

Psychosocial Implications of Prostate Cancer Survivors: The Lived Experience of African American Men

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Abstract

According to the American Cancer Society, African American men have the highest incidence, and mortality rates of prostate cancer among all ethnic groups in the United States (ACS, 2012). This study explored the experiences, coping strategies, and environmental stressors that impacted their lives during diagnosis and treatment.

This psychological phenomenological study entailed a description of the experiences of 24 interviews with the intent of learning how interviewees coped with the reality of surviving prostate cancer. Reducing the information to significant quotes and combining these statements into themes analyzed the data. The narratives were developed with men recruited from local barbershops, houses of worship, and prostate cancer support groups. Qualitative data were gathered using a semi-structured questionnaire to guide in-depth interviews. Additionally, a socio-demographic survey elicited information about age, educational background, marital and family status, employment, insurance coverage, and history of prostate cancer. The men also completed a social support index in order to gauge levels of support among significant others. The research shows how these men combatted the effects of social isolation, reframed a life threatening illness, and reconstructed personal identities, enabling them to live more purpose-driven and productive lives. In the study, participants reported stronger commitments to family life and to spiritual and religious beliefs.

The study explored how these men dealt with trauma, stress and what life changes were essential in order for them to not only make meaning of these events, but also adapt, and grow in the process.

Keywords: Prostate Cancer; Psychosocial; Environmental stressors; Planned behavior

Discussion of Findings

The men in this study bring both credibility and direct knowledge relating to prostate cancer screening that can be openly shared and genuinely communicated with other men who may have apprehensions about PSA tests, and other prostate cancer screenings. On the other hand, issues relating to affordability and accessibility will require macro related interventions. In all likelihood, a legislative agenda that pressures elected officials to provide more direct funding for prostate cancer research, outreach, awareness, and educational programming will be needed.

The findings indicated that connecting these men with an empowered self-help group of cancer survivors, who share common interest, barriers, and histories, serves to advance a broader level of group consciousness and the recognition that they are not alone. The psychological and emotional effects of a prostate cancer diagnosis can have a profound impact on the lives of men and their families. However, the manner in which men choose to respond to the disease can mitigate or intensify the overall experience.

Sixty-two percent of the men in this study were college educated middle-class men. They exemplified a range of emotions and thought processes during the initial phase of the diagnosis. Many struggled with how to convey the news to loved ones while maintaining some degree of calm and composure in face of adversity. This seems to speak to the importance of family life, stability, and continuity in the lives of these men. The importance of spirituality and faith in a supreme power seemed to have somehow sustained many of them to press forward and persevere in spite of unfavorable circumstances.

The relationships with medical professionals and understanding the medical terminology represented challenges that were minimized

to some degree because of the role of significant others, who served as pivotal social support systems throughout the treatment and recovery process.

The side effects encountered by these men were quite graphic in reliving the debilitating effects of incontinence, erectile dysfunction, and bouts of depression. These issues reflect the interrelatedness between one's perceptions of sexual prowess, intimacy, and manhood. This may also 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 role of traditional prostate cancer support groups was grossly under-utilized by the participants in this study. Although 61% indicated that their medical professional had informed them about support groups, few availed themselves of the service. The reasons varied among them; the most common theme was that they did not see the relevance of attending these groups. The social support systems available to these men seemingly already existed in their own communities. The role of organized religion, fraternal associations, family, fictive kinships and informal social relationships seem to play a more significant and meaningful role in their lives on the road to recovery.

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The issue of medical mistrust did not seem to be a major issue for most of the men in this study. The fact that they were mainly middle to upper middle-income individuals may have increased the likelihood of being more trustful of other professionals.

The recommendations that came from these men stressed the importance of having PSA screenings completed at community-based locations, such as religious institutions, Masonic lodges, and recreation centers, as opposed to hospital settings. These community-based locations would also serve as an information and referral network for men and family members who are seeking to identify resources and learn more about the disease. An outreach ministry was recommended as an outgrowth of prostate cancer programs that already exist in several churches. The recommendation would formalize and coordinate these outreach efforts across the City of Philadelphia. The use of social media was another recommendation that would broaden outreach potential and allow men to conveniently access information and in the comfort of their own homes. The popularity of sports and sport related activities that tend to draw significant numbers of men was also viewed as opportunities to distribute and educate African American men of all ages about prostate cancer and the benefits of PSA screenings. Finally, these men saw the involvement of their wives as important advocates that could also reach out to the broader community in advocacy campaigns and educational initiatives.

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. Prior to conducting each interview, the researcher was able to engage these men around common interest and mutual concerns that aided in the development of trust and the establishment of a comfort level that facilitated the actual interview process. Past research on the invisibility of African American men in clinical practice has shown that the social work profession has largely ignored their perceptions [1]. Interestingly, the recommendations from these men seemed to reflect a cadre of active problem solvers as opposed to mere recipients of services.

Advice about how to best motivate African American men to become more proactive about their health, and particularly in regard to prostate cancer education, awareness, and screenings, specific recommendations were put forward. These recommendations focused on activities that can primarily be initiated, developed and sustained by African Americans through civic engagement and at various spectrums of the society, encompassing prostate cancer survivors, medical professionals, community grassroots supporters, and African American women.

Theoretical Perspectives

The theoretical perspectives presented in this section will inform our understanding of the lived experiences of African American men with prostate cancer. The following theories will be covered: Theory of Reasoned Action, Theory of Planned Behavior, and Social Support Theory. These perspectives cover a range of research studies that help explain complex socio-cultural issues that impact African American men in the treatment of prostate cancer.

Theory of reasoned action

The Theory of Reasoned Action (TRA) is an analysis of relationships between one's beliefs and actual behavior. Fishbein [2] purported that one's attitude toward a behavior is a better predictor of behavioral

responses than one's attitude toward a targeted outcome.

Parchment [3] utilized the Theory of Reasoned Action in the study of health belief of prostate cancer in a sample of African American and Caribbean men. His sample involved 100 African American and Caribbean men ages 37-89. His results indicated that one's intentions to pursue treatment and participate in prostate cancer screenings were influenced by health beliefs. His study highlighted the importance of enhanced educational programs that are specifically targeted toward ethnic minorities in the United States.

The outcomes indicate that behavior is quite often dependent upon the value an individual places on a particular outcome. This theory is based on the notion that beliefs about consequences should predict behavior. It assumes that human beings are rational and apply information that is available to them in a systematic manner, weighing both the costs and benefits of a particular action.

Theory of planned behavior

The Theory of Planned Behavior (TPB) looks at the relationship between individual behaviors, beliefs, and attitudes and one's perceived level of control over the illness. In this model, the intent of the behavior is impacted by both individual attitudes and by the beliefs that significant others approve or disapprove of behavioral responses. Shelton, Weinrich, and Reynolds [4] utilized TPB in their study of the relationship between perceived barriers and the participation of African American men in free prostate cancer screenings. Their study included 1,395 African American men, 40-70 years of age. In the utilization of the constructs from the TPB model, the barriers cited most often by these men in response to prostate cancer screening were lack of insurance, insufficient funds, and lack of medical knowledge concerning referrals.

This model represents an extension of the Theory of Reasoned Action. It asserts that there is a relationship between one's intention to perform a given act and behavioral outcomes that follow. In this sense, the intention of one's actions is measured by how hard they are willing to exert themselves in the process of overcoming obstacles. Hence, the stronger the intention, the more likely they will move toward more favorable outcomes. However, the reality of external factors, such as time, money and cooperative relationships as exemplified by the above study, reflect key factors that may serve as deterrence to overall outcomes.

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 [5]. 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 [6]. For many cancer patients, social support has been shown to minimize the risk of psychological distress [7,8]. The belief that support is in fact available can reduce the effects of stress and contribute toward a more positive appraisal of the event. This theory encompasses three basic levels of analysis; perceived support, social integration, and enacted support [9]. 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 [10]. 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 [11] 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 the 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 [12]. The adoption of narrative theory is viewed as a foundation for practice intervention. It is a collaborative exchange that takes place between the social worker and the client. The theory was first developed in psychology during the 1980's [13], and in sociology during the 1990's [14,15].

Narrative theory allows for the examination of significant events over the course of the life span and helps to uncover episodes of resiliency during different stages of life. This relates to the strength-based approach, as a reminder of how in this case, prostate cancer survivors may have in the past successfully overcome other life challenging events. 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 has been set into place.

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 [16]. Some of the research on empowerment points to the use of self-help groups as a major stimulus [17-20]. 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 [20].

An important element of empowerment involves consciousness-raising [21]. Consciousness-raising includes making men aware of the social determinants of healthcare disparities that exist in society. It also involves working with others, mobilizing resources, and advocacy. In the utilization of this theoretical approach, the social worker's role involves linking clients to resources, and in some instances, educating other professionals and communities at large about healthcare disparities.

For the men who might be under-going a prostate cancer treatment, or others who may be contemplating whether or not to undergo PSA screening, connecting these men with an empowered self-help group of cancer survivors who share common issues, barriers, and histories, serves to advance a broader level of group consciousness, and the

recognition that they are not alone.

Social work practice in healthcare settings has evolved from attending to acute inpatient care and discharge planning to now addressing a continuum of care. This new wave includes disease prevention as well as health promotion. Social workers must receive training that prepares them to become conversant in medical terminology and work collaboratively as key members of interdisciplinary and health care teams [22].

Implications for Social Work Practice

Although medical professionals specialize in the biological aspects of the human experience, they often place a limited degree of attention on the psychological and social behavior of the patients they serve. On the other hand, social workers typically address a wide range of psychosocial issues that includes the identification of strengths and enhancing coping capabilities. African American prostate cancer survivors could benefit from an ecological, strength based approach that links them to community resources and employs strategies that reduce environmental stressors. The social work profession can provide a useful framework in the examination of social relationships and individual characteristics that involve these men in the utilization of medical services and that emphasize holistic approaches to treatment, and is multi-leveled, involving the family, the individual, and the community.

Beyond the provision of direct social service delivery, social workers can become more involved in interdisciplinary research, particularly in areas that address quality of life issues, such as aging and palliative care. Additionally, social workers can engage prostate cancer survivors in various forms of treatment, including family work, individual counseling, mutual support, and self-help initiatives. By incorporating a systems theory perspective, social workers care uniquely prepared and skilled in the completion of psychosocial assessments and challenges faced by prostate cancer survivors. The effective utilization of systems theory involving African American men with prostate cancer has been shown in studies involving early detection and informed decision-making 9 Myers, 1990. The role of the social worker in this process is viewed as a catalyst in the facilitation of resources and problem-solving skills.

Social Workers can serve as advocates in the larger community in relation to educating the general public about healthcare disparities and barriers encountered by African American men who are impacted by the disease. The process of linking African American men to others who share a common history and unique circumstantial dispositions is viewed as an essential social work intervention that can potentially lead toward new levels of empowerment.

An illustration of resource development and facilitation of linkages that social workers can replicate can be found in looking at the Barbershop program that evolved from a unique partnership. It involved a small cohort of nurses, university faculty, and a local community organization [23]. In this program, barbershop owners and their employees were active participants in providing culturally relevant prostate cancer educational programs in non-traditional settings. The participants from this study were overwhelmingly middle-class, based on income, residential locations, and educational levels of attainment. Although this was not the intent, ironically few research studies have focused on middle class African American men [24]. An examination of middle class African American prostate cancer survivors provides insights that may guide the development of culturally sensitive social work interventions. The findings from this study suggest a strength-

based ecological approach in addressing the alarming prevalence of prostate cancer among African American men. This approach considered both micro and macro level factors [25].

Because of the heterogeneity of the African American community, intervention strategies aimed at eradicating prostate cancer disparities should represent a multi-leveled approach that involves the individual, family, and practice modalities that take place in a wide variation of community settings. Program strategies that strengthen social and indigenous support networks represent potential community organizing initiatives that can be facilitated by social workers [26]. This study indicated that the social context in which services can be delivered to this population can be facilitated by involving faith-based institutions and local barbershops, as they not only represent frequent locations where many African American men congregate, but also tend to cut across socio economic divisions. The importance of working closely with the community through all stages of intervention and planning are key components in this process.

Social Workers are well suited to address these issues because of their possession of specialized skills in the facilitation of groups, understanding of ecological systems, and commitment to social justice. This work involving men at risk, positions social workers to assume greater leadership roles in the advancement of men's studies, interdisciplinary exchange, and normative developmental challenges encountered by men across socio-economic and racial boundaries.

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