Psychosocial Trajectories of Men Monitoring Prostate-Specific Antigen Levels Following Surgery for Prostate Cancer

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Purpose/Objectives: To describe the psychosocial trajectories of men treated surgically for prostate cancer after monitoring their prostate-specific antigen (PSA) levels until 24 months post-treatment.

Design: Descriptive longitudinal study.

Setting: Urology clinic at Duke University Health System.

Sample: 12 men diagnosed and treated for prostate cancer.

Methods: Men were interviewed in their homes at baseline and at 24 months and via telephone at 6, 12, and 18 months. Scores from the Profile of Mood States, Mishel Uncertainty in Illness Scale, Self-Control Schedule, and Cantril's Ladder were entered into a database for analysis. Graphs of individual participants' scores were plotted.

Main Research Variables: PSA values, mood state, cognitive reframing, impact of event, quality of life, illness uncertainty, and growth through uncertainty were measured.

Findings: Three trajectories were identified (i.e., stable, unstable, and mixed) and graphed using a typological or health pattern approach.

Conclusions: Monitoring PSA levels is critical for men treated for prostate cancer. This study provides preliminary data on the psychological trajectories of men during the first 24 months postprostatectomy.

Implications for Nursing: Rising PSA levels that are associated with the recurrence of disease can cause psychosocial distress among men with prostate cancer.

Key Words: prostate cancer; quality of life; survivorship; coping

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The American Cancer Society ([ACS], 2014) estimated that 233,000 new cases of prostate cancer will be diagnosed and 29,480 men will die from this disease in 2014. Prostate cancer is the most common noncutaneous cancer in men, particularly older men, and the second leading cause of death from cancer among men in the United States (ACS, 2014). For men diagnosed with localized prostate cancer, treatment strategies include active surveillance, radiation therapy, cryotherapy, surgery, and prostatectomy. A study of 11,892 men enrolled in the Cancer of the Prostate Strategic Urologic Research Endeavor database, a national registry of men with prostate cancer, found that 50% (n = 5,931) of participants underwent prostatectomy for their disease (Cooperberg, Broering, & Carroll, 2010).

After prostatectomy, prostate-specific antigen (PSA) values are used to provide information about potential progression or recurrence. Dinnes, Hewison, Altman, and Deeks (2012) reviewed guidelines from nine organizations and reported the lack of systematic guidelines to monitor treated patients. Some studies used any detectable PSA, and others used PSA doubling time. In a review of the monitoring role of PSA, Payne and Cornford (2011) reported that PSA doubling time can determine risk for clinical progression in men who experience a rise in PSA results postprostatectomy. You et al. (2009) reported the importance of PSA clearance, identified as four PSA values obtained during the first month following surgery, was predictive of relapse risk in treated men. PSA is a useful tool for monitoring disease status following prostatectomy; however, uncertainty remains for patients and providers on what values may prompt additional treatment in the case of biochemical recurrence, defined as a PSA value of at least 0.4 ng/ml followed by a second increase in value.

Despite the potential clinical use of PSA measurement after treatment, recurrent PSA testing may cause psychological distress and lead to a decrease in health-related quality of life in men who use those values to monitor disease status post-treatment. A study by Dale, Bilir, Han, and Meltzer (2005) revealed that men experienced anxiety while undergoing initial PSA testing for prostate cancer and when it was used to determine if the disease recurred. However, no studies have explored illness uncertainty in the context of PSA monitoring following treatment for localized prostate cancer. The purpose of this exploratory pilot study was to describe the psychosocial trajectories of men newly

diagnosed and treated with surgical management for early-stage prostate cancer. All participants were monitoring their PSA levels during the first 24 months post-treatment. The authors explored the following research question: How do patterns of psychosocial functioning vary on the constructs of psychological distress, cognitive reframing, and quality of life across five time points (i.e., at baseline and at 6, 12, 18, and 24 months) during PSA monitoring?

Literature Review

PSA values that increase over time after treatment for prostate cancer can cause stress and worry. Klotz (1997) described a condition known as PSAdynia, in which an elevated PSA level leads to emotional or physical distress. In men treated with surgery who experience a rise in PSA levels, the condition is known as PSAdynia cancer of the prostate: radical prostatectomy.

Pietrow, Parekh, Smith, Shyr, and Cookson (2001) examined the effect of PSA recurrence on health-related quality of life in patients following surgery for prostate cancer. Follow-up occurred between 4–86 months via mailed questionnaire. A total of 88 patients with PSA recurrence and 260 without recurrence participated in the study. Small but statistically significant differences were noted in two (i.e., physical functioning and pain) of the four physical health domains. A decrease was found in one category of mental health domains (i.e., role limits because of emotional health) for men with PSA recurrence. However, these differences were probably clinically insignificant and may have little impact on overall health-related quality of life. Forty-one percent of men with PSA recurrence were on adjuvant hormone ablation therapy, and satisfaction was almost identical between the groups.

Clark, Bokhour, Inui, Silliman, and Talcott (2003) constructed patient-centered measures of the outcomes of treatment in early prostate cancer using focus groups and surveys developed from those findings. Forty-eight men with early-stage prostate cancer who were 12–24 months post-treatment participated in the study. Men reported uncertainty about whether the treatment worked and how could they know whether the cancer was controlled or cured. One patient was uncertain as to why he had to continue PSA testing because he thought the removal of his prostate gland was curative. Some asked what specific symptoms of recurrence should be monitored. The survey had two health worry items (i.e., feeling like one's health could take a turn for the worse and living in fear of PSA rise). In addition, the scale contained two PSA concern items (i.e., keeping close track of PSAs and taking comfort from knowing one's PSA). Patients reported low scores on the health worry items, indicating reduced levels of quality of life and high levels of concern related to PSA testing.

Ullrich, Carson, Lutgendorf, and Williams (2003) examined fear and mood related to cancer in 126 men with prostate cancer who were treated with radical prostatectomy. The average time since surgery was four years. The results showed that 45 men had evidence of biochemical recurrence as measured by elevated PSAs, and 81 men had no evidence of recurrence. Patients with elevated PSA and high levels of urinary tract symptoms reported elevated levels of fear and mood disturbance.

Despite the literature cited, no study was found that explored uncertainty, cognitive reframing, mood state, impact of event, or quality of life in men treated for localized prostate cancer in the two-year period following treatment. The current study sought to explore those factors in men with prostate cancer during the first two years post-treatment.

Conceptual Framework

A trajectory approach based on the work of Clipp, Elder, George, and Pieper (1997) and Mishel's Uncertainty in Illness Theory (Mishel, 1988, 1990) served as the framework for this study. Health trajectories reflect the direction of a chronic illness over time and the strategies used by the individual to manage their disease (Corbin, 1998). Clipp et al. (1997) proposed a typological or health pattern approach to health assessment over time that permits the creation of "broad within-individual patterns" (p. 179) of health-related processes.

Illness uncertainty has been defined as the inability to structure meaning for illness-related events when patients are unable to predict outcomes (Mishel, 1988). In chronic illness that evolves over time, Mishel (1990) proposed that uncertainty spreads from uncertainty about symptoms and disease state to uncertainty about broader life issues and the ability to achieve valued goals. Uncertainty in chronic illness results from the unpredictability of symptoms, continual concerns about exacerbation, and an unknown future because of physically limiting problems (Mishel, 1999). Empirical support for uncertainty is found in the experience of patients living with cancer (Bailey, Wallace, & Mishel, 2007). As uncertainty spreads, the meaning attached to usual routines is disrupted, and continued uncertainty can dismantle a person's sense of structure and worsen psychological outcomes. According to Mishel's Uncertainty in Illness Theory, the result of continued uncertainty is depression and poorer psychosocial adjustment (Mishel, 1988, 1997a, 1999).

Managing illness uncertainty is critical for successful adaptation to illness (Mishel, 1988), and interventions

to reduce uncertainty have been shown to be effective (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004; Mishel et al., 2002). A trajectory perspective can generate a rich understanding of the impact of illness markers on symptoms, illness uncertainty, and quality of life.

Methods

This was an exploratory longitudinal descriptive pilot study of PSA-related uncertainty, symptoms, and quality of life in patients who were monitoring their disease following surgical intervention for early-stage prostate cancer. A convenience sampling strategy was used to recruit men who had undergone surgical intervention for localized prostate cancer within the past six months. These men received their care from the genitourinary service of Duke University Health System in Durham, NC. After approval by the Duke University School of Medicine Institutional Review Board, participants were identified by review of eligible patients being seen in the urology clinic, review of eligible patients in the electronic medical record, and contacting participating physicians about eligible patients. Once patients were identified, the participating physician sent a letter explaining the study and a letter from the principal investigator (PI) to the men that met the criteria for study inclusion. A postcard enclosed in the letter could be mailed back by the patient if he did not wish to be contacted about the study. The PI contacted patients that did not return a postcard to inform them about the study and, if they agreed, a home visit was scheduled for the purpose of informed consent and data collection. Enrolled participants received $20 for each data collection visit for a total of $100 for five visits over the course of the two-year study.

Questionnaire data were collected on all participants at baseline as well as at 6, 12, 18, and 24 months. Baseline and 24-month data collection occurred in the participants' homes, and 6-, 12-, and 18-month data collection was conducted in a telephone interview. At enrollment, all men had PSA values collected from their medical records. The baseline PSA result was the first value reported after treatment, and subsequent data collection points included PSA levels at 6, 12, 18, and 24 months. Reported baseline PSA values were measured from one week to six months after study enrollment.

Participants completed the Profile of Mood States (POMS) questionnaire consisting of 37 items measuring six mood states (anxiety, depression, anger, vigor, fatigue, and confusion) (Curran, Andrykowski, & Studts, 1995). Participants responded to items using a scale of 0 (not at all) to 4 (extremely). A composite variable of negative mood was developed by summing the values of three subscales (i.e., anger [seven items], depression [eight items], and anxiety [six items]) for a total negative mood score (Song, Lin, Ward, & Fine, 2013). Scores on the negative mood scale range from 0–84. Higher scores indicate greater mood disturbance. Validity for the POMS has been supported by factor analysis replications of the six mood scales with only one instrument items (i.e., uncertainty) crossloading more than 0.2, with tension (0.36) and confusion (0.51, 0.39) in two different adult samples (Terry, Lane, & Fogarty, 2003). The Cronbach alpha for negative mood was 0.85 in the current study.

Illness uncertainty was measured by the Mishel Uncertainty in Illness Scale (MUIS) (Mishel, 1981), a 33-item scale that can be totaled or scored in four subscales, each representing a distinct type of uncertainty. MUIS scores range from 33–165. Higher scores indicate greater illness uncertainty. The scale has been used widely in studies involving cancer and chronic illness samples. Mishel (1984) reported that the validity of the scale is supported by the finding that MUIS discriminated among medical, surgical, and diagnostic patient populations in the predicted directions. The total scale has a high level of internal consistency, with a total scale alpha of 0.91 (Mishel, 1981, 1997b). The Cronbach alpha for the current study was 0.95.

Cognitive reframing, or the ability to address concerns from a positive point of view, was measured with the 10-item cognitive reframing subscale from Rosenbaum's (1990) Self-Control Schedule (SCS). Participants responded using a 0–10 scale to rate items such as, "When I am faced with a difficult problem, I try to deal with it one step at a time." SCS scores range from 0–100. Higher scores indicate greater cognitive reframing ability. The subscale's validity was supported by significant positive correlations between the SCS and like instruments measured in two samples, including adaptive functioning ($r = 0.27$, $p = –0.053$; $r = 0.45$, $p = 0.001$) and life satisfaction ($r = 0.38$, $p = 0.01$; $r = 0.31$, $p = 0.001$). Significant negative correlations were found between the instrument and depression ($r = –0.3$, $p = 0.035$; $r = –0.25$, $p = 0.003$). The Cronbach alpha for the current study was 0.87.

Quality of life was measured by Cantril's Ladder (Kilpatrick & Cantril, 1960; McKeehan, Cowling, & Wykle, 1986). Cantril's Ladder consists of two items that ask participants to rate their life at the present and in six months on a scale ranging from 0–10, with 0 representing the worst possible life and 10 the best possible life. Higher scores indicate greater quality of life. The measure is global and allows patients to respond according to facets of their lives that they believe are most important. It has been used with men electing watchful waiting as an alternative to treatment for prostate cancer (Bailey et al., 2004). Despite the wide use of Cantril's Ladder, psychometric properties of the instrument have

not been well supported in the literature. The American Thoracic Society (2007) reported that the content validity of the instrument is supported each time investigators determine that the single item on this question is appropriate for measuring the concept, indicating validity when used to measure quality of life. Brown, Rawlinson, and Hilles (1981) reported that construct validity of the instrument has been supported through correlations with other like instruments. The Cronbach alpha for the current study was 0.87.

To understand whether men could use the experience of a prostate cancer diagnosis to see their lives in a new light, the subscale from the Growth Through Uncertainty Scale (GTUS) (Bailey et al., 2004) was used. The scale was developed to measure the process of growth through uncertainty where individuals relinquish their old life perspective and experience a change in life view. Scale items included statements such as, "I have structured a new way of living," "I have a sense of what is important," "I now consider many different alternatives," and "I create new rules and expectation for life." GTUS consists of 39 items generated from studies investigating the process of uncertainty management in women after a cardiac event or after treatment for breast cancer. A total score is obtained by summing all items. The Cronbach alpha for the total scale was 0.95 in a sample of patients with breast cancer and female patients with cardiovascular disease. The scale's construct validity was supported by the inverse relationship between the GTUS and POMS (Mishel & Fleury, 2001). The Cronbach alpha for the total scale in the current study was 0.95.

The authors computed test-retest reliability for the POMS (negative mood composite), MUIS, cognitive reframing scale, and GTUS. Results were analyzed using SPSS®, version 20.0, and the authors computed the intraclass correlation coefficient (ICC) as a measure of instrument reliability for the POMS, MUIS, cognitive reframing, and GTUS (McGraw & Wong, 1996; Shrout & Fleiss, 1979). A moderate to high degree of reliability was found for all measures (POMS = 0.707, MUIS = 0.866, cognitive reframing = 0.447, GTUS = 0.921), demonstrating that the selected measures are reliable and consistent with multiple administrations.

Analysis

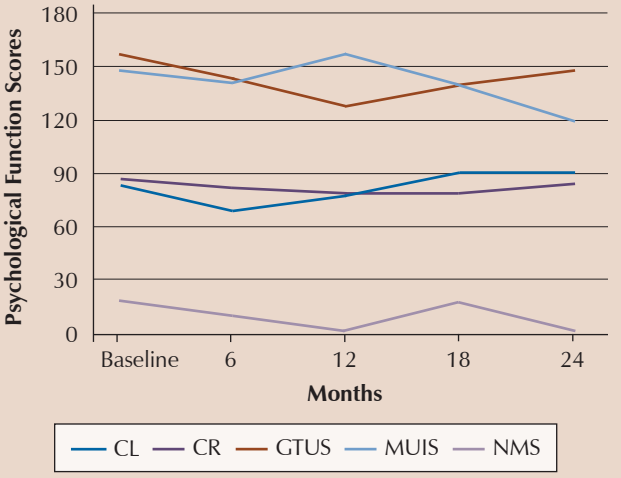
Graphs of summed total scores for all measures for each participant were used to plot the change in scores over time to answer the research question, which follows the health pattern approach described by Clipp et al. (1997). Based on the analysis of the 12 participants, three trajectory patterns emerged. The three patterns included a stable trajectory, an unstable trajectory, and a mixed trajectory.

Results

The 12 men who participated in this exploratory pilot study were aged from 49–72 years ($\bar{X}$ = 59.3 years), with an average of 16 years of education. Nine of the participants were Caucasian, two were African American, and one was Asian American. Most men were married or living with a partner (n = 10); two were divorced. The majority (n = 10) reported incomes greater than $40,000 per year. They reported between 0–6 additional health problems. At baseline, scores for the negative mood composite ranged from 0–35, MUIS scores ranged from 82–148, cognitive reframing scores ranged from 19–88, Cantril's Ladder scores ranged from 50–110, and GTUS scores ranged from 121–231. Higher scores on Cantril's Ladder and GTUS indicated greater quality of life.

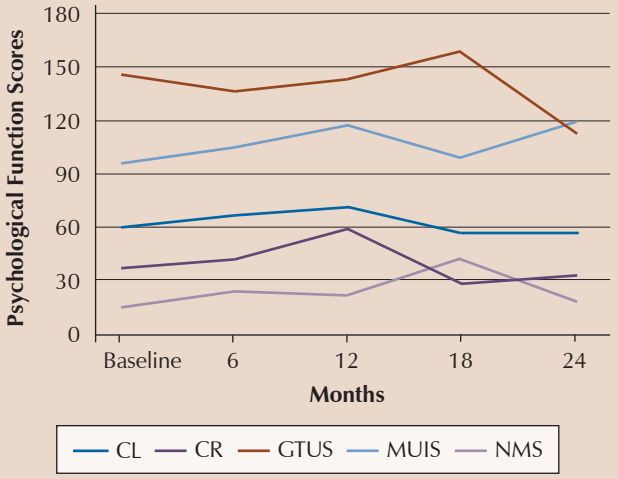
The authors identified three trajectory patterns among the 11 participants who completed the study; one participant was unable to complete follow-up measures. Five participants were labeled as having a stable trajectory based on improving or stable scores on the psychosocial measures and PSA values over the course of 24 months, one participant was categorized as unstable, and five participants were viewed as having a mixed trajectory because of fluctuating values on the psychosocial measures and PSA values.

The first pattern that emerged among participants was labeled a stable trajectory (see Figure 1). In this exemplar case, the participant's PSA values remained at levels less than 0.1 ng/ml (i.e., undetectable). The participant's mood state, using a composite score from the anger, depression, and anxiety subscales,



CL—Cantril's Ladder; CR—cognitive reframing; GTUS—Growth Through Uncertainty Scale; MUIS—Mishel Uncertainty in Illness Scale; NMS—negative mood state

Figure 1. Changes in Psychosocial Function Scores for a Patient With Stable Trajectory



CL—Cantril's Ladder; CR—cognitive reframing; GTUS—Growth Through Uncertainty Scale; MUIS—Mishel Uncertainty in Illness Scale; NMS—negative mood state

Figure 2. Changes in Psychosocial Function Scores for a Patient With Unstable Trajectory

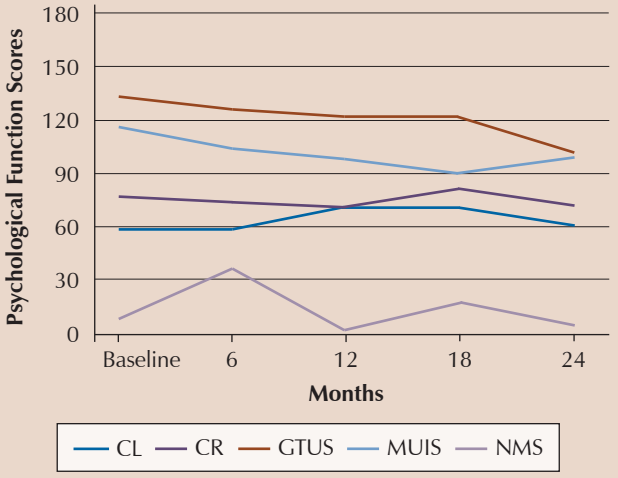
remained low during the 24 months with a range of 1–13. Cognitive reframing scores ranged from 82–88 on a scale of 0–100, indicative of a heightened ability to manage problems. Quality of life, as measured by Cantril's Ladder, was high and stable over time, ranging from 7–9 on a 10-point scale. Uncertainty levels remained elevated but stable over time, with scores that ranged from 133–153 on a scale that ranges from 33–165. The GTUS score remained relatively stable over time, ranging from 115–154 on a scale that ranges from 39–234. Overall, the data from this participant suggested a stable pattern of psychosocial functioning in the context of illness uncertainty.

The second pattern revealed an unstable trajectory (see Figure 2). One participant's PSA values were undetectable at baseline and at six months post-treatment. However, at 24 months, the value spiked to 0.6 ng/ml (i.e., biochemical failure), and the participant was informed that his disease had recurred. Negative mood state was elevated, ranging from 18–44 across the five time points with a possible range of 0–84, and it spiked to 44 at 12 months. Cognitive reframing scores were low, ranging from 29–60 across five time points, with a possible range of 0–100, and quality of life remained low at the last time point. Uncertainty levels increased to a score of 118 at 18 months, indicative of a worsening pattern of psychosocial functioning. At 18 months, a decrease in psychosocial functioning was indicated by a decrease in GTUS to 108. At 24 months, the GTUS score increased slightly to 136. Those data support an unstable pattern of psychosocial functioning.

The third pattern that emerged among men in the current study is described as a mixed trajectory with declining and improving patterns (see Figure 3). PSA values were 0.2 ng/ml (i.e., borderline detectability) over the five time points post-treatment. However, doctors told the participant at the six-month follow-up appointment that they may not have removed all of the cancer. Because of that, his mood state fluctuated over time, with a negative mood state score of 10 at baseline, 36 at six months, and 13 at 24 months, with a possible range of 0–84. Cognitive reframing scores, which range from 0–100, also fluctuated from a score of 76 at baseline to 71 at 12 months, then up to 81 at 18 months and decreasing again at 24 months to 74. Quality of life fluctuated slightly over time with scores ranging from 6–7. Uncertainty levels, which range from 33–165, decreased from 116 at baseline to 97 at 18 months and decreased again at 24 months to 91. The participant's GTUS score, which ranges from 39–234, decreased from 133 at baseline to 96 at 18 months, with a final score of 121 at 24 months. Those data indicate a fluctuating pattern of psychosocial functioning.

Discussion

A substantial body of literature supports the effect of a cancer diagnosis on psychosocial functioning. A commonly reported response to a cancer diagnosis is fear of pain, treatment, and mortality (Ullrich et al., 2003). Kuijpers, Groen, Aaronson, and van Harten (2013) suggested that, because of the long remission period associated with many cancers, disease management may be better understood within a chronic disease framework. Within that period, cancer survivors continue to cope with the psychosocial effects of the disease.



CL—Cantril's Ladder; CR—cognitive reframing; GTUS—Growth Through Uncertainty Scale; MUIS—Mishel Uncertainty in Illness Scale; NMS—negative mood state

Figure 3. Changes in Psychosocial Function Scores for a Patient With Mixed Trajectory

Knowledge Translation

A typological approach can help identify men with prostate cancer in follow-up clinics who are experiencing concerns about post-treatment side effects and teach them to manage these problems.

Because of the lengthy trajectories associated with many cancers, disease management may be better understood within a chronic disease framework.

Nurse-led support groups and patient-driven nursing interventions may assist in the management of psychosocial responses to prostate cancer.

In the case of prostate cancer, disease recurrence is clinically insidious and begins with PSA elevation. Monitoring PSA levels following treatment is important, but controversy remains surrounding what values warrant additional treatment (Payne & Cornford, 2011; You et al., 2009). The PSA blood test was approved by the U.S. Food and Drug Administration in 1986 to track the progression of prostate cancer and is commonly used after cancer treatment to detect early signs of cancer recurrence (National Cancer Institute, 2014). Consequently, PSA testing is performed regularly after treatment to determine if cancer has recurred. Rising PSA levels (i.e., biochemical recurrence) do not always indicate cancer recurrence; however, the possibility of relapse has been shown to result in anxiety among men with prostate cancer (Ullrich et al., 2003). In the current study, the authors identified and described three distinct trajectories of psychosocial functioning using the health pattern perspective described by Clipp et al. (1997). The results revealed that PSA testing may affect psychosocial functioning among men with prostate cancer, as shown in the three exemplar patterns presented. Similarities were observed between PSA levels, illness uncertainty, and overall psychosocial functioning, which reflected the course of a chronic condition over time.

In men with stable PSAs, psychosocial measures remained stable throughout the two-year period following surgical treatment for prostate cancer. In men with unstable and mixed trajectories, changes in PSA and receiving information regarding cancer progression resulted in stable, unstable, and mixed trajectories of psychosocial functioning. The findings of the current study are similar to other research studies using a trajectory framework. Robinson, Nuamah, Cooly, and McCorkle (1997) conducted a study of 79 older breast, prostate, or gastrointestinal patients with cancer using the Corbin and Strauss (1991) trajectory framework. Psychosocial responses to illness were not measured in this study, but eight patients in stable phase and 10 patients in the unstable phase had physical symptoms that affected their health. Robinson et al. (1997) suggested that health symptoms required different nursing care interventions depending on the assignment of stable or unstable. The findings of the study underscore the relationship between physical symptoms and overall function, as well as the need to personalize nursing interventions based on disease phase.

Implications for Nursing

PSA monitoring is important following surgical treatment for early-stage prostate cancer to determine disease recurrence. However, monitoring may lead to psychological distress and decreased health-related quality of life. Data in the current study pointed to specific time points in the first 24 months post-treatment when men could benefit from nursing intervention. Particularly, men may benefit at the point of recurrence. Northouse et al. (2007) recognized the importance of interventions to manage uncertainty and enhance self-efficacy for patients and spouses after a diagnosis of cancer recurrence. This evidence supports the essential role of nursing in enhancing communication between patients, families, and healthcare providers at key time points during disease remission or recurrence, particularly during times of PSA testing or when progressing symptoms are assessed (Mishel et al., 2002).

Nurse-led support groups may assist in the management of psychosocial responses to prostate cancer by providing necessary information as well as an avenue for communication and sharing experiences, and they should continue to be researched (Chambers, Foley, Galt, Ferguson, & Clutton, 2012; James, McPhail, Eastwood, & James, 2005; Katz et al., 2002). Chambers et al. (2012) reported that a mindfulness-based intervention for men with advanced prostate cancer delivered in a support group format would be beneficial. In addition, attention has been directed toward the role of self-management interventions in improving outcomes in prostate cancer survivors. Research by Oliffe, Davison, Pickles, and Mróz (2009) revealed that interventions such as living a normal life and doing something extra (e.g., assuming healthier diets, reducing alcohol intake, beginning an exercise program) improved uncertainty and quality-of-life outcomes among patients with prostate cancer. Kazer, Bailey, Sanda, Colberg, and Kelly (2011) found early evidence that an Internet-based intervention incorporating cognitive reframing and self-management strategies showed good acceptability and positive changes in quality of life and uncertainty among men with prostate cancer.

Sturmberg (2012) suggested that psychosocial issues may be just as important as medical causes of deterioration among patients. Therefore, healthcare providers should not allow patients with prostate cancer to proceed unassisted through the post-treatment period.

Future longitudinal work could help clarify additional time points across the survivorship trajectory where nursing can support effective management of chronic illness trajectories to improve quality of life.

The findings presented in the current article may be used by nurses to improve care for men who are monitoring PSA values after surgery for localized prostate cancer. Implementation of support services before, during, and after visits to healthcare providers to monitor cancer progress may result in the stabilization of chronic illness trajectories over time. Interventions targeted at the time of disease recurrence and initiation of new therapies will likely result in more stable psychosocial function and higher quality of life for patients and families.

Conclusion

The current study had limited ethnic diversity, and most participants were of middle to high socioeconomic status. The authors also recognize that hormone therapy may have affected the psychosocial responses of one participant. In addition, these data were collected from a single institution. Future studies could strive to enroll a larger, more heterogeneous sample. However, findings from the current study help to focus attention on the need for timely nursing care to better manage the psychosocial responses to prostate cancer.

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