Measurement of Quality of Life in Men With Prostate Cancer

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Prostate cancer continues to be one of the most common cancers diagnosed in men. In light of the excellent survival rates for prostate cancer, quality of life is a primary concern during and following prostate cancer treatment. Quality of life is defined and determined in multiple ways. This article explores quality of life in men with prostate cancer. Quality-of-life dimensions, measurement tools, and implications of quality of life with prostate cancer on clinical practice for oncology nurses will be presented.

Prostate cancer is the most common non-skin cancer diagnosis in men, yet mortality rates from prostate cancer continue to decline (American Cancer Society, 2007). Men have a one in six lifetime risk for prostate cancer, and older men, African Americans, and men with a family history of prostate cancer have the greatest risk (American Cancer Society). Given the survivor rate—99% for five years—quality of life is a central focus in the care of this patient population (American Cancer Society). Ninety percent of prostate cancer cases are diagnosed in the early stages and are clinically localized within the prostate organ (American Cancer Society). The issues and choices facing men diagnosed with prostate cancer differ depending on whether the cancer is organ contained or has spread beyond the prostatic capsule (the outer layer of the prostate). Men may live for many years if prostate cancer is discovered in the early stages, but later stages of the disease can be very debilitating (Herr, 1997).

Men face a difficult decision when choosing treatment options, such as radical prostatectomy, robotic-assisted laparoscopic prostatectomy, external beam radiation, brachytherapy (radiation seed implants), hormone ablation therapy, or the watchful waiting approach. The potential cure for the disease must be weighed along with the potential impact of treatment on quality of life. All prostate cancer treatments carry the risk of side effects that compromise quality of life. For instance, prostate surgery and radiation therapy are considered potentially curative for organ-contained prostate cancer, although both treatment modalities may result in sexual dysfunction and/or bowel and urinary issues (Clark et al., 2003). Hormone ablation is considered palliative and is associated with sexual dysfunction, hot flashes, weight gain, fatigue, sleep disturbances, and osteoporosis (Penson & Litwin, 2003). The side effects may impact quality of life. To complicate matters further, researchers disagree about the need to treat some men with prostate cancer because survival with treatment may be comparable to survival with watchful waiting (delaying treatment or not treating the prostate cancer) (Warner & Whitmore, 1994).

At a Glance

- Quality-of-life issues for men with prostate cancer may differ depending on the stage of the disease and treatment choice.
- A comprehensive approach to quality-of-life measurement in men with prostate cancer includes general, cancer, and prostate-specific assessments.
- Quality-of-life instruments are available for use in the clinical setting or for research purposes to better elucidate patients' struggles in living with prostate cancer and deleterious outcomes from prostate cancer.

The negative impact of treatment on quality of life in older men with very slow-growing tumors may be greater than the impact of prostate cancer without treatment. This particularly applies to cases of older men with multiple comorbid conditions who are likely to die from other causes within 10–15 years. These reasons have thrust quality of life into the center of the treatment decision-making process.

The Concept of Quality of Life

Quality of life has been defined in many ways, but a consensus definition does not exist. Quality of life has been conceptualized as normal functioning, social usefulness, general well-being,
The negative impact of treatment on quality of life in older men with very slow-growing tumors may be greater than the impact of prostate cancer without treatment. For localized prostate cancer, but research by Potosky et al. (2004) suggests that the risks associated with these definitive treatments negatively impact quality of life without necessarily improving chances of survival. The treatment options are curative, but, in some men, survival rates may be just as good without treatment; therefore, further research is needed. For this reason, the potential impact of treatment on quality of life for men with localized prostate cancer may become the central focus when making treatment decisions. Prostate cancer treatment may not even be necessary in all men. How can healthcare professionals determine which men would benefit from treatment and which would not? What would the quality-of-life differences be? These are difficult questions to answer, and further research is needed.

Some men choose hormone ablation to treat their prostate cancer. Hormone ablation is not designed to remove or destroy prostate cancer cells, but rather to stop testosterone production in an effort to diminish the growth and livelihood of hormone-dependent prostate cancer. Side effects of hormone ablation include hot flashes, gynecomastia, sexual dysfunction, weight gain, fatigue, and osteoporosis (Potosky et al., 2002). The side effects may negatively impact quality of life.

Another option for prostate cancer treatment is watchful waiting. Watchful waiting involves carefully monitoring prognostic indicators, such as regular prostate-specific antigen testing and periodic prostate biopsy, to determine if and when further treatment might be needed. Older men, or those with limited life spans related to other health issues, may opt for watchful waiting, given the potential negative effects of surgery and radiation therapy on sexual, bowel, and bladder function. These effects may lessen with watchful waiting, but psychological sequelae, such as anxiety, stress, and fear of the unknown, may increase (Chodak & Warren, 2006). For men who choose watchful waiting, bladder problems (e.g., incomplete emptying, frequency, urgency, incontinence) related to the obstruction of the bladder...
neck and urethra eventually may develop as the prostate cancer grows. Severe bone pain also may develop if the disease becomes metastatic. This negatively impacts quality of life.

Nurses are concerned with improving the quality of life of all patients with cancer, but men with prostate cancer present unique challenges. Although side effects from the various treatments are similar, significant differences do exist. Men with prostate cancer must consider quality-of-life issues when making treatment decisions, including disease-specific challenges, as well as the physical, emotional, social, spiritual, and economic challenges.

**Quality-of-Life Measurement in Men With Prostate Cancer**

Quality of life is a multidimensional construct generally consisting of physical, psychological, and social dimensions (Ferrans, 2005). Economic, spiritual, and family dimensions also are frequently incorporated into quality-of-life measurements. Prostate cancer may affect one or many quality-of-life dimensions. Part of the difficulty associated with measuring quality of life in men with prostate cancer is related to this multidimensionality. Determining which dimensions are most important to men with prostate cancer, and whether they should be measured equally, may be beneficial to understanding quality of life issues.

Measuring quality of life in men with prostate cancer presents unique challenges. Psychological adjustment and spirituality play key roles in prostate cancer adjustment. Psychological adjustments stem from the physical changes associated with prostate cancer treatment. Erectile dysfunction, the lack of ejaculation with orgasm, and drawing in of the penis with reanastomosis of the urethra after removal of the prostate, as well as side effects of hormone ablation (e.g., sexual dysfunction, fatigue, hot flashes, weight gain), are disease-specific elements in quality of life that may not be captured by generic measures (Clark et al., 2003). Spirituality plays a key role in quality of life in terms of physical, psychological, and sexual function (Krupski et al., 2006). Social support also is an important aspect of quality of life in men with prostate cancer, who may need physical, psychological, and economic support after diagnosis and during treatment. Economic factors, such as access to health care and treatment choices, also impact quality of life.

Prostate cancer treatment primarily affects sexual, bowel, and bladder function as a result of the anatomic location of the prostate at the bladder neck and proximal to the rectum and its role in the reproductive system. Disease-specific quality-of-life measures are necessary to examine unique aspects in men with prostate cancer. Validated and reliable measurement tools for sexual dysfunction, such as the International Index of Erectile Function (Rosen et al., 1997), and for bladder dysfunction, such as the International Prostate Symptom Score (Gray, 1998), may be beneficial in evaluating symptoms. Additional disease-specific quality-of-life tools are available for this population, such as the University of California, Los Angeles, Prostate Cancer Index (UCLA PCI), which assesses bowel, bladder, and sexual function (Litwin, Hays, et al., 1998). In men with localized prostate cancer, quality-of-life assessments include overall life satisfaction and the various dimensions of life, as well as disease-specific quality of life related to sexual and urinary side effects.

The stage of disease also may influence quality of life in men with prostate cancer. Quality of life for men with advanced disease may be influenced by different factors compared to men with organ-contained disease. In men choosing watchful waiting, quality of life must be measured by assessing overall satisfaction as well as physical, psychosocial, and disease-specific dimensions. For men with advanced prostate cancer facing end-of-life issues, quality-of-life assessments should also include functional independence, pain and symptom management, relationships with others, and meaning of life (Cohen & Mount, 1992). Patients at the end-of-life stage do not represent the majority of patients because prostate cancer survivorship continues to be excellent, but they do represent a portion of the population with unique elements that impact quality of life.

**Subjective Versus Objective Measures**

Quality of life in men with prostate cancer must be assessed through unique individual perspectives. Quality-of-life assessment should capture those individual perceptions of life in regard to dimensions such as health status, physical functioning, psychological adjustment, spirituality, social support, and access to health care. Additional disease-specific dimensions, such as bladder, bowel, and sexual function, must be assessed from individual perspectives. The various dimensions of function and the psychological adjustment to decreased function can be understood only by knowing each individual’s satisfaction with that level of function. One individual may adjust well to sexual dysfunction issues if sex was not a priority in his life, whereas another man, whose sexuality was integral to his sense of self and his life, may evaluate satisfaction with life very differently. Although healthcare professionals may believe they accurately assess quality of life in their patients, a study by Litwin, Lubeck, Henning, and Carroll (1998) showed that men with prostate cancer and physicians did not rate quality of life in a similar manner. The individual is the best person to rate his own quality of life.

Capturing all pertinent quality-of-life information is a challenge for researchers and clinicians. An individual’s true feelings cannot be completely captured through questionnaires; therefore, men must have an opportunity to express their quality of life through open-ended questions. Questionnaire scores cannot capture the layered richness of individual experiences. Quantitative and qualitative methods of quality-of-life research should be conducted to capture the broad range of experiences among men with prostate cancer. Clinicians who use quality-of-life research must not only take into account the findings from quantitative and qualitative research, but also couple them with true engagement of the patient in conversation that can lead to an understanding of that individual’s needs, wants, and goals. This aesthetic intuition and understanding of the patient, as described by Carper (1992), along with the evidence from quality-of-life research, are essential as patients move toward their goals. Subjective measures should capture the patient’s valuation of each aspect of quality of life that may be impacted by prostate cancer.
Measurement

Wilson and Cleary (1995) developed a conceptual model of patient outcomes that linked clinical variables with health-related quality of life, dimensions of function, and overall well-being. Health-related quality of life specifically concerns the relationship of health and functional status to overall life satisfaction. The five measurement levels of health outcomes—biologic function, symptoms, functional status, general health status, and overall quality of life—were described for use by nurses and healthcare professionals (Ferrans et al., 2005). They are influenced by individual characteristics as well as cultural and environmental factors. This framework fits well with the notion that the individual is the best judge of his or her own quality of life. Many tools that measure quality of life are consistent with the Wilson and Cleary model, but the best for measuring quality of life in men with prostate cancer is unclear.

Different quality-of-life instruments measure different aspects of life, and the information obtained will vary from one instrument to the next. The quality-of-life information needed should guide instrumentation choice. An excellent resource site for the many available tools can be found at www.qolid.org. Measurement tools helpful in evaluating patients with prostate cancer include generic quality-of-life measures, cancer-specific quality-of-life measures, and disease- or symptom-specific measures.

Finding a valid, reliable tool to measure quality of life in men with prostate cancer is important. Some validated and reliable instruments include general quality-of-life instruments, such as the Medical Outcomes Study 36-Item Short Form Health Survey (Ware & Sherbourne, 1992); cancer-specific instruments, such as the Quality of Life Index (QLI) cancer version (Ferrans, 1990) and the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC-QLQ C30) (Aaronson et al., 1993); and prostate cancer–specific instruments, such as the Quality of Life Scale (Ferrans, 1990); Bowel, bladder, and sexual function are the focus of this 20-item questionnaire. The effect of erectile dysfunction on quality of life is determined in this 15-item questionnaire. Responses range from “not at all” to “a great deal.” The total score is categorized into mildly, moderately, or severely affected.

<table>
<thead>
<tr>
<th>MEASUREMENT TOOL</th>
<th>CATEGORY</th>
<th>STUDY</th>
<th>DESCRIPTION</th>
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<tbody>
<tr>
<td>Medical Outcomes Study 36-Item Short Form Health Survey (SF-36)</td>
<td>Generic quality of life</td>
<td>Ware &amp; Sherbourne, 1992</td>
<td>General health-related quality of life is examined in this 36-item questionnaire. The eight health concepts covered are limitations in physical, social, and role activities related to physical problems; bodily pain; general mental health; limitations in role activities related to emotional problems; general vitality; and general health perceptions.</td>
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<tr>
<td>Global 1-Item Quality of Life Scale</td>
<td>Generic quality of life</td>
<td>Patrick et al., 1973</td>
<td>The quality-of-life visual analog scale ranges from 0–100.</td>
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<tr>
<td>Quality of Life Index (QLI) cancer version</td>
<td>Cancer-specific quality of life</td>
<td>Ferrans, 1990</td>
<td>Made up of two sections with 33 items each, this tool uses four domains: health and functioning, family, social and economic, and psychological and spiritual.</td>
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<tr>
<td>European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC-QLQ C30)</td>
<td>Cancer-specific quality of life</td>
<td>Aaronson et al., 1993</td>
<td>36 items measuring physical, emotional, role, cognitive, and social functioning subscales; a global health scale; three multi-item symptom scales (pain, fatigue, and nausea); and six single-item questions (dyspnea, insomnia, appetite loss, constipation, diarrhea, sleep disturbances, and financial impact).</td>
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<td>University of California, Los Angeles, Prostate Cancer Index (UCLA PCI)</td>
<td>Disease-specific quality of life</td>
<td>Litwin, Hays, et al., 1998</td>
<td>Bowel, bladder, and sexual function are the focus of this 20-item questionnaire.</td>
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<tr>
<td>Erectile Dysfunction Effect on Quality of Life (ED-EQOL)</td>
<td>Disease-specific quality of life</td>
<td>MacDonagh et al., 2002</td>
<td>The effect of erectile dysfunction on quality of life is determined in this 15-item questionnaire. Responses range from “not at all” to “a great deal.” The total score is categorized into mildly, moderately, or severely affected.</td>
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<tr>
<td>International Index of Erectile Function (IIEF-15)</td>
<td>Specific sexual issues</td>
<td>Rosen et al., 1997</td>
<td>Prostate cancer treatment’s effect on erectile function, orgasm, desire, and satisfaction with sex is the focus of this 15-item questionnaire.</td>
</tr>
<tr>
<td>Sexual Health Inventory for Men (IIEF-5)</td>
<td>Specific sexual issues</td>
<td>Rosen et al., 1999</td>
<td>The severity of erectile dysfunction is determined in this five-item questionnaire.</td>
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<tr>
<td>Self Esteem and Relationship Questionnaire (SEAR)</td>
<td>Specific sexual issues</td>
<td>Cappelleri et al., 2004</td>
<td>Sexual self-confidence and sexual self-esteem are the focus of this 14-item questionnaire.</td>
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quality-of-life domains and should be considered to understand the extent and impact of that dysfunction on the individual. Disease-specific measurements such as the UCLA PCI, the Sexual Health Inventory for Men, the Self-Esteem and Relationship Questionnaire, or the International Prostate Symptom Score questionnaire can be combined with a quality-of-life satisfaction questionnaire to provide disease information in conjunction with life satisfaction information.

Instruments aimed at evaluating symptoms provide information that cannot always be gleaned from general or cancer-specific quality-of-life instruments. The Sexual Health Inventory for Men is used to assess severity of erectile dysfunction (Rosen, Cappelleri, Smith, Lipsky, & Pena, 1999). The International Prostate Symptom Score is used to evaluate bladder dysfunction (Gray, 1998). The Self-Esteem and Relationship Questionnaire is a patient-reported tool that assesses sexual confidence and intimacy (Cappelleri et al., 2004). Men with clinically localized prostate cancer who are not treated for various reasons (e.g., advanced age, personal preference, health status) may not have sexual or urinary issues but will have to deal with the psychological impact of watchful waiting. Particular attention should be paid to the psychological adjustment and social dimensions related to anxiety associated with watchful waiting.

Men with advanced prostate cancer that has spread beyond the prostatic capsule have different quality-of-life issues. Hormone ablation treatment is common for men with metastatic prostate cancer, but treatment may be delayed until either prostate-specific antigen levels rise to a certain level, a healthcare provider determines that action is necessary, or symptoms are present. Herr and O’Sullivan (2000) found that men who deferred treatment until they were symptomatic had better quality of life. Hormone-refractory prostate cancer may be associated with decreased quality of life because of subsequent pain and deteriorating physical function (Melmed, Kwan, Reid, & Litwin, 2002). Other treatments for advanced prostate cancer include radiation therapy for bone metastases and chemotherapy treatment.

Urinary dysfunction can occur if prostate cancer progresses and obstructs the urethra. Quality of life can decline quickly during the final year of life in men with advanced prostate cancer. Therefore, pain and function issues must be addressed. The EORTC QLQ-C30 (prostate module) measures advanced prostate cancer and has been used in patients with metastatic disease (Albertsen, Aaronson, Muller, Keller, & Ware, 1997). The questionnaire can be used in conjunction with other quality-of-life instruments.

Assessing quality of life at appropriate intervals is another important factor to consider. The right time to measure quality of life in men with prostate cancer is determined by research questions or guided by clinical practice. Allowing enough time to pass after treatment is crucial to evaluating quality of life. Radiation therapy has a cumulative effect, and the impact on bowel, bladder, and sexual function may not be evident until 18–24 months after treatment (Merrick et al., 2005). With penile erectile nerve-sparing techniques applied during prostate removal, men may not recover maximum erectile function for up to 24 months (Korfage et al., 2005; Penson et al., 2005). Research by Talcott et al. (2003) supports using a minimal time frame of 24 months after treatment when trying to compare treatment outcomes between prostatectomy and radiation therapy treatment.

Conclusion

Quality of life is an essential outcome measure for men with prostate cancer. Regardless whether a man has localized or advanced prostate cancer, every treatment decision must be weighed in terms of quality of life, including the choice not to treat. Healthcare professionals have differing views on prostate cancer treatment, often leading to confusion among patients. Nurses play a vital role in educating men so that they can make informed treatment decisions. Nurses can provide unbiased education about all options and their possible impact on quality of life. Men should enter treatment fully aware of possible outcomes and feel confident in their decisions. Nurses have been identified as the most trusted healthcare professionals (Gallup Organization, 2004), and men need a trusted source when deciphering information about prostate cancer treatment.

Quality-of-life measures can be used in clinical practice and research to determine the individual's perspective on dealing with prostate cancer and treatment. Quality of life is best understood as an individual's satisfaction with the various aspects of his or her life and satisfaction with life as a whole. This definition is easy to understand, yet broad enough to encompass multiple dimensions, including health status and physical functioning, psychological adjustment, spirituality, social support, and access to health care. Quality-of-life assessment should include an overall assessment of life satisfaction, assessments of important dimensions, as well as the prostate-specific problems related to urinary and sexual dysfunction. Quality of life in men with prostate cancer must be understood from the subjective perspective of the individual through communication and understanding within the nurse-patient relationship.

The authors gratefully acknowledge Carol Estwing Ferrans, PhD, RN, FAAN, in the College of Nursing at the University of Illinois at Chicago for providing guidance in quality-of-life research to the authors during their doctoral training.

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References


