist in sexual dysfunction that may come at the expense of treatment.

One of the major concerns for PCa survivors and their partners is how the disease and treatment affect their sexual activities. PCa and its respective treatments can cause a reduction in penile functioning, including erectile dysfunction, urinary incontinence, and reduction in physical stamina. Rivers et al. (2011) found that these physical issues and concerns can lead to emotional

issues such as lowered self-esteem and anxiety about sexual performance. Rivers et al. (2011) also found that sexual functioning played a primary role in assessing quality of life (QoL) for men, whereas survival of their spouse was considered the most important consideration for women, making priorities different within a relationship. African American men were more likely than White men to choose treatment based on sexual side effects of a treatment, although African American men were also more likely than White men to seek help for sexual dysfunction post-PCa treatment (Jenkins et al., 2004). Sexual issues, including masculinity, also seemed to be a barrier to communication within African American couples facing PCa (Friedman et al., 2012). The role of masculinity and sexuality is pervasive in the PCa literature and is echoed in literature on African American couples when considering treatment decisions, sexual aids, and other concerns (Bamidele, Lagan, et al., 2019). Given that the experience of having PCa, from diagnosis to survivorship, has psychosocial effects unique to African American survivors and their partners, it is important to examine some of the counseling concerns that are specific for African American couples facing the disease (Rivers et al., 2012).

## **COUNSELING CONCERNS FOR AFRICAN AMERICAN COUPLES WITH PCA**

The reason for providing counselors with the preceding information is to increase understanding and awareness of the initial physical concerns and backgrounds of African American PCa survivors and their partners to see how they fit with concerns that counselors are adept at addressing. These concerns pertain, but are not limited to, the couples' QoL, sexual functioning, and caregiving concerns. Many of these concerns may start as individual concerns for men with PCa, such as depression, anxiety, and lower social support (Song et al., 2012; Watts et al., 2014), as well as the varying effects of treatment (e.g., Chipperfield et al., 2013). Connecting to the concerns of couples, issues related to masculine norms, intimacy, and long-lasting effects of the disease (e.g., impotence, incontinence) also result in lower QoL and potential discord within couples (e.g., Ezer et al., 2011). It is our assumption that these are areas in which counselors can excel in treating but often do not have the training to understand how these topics affect clients. These mental health and psychosocial concerns are important to consider in counseling African American PCa survivors and their partners and as a way to close health disparities in psychosocial concerns.

## **PCA CONCERNS FOR COUPLES**

Couples are often distressed by PCa's effects on their QoL, marriage, and other issues (Song et al., 2012). Previous researchers have found that PCa is inherently a "couple's disease" (Couper, 2007, p. 231) and that it has effects on a

“communal body” (Fergus, 2011, p. 95). Foundational couples-based issues like communication are hampered in general by PCa (Song et al., 2012) but increase exponentially with African American couples facing PCa (Rivers et al., 2012). As previously discussed, African American men are statistically more likely to be diagnosed with PCa, to die from PCa, and to have worse prognoses when diagnosed (e.g., greater rates of recurrence; Evans et al., 2008; Taksler et al., 2012). As such, PCa survivors are more likely to experience lower emotional and physical functioning (Rivers et al., 2012). PCa affects multiple areas of the survivor’s life, including reduced physical functioning, energy, and sexual performance. Diminished physical functioning also correlated with a reduction in social activities and changes in social and familial roles.

Partners of PCa survivors face unique issues in caregiving activities or in providing general support (Piervil et al., 2019). The role of partners can include that of support to the survivor, as well as someone who takes care of activities that the survivor is not able to do, including household activities, hygiene, or transportation. Partners and caregivers also provide care management, ensuring that treatment is being followed and providing both emotional and behavioral support. The types of support provided can differ between racial groups (Vines & Demissie, 2013); for example, some African American partners emphasize spiritual support more compared with White partners. Furthermore, the concerns of partners may differ from the concerns of survivors, who worry more about mortality than the side effects of the disease or treatment (Rivers et al., 2011). Bamidele, Lagan, et al. (2019) found that partners experience isolation and sometimes feel as though they are a “co-patient” (p. 1092). Although much of this information is provided by medical professionals, one of the main sources of information for Africa American PCa survivors are their partners (Walsh-Childers et al., 2018). Additionally, PCa survivors and their partners look to familiar sources of information in their communities, such as the Black Church. The connection between religion, health, and community makes the Black Church an influential source of support for PCa survivors and their partners, especially during the COVID-19 epidemic when there has been much confusion and conflict over safe and relevant health information for Black people (Robbins et al., 2021; Williams et al., 2018). Some researchers have found the Black Church to be a source of information and knowledge about PCa and other health issues for those with the disease (e.g., Husaini et al., 2008). Further community engagement—built from within the community rather than imposed on the community—can also be beneficial (Schoenfeld & Francis, 2015). Communication about PCa within the community can be helpful, but counselors’ communication with a couple should also be considered when addressing issues surrounding PCa.

Song et al. (2012) found that open communication in couples managing PCa issues decreased over time from diagnosis to 4-, 8-, and 12-month follow-ups. In addition, Song et al. (2012) found that open communication and social

support had a positive relationship, meaning that as open communication increased, so did social support. This finding is important partly because of the evidence that social support can be a predictor of QoL for those with PCa (e.g., Imm et al., 2017). The influence that later stages of cancer have on the QoL of survivors (Vanagas et al., 2013) and their partners also differs based on disease stage and age (Harden et al., 2008). The social role of the provider is greatly threatened as a result of a PCa diagnosis and treatment. Treatments such as radiation and chemotherapy may reduce what the PCa survivor is able to do outside of the home, which may impact their employment and financial standing within the couple. Because many African American men with PCa are younger than their White counterparts, this factor could become an intersectional issue of physical health, psychosocial health, and financial health (Imber et al., 2020). Within the African American community, the role of the male provider is a pervasive and important role. The loss of this status can affect the way in which PCa survivors respond and communicate with their partners and possibly adversely affect treatment as the survivors continue to attempt to engage in their activities of daily living. For example, prostatectomy requires the survivor to reduce heavy lifting, reduce energy-exerting activities, possibly wear a colostomy bag following surgery, and attend several follow-up appointments with their surgeon and urologist. In a recent study, Hoffman et al. (2020) found that in a 5-year follow-up posttreatment, men who underwent prostatectomy had worse incontinence and worse sexual function as compared with those who underwent other treatments. Although some treatments were associated with increased functioning after a 5-year period, some effects of treatment can last throughout the rest of survivors' lives. Although these concerns can be difficult to understand, researchers have found some beneficial interventions worth considering.

## RECOMMENDATIONS FOR INTERVENTIONS

Given the multitude of intersecting issues faced by those with PCa, counselors should examine various interventions to find what would best fit a potential client. In tailoring interventions for African American couples and their concerns related to PCa, we briefly examine couples-based research and the unique issues faced by African American couples with PCa to synthesize an approach for counseling these clients. In a review of interventions for couples coping with any type of cancer, particularly studies on breast and prostate cancer, Badr and Krebs (2013) found that, on average, couples-based interventions (e.g., interpersonal counseling, psychoeducation, behavioral marital therapy) increased QoL for couples. Furthermore, Regan et al. (2012) found that couples-based intervention was at least as effective as patient-only or caregiver-only interventions in improving communication, psychological distress, and relationship functioning. According to Chambers et al. (2011), cognitive behavior therapy,



psychoeducation, and coping skills training were effective in increasing QoL for survivors and/or their partners. Unique applications of theory have also been found to be helpful in decreasing the negative impact of PCa for couples (Collins et al., 2013). Northouse et al. (2007) found that an integrative treatment that focused on family involvement, optimism, coping, uncertainty reduction, and symptom management led to less uncertainty, hopelessness, and symptom distress, as well as better communication, higher QoL, and higher self-efficacy. The use of cognitive-behavioral couple therapy would be especially powerful for working with African American PCa couples because it provides the couple with opportunity to work through their distress issues (Fischer et al., 2016).

Technology can also be effective, as tested in an internet-based couples sexual counseling program, yielding increases on measures of sexual functioning (Schover et al., 2012). Web-based PCa education has also been helpful in improving QoL and reducing treatment side effect symptoms (Song et al., 2015). Researchers have also shown that use of media can be helpful in an intervention (e.g., Chien et al., 2020). Web-based PCa education would be especially beneficial for those African American PCa couples who find the idea of engaging in traditional counseling intimidating or who may be hesitant to discuss issues related to PCa (Rivers et al., 2012). The increase in telehealth and tele-mental health during the COVID-19 epidemic has opened the door for more phone and internet-based counseling options for these couples through community mental health counseling clinics, private practices, medical practices, and mental health-based platforms (e.g., Talkspace).

Some researchers have looked to sex- and intimacy-based interventions for couples facing PCa because the disease and treatment can have long-lasting effects of impotence (e.g., Mehta et al., 2020). Several of these interventions can lead to more use of medical treatments and medication for erectile dysfunction (Chambers et al., 2014), improved communication about sexual recovery (Mehta et al., 2020), and increase in both self- and perceived disclosure (Manne, Kashy, Kissane, et al., 2019); some of these interventions have led to better posttreatment outcomes and better relationship satisfaction (Manne, Kashy, Zaider, et al., 2019; Manne et al., 2020). Given the importance of sex and intimacy in most romantic relationships, paired with research examining the psychosocial needs of African American couples facing PCa (e.g., Rivers et al., 2011), a couples-based intervention should include information on the sexual and intimate repercussions of the disease. Sexual and intimacy-related topics could occur through psychoeducation, including use of medication or medical devices (e.g., vacuum pump).

A constant undercurrent for counseling African American PCa survivors—whether in a group, individual, or couples’ settings—should be a focus on integrating information on how the disease is affecting them. That is, how are mental health and physical health being discussed with the survivor and members of their care team (e.g., counselor, nurse, doctor)? Collaboration between

professionals has been found to be effective in controlling for psychosocial variables experienced by individuals with cancer and allows mental health care to be seen not as an additional form of care but as a part of cancer care (Cassileth, 2014). Campbell et al. (2007) found that self-efficacy of symptom control on the part of both African American survivors and their partners led to higher QoL outcomes.

Support groups led by PCa survivors can provide credibility to the group in addressing the needs of PCa survivors, leading more survivors to join and benefit from group experiences (Thaxton et al., 2005). Outcomes for some support groups have been positive (e.g., R. L. Smith et al., 2002), but counselors should also look to ways of including partners or being flexible with the location of peer support (Friedman et al., 2012). A benefit of utilizing group therapy with PCa survivors and their partners is the opportunity to engage in social activities where complications (i.e., incontinence and exhaustion) are fully understood by the group, which may help to increase social support as well (Song et al., 2012). There are several options available to support African American PCa couples, and each should be evaluated to best suit the unique needs of each couple.

There is very little evidence of couples-based treatment for African American couples facing PCa, with the exception of a study by Campbell et al. (2007) on a telephone-based coping skills training. Despite the lack of evidence on couples-based treatments (Chambers et al., 2011), there is evidence of unique health disparities and cultural experiences of African American couples facing PCa (e.g., Bamidele, Lagan, et al., 2019; Rivers et al., 2012). Furthermore, there is also a documented lack of professional support for PCa couples' posttreatment distress (Bamidele et al., 2018). Therefore, it is necessary to take a deeper look at what couples-based interventions could look like for this population and to test the efficacy of the interventions. Although there are real challenges in conducting this type of development and research on outcomes (Bamidele, McGarvey, et al., 2019), it is necessary to provide better and more comprehensive care for PCa couples. Based on the review of couples-based intervention research and what has been done with a general participant pool, we suggest that counselors working with African American couples facing PCa focus their work on a few areas: general cancer support, psychosocial support, sexual support, relational support, peer support, and spiritual support. To better illustrate the role of the interventions discussed, we provide a case study addressing treatment concerns.

## CASE STUDY OF JAMES AND MARTHA

James, age 56, and Martha, age 54, are an African American couple currently facing PCa. James was diagnosed with PCa approximately a year ago, and after a year of watchful waiting, they both decided to pursue external radiation therapy based on the progress of the disease. Their decision came after a

series of discussions that at times evolved into arguments about what course of action to take. James preferred to wait longer to see if there would be any significant progress, but Martha wanted to go ahead with treatment after the diagnosis was made. James argued that he did not want to be “taken out of action” while at work to get his treatments. The external radiation therapy treatment consisted of driving 30 miles to the treatment center, waiting for his appointment, receiving the treatment for approximately 15 minutes, and then driving 30 miles back to his work or home, depending on the day. Additionally, he had to take medical leave from his work, thus relying on his wife and son to help with bills and common household chores. Martha was supportive but felt disconnected physically and emotionally from James, who was hesitant to initiate physical contact because he felt like he “can’t perform.” This caused further disconnection between them, with Martha getting into verbal fights and James becoming agitated, especially when he was unable to perform tasks he could normally do prior to starting treatment. James’s oncologist referred them to a counselor because their relationship issues have caused James to be late to treatments and even to miss treatments at times.

Given the situation, the counselor decided to begin the sessions with basic psychoeducation (Badr & Krebs, 2013) about PCa, including some common effects of cancer and treatment that Martha was not aware of and that James did not consider were linked to his cancer and treatment. The counselor also worked on understanding the cultural experiences of James and Martha and the cultural implications of cancer, and more specifically, PCa (Rivers et al., 2012). Culture-specific forms of support play a role in understanding what can be helpful for the couple and in referring them to additional sources of support outside of their sessions (Vines & Demissie, 2013). This was James and Martha’s first time in counseling as a couple and as individuals. The counselor spent time during the initial sessions discussing their emotions about being in counseling, addressing any questions or culturally based biases the couple had expressed about counseling and what they had heard about counseling from friends, family, and the media. This step is crucial because the buy-in sets the stage for a supportive therapeutic alliance between the counselor and the couple.

The focus on psychoeducation combined with symptom management and then the integration of coping skills training for both James and Martha supported the couple in their intrapersonal reactions with each other (Campbell et al., 2007; Northouse et al., 2007). Once the counselor was able to obtain buy-in from James and Martha and develop a therapeutic relationship, their sessions focused on a variety of topics tied together with cognitive-behavioral couple therapy (Fischer et al., 2016). These topics included communication around issues that might cause shame (e.g., incontinence), as well as strategies to increase intimacy outside of sexual intercourse (Manne, Kashy, Kissane, et al., 2019; Mehta et al., 2020). Later sessions covered medications or medical devices for erectile dysfunction (e.g., Chambers et al., 2014).

The counselor also spent time to make sure that Martha did not feel isolated in the role of a caregiver (Bamidele, Lagan, et al., 2019). This was done by infusing strategies from relational-cultural theory into the sessions to increase communication and understanding between James and Martha, such as examining relational disconnects and fears of sharing experiences with cancer in the relationship and increasing disclosure around sexual issues brought on by PCa and its treatment (Raque-Bogdan, 2019). Concurrently, the counselor looked for ways for James to feel more “of use” in his life, for example, by volunteering for low-impact service during his treatment (e.g., helping out at church or community organizations). Furthermore, the counselor encouraged James and Martha to attend a PCa support group on a weekly basis. Although hesitant to share in their first few meetings, they both found that attending the group helped to normalize their issues and to see how couples were able to make it through treatment. Finally, the counselor focused on helping James and Martha to advocate for individuals at risk for PCa in their community, using the American Counseling Association Advocacy Competencies (Toporek & Daniels, 2018; Toporek et al., 2010) and discussing this topic at church and other places (e.g., barbershops; Luque et al., 2011) where they felt they could help their community by having people screened and treated for PCa.

It should be noted that a telehealth-based approach of having sessions in their home could also be used to provide more comfort to James and Martha. This could provide a sense of bringing the counselor into their home, which may have some cultural relevance and increase trust with the counselor. During the COVID-19 pandemic, telehealth sessions would be safer than in-person sessions because of the additional health risk factors from James’s cancer. Use of telehealth may also incorporate members of James’s care team into a session, such as James’s oncologist or one of the oncology nursing staff (Cassileth, 2014).

## AREAS FOR FUTURE RESEARCH

Future research on the counseling needs of African American PCa survivors should acknowledge the deficits of current psychosocial outcome research with the disease. Qualitative investigations centered on counseling perceptions, needs, and access may be helpful in determining the best forms of treatment. Following qualitative investigations, novel forms of care adapted for PCa survivors may be tested to investigate efficacy. In addition, research on interventions for partners and/or informal caregivers will also be helpful to encourage a holistic system of care (Applebaum & Breitbart, 2013). Future work could also examine integrating counselors into health centers and how to foster relationships across health professionals to better meet the needs of PCa survivors. This research should consider the work of authors who have written about the difficulties in recruiting African American couples to PCa-specific interventions (e.g., Bamidele, McGarvey, et al., 2019).

## CONCLUSION

Counselors have made strides in adapting to the mental and physical health needs of the African American community. Because PCa is a prominent disease in this population, counselors should become familiar with some of the medical struggles and treatments of African American men with PCa and how their mental health is affected. As counselors, we are well aware of the benefits of promoting both the mental and physical wellness of our clients and those they love. Expanding our knowledge of physical health is a necessary step in continuing to provide the best services to support their mental health. Our review of PCa concerns for African American couples, common medical treatments, and suggested clinical interventions is one way of continuing our mission to expand mental health to traditionally marginalized populations in need.

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