

Prostate Cancer Survivorship among African American Men

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Abstract

This article describes how African American prostate cancer survivors negotiate medical systems create guideposts for survival, and strategies for rehabilitation. The intent is to explore the availability and significance of formal and informal psychosocial support systems that are utilized by African American prostate cancer survivors and to better understand the coping and adaptation of survivors and their families. The article will address the role of social support systems, prostate cancer support groups, and self-help groups. Prostate cancer survivorship will be viewed within the larger context of cancer survivorship initiatives in the United States. According to the SEER statistics, 5 year survival by race is 99.6% for White men and 95.9% for African American men. The lower survival rate and higher mortality rate among African American men have resulted in diminished outcomes and poorer quality of life experiences.

Keywords: Prostate cancer; African American; Survivors; Support systems; Illness

Survivorship Disparities

The term survivorship is characterized here as having successfully lived beyond the stage of actual treatment, and having adapted to a current lifestyle. However, survivorship is also viewed as years lived beyond treatment [1-6]. The following section will address survivorship from a multidisciplinary perspective. A review of the treatment of African American prostate cancer survivors will be explored within the general context of cancer survivorship.

The utilization of an age-adjusted prostate cancer related mortality shows that African American men die at a rate that is more than twice that of White men [7]. Prior research in this area attributes racial disparities in survival to differences in socioeconomic status and to lower surgical treatment rates [8].

More recent findings have shown that African American survivors report significantly higher levels of stress when compared to non-African American survivors [9]. However, in contrasting studies, researchers have found no significant influence of stress on this population group when compared to non-African Americans [10]. They did however note general complaints that were common among all races that involved sexual, bladder, and bowel problems.

Additional factors that may contribute to disparities in survival rates may have to do with obesity and dietary factors. A team of researchers explored the relationship between obesity and the risk of a PSA recurrence in African American men, and found that obese African American men had a greater risk of PSA recurrence [11]. There were similar findings reported in related studies [12]. In reference to dietary factors, prior studies have indicated that African Americans tend to maintain high-fat diets at levels that exceed other racial groups and link this a factor, contributing to survival rates [13].

There are still other factors that should be considered when looking at racial disparities in survival rates of prostate cancer. They relate to co-morbidities and the underutilization of hospice care. Several researchers have reported that African American men tend to present with greater levels of comorbidity than Caucasian men [14]. Several researchers have addressed the under-utilization of hospice care among African American men [15]. However, in another research study, it was concluded that survival outcomes were equal between African Americans and Caucasians when treatment was administered in the same fashion and without regard to race [16].

Overall, the survivorship experience seems to encompass

several repetitive themes that are not necessarily in sequential order. Historically, one of the primary experiences relates to mortality and the acknowledgement of a terminal illness [17-22]. Finally, there is the individual quest for meaning. This individual search for meaning seeks to develop a deeper understanding of one's essential purpose in life and the quest to maximize self-actualization.

Stages of Survivorship

Generally, the experiences of prostate cancer survivors run the gamut of spiritual, social, psychological and emotional ordeals. Such occurrences may or may not occur in a sequential order. However, there are commonalities that tend to characterize stages of the survivorship experience over the course of time. These stages will be further elucidated in the following section.

Acknowledgement of a Terminal Illness

Coming to terms with the reality of prostate cancer is the acknowledgement of the possibility of one having a terminal illness. During this stage, cultural beliefs about male physical strength may be confronted for the first time. The long-term side effects of prostate cancer and fear of recurrence can become overwhelming factors that bring men toward a realization of the terminal effects of the disease. During this stage the focus often becomes how these men cognitively process and ultimately frame a prostate cancer illness. There are also environmental factors that may facilitate this such as the passing of a friend or family member, or even stories in the media that brings these issues into the public forum.

Alienation and Isolation

At some stage of the illness, men may experience levels of uncertainty [23,24]. This experience of uncertainty can impact psychosocial functioning, how well men adapt to these conditions and overall outcomes [25]. Several health-related studies have shown that

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experiences of uncertainty can also be linked to mood disturbances [26]. This experience of isolation and alienation may very well characterize many prostate cancer survivors. On the other hand, uncertainty also presents opportunities for these men to adopt new coping skills as avenues in reducing levels of stress and anxiety [23,27]. The idea of uncertainty in relationship to prostate cancer patients as described here represents a state of being in which the individual constantly questions the likelihood of recurrence and its impact on his future wellbeing [24].

Search for Meaning

The acceptance of a prostate cancer diagnosis and management of the uncertainty of one's future can provide new opportunities for personal growth and a search for greater meaning and purpose in the journey of life. This may also serve as a basis in helping others to positively confront and overcome the struggles involved in surviving prostate cancer. This transformational process often leads to a re-assessment of what is important in life [3,6]. The goal is that as prostate cancer survivors continue to broaden their perceptions of the past, levels of uncertainty begin to become normalized within the context of everyday life events.

African American prostate cancer survivors continue to die at rates that are more than twice that of Caucasian males [28]. There are several factors that go into providing reasonable explanations for existing disparities. The issue of co-morbidities may offer some perspective when looking at additional health related ailments that tend to shorten the life span of African American men. Some may be related to personal lifestyle preferences such as dietary habits. However, one overriding determinant seems to relate to socioeconomic status and lack of education and awareness of treatment options.

It appears that overall survival outcomes among prostate cancer survivors regardless of race or ethnicity are equivalent when treatment is assigned in a uniform manner [16]. It can be surmised here that the late stage of diagnosis among African American men may account for higher mortality rates in view of a comparative analysis. These disparities tend to exist at various levels of diagnosis, treatment, and stages of survival. Their determinants convey a complex and inter-related web of socio-economic, socio-cultural, and biological characteristics.

Spirituality and Religious Life

Several researchers point to spirituality and religious life as key indicators of physical and emotional health among African American prostate cancer survivors [29]. Particularly, spirituality in the African American community has been identified as an important protective and mediating factor in coping with health related issues [30]. Spirituality in this context is viewed as a significant cultural experience and affirmation of one's belief that influence health behaviors among African Americans. Taking all of these factors into account, the recent controversy over the general usefulness of prostate cancer screening has seemingly added another layer of complexity as how best to address the escalation of prostate cancer among African American men.

Need for Support

Psychosocial support has been widely cited in research studies as contributing factors in the ability of cancer patients to cope as well as enhancing the survival process [31-33]. Consequently, the identification of both formal and informal sources of support becomes key elements in sustaining prostate cancer survivors. These men, who have undergone treatment, will seek to embrace support systems that are most convenient and readily accessible. Existing literature indicates that when psychosocial

support systems are integrated as part of an overall treatment plan, the quality of life for cancer survivors increases dramatically [33]. As prostate cancer survivors adapt to the uncertainty of their plight, a significant aspect of their recovery rests on the availability and utility of social support resources and health care providers [23,24].

Prostate Cancer Support/Self-Help Groups

Self-help cancer support groups were initiated in the United States during the 1980s by breast cancer survivors and have developed through women uniting at a grassroots level and garnering governmental support (Kurtz). Prostate cancer self-help/support groups began to appear during the 1990s [34]. There has been some evidence of the social and psychological benefits of prostate cancer support/self-help groups [35]. Additional studies have shown that these groups help to develop new knowledge, enhance coping strategies, and reduce isolation [36].

The social resources available to African American prostate cancer survivors usually come from an extended network of family and friends. Within these social networks, these men receive both informational and emotional support [37]. Moreover, church is a major source of support. Many churches have organized prostate cancer support groups [38] and provide formal support services such as assistance with personal care housekeeping, and transportation.

The utilization of African American churches as a channel for dissemination of health information that increases knowledge and awareness, has been well documented and involves a wide range of health issues, such as substance abuse, prostate cancer, and hepatitis C [39-41]. The African American church has a long history of serving the spiritual and physical needs of the community [42,43]. It has been the focal point around several health promotion initiatives, tobacco-related [44]; prostate cancer [45-47]; cardiovascular disease [41,43,48].

African Americans tend to prefer more informal sources of support. The stigma often attached to a cancer diagnosis, location of meetings and disclosing sensitive information to strangers may help to explain why African American men seem to prefer more informal support systems. For many African Americans, a focus on the community, the extended family, and the collective reflects a historical pattern of mutual aid and self-help initiatives.

The central question of how the lived experiences of African American prostate cancer survivors' involvement with treatment, diagnosis and screening can advance cancer education program participation, is relative to the growth and development of prostate cancer support and self-help groups at large. Despite the growth and perceived impact of the prostate cancer support and self-help movement, very little empirical research has been conducted. This reality is even more dismal in relationship to African American prostate cancer survivors. The support group model is designed to develop a system of reciprocity among members as opposed to impacting interpersonal, social or behavioral change [49].

In this regard, Us Too and Man to Man, represent the largest network of prostate cancer support groups in the United States, and embody basic characteristics of both support and self-help approaches in addressing prostate cancer survivorship. Both organizations were formed in the early 1990's [50]. Us Too, were co-founded in Chicago by a prostate cancer survivor and his urologist. The organization received administrative support from the American Foundation for Urologic Disease [51]. The mission of Us Too is to help men and their families make informed decisions about prostate cancer detection and treatment through support, education and advocacy.

A prostate cancer survivor also started the Man-to-Man group in 1994. The group became a cancer support program of the American Cancer Society in 1994 [52]. The goal of both groups is fundamentally based on the support and education of prostate cancer survivors. They achieve this by monthly program meetings often featuring invited speakers, with some area of expertise, and also provide opportunities for sharing of personal experiences. The basic intent of these organizations is to provide technical information as opposed to the provision of emotional support. However, since its beginnings, critics have questioned the virtual absence of outreach efforts that target at-risk populations. These criticisms tended to focus on the general location of meetings, format and sponsorships [53]. There is no current research that shows how these groups have brought about positive outcomes for African American men.

In contrast to prostate cancer support groups, self-help groups generally tend to emerge from peer affiliations. In many instances, peers come together for mutual assistance. They are often characterized by a perceived need for empowerment and operate on the basis of democratic decision-making processes. Additionally, self-help groups tend to exemplify a sense of community, provide opportunities for advocacy and avenues for personal transformation [34]. African American survivors of prostate cancer may particularly benefit from self-help groups because of its basic orientation towards self-affirmation and acceptance.

In order to compile a comprehensive listing of published research studies on this topic, the key word search *prostate cancer and (support groups or self-help groups)* was performed in the following electronic databases: PsycINFO, AIDS and Cancer Research Abstracts, Current Contents, Web of Science, Alt-Health Watch, CINAHL: Nursing and Allied Health, and Health Source: Nursing/Academic Edition. In addition, the search *prostatic neoplasms and self-help groups*, was performed in PubMed after identifying the appropriate medical subject headings for this database. Based on a review of the literature in this area, it appears that socialized societal expectations are major factors that help explain the reluctance of men in general to participate in prostate cancer support group meetings.

Although research involving African American prostate cancer survivors has recognized the types of support that enhance the survivorship experience, situations also exist where such support is lacking. Qualitative studies suggest that these survivors fear being stigmatized and socially isolated [54]. Additionally, many may be reluctant to communicate their needs for support in specific instances [55].

In a 10-year qualitative study of older African Americans and their experiences with a chronic illness, Becker and Newsom [56] concluded that African Americans reported themes relating to spirituality and survival on a consistent basis, as well as themes relating to resilience. As an explanation of why African Americans are less likely to seek out professional services such as those provided by existing prostate cancer support groups, a study by Anglin et al. purports that African Americans are more likely to believe that distressful life events will get better over time without professional intervention [57-59].

Although prostate cancer support groups play an important role in targeting the educational needs of men recovering from prostate cancer, there are important psychosocial needs and concerns that are not addressed. These issues include coping with the emotional aspects of prostate cancer, behavioral, as well as cancer related issues of self-image and distress. For many African American men particularly, the general

location of these meetings may preclude active levels of participation. The major prostate cancer support organizations, although well established and supported by mainstream cancer-related organizations, may need to increase their outreach efforts in areas where African American men tend to congregate on a consistent basis. As much of the research in this area indicates, African Americans' utilization of both support groups and self-help groups tend to be strongly rooted in their communities, particularly in religious institutions, fraternal associations, and extended kinship ties. The key to bringing about greater levels of education, awareness and participation in supportive services may rest in the notion that pockets of informal support already exist, but lack a coordinated network of service delivery.

Based on these realities, there may be a separate step needed to ensure that African American men feel safe first. This would entail possibly meeting individually with them to describe the purpose of the group, to communicate that they will not be judged and to emphasize the shared nature of the experience. The doctors' office may not be the best way to reach these men. It might be better to work through religious organizations first. These meetings could be held at community sites rather than institutional settings.

In conclusion, peer support groups may present an effective forum in the provision of psychosocial support for prostate cancer survivors. These groups provide a sense of hope, belonging as well as a barrier against social isolation. This requires a model that facilitates more natural forms of interaction and support, augmented in ways that provides bonding, dissemination of information and a sense of empowerment. In addition, the following recommendations are proposed as practical considerations in regard to prostate cancer survivorship among African American men.

1. Compilation and publication of a regional African American prostate cancer survivor's directory for dissemination to medical professionals, social work oncologists and cancer centers.
2. Publication of a central clearinghouse and repository of resources and materials that targets African Americans and prostate health for dissemination to faith-based organizations, fraternal associations, civic and social groups.
3. Formalization of a speakers' bureau comprised of trained African American prostate cancer survivors as advocates to promote education and awareness about the disease.
4. Memorandums of Understanding (MOUs) involving area hospitals/Cancer Treatment Centers and Black Clergy Associations, that promotes active participation in prostate cancer education, awareness and screening programs.
5. Series of community-based prostate cancer educational seminars in conjunction with the National Medical Association (local chapters) that targets high-risk communities based on data from the State Cancer Registries.

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