

## A Qualitative Study of Psychosexual Implications of Prostate Cancer among Black Prostate Cancer Survivors

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### Introduction

Black men have an incidence rate of prostate cancer that is 60% higher than Caucasian men (ACS, 2014.). However, eighty-nine percent of prostate cancers in African American men are diagnosed where the 5-year survival rate approaches 100% (Institute of Medicine, 2006). Both incontinence and erectile dysfunction represent potential side effects post prostate cancer treatment, particularly in relation to surgery and radiation therapy. As a consequence, such occurrences invariably impact masculine identities in a culture driven by societal stereotypical views. For many men, conceptualizations of masculinity are often influenced by early life social and cultural factors. Incontinence and erectile dysfunction post prostate cancer treatment present inherent challenges to perceived masculine identities. Numerous studies have examined the impact of erectile dysfunction and incontinence on quality of life issues (Kao et al., 2000, Lubeck et al., 2001). Additionally, prostate cancer treatment limit men's ability to work and challenges his sense of being a man and being able to provide for his family.

The need to control ones' emotions, to be mentally strong represent key masculine notions of manhood as portrayed in the larger society. Moreover, the sense of male sexual performance is most impacted by erectile dysfunction, perhaps feeling "less than a man." Although such masculine stereotypes are socially constructed, they represent realistic notions of masculinity for many men having undergone invasive levels of prostate cancer treatment. As noted by Stansbury and colleagues (2003), "individuals with rigid ideas

about masculinity suffer greater stresses with illness than are suffered by those who do not hold such views." These ideas are strongly rooted in the male psychic of strength, power, self-control, protectiveness, and stoic bearing of pain (Mosse, 1996). Moreover, several studies indicate that spouses often report increased emotional stress as these traits play out in committed relationships (Powe, Hamilton, Hancock, 2007). Understanding these issues in terms of management and adaptation particularly among Black prostate cancer survivors is critical in the development of culturally appropriate interventions. In this respect, there may be an overall fear of the loss of sexual ability that men associate with manhood, and compounded by a fear of the disease and in particular the digital rectal exam. The purpose of this study is to provide a descriptive account of Black men living with incontinence and erectile dysfunction as a result of prostate cancer treatment. This study seeks to highlight the importance of encouraging men to talk about sexuality, uncover the evolving nature of masculinity transformation, and project a movement toward strategic approaches that reconstruct impending notions of masculinity after prostate cancer treatment.

### Overview of the Literature

For cancer survivorship in general, there is a growing need for guidance in relation to quality survivorship care (Greenfield, 2006). Differential treatment outcomes impact African American prostate cancer survivors in relation to urinary, and sexual health-related quality of life (Johnson, Gilliland, Hoffman, 2004). The ultimate aim

of prostate cancer survivorship is to optimize the health and quality of life of the men that have been impacted by the disease. There is an impending need for more frequent PSA monitoring during the early survivorship experience for men particularly men with higher risk of prostate cancer recurrence. Survivorship issues relating to sexual dysfunction, erectile dysfunction, sexual intimacy, and urinary dysfunction will require professionalized coordinated responsive care from every spectrum of the healthcare community. The management of distress, depression, and anxiety associated with these occurrences necessitate the involvement of in-office counseling resources as well follow up treatment from appropriate specialists. Several researchers have concluded that little research is known about the psychosocial issues that relate to the sexual functioning of African American prostate cancer survivors (Powe, Hamilton, Hancock, et al., 2007). Research studies that have addressed this issue report that men found it difficult to share concerns of sexual inadequacy with their wives (Banthia, Malcarne, Varni, Ko, Robbins, Greenberg, 2003).

The radical prostatectomy (surgical removal of the prostate) can lead to physical complications including persistent incontinence, urethral stricture, cardiovascular problems, blood clots in the legs, and rectal injury (Bostwick et al., 1996). There are also side effects associated with other treatment options. For example, men who obtain radiation therapy may be at risk for intestinal problems, rectal irritation, and diarrhea, in addition to incontinence and impotence (Carson & Akwari, 1980; Hanlon et al., 1997). Hormonal therapy as a treatment option can lead to reduction in the amount of testosterone in the body, impotence, hot flashes, diarrhea, liver toxicity, breast enlargement, and decreased libido (Bostwick et al., 1996; Clark et al., 1997). These complications can lead to cumulative depressive episodes of behavioral disorders. Societal messages and socially constructed views about masculinity and sexuality often inform notions of manhood and sexual identity.

Studies regarding prostate cancer social support groups indicated that sexual issues were important to prostate cancer survivors and that survivors were willing to discuss such issues. These studies also suggest that based on narrow views of sexuality, many survivors did not know how to discuss it with fellow survivors and group leaders (Andriote, 1998; Bronner, 1998; Hirschmann, 2001; Thompson, 1994; Arrington, 2000).

The notion of identity reformulation in view of undergoing a chronic illness raises issues of concern for both men and women. It may be particularly sensitive among men who have internalized fixed views of masculinity and socially prescribed gender roles. By the 1970s a review of literature that examined differences between men's and women's health, indicated that men's higher mortality in the United States were in part, related to "gender role socialization" (Harrison, 1978). This research has been further corroborated by follow studies (Nicholas, 2000). Eisler and Blalock (1991), assert that a "male behavior template" based on aggression, combativeness, and related male coping styles contribute to rigid ideas about masculinity resulting in greater stress and illness. They identify sexual performance as an important component of the masculine identity and point to failures in sexual performance as being damaging to one's self-esteem. This analysis points to a cultural construct re-enforced through gender role socialization. This research further suggests that men with a strong commitment to a masculine ideology may also have difficulty seeking out emotional support. Nevertheless, such mental configurations remain fluid and can be redefined and re-formulated through clinically driven evidenced-based interventions.

African American men tend to gravitate toward a traditional Westernized idea of masculinity (Levant, Majors, & Kelly, 1998). Several studies have examined the impact of erectile dysfunction and/or incontinence on QOL (Kao et al, 2000). We do not have substantial research that captures the impact of erectile dysfunction and incontinence from prostate cancer treatment on the lives of Black men and how cultural beliefs around urinary and sexual function define the influence of masculinity. Understanding these symptoms and is critical for the development of culturally appropriate interventions. From a socially constructed viewpoint, men are expected to be stoic, productive, and strong. The process of renegotiating masculine identity as a result of prostate cancer treatment must involve understanding the socially constructed nature of this phenomenon.

## Methodology

The utilization of a qualitative approach relating to the data collection and analysis captured the cultural meanings of the content conveyed in this study. The development of a subsequent model of post prostate cancer treatment incorporated grounded theory techniques (Strauss, 1997). Qualitative research is seen as useful for this study in that it provides a detailed understanding of an issue and gives participants opportunities to share their stories. The

basic rationale for this approach is that the human experiences of these men can be best captured through narrative descriptions and interviews. To be eligible to participate in this study the men had to self-identify as African American and diagnosed via biopsy confirmed prostate cancer, subsequently treated, and successfully recovered from treatment. Descriptive statistics were generated in order to characterize participants in terms of age, marital status, education, income, employment status, religion and insurance. Many of these men were reluctant to discuss their experiences in a group setting. They cited privacy as a major concern and expressed discomfort to having open discussions about this topic with people they perceived to be strangers, thus individualized approaches were needed.

### Sample

The sources of information are African Americans, between the ages of 41 -80 years of age who have been diagnosed, treated, and now in recovery from prostate cancer. The procedure involved a purposive sample utilizing a snowballing strategy identified and selected 25 African American prostate cancer survivors residing in the Philadelphia Metropolitan region, from barbershops, Houses of Worship, and prostate cancer support group meetings. The interviews lasted 1 to 2 hours. The participants were asked to talk about their treatment beginning with learning about having prostate cancer. The interviews were characterized by open-ended topical prompts. All interviews were transcribed verbatim. Transcripts were examined for salient informational sources that were later categorized. The general strategy for measuring and classifying the data entailed developing categories of information, interconnecting categories, and developing narratives that connected categories. Drawing on grounded theory, close line-by-line coding was utilized (Strauss & Corbin, 1990). Note, p.180 (dissertation)

### Sample Characteristics

A purposive sample of 25 African American prostate cancer survivors participated in this study. The average age was 63.1%. The majority was college educated, (62.5%); and were married (66.7%). The average time from a prostate cancer diagnosis was 3-4 years. There was a high degree of homogeneity in terms of religious affiliation in that ninety percent self-identified as belonging to Christian denominations.

### Setting for Data Collection

The in depth interviews took place at several locations and were based on what was most convenient for each participant as well

as where there was a high degree of privacy. To enhance comfort participants were encouraged to select the most convenient and comfortable times and place for the interview. The interviews were conducted in private one- on one -sessions. In some instances, visits were made to the home residence; other sessions took place at private office locations. Each setting reflected a relaxed, casual atmosphere to facilitate open disclosure and positive interactions. The home visits were particularly beneficial, allowing for informal exchanges that occurred prior to the formal interview. Overall, the locales were participant driven, culturally centered, and provided opportunities for exploration of highly personal and heavily charged emotional issues in a safe environmental setting.

### Findings

The primary concerns encountered by participants centered on quality of life issues. They related specifically to incontinence and sexuality. Both issues represent impending side effects of prostate cancer treatment. These issues are difficult to prepare for prior to treatment for several reasons. First, the medical procedure and physical response to treatment has to be taken into consideration. Secondly, consideration must be given to partner responses, in relation to changes in sexual relationships. Finally, post treatment psychological and emotional responses are often impacted by temporal, environmental and economic factors. Another important factor during particular phase related to the effects of depression. Depression surfaced as an issue that men discussed in the study. In conjunction with depression, the issue of coping with stress emerged as a related issue.

### Dealing with Incontinence

Dealing with the effects of incontinence was an issue that men talked about in relation to social interactions and the frustration of wearing pads, often accompanied by the embarrassment of constant bathroom visits.

### Fictitious Names

**Lance:** I went to a conference for incontinence. I was surprised to see the large amount of men and women having the same issue that was like I'm not by myself. I had somebody that I could talk to when needed.

**Aaron:** It just seems to me that that the initial period after surgery and thereafter that there was a lot of incontinence which requires that I wear pads, which annoys me, but I think that the fact that now , I know I don't have cancer anymore, so that's the reward I guess.

**Jonathan:** Some men are going to be having a problem wearing protective underwear and some men can deal with it and some can't face it. I did use it and you know and I got to wear them for 16 months. I had to do that. I went from changing probably 6 times a day down to 3. And that was before I had the sling surgery.

**Rufus:** If I cough or something like that, I drip a little bit. And right now, I still have stress incontinence. So I wear pads. I've been wearing one for the last 17 years.

**Eugene:** One of the hurdles I had to overcome was getting my urine under control as far as going to the bathroom. After talking to several people who had the surgery, considering how long it took them, it seemed like I was ahead of as far as getting that addressed. Now on the erection and all that, the sexual side, that was a huge hurdle and is still one today.

The issues of incontinence as a quality of life issue looms large for the men in this study. Although its effect was viewed as most intense immediately following treatment, the lingering effects remained. Most of the men were able to reframe this occurrence as bearable when compared to the prospects of prolonged suffering and the ultimate probability of death. Their persistence to re-establish a normal life pattern seemed to have propelled them to endure the discomfort often associated with incontinence.

### Sexuality as a Quality of life Issue

Sexuality as a quality of life issue often surfaced during individual interviews. The key issues involved stories about changes in sexual activity and re-defining one's sexuality. The men in this study affirmed the value of maintaining an active sex life. This seems to indicate that preserving their sex life may have been a factor that influenced treatment decisions as well. Moreover, what seemed to motivate them more than anything else was the will to live, and to live cancer-free. However, the need to perform sexually for these men remained prevalent during most discussions. This suggests that psychosexual interventions are important considerations in addressing heavily ingrained masculine constructions of sexuality. The issue of sexuality as discussed by the men in this study seems to underscore the importance of maintaining a sex life after undergoing treatment. Several researchers have concluded that little research is known about psychosocial issues that relate to the sexual functioning of African American prostate cancer survivors (Powe, Hamilton, Hancock, et al., 2007). Research studies that have addressed this issue report that the men found it difficult to share

concerns of sexual inadequacy with their wives (Banthia, Malcarne, Varni, Ko, Robbins, Greenberg, 2003). However, the men in this study did not seem to have difficulty sharing concerns of sexual inadequacy with their partners. The need to create a forum and safe haven where the thoughts and emotions of African American men are respected and validated seemed warranted both at a personal and professional level. This is because of the sensitive nature of this disease that strikes at the very essence of how men relate to issues of self-identity involving masculinity and sexuality. Having a fulfilled sex life and being able to perform sexually represented an important issue that some of the men were able to openly discuss. This included the use of medications, sex apparatuses, and non-traditional means of sexual satisfaction post-treatment.

Luke (fictitious name), recalled being surprised and somewhat dismayed during his recovery. As a side effect of treatment, Luke reported being bothered by the deterioration he experienced in his sex life. He was diagnosed at age 56, and at the time, still reeling from a divorce. For him the primary issue he encountered during recovery started as he began dating. He expressed shock that doctors did not fully disclose the sexual repercussions men face during recovery.

### Fictitious Names

**Luke:** Sometimes I see why doctors don't necessarily share all the information, because I think it might scare people away. See, you know, Black men and ego, the issues of sex, like people who make the decision on sexual side of it rather than the cancer side of it. There are always issues about your ability to perform sexually. So you worry about that, and you have a thousand questions regarding that.

**Wallace:** It's going to affect your interactions. It affects your social life. You look at gee how I can sustain a relationship when you can't satisfy or deal with a woman sexually. Then the doctor explained to me there are things you can do, like Viagra or you can take a shot before a sexual encounter. The other one was to get a penile implant. A lot depends on how conservative you are or how liberal you are sexually. I know guys who had the same illness, and when they could not perform, the wives ended up divorcing them or left them.

**Kevin:** One of the things that really surprised me was I could not get an erection. Everything else seemed to be fine. The first couple of times I went to this young lady things were fine, the last time, the more times I was having sex with her, the less I was able to have an erection, I couldn't handle it.



**Omar:** *Part of the problem is within us this whole level of sexual desires that comes into play. Because most brothers that I talk to that is all they talk about. The number 1 thing is sex. Not whether I am going to live or die, but sex man. And let's be real man, it is embarrassing. Men encounter embarrassment in this process.*

**Martin:** *Basically as far as I am concerned, my first thought was are you going to live. The other aspect is called the life after because shooting blanks becomes a real term. After surgery I had all the side effects that was not pleasant. Unfortunately for me the doctors up and lied. They said side effects may happen to a small number of folks. That's an outright lie.*

The issue of sexuality was something that the men in this study identified as an important issue. Being able to perform sexually was linked to a sense of maintaining manhood. The level of importance was exemplified by the extent to which the need for sexual stimulants were sought after and obtained in order to attain some level of sexual satisfaction for both themselves and their partners. These practices seem to be more prevalent among men who were single and re-entering the dating game.

## Discussion of Findings

The findings indicated that connecting these men with an empowered self-help group of cancer survivors, who share common issues, barriers, and histories could very possibly advance a broader level of group consciousness and the recognition that they are not alone. The side effects encountered by these men were quite graphic in re-living the debilitating effects of incontinence, erectile dysfunction, and bouts of depression. These issues reflect the inter-relatedness between one's perception of sexual prowess, intimacy, and manhood. They may represent an area where social work interventions, particularly social work oncologists and sex therapists can effectively target treatment modalities that are relevant to this population. The findings from this study indicated that African American men have a lot to say about policy and practices that impact their lives. The unwillingness to talk in groups is an indication that trust has to be established with these men prior to more elaborate forms of discussion and communication.

## Theoretical Perspectives

The following theoretical perspectives informed our understanding of the lived experiences of African American prostate cancer survivors: Social Support theory, Narrative theory, Empowerment theory.

## Social Support Theory

Generally, social support tends to reduce effects of stressful life events on health through the perception of reality that support, advice and/or reassurances are available if needed (Lazarus, 1996). The hypothesis is based on the notion that enhanced social support protects people by improving their ability to cope in stressful situations. It can also lead toward more positive appraisals or interpretations of stressful occurrences (Cohen & McKay, 1984). For many cancer patients, social support has been shown to minimize the risk of psychological distress (Carpenter, Fowler; Maxwell & Anderson, 2010). The belief that support is in fact available can reduce the effects of stress and contribute toward a more positive appraisal of the event. The theory encompasses three basic levels of analysis; perceived support, social integration, and enacted support (Lakey & Drew, 1997). The perceived level of support is based in the notion that friends and family can be counted on to provide assistance if needed. The social integration concept refers to a network of social relationships that may exist in a person's life, such as memberships in organizations, sibling relationships, or marital status (Barrera, 1986). The enacted support model relates to particularized actions of support, such as performances of specific actions that serve to relieve stressful life events. A key component related to our understanding of this theory relates to one's belief in causality, sometimes referred to as a locus of control. This suggests that some people are better able to make use of social supports as stress reducers than others. Sandler and Lakey (1982) were the first to test this hypothesis. Their research revealed correlations between anxiety and depression based on beliefs about causality and perceptions of control.

## Narrative Theory

As men in this study began to talk about their experiences with prostate cancer, their stories prompted a deeper understanding of their plight. This became particularly evident after the formal interview process came to an end, and informal verbal exchanges were able to take place. It was during these times that several of the men indicated that they had not talked openly about this issue prior to our meeting. Some of the research in this area indicates that during the course of narrative therapy the storyteller develops greater knowledge of himself as the listener develops greater knowledge of the storyteller (Carlick and Biley 2004). The adoption of narrative theory is viewed as a foundation for practice intervention. The theory was first developed in psychology during the 1980s (Sarbin, 1986), and in sociology during the 1900s (Frank 1995; Maines,

1993; White, Epston, 1990). The implication is that changing the narratives and stories of these men has therapeutic value. As they are encouraged to share their constructions of new narratives with other prostate cancer survivors, or with those who have been newly diagnosed, the emergence of a self-help approach to treatment can be set into motion.

### Empowerment Theory

It is quite common that recovery from a major illness and subsequent treatment can result in feelings of powerlessness. The aim of empowerment is to increase a sense of control over one's life (Rapaport, 1984; Gibson, 1995). Some of the research on empowerment points to the use of self-help groups as a major stimulus (Gray et al., 1997; Sharf, 1997; Mok & Martinson, 2000). Cancer research on self-help support groups that involved Chinese cancer patients, and women with breast cancer showed stark improvements in the ability to make informed decisions as well as an enhanced sense of hope among participants (Mok & Martinson, 2000). Connecting these men with an empowered self-help/support group of prostate cancer survivors who share common issues serves to advance a broader level of group consciousness, and the recognition that they are not alone.

The theoretical findings from this study suggest a need for both formal and informal social support systems, strategic utilization of narratives, and the implementation of empowerment strategies.

### Implications for Clinical Practice

The participants in this study preferred formal and informal sources of support that often take place within their immediate social context. This indicates that psychosexual interventions that are designed to address this population will need to tailor strategies that meet men where they are, and where they are most likely to be receptive. Another significant finding indicated that almost sixty-eight percent of participants were married and accompanied by their spouses when making decisions concerning treatment options. The implication is that clinical interventions should adopt a family centered approach. There are also psychosexual issues relating to sexual functioning among African American prostate cancer survivors and their spouses. This is particularly important as studies indicate that an estimated 33-98% of prostate cancer survivors report poor quality of life (QOL), due to sexual dysfunction after treatment (Sanders, Pedro, Bantum, Galbraith, 2006). There have also been related studies on the negative impact of prostate

cancer treatment on a spouse's QOL (Powe, Hamilton, Hancock et al., 2007).

### Utilization of Social Media

Webinar and webcasts represent technologies that allow for online web conferencing, complemented by electronic meeting systems that can assist in the dissemination of prostate cancer information. Webcasts can be utilized as one-way broadcasts, where a presenter provides information with limited audience interaction. These webinars and conferencing events can be shared at remote locations and can allow for more collaboration between the audience and the presenter. Interactive conferences allows real time point-to-point communications as well as multicast communications from one sender to many receivers, via text-based, voice and/or video chat utilizing the Internet on any computer or smart phone. Participants receive information from the presenters, and can ask questions and receive an answer in real time. This allows participants to participate in the comfort of their own homes or offices, and remain anonymous if they desire. This certainly could facilitate the dissemination of relevant psychosexual information because men merely have to turn to his computer or smart phone. The presenters could utilize video streaming, slide shows, whiteboard annotations, text chats, allowing for feedback via polls and surveys, data gathering and subsequent analysis.

### Implications for Future Research

The findings from this research could be useful in the development of targeted interventions that enhance our understanding of health influences, perceptions, and belief systems of African American men across a broad spectrum of life experiences. More studies are needed to focus on quality of life outcomes among African American prostate cancer survivors and their families. There is an urgent need to bring together trans-disciplinary teams in order to study complex socio-cultural characteristics of prostate cancer among African American men. This approach could involve social workers, sex therapists, and behavioral scientists.

The men in this study were reluctant to attend support groups during recovery; however, Temple University in Philadelphia, PA has been successful in attracting African American men to their program. The program "MAN TO MAN" is sponsored by the American Cancer society and meets on the 4th Thursday of every month from 5:00- 7:00 pm. The facilitator is an African American male, and has a Master's Degree of Social Work. The men are given free parking, and there is a collation at each meeting. There are notifications sent

out to remind men of the meetings, and they are then followed up by personal telephone calls. These sessions are well attended by prostate cancer survivors of various races, however, the majority of the men who attend are African American. Occasionally, the wives/partners attend as well. It appears that this group has found a way to attract survivors of prostate cancer to their support group. The fact that the men attend seems to imply that they are actively addressing the side effects of this disease. Having attended these meetings myself this researcher found the participants relaxed and engaged. These interactions represent opportunities for men to get together to discuss issues that only a man who has experienced it could fully understand. Future studies could interview these men in order to ascertain what factors influenced them to maintain active levels of attendance and participation as well as serve as a possible model in the development of viable prostate cancer support groups at other locations.

Additionally, more research studies are needed to evaluate the efficacy of prostate cancer support groups among African American men. This can be expanded to include self-help, psychotherapy, cognitive-behavioral, and Internet support groups. This may involve random assignment to experimental, and control groups. Although 65% of the participants involved in this study were made aware of prostate cancer support groups by medical staff, only 5% actively participated in these groups. This raises interesting questions about the perceived efficacy of prostate cancer support groups.

Almost 68% of participants involved in this study were married and accompanied by their spouses when making decisions regarding treatment options suggesting that subsequent interventions must adopt a family centered approach. This often relates to sexual functioning among African American men and significant others. Because of the relational stress and changes in the survivor's sex lives, research implications are that in-depth investigations of the sexual functioning of African American prostate cancer survivors and their partners will warrant further inquiry.

The overall promotion of greater levels of cultural sensitivity that involve African American prostate cancer survivors can aid in the identification of modifiable risk factors, and help in the guidance of evidenced-based interventions.

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