What Men Say About Surviving Prostate Cancer: Complexities Represented in a Decade of Comments

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The experience of men who have completed cancer treatment and transitioned into survivorship is not well understood; therefore, a qualitative, descriptive, narrative analysis was conducted with open-ended questions that participants responded to annually during the course of a 10-year period. The participants expressed that the experience was complex and three themes were identified: "symptoms," "can’t go back," and "needs." Time also emerged as an important concern. Participants indicated that sexual and physical symptoms impacted their entire life and that acknowledgment, information, and help from others were important to their recovery. Returning to baseline functioning was no longer possible; rather, a new normal now existed. The findings will help oncology nurses better understand the experience of being a prostate cancer survivor. The need for long-term interventions with information delivered prior to, during, and beyond the treatment process was identified. Clinical interventions should move toward a more integrated approach that helps men develop their new normal.

More than 11.4 million cancer survivors are living in the United States, and the number is expected to increase in the next several decades. Men with prostate cancer make up about 20% of all cancer survivors (National Cancer Institute [NCI], 2011) and, of all survivor groups, the number of prostate cancer survivors is increasing at the most rapid rate (American Cancer Society [ACS], 2011; Institute of Medicine [IOM], 2006).

Although prostate cancer is unique to men, the aftermath of treatment impacts their lives and their relationships with others. As in other chronic illnesses, treatment and its sequela place an enormous burden on the physical and emotional resources of survivors. Challenges with communication and interruptions in intimacy often occur as survivors are faced with the long-term physical and psychosocial consequences of diagnosis and treatment (Badr & Taylor, 2009; Gomella, Johannes, & Trabulsi, 2009; Mols et al., 2009; Sanda et al., 2008). However, many members of the oncology healthcare team may not have sufficient information about the many challenges faced by survivors and, therefore, are not able to offer the most appropriate and effective treatment options.

The experience of men who have completed acute cancer treatment and transitioned into survivorship is not well understood (IOM, 2006, 2008; NCI, 2005), in part because the healthcare focus has been on curing the cancer, not on helping survivors live with treatment-related sequela. However, survivors and their partners are left to live with the unintended treatment-related outcomes. Oncology nurses are in key positions to assist men and their partners in obtaining the information and the support needed to effectively cope with the challenges. The purpose of this article is to describe the experiences reported by men, in their own words in a 10-year time period, who have been treated for early-stage prostate cancer.

Literature Review

Prostate cancer is the most common non-skin cancer diagnosis for men, accounting for an estimated 29% (240,890 cases) of all new cancer cases in 2011. Although the five-year survival for early-stage disease is about 100% and the 10-year survival rate is close to 91%, the process of diagnosing and treating men with prostate cancer has long-term physical, psychological, and emotional effects (ACS, 2011; Skerrett, 2005). Most prostate cancer survivors report adverse urinary, bowel, and sexual health outcomes that continue years after treatment. Those symptoms,
Survivors of prostate cancer reported feeling dismissed and objectified by physicians and other members of the healthcare team when they tried to bring up their concerns. (Dandapani & Sanda, 2008; Incrocci, Slob, & Levendag, 2002; Singh, Trabulsi, & Gomella, 2010a).

Although most longitudinal studies have focused on mortality and morbidity for prostate cancer survivors, a number have focused on long-term health-related quality of life (HRQOL) (Gore et al., 2009; Pardo et al., 2010; Singh, Trabulsi, & Gomella, 2010b). The number of studies describing the HRQOL of men who have been treated for localized prostate cancer has increased substantially since the mid-1990s (Albaugh & Hacker, 2008; Chen, Clark, & Talcott, 2009; Couper, Love, et al., 2009; Galbraith, Arechiga, Ramirez, & Pedro, 2005; Galbraith et al., 2001, 2008). Although men have expressed concern in areas affecting their HRQOL (e.g., physical function, emotional function) and relationships, research on interventions is limited (Lintz et al., 2003; Sanders, Pedro, O’Carroll Bantum, & Galbraith, 2006). Some men seek professional help for their sexual dysfunction; however, those attempts often do not resolve the underlying problems. Researchers and clinicians have focused primarily on reversing erectile dysfunction with chemical or physical modalities, but often fail to address the broader issues of relationships and self-concept (Badr & Taylor, 2009; Chen et al., 2009; Michaelson et al., 2008; Singh et al., 2010b; Song et al., 2011). For example, a study using counseling interventions with 84 couples focused primarily on the use of medical interventions for erectile dysfunction (Canada, Neese, Sui, & Schover, 2005). The intervention was initially successful; however, after six months, sexual functioning had decreased to pretreatment levels. Another study of 116 patients with prostate cancer and their partners reported the association of erectile dysfunction and communication with their partners. Results demonstrated that, when erectile dysfunction was present, the partners reported less communication and increased relational distress (Badr & Taylor, 2009). Harden et al. (2009) focused on assessing how satisfied patients with prostate cancer and their spouses were with a family-based educational intervention that was designed to improve their coping skills as they managed the effects of prostate cancer and treatment. Patients and their spouses reported increased self-efficacy, increased coping skills, less uncertainty, and better communication with each other.

Others have reported that men describe frustrations with their relationship and their ability to cope effectively with the emotions and concerns expressed by their partner (Couper, Block, et al., 2009; Roth, 2005). A survey of 134 patients with prostate cancer and their partners found that the partner’s satisfaction with the couple’s sexuality and intimacy was the strongest predictor of the man’s quality-of-life score (Perez, Skinner, & Meyerowitz, 2002). Another study found that, when patients and partners reported high rates of sexual dysfunction, couples were more likely to avoid open communication about sexual issues, which led to additional marital distress and poorer relational adjustment (Badr & Taylor, 2009).

Survivors of prostate cancer have identified important issues that go beyond the mechanics of sexual dysfunction, including communication and information needs about intimacy and how to manage treatment-related sexual challenges (Beck, Robinson, & Carlson, 2009; Hawkins et al., 2009; Sanders et al., 2006). The health of relationships for prostate cancer survivors possibly could be enriched through strengthening communication and focusing on the challenges to a relationship that occur from one member being a long-term survivor of prostate cancer (Berg et al., 2008; Peltier, van Velthoven, & Roumeguere, 2009). Survivors of prostate cancer and its treatment are living with a chronic illness that can have a negative impact on their relationships. As a result, communication becomes an important area in which researchers should focus (Badr & Taylor, 2009; Gustavsson-Liljus, Julkunen, Keskivaara, & Hietanen, 2007; Sanders et al., 2006).

Research in the areas of HRQOL for survivors of prostate cancer and treatment has increased since the mid-1990s. However, gaps remain in understanding how encompassing the experience of becoming a long-term survivor of prostate cancer is from the survivor’s perspective. More research in that area will help oncology nurses and other healthcare providers understand the concerns of the patient population so needs will be recognized and the healthcare community can appropriately intervene.

Methods

Data were collected during two longitudinal quality-of-life studies with patients with prostate cancer and their partners during a 10-year period. A complete description of methods and participants can be found in Galbraith et al. (2001, 2005, 2008). A total of 401 men and 364 partners were enrolled between 1998 and 2004. The mean age was 68 years, about 70% had at least some college education, 84% were Caucasian, and the average prostate-specific antigen (PSA) at the time of enrollment was 10.8 ng/ml. At the end of data collection, 157 men (39%) still were participating. Study participants completed questionnaires on HRQOL, health status, and relationship satisfaction every six months during the first 1.5 years of the study, then annually after. This article reports on the analysis of two


open-ended questions that were included in the two studies: “Can you think of any additional ways that being treated for prostate cancer has affected the quality your life?” and “Do you have any additional comments?” About 33% (n = 135) of the participants elected to respond to the two questions. Using qualitative analytical techniques, all narrative responses to the two questions were collated and transcripts were coded using a three-step qualitative narrative content analysis (Morgan, 1993). For example, after reviewing each line of the narrative data, inductive codes were developed. The codes then were organized into categories. Finally, themes were identified.

Findings

The coding of the narrative data line by line resulted in 700 inductive codes (Creswell, 2003), which led to the following eight categories: physical symptoms, sex, relationship impact, reflections, healthcare experience, cancer vigilance, complexity of change, and psycho-emotional responses. Three themes were identified from these categories: “symptoms,” “can’t go back,” and “needs.” Credibility, validity, and dependability of the data were maintained through debriefings and consensus of the research team. The categories were directly traceable from responses of the participants (Creswell, 2003; Lincoln & Guba, 2000; Marshall & Rossman, 2006). Examples of statements from the men in each of the eight categories are described in this article.

Physical Symptoms

Healthcare providers may have trouble comprehending the experiences of prostate cancer survivors without hearing testimonials from the survivors themselves. One survivor said, “I was told of the incontinence of bowel and bladder . . . but no indication of the total misery.” Another man said, “I change diapers.” Numerous comments were made related to rectal bleeding, diarrhea, flatus, bloating, and rectal damage.

My life is pretty normal with these few exceptions: usually hemorrhage out of the urethra every six weeks. It shuts me down for two to three days. Sexually dysfunctional. Leak badly when I kneel or stoop, so [I] switch between pads and diapers.

A few respondents indicated that they had minimal physical sequela and stated that the entire experience of being treated had resolved their prostate cancer.

Sex

A range of comments were made on this topic. Some reported that sexual dysfunction was not a problem and others stated that the treatment had permanently interrupted their sex life. That dichotomy is represented by the following statements. “Impotency, not a problem. . . . At 75 years of age, I feel this is no big problem.” By comparison, another patient said, “A suction device with constrictor that will nearly severe your peenie, a needle in the peenie, or pill stuffed up your peenie . . . none are conducive to free enjoyable intercourse.” And, “My sexual life is over and that is bad for the mind.”

Relationship Impact

The participants’ comments expressed a wide range of perspectives. Comments demonstrated how aspects of treatment for prostate cancer had positively and negatively impacted relationships. An example of a positive comment that supported how relationship growth had occurred, particularly in the areas of communication and experiencing a greater appreciation for life was, “My wife and I have adjusted to more foreplay.” Examples of how the treatment for prostate cancer had a negative impact on their relationship were, “I cannot get her to get instructions on how to inject my penis,” and, “My wife and I have filed for divorce and we now sleep in separate bedrooms.”

Cancer Vigilance

The participants were vigilant about their PSA levels, highlighting the concern that cancer could come back at any time and exemplifying the uncertainty that comes with being a prostate cancer survivor. One man said, “A PSA of 0.01 produces anxiety and probably always will.” Another participant stated, “Tired of being in limbo. Doctors say I’m not sick but the cancer is still growing at a slow rate. They say there is really no treatment for me now.

Each follow-up examination was anticipated with a degree of anxiety as any anticipated carefree future was transformed into vigilance regarding PSA numbers. “This is a disease that can return and makes long-term planning difficult.”

Complexity of Changes

The men reported that change had occurred in many aspects of their life that would not often be appreciated by others, such as, “I can’t get life insurance, I can’t give blood.” In addition, daily routine of life had been curtailed by prostate cancer and treatment. Travel plans had to be altered, daily activities had to be changed so a bathroom was never too far away, and some men were forced to wear diapers. The sequela of prostate cancer treatment hampered participants’ ability to positively adjust to their new normal.

Psycho-Emotional Responses

Many psycho-emotional effects were identified by participants, including reactions such as anxiety, anger, frustration, depression, and the need for external validation as men.

I do not think that people who have not experienced prostate cancer have any idea of the emotional impact . . . the use of Viagra® [sildenafil citrate], the pump, whatever to obtain an erection takes part of the wholeness out of your body and I miss that wholeness.

However, some men reported that they experienced emotional growth, increased intimacy, and an improved appreciation of life when their partner was more involved.

Healthcare Experience

Healthcare providers had a significant impact upon the survivor’s experience of prostate cancer treatment, revealing powerful
reactions to a lack of empathic care: “I was like an experiment that went bad, like my life was not important,” “Cavalier attitudes expressed by the treatment team was disquieting,” and, “We were treated like test subjects, not equals.” The men in the study again expressed a range of positive and negative comments about what it was like to interact with the treatment team. The range included a majority of intense reactions to what they perceived as frequent depersonalization experiences from the healthcare professionals. However, some had positive experiences of acknowledgement, information, and the offer of other services. Positive experiences were considered to improve health outcomes.

Reflections

A number of unmet needs were reported, including a consistently expressed need for more information and education concerning treatments for prostate cancer and possible side effects. Participants also needed physical comfort aids and counseling. Overall, a sense of being underprepared for the treatment experience was felt as evidenced by, “Why weren’t we told about the possible side effects of treatment?” and, “Counseling . . . my wife needs help.” Some participants indicated that they felt “numb” and had a great deal of uncertainty. In addition, many participants desired to help others who had been diagnosed and treated for prostate cancer as a way to provide a meaningful outcome from their challenges with prostate cancer and its treatment.

The eight categories described here were integrated into three themes (Guba, 1978): “symptoms,” “can’t go back,” and “needs.” Those broad themes provide language to understand the complexity of the journey experienced throughout the continuum of living with prostate cancer, its treatment, and the long-term sequela (Creswell, 2003). Those themes will enable oncology nurses to identify needs when planning care for this population.

Symptoms: The symptoms theme is an umbrella term that includes physical symptoms, sex, and relationship impact categories. The symptoms theme represents the concrete outcomes of treatment. Men’s responses include dichotomous ranges of those who dismissed the impact of the situation and those who grappled directly with the reality of the impact of their experience. Those who dismissed their symptoms normalized the experience and attributed the presence of symptoms to their aging or stated that the cancer experience was in the past. However, those who grappled with their symptoms often related bowel, bladder, and sexual symptoms as well as relational concerns, in the present tense.

Can’t go back: The can’t go back theme emerged as a way to describe the profound and permanent life-altering experience of prostate cancer, exemplifying a forward-only movement in time. The categories of cancer vigilance and complexity of change described how the outcome of treatment is not recovery, but rather requires a constant adjustment to a new normal. However, not all men reported the ability to make the required adjustments positively. Few men directly stated that they were unable to recover to baseline functioning and health; however, many indirectly postulated that theme through their emerging comments. Those who grappled with the significance of impact from symptoms and relational health recognized modifications in self-care that were required in their lives, instead of achieving a full recovery to baseline. Others who dismissed the impact of prostate cancer did not overtly recognize the need for modifications, and instead described issues that became an evolving theme of how their lives had changed.

Needs: The needs theme represents the expressed unmet needs the men felt during the treatment process. The categories of psycho-emotional responses, healthcare experiences, and reflections expressed how participants could have been more fully prepared for what they might experience. Things like more timely and accurate information and resources to help them manage daily living impacted by treatment sequela could have facilitated meeting their needs. The participants strongly expressed a need for the healthcare team to acknowledge their experiences of uncertainty, anger, and grief or loss. A number of men indicated that they healed by giving their experience meaning through involvement with helping others who faced the same experiences. The category best identifies the many interventions the men stated they needed from healthcare providers to improve their lives during survivorship. The model in Figure 1 depicts the interrelationships of the participants’ emerging themes in response to ensuing survivorship of a prostate cancer diagnosis, its treatment, and related sequela. In addition, the complex experience is contextualized in time, becoming a unidirectional journey as the patient with prostate cancer is moved to a new normal, requiring adaptations to improve overall quality of life and relationships. The model shows the themes in order of emergence; the concrete symptoms and their impact create the realization that life can’t go back to the previous normal. Needs are eventually recognized through reflection, highlighting the importance of psycho-emotional needs and how health care can intervene earlier and with greater understanding to impact the healing outcome. If the needs theme is addressed by oncology nurses and other members of the healthcare community, all other aspects of the journey are affected and likely impact future outcome.
Conclusions and Clinical Implications

Although more attention has been given to prostate cancer since the early 2000s, the long-term effects of surviving prostate cancer and treatment still are not well understood (IOM, 2006, 2008; NCI, 2005) and are poorly acknowledged by healthcare providers. Analysis suggests that men experience a complex journey, a substantial number of treatment-related sequela, and believe they cannot return to their pretreatment level of functioning; rather, they must find a new normal. Those findings are consistent with what others have reported regarding men’s experience with long-term physical, psychological, and emotional effects from prostate cancer and treatment (ACS, 2011; Curtiss & Haylock, 2006). The specific examples of long-term physical and irreversible effects of urinary, bowel, and sexual treatment-related sequela described by the participants in the current study also have been reported by others (Casas et al., 2010; Ferrer et al., 2008; Mols et al., 2009). However, strategies have been suggested that can help oncology nurses and other members of the healthcare team gain a better understanding of patients’ needs and offer appropriate interventions (Williams et al., 2008). Specifically, healthcare providers are encouraged to decrease the amount of medical jargon used when talking with patients. In addition, they are encouraged to tailor the amount of information given to patients. However, that approach implies healthcare providers have already developed the kind of relationship with their patients and their partners that would allow for individualized care (Curtiss & Haylock, 2006; Pelusi, 2006).

Sexual side effects have been noted by many as the most important long-term sequela of treatment for prostate cancer (Gore et al., 2009; Litwin et al., 2007; Ream et al., 2008). However, the men in the current study suggested that all symptoms from treatment are experienced as an integrated response to becoming a prostate cancer survivor. Consequently, it becomes important for oncology nurses to assess the underlying reactions of their patients. The survivors often experience their symptoms in clusters and, subsequently, would benefit from a more integrated strategy of intervention implementation.

In addition, the current study demonstrated a wide range of responses, expressing the complexity of the experience as a survivor of prostate cancer. The survivors’ responses ranged from defensive reactions aimed at diminishing the impact of the treatment on their life to embracing more effective approaches to manage the changes they faced. The men spent more time reporting their various physical symptoms than their psycho-emotional reactions. That observation is consistent with what other researchers have reported with survivors of other types of cancer (Beck et al., 2009; Schover et al., 2002). However, oncology nurses must focus on understanding the underlying psycho-emotional disruptions of the physical reports and assist the patient and his partner in coping with their responses. A study by Mah, Bezjak, Loblaw, Gotowiec, and Devins (2011) used the Illness Intrusiveness Response Scale (IIRS) (Devins et al., 1985), to assess the short- and long-term impact of cancer treatment sequela on daily activities, intimacy, and relational or personal development. Mah et al. (2011) used IIRS to evaluate across types of cancer survivors and found prostate cancer survivors were more affected in the intimacy domain than other types of cancers such as lymphoma, head and neck, gastrointestinal, and lung; however, impact also was noted on activities and relational or personal development. Use of the IIRS’s 13-item measure at each clinic visit may quickly screen the treatment impact in those domains and assist the healthcare team to tailor interventions. That type of patient-centered care and ongoing monitoring may facilitate improved rehabilitative outcomes.

In addition, ongoing assessment and monitoring can help to ensure that adequate time is allotted for discussion, questions, and answers during each clinic visit. Because those issues are difficult, it may take time for a couple to become comfortable with the healthcare team and divulge areas in which they desire help. A historical response from the healthcare team has been to discuss erectile dysfunction assistance through suggestions of medication or devices to be used before each sexual encounter, including oral, intracavernosal injection, or transurethral administrations. Although the interventions have demonstrated efficacy, they still are reminders of the loss the man has experienced, representing a minimal chance of recovery (Beck et al., 2009). Suggestions, therefore, may not be initially interpreted as helpful. No longer being able to take part in spontaneous sexual activity leads to a loss of self-confidence, challenging a man’s self-concept, a topic not easily discussed or emotionally processed. However, as suggested earlier, if interventions are discussed in the context of a professional relationship in which trust has been developed over time, the patient and his partner may be more open to including approaches designed to reduce the functional strain and increase the emotional well-being in their sex life (Ashing-Giwa & Lim, 2009).

In addition, the grief and loss experienced by men who are survivors of prostate cancer and treatment are not well understood by the healthcare team. In fact, the men in the study reported feeling dismissed and objectified by physicians and other members of the healthcare team when they tried to bring up their concerns. However, oncology nurses are in a critically important position on the healthcare team to help survivors and their partners address areas in which they feel like they

### Implications for Practice

- Prostate cancer survivors are increasing in number and experience complex physical and emotional treatment-related sequela that can impact them years after treatment has been completed. That presents additional clinical opportunities and challenges related to assessment and treatment.
- Challenges include concerns about persistent physical symptoms, sexual problems, relationship issues, experiences with the healthcare team, worry over the possible return of cancer, dealing with the complexity of changes they are going through, and their psycho-emotional responses to the survivorship experience. Those challenges provide a number of clinical educational opportunities.
- Oncology nurses are in a key position to help men who have been treated for prostate cancer obtain information about how best to manage their symptoms, offer resources to assist in meeting their relational and emotional needs, and work with them in developing strategies to cope with their new normal.
have suffered losses. Consequently, as identified by the needs theme, a key component of the men’s healing process is to be able to interact with a healthcare system that actively and individually responds to their concerns about the adverse effects of prostate cancer treatment and refuses to objectify them by approaching the patients with empathy. Those who reported they had been acknowledged and had received supportive services indicated more positive health and relational outcomes. Conversely, those who reported unmet needs communicated that they were continuing to struggle in their survivorship. A proposed comprehensive response to that data by oncology nurses in collaboration with the healthcare team is presented in a model in Figure 2.

Oncology nurses can help meet the population’s needs through adequate preparation, frequent sensitive communication, and education about how to better manage the daily complex sequelae that results from being a prostate cancer survivor. Examples of education strategies could focus on approaches to communication men can use with their partners in dealing with sensitive topics. The use of ‘I’ messages, active listening skills, and role playing could facilitate improved communication (Stanley, 2005). That approach may impact a patient’s choice to dismiss or grapple with the challenges of survivorship. Including the patient’s partner and offering counseling referrals clearly were important needs, underscoring the importance of needed movement toward intimacy healing. Peer-to-peer counseling also was stated as being helpful because it can serve to increase the meaning of the experience for the patient and honors the profound experience of survivorship. In addition, referrals for appropriate complementary and alternative treatments (e.g., diet, exercise, vitamins, herbs) may demonstrate a more authentic concern for the survivors’ whole life needs beyond treatment (Mitchell, 2006). However, care must be taken to instruct the patients about informing the healthcare team of the approaches they are using to avoid potential negative interactions between complementary treatments, routine care, and ongoing health monitoring (Chan et al., 2005). Those approaches by oncology nurses and other healthcare providers will impact the healing of the prostate cancer survivor, thus supporting the survivor to thrive to whatever extent is possible for him. The healing of the whole person is the goal of care, particularly when the impact on the survivor’s life is predominantly from treatment sequelae.

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References


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