The Lived Experience of Men Diagnosed With Prostate Cancer

Kelly A. Krumwiede, PhD, RN, and Norma Krumwiede, EdD, RN

Prostate cancer is the second most common type of cancer among men and the second leading cause of cancer-related death for men in the United States. In 2012, an estimated 241,740 new cases of prostate cancer will be diagnosed in the United States and about 28,170 men will die from the disease (American Cancer Society [ACS], 2012). Although prostate cancer is most commonly diagnosed in men aged 65 years and older, the incidence begins to rise at age 50. ACS (2012) estimates that 1 in 6 men will be diagnosed with prostate cancer during their lifetime. Fortunately, prostate cancer diagnosed early is highly treatable. To date, more than two million men in the United States have lived the prostate cancer experience (ACS, 2011).

Exploring the perceptions and experiences of men with prostate cancer will expand nurses’ understanding of the disease, as well as the responses, coping mechanisms, and concerns that are prevalent. The purpose of this article is to investigate the lived experience of older men who have been diagnosed with prostate cancer.

Methods

Phenomenology is the thorough, systematic study of human experience that aims to produce insightful descriptions of the way people experience their world (Creswell, 2009). Phenomenologists believe that knowledge and understanding are embedded in everyday life, and that truth and understanding can emerge from life experiences, which comprise thoughts, feelings, values, emotions, purposes, and actions (Burns & Grove, 2009). The hermeneutic phenomenologic structure for van Manen’s (1990) human science research consists of six steps: (a) turning to a phenomenon which seriously interests us and commits us to the world, (b) investigating experience as we live it rather than as we conceptualize it, (c) reflecting on the essential themes that characterize the phenomenon, (d) investigating experience as we live it rather than as we conceptualize it, (e) maintaining a strong and orientated caring relation to the other, and (f) investigating experience as we live it rather than as we conceptualize it.
Being bodily present in the world. This phenomenon, and (f) balancing the research context by considering the parts and the whole.

The semistructured interview technique used in this article was guided by van Manen’s (1999) approach as a way to gain access to the lived experience of men with prostate cancer. The interview method provided a means for exploring and gathering experiential narrative material that served as a resource to derive meaning of the lived experience.

Sample and Setting

After approval was granted from the institutional review board at Bethel University in St. Paul, MN, the first participant was identified and the snowball technique was used to obtain a convenience sample of 10 men with prostate cancer. Participants were Caucasian, English-speaking adults ranging in age from 62–70 years with a mean age of 66.2 years. Time since diagnosis ranged from a few months to five years, with the mean being 2.4 years. One participant received hormone therapy followed by radiation treatment, and the remaining participants had radical prostatectomy, four of which had the robotic radical prostatectomy procedure. Except for one participant who was divorced, the participants were married and had supportive spouses and family.

Data Organization and Analysis

Phenomenology of praxis proposed by van Manen (1999) guided the data analysis and transformed personal experiences into disciplinary understanding. Van Manen’s four fundamental existentials of lived space (spatiality), lived body (corporeality), lived time (temporality), and lived other (relationality) describe the way humans experience the world. These life world existentials acted as guides for reflection and were used to guide the analysis of the data (see Table 1). These four existentials can be differentiated but not separated—they form an intricate unity van Manen (1990) called “our lived world.”

Rigor was enhanced by sensitivity, or a researcher’s ability to identify subtle nuances and cues in the data text that lead to meaning. Sensitivity allows a researcher to become immersed in the data in hopes of presenting the view of participants (Creswell, 2009). Trustworthiness of the data and rigor were established through credibility, dependability, transferability, and confirmability as described by Lincoln and Guba (1985). Credibility was established through extended immersion, bracketing, and use of triangulation. Bracketing is a process of identifying and setting aside one’s lifeworld beliefs and biases, therefore allowing the researcher to be open to data as they are revealed. All interviews were audio recorded, transcribed, and subsequently analyzed to ensure dependability. Transferability was established through the use of member checks. An extensive audit trail was created to ensure confirmability.

Findings

Six themes and corresponding subthemes were identified during data analysis and are representations of the narrative stories shared by the participants: living in the unknown, yearning to understand and know, struggling with unreliability of body, bearing the diagnosis of cancer, shifting priorities in the gap, and feeling comfort in the presence of others. The six themes were identified during data analysis and are representations of the narrative stories shared by the participants. Figure 1 contains the themes and subthemes of the lived experience for men with prostate cancer.

Lived Space (Spatiality)

Lived space comprises two themes that have an impact on the day-to-day life experience of men with prostate cancer: living in the unknown and yearning...

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*Note.* Based on information from van Manen, 1990.
to understand and know. The main findings associated with living in the unknown were being vigilant; the findings associated with yearning to understand and know were seeking and sharing information and measuring and comparing.

**Living in the Unknown**

Living in the unknown affects the participant’s lived space of how a person perceives, lives, and deals with day-to-day life. When the participants voiced not having answers to questions or a clear direction of which to guide one’s life, this precarious state of confusion and living in an unfamiliar environment caused the participant to experience varying degrees of anxiety. Living in this indeterminate state can cause worry and fear. Being told of a possible cancer diagnosis brings the future into question. After having treatment, the patient may wonder about the reoccurrence of cancer. The theme of living in the unknown emerged as participants spoke of receiving different information about prostate-specific antigen (PSA) readings, fear of misdiagnosis, and unpredictability of the cancer experience.

Four of the men expressed concern that a prostate cancer diagnosis could be missed, overlooked, or incorrect. For example, one participant questioned whether his prostate cancer diagnosis was correct. He received confusing information after surgery.

The medical staff took my prostate out and sliced it up into a hundred pieces and looked at it under a microscope and said that they could not find any cancer. So does that mean that I didn’t have to have this [surgery] done? Or does that mean that I should be thankful that I don’t have cancer?

This participant had signs of prostate cancer, including a PSA reading that rose from 5 to 10.3 in one year and one of the biopsy specimens had determined a diagnosis of cancer. Why then, in his mind, was he told after having the prostate removed that it was not cancerous? Unanswered questions such as this can be bewildering to patients, promoting distrust in the healthcare system and causing men to live in the unknown.

**Being vigilant:** Vigilance is how the participants learned to live in the unknown. Being vigilant consisted of watching, monitoring, and preparing oneself in relation to one’s condition. All of the men had received information about their PSA readings; however, the information the men received seemed to conflict with what they heard from other men in the community. One participant questioned whether his physician had missed the diagnosis of prostate cancer the year prior. The participant felt angry and stated more than once during the interview that “men should have a proficient physician who does a thorough exam[ination], including a thorough digital exam[ination] and not just a quick finger sweep.” The most effective screening methods include both PSA and digital rectal examination. Biopsy of the tissue is used to diagnose prostate cancer.

One participant questioned whether his physician had missed the diagnosis of prostate cancer the year prior. The participant felt angry and stated more than once during the interview that “men should have a proficient physician who does a thorough exam[ination], including a thorough digital exam[ination] and not just a quick finger sweep.” The most effective screening methods include both PSA and digital rectal examination. Biopsy of the tissue is used to diagnose prostate cancer.

Although all of the participants acknowledged their survival and good outcome of the prostate cancer treatment, many of the men revealed lingering thoughts about the chance of recurrence. This unpredictability
of prostate cancer and recurrence of the disease instills fear of the “missed cancer cell.” Although this uneasy feeling of the unknown exists, the men are determined not to live the rest of their lives in fear. With the unpredictability of recurrence, the participants have developed a new meaning for the PSA readings. The readings are no longer a screening for prostate cancer, but a sign that they made the right choice and are free of prostate cancer. The men now find comfort and hope in having low to undetectable PSA readings.

**Yearning to Understand and Know**
In the quest to develop an understanding, the participants often looked to other men who have had the same experience and to nurses for honest and accurate information. This yearning for answers to all of their questions was revealed in the longing for understanding and the ability to make sense of one’s situation. Once the participants were able to understand one or more aspects of the prostate experience, the men were able to continue their life’s journey.

**Seeking and sharing information:** Participants desired to understand and know what was happening within their bodies. Several of the men became proactive after their diagnosis and began seeking information to learn more about prostate cancer and its treatments. Participants looked for answers as a way to alleviate their anxieties, to achieve a sense of comfort, and to provide a sense of stability. Many searched for information on the Internet, from friends or family, and all received information from their physician. Participants indicated that gaining a better understanding of their situation helped them in decision making, particularly about treatment choices.

Many talked about seeking information from others who had gone through this experience as being supportive, alleviating fears, and having an enormous impact on the decision-making process. Even if the information was negative, participants felt more secure knowing. The information shared provided reassurance that the prostate cancer experience contains common reactions—that others have gone through it and they can, too.

Promoting awareness was important to all participants. With prostate cancer being so common among men yet “so easy to take care of,” many individuals expressed a strong desire to promote prostate cancer awareness and encourage men to seek information on prostate cancer. Most men expressed the desire for others to have the knowledge that they did not have when they first started their experience.

**Measuring and comparing:** The ability of all participants to use stories and compare notes in an attempt to observe or discover similarities or differences was a central theme that allowed the individual to measure one’s situation against that of others. The stories of men with prostate cancer allowed the participants to determine whether they were better or worse off than other men in this situation. Despite the fact that each participant’s experience was significant, in the end many of the participants felt that their experience had not been as bad as others.

**Lived Body (Corporeality)**
The main theme for lived body is struggling with unreliability of body. The main findings associated with lived body are enduring and conquering distressing discomfort and concern for changed sexual expression.

**Struggling With Unreliability of Body**
The participants felt discomfort with the sensation of being disassociated from their bodies. Often times, participants thought that they were healthy and “didn’t have any problems” until the diagnosis was made. An unfamiliar sense of being disconnected with oneself arose in the participants. One, for example, wondered, “How can I have this, I feel so good?” Not knowing that they had cancer inside their body was unsettling. Another participant described prostate cancer as “like ovarian or breast cancer in women. It is very silent.” For the men in this study, prostate cancer was a disease that did not make its presence known and, for one of the men with the disease, was already outside the prostate when cancer was discovered.

**Enduring and conquering distressing discomfort:** The course of the disease requires men to hold up under multiple stress-provoking situations. All of the participants were physically and psychologically affected by the diagnosis of prostate cancer and treatments they endured. One individual had androgen deprivation therapy and then radiation treatment; the other nine participants had radical prostatectomies, four of whom had the robotic radical prostatectomy procedure. All of the participants experienced complex side effects. The side effects from androgen deprivation therapy included hot flashes, diaphoresis, fatigue, depression, and erectile dysfunction. The individual who had radiation experienced burnt skin, fatigue, diarrhea, and occasional nausea. The men who had a prostatectomy experienced brief or prolonged episodes of incontinence, impotence, erectile dysfunction, and/or loss of libido. The two most significant negative outcomes of surgery included incontinence and erectile dysfunction. Dealing with incontinence and sexual dysfunction was difficult for these men and caused humiliation and shame.

A significant finding was the impact the urinary catheter had on the individuals who elected to have surgery.
The most difficult emotional experience, according to one participant, was having urinary leakage around this catheter tubing. The stress and embarrassment led to social withdrawal. The catheter was a constant reminder of the prostate cancer and served as a threat to hope.

The men were aware of postoperative catheter treatment but were emotionally unprepared for the effects. Many participants described the catheter as the worst part of the experience. Having the catheter in place for 10–21 days on average, they developed a sense of “putting up” or “dealing with it.” The men feared pulling the catheter out at night and endured bladder spasms as the antispasmodic medications prescribed often failed to prevent or decrease the discomfort.

Removal of the catheter was distressing for the participants, as they often experienced urinary incontinence for the first time. A few discussed the embarrassment of having to purchase urinary pads. Short-term incontinence was experienced by all participants in this study—two continue to struggle with urge incontinence—and all suffer from stress incontinence. Although the men had been warned to expect decreased control, actually experiencing it was stressful and embarrassing.

**Concern for changed sexual expression:** Sexuality and sexual expression are very personal issues. All the participants in this study discussed aspects related to their sexuality in the context of sexual functioning following treatment for prostate cancer. Loss of erectile functioning was significant to most men in this study, although they varied a great deal in response to the experience. In this study, two of the nine men who had had prostatectomies experienced erectile dysfunction following treatment.

Most of the participants experienced significant impairment regarding sexual functioning, although this did not appear to be as significant of a problem compared to incontinence. For one of the participants, erectile dysfunction involved adjusting his thinking and appreciating other aspects of life. A few of the men felt more sympathy toward their spouses; they felt their spouses were the ones greatly impacted by the sexual dysfunction.

**Lived Time (Temporality)**

Bearing the diagnosis of cancer and shifting priorities in the gap are the two themes related to lived time. With bearing the diagnosis of cancer came troubled waiting. With shifting priorities in the gap, participants developed an awareness and appreciation for living and were living in the present with an eye toward the future. Prostate cancer and its treatments are an experience in time.

**Bearing the Diagnosis of Cancer**

The participants described the intense, life-altering experience of being diagnosed with prostate cancer. The turmoil that a person experiences from the initial physician’s appointment and waiting for test results to be completed is one of intense waiting. The participants varied in their reactions of being diagnosed with prostate cancer: some were totally surprised, one stated that he was in denial, and others were anticipating the diagnosis. However, all the participants had to bear the vulnerability of being diagnosed with prostate cancer.

One participant stated he did not get “freaked out” when he was told he had cancer but thought, “This is really weird. Cancer is in my body. It is like a pimple that you would like to squeeze and get rid of but you can’t touch it and it is trying to kill you.” For many it was a shock to receive the diagnosis of cancer. Another participant described his experience of being told that he had prostate cancer as, “It was sort of a surreal time for me.” Yet for one of the participants, the diagnosis was “not a surprise,” as he said that his three brothers and his father all had been diagnosed with prostate cancer. Although a few participants were not surprised by the diagnosis, periods of waiting were present for all the participants during this phase of the experience.

**Troubled waiting:** Diagnostic confirmation takes a few days. This lapse in time caused many men to become anxious about the diagnosis and the threat of potential side effects from treatments. In addition, the potential for death caused emotional distress. Time seemed to stand still when some of the participants received information about their high PSA reading and their biopsy results and before they started treatment. One participant stated, “The two days [after] the biopsy were probably the longest two days of my life.” Most of the men stated it was a shock to hear the diagnosis of prostate cancer. Although being diagnosed with prostate cancer is a traumatic event, most of these men were told of options for treatment directly after receiving the diagnosis. Their first reaction was just to get rid of the cancer. Some did not want to hear all of the treatment options and went straight to requesting a prostatectomy. Waiting for treatment to start caused a great deal of anxiety for the participants.

**Shifting Priorities in the Gap**

The gap (time spent waiting for screening results, biopsy results, and treatment to begin) affects a person’s lived time and causes a break in past, present, and future priorities. Feelings of having a positive attitude and the desire to appreciate one’s life and the lives of those around them developed. Patients’ altered perspectives of themselves and of life manifested in several
ways. Many patients underwent a reevaluation of their values, beliefs, life goals, and priorities. One participant described a positive moment in his experience as learning “to respect health and the maintenance of health and not to take things for granted.” Another participant mentioned that prostate cancer had an impact on his outlook on life. He stated that life has “a whole different meaning. . . . You live each day to the utmost and you do things you can do when you can. You just have a whole different philosophy of life.”

Developing an awareness and appreciation for living: Cancer is an experience that affects all aspects of a person’s life in ways that people without cancer cannot begin to imagine. The experience caused the participants to prioritize the people and things that are most important to them. As a result, they were compelled to evaluate their lives and to incorporate the experience of cancer into their understanding of themselves. The experience of prostate cancer can stimulate a renewed appreciation for living. The participants learned not to take life for granted, and past and current struggles do not seem as important because they survived cancer. One participant felt God was telling him to let go of his bitterness and that he was given another chance at life. Thinking positively was a significant aspect in participants’ ability to appreciate and live life.

Living in the present with an eye toward the future: The participants’ uncertainty allowed for wondering what the future will hold and a desire to live life to the fullest. Being determined to enjoy their lives in the present despite being diagnosed with prostate cancer had a positive impact on the men’s outlook on life. Life goals were not diverted, only shifted. The men were determined to enjoy life by spending more time with family, golfing, helping others, gardening, or fishing.

Having an eye toward the future has been a result of the removal of the prostate cancer. For the nine participants who had had prostatectomies, the fear of having prostate cancer again has been eliminated. The prostate had been removed and is no longer a factor in the equation. However, the men realize they need to make each day count and enjoy what they have, particularly in regard to their relationships with others.

Lived Other (Relationality)

The theme of feeling comfort in the presence of others is the relationship that men with prostate cancer maintain with family members, peers, healthcare workers, and a higher power. Men spoke of feeling comfort through the development of trusted connections and the unwaivering support they received throughout their experience with prostate cancer.

Feeling Comfort in the Presence of Others

This theme best describes the essence of how these participants viewed their relationships with others. The men gained strength and confidence through the support of others. Some did not feel that they would have been able to make it through the experience without that support.

Trusted connections: Connections were made with healthcare providers, friends, and family. Having a trusted relationship with one’s healthcare provider had a significant impact on the men’s comfort level during their experience. Open communication and receiving all of the facts from physicians and nurses created a trusting relationship. However, inconsistent nursing care (i.e., not responding to needs in a timely manner, not appearing competent in the treatment process, and not communicating in a caring manner) placed a strain on the nurse-patient relationship. More than one participant commented on how the nursing shortage impacted confidence in the healthcare system. Ultimately, the men felt devalued when inconsistent nursing care and lapses in communication occurred. The opposite also proved to be true—the men found comfort with consistent nursing care, open communication, caring nursing attitudes, and the use of humor by nurses.

Unwaivering support: Many participants expressed gratitude for the support they received from family and friends. One man felt that, “Family is probably the biggest support you really need” during the experience. Having support from your family seemed to bring about a sense of relief and comfort about the treatment decision they made. Another participant stated, “My wife was very supportive. She believed that I made the right choice even though there was a risk of sexual activity loss and I was concerned about incontinence.” The participant felt that family should support the treatment decision and the couple should talk about the options together. One participant also acknowledged that “it would be tough not to have any family . . . to go through it on your own.” All of the married men indicated that the most significant emotional and physical support was received from their spouse. The support provided a sense of comfort and reassurance in their time of uncertainty.

Discussion and Implications for Nursing

Oncology nurses are concerned with providing holistic nursing care. Nurses must understand the lived experience of prostate cancer to better care for these men. Lived space (spatiality), lived body (corporeality), lived time (temporality), and lived other (relationality)
make up the landscape by which people experience phenomena (van Manen, 1990).

**Phenomenology as a Nursing Practice Approach**

Phenomenologic study identifies the essence of a phenomenon and describes it through the lived experience. By using phenomenology to explore common events and emotions, lived experiences of individuals can become meaningful to others. Therefore, the lived experience of individuals with prostate cancer can now inform nursing practice. To increase the nurse’s understanding of the lived experience of prostate cancer, nurses must encourage men to describe their diagnosis story and illness experience to gain meaning of the prostate cancer experience and to understand the needs of the men.

**Lived Space (Spatiality)**

Nurses have many opportunities to take a leadership role when interacting with men who have prostate cancer. The men need accurate information about PSA prior to having the procedure done. Because they felt the healthcare system did not provide consistent information, PSA levels caused confusion and uncertainty for these men. In a study by Bailey, Mishel, Belyea, and Stewart (2004), the authors found that the men in their study often were confused about prostate cancer and the meaning of PSA values.

The men also needed more time to learn about the disease and absorb the shock of their diagnosis before deciding on a treatment option. Although patients need to hear about the possible treatments the day they receive their diagnosis of prostate cancer, there should be a follow-up appointment at a later time (preferably within a week) to discuss the various treatment-related side effects, review what was discussed, and clarify any concerns that may have arisen. In addition, a spouse and family members should be encouraged to attend the appointments.

The need for nursing support is great during this vulnerable stage (Fan, 2002). Nurses should provide accurate, complete, and consistent information to help patients understand the full implications of the disease process and all treatment options, not just the treatment options available at the facility of care.

**Lived Time (Temporality)**

The troubled waiting caused a shared experience of restlessness and impatience and threatened the psychosocial integrity of the men (Cummings, 2005). This sense of troubled waiting discouraged all of the participants from undertaking the active surveillance approach for their prostate cancer, although research supports this method (Davison, Oliffe, Pickles, & Mroz, 2009). Prostate cancer surgery means probable incontinence and a loss of sexual functioning that can affect a man’s quality of life. Nurses can try to help coordinate biopsies early in the week to avoid a delay over a weekend for pathology to reoccur. This may help reduce the troubled waiting. The participants reported great relief once something was being done about the prostate cancer. Most of the men commented that they were anxious, restless, and in a hurry to get the cancer out of their bodies.

**Lived Other (Relationality)**

Nurses must be prepared to support the patient and his family throughout the cancer experience. Men spoke of feeling comfort through the development of trusted connections and the unwavering support they received throughout their experience with prostate cancer. All of the men indicated that support from their family was important and that it allowed them to deal with the difficult circumstances of prostate cancer. The support of family members, friends, and healthcare workers was identified by the participants as an important aspect of living with prostate cancer. Nurses need to be aware of the impact of the cancer diagnosis and treatment on the man’s family as a supportive unit (Eggenberger, Meiers, Krumwiede, Bliesmer, & Earle, 2011). All of the men, except for one who was divorced, had close relationships with spouses who collaborated with them, worried with them, and provided physical and emotion support during their experience. Because of the amount of assistance received from spouses, nursing education and support should be aimed at men and their spouse or an identified...
caregiver. The nurse should include family members in all aspects of health care. Nurses also need to emphasize the importance of the support system to help cope with the uncertainties of the disease.

Conclusion

Based on findings of the current study, the following recommendations are proposed to enhance the nursing care provided to men with prostate cancer. Patients need to be encouraged to take time to process the meaning of their diagnosis before making any decision or having discussions with their spouse. Improved education is needed for patients and must incorporate the men’s insights and experiences during the treatment course. Nurses can use the four existential life worlds to guide nursing actions. This approach to nursing care will incorporate the meaning and understanding of the lived experience of prostate cancer and individualize the patient’s care.

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References


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1. Prostate cancer fundamentally changes how a man sees and experiences his body. How does this compare to gynecologic cancer in women?
2. Recent recommendations state that prostate-specific antigen screening does not save lives and should not be performed routinely. What would the men in this study say about that?
3. The men in this study spoke about the distressing nature of having a catheter and that they were unprepared for this. How would you talk to men about this and what would you say to prepare them?
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Krumwiede is a professor in the College of Nursing at Minnesota State University in Mankato. Her previous research has focused on the investigation of family caregiving experiences with neutropenia and rural nursing.

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