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Symptoms and Symptom Distress in Localized Prostate Cancer

KEY WORDS

Localized prostate cancer
Symptom
Symptom distress

For over a decade, symptom distress has been a key concept in several studies of cancer. However, the definition of symptom distress is still unclear, and there are few measures targeting symptom distress, in general, and specific cancers, in particular. Prostate cancer is the sixth most common cancer worldwide and the second leading cause of death in American men. Many men with clinically localized prostate cancer may experience unique and multidimensional symptoms that occur from diagnosis through treatment, and thereafter. These symptoms associated with the disease and its treatments are in the form of physical and psychological sequelae such as urinary and bowel problems and sexual dysfunction. The purposes of this article are to (1) systematically review literature on symptoms and symptom distress in localized prostate cancer and (2) synthesize evidence of symptom distress applications and measurement in this group. A comprehensive, systematic review was conducted to identify original, data-based studies of symptoms and symptom distress in localized prostate cancer. Clarification of symptom distress and more comprehensive information about symptoms and symptom distress will provide nurses with a better foundation for developing self-management interventions aimed at ameliorating symptom distress and, ultimately, enhancing the quality of life of patients with localized prostate cancer.

Prostate cancer is the sixth most common cancer worldwide and the most commonly diagnosed cancer and the second leading cause of death in American men.¹⁻³ In 2006, approximately 234,460 American men were diag-

nosed with prostate cancer, and 27,350 died of the disease.³ Current estimates are that almost 1 (17%) in every 6 men in the United States will experience prostate cancer in their lifetime.^{1,3} However, 5-year survival rates have steadily improved

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since 1974, and the relative 5-year survival for all races within the United States is 97%.^{1,3} The prevalence of prostate cancer extends beyond the US boundaries, as it is one of the most common malignancies in men in Sweden, Japan, China, and Taiwan.^{1,4-6} Prostate cancer, therefore, is a public health problem throughout the world.

Many men have clinically localized prostate cancer, which consists of low-grade tumors that do not extend beyond the prostate gland. Men with localized prostate cancer have several therapeutic options, which include radical prostatectomy, radiation therapy (external beam radiotherapy [EBRT] and brachytherapy [BT]), watchful waiting/expectant management, and cryotherapy.^{1,7,8} Men receiving these treatments may experience unique and multidimensional distressful symptoms during diagnosis, through treatment, and thereafter.^{4,7,9} Symptoms are in the form of physical and psychological sequelae,^{10,11} and may cause symptom distress.

Symptom distress has the potential to affect quality of life through alterations in self care, physical functioning, symptom management, and treatment tolerance.¹² For example, symptom-related distress in patients with cancer has been found to significantly and independently predict changes in physical functioning and performance status.^{13,14} The occurrence of multiple symptoms in patients with prostate cancer has been shown to predict treatment failures and poor therapeutic outcomes.^{14,15} Symptom distress also has been attributed to length of survival in patients with cancer.^{13,16-18} Interventions targeting symptom distress may change functional status, improve symptom self-management and quality of life, and influence patient's outcome, including morbidity and mortality.¹⁹

Developing effective strategies of symptom self-management that ultimately enhance the quality of life in patients with localized prostate cancer requires an understanding of how patients perceive their symptom distress and how they manage their symptoms. The purpose of this article is 2-fold: (1) to systematically review literature on symptom distress and symptoms in localized prostate cancer and (2) to synthesize evidence of symptom distress applications and measurement in men with localized prostate cancer. This review may assist health professionals in identifying symptom self-management strategies for men with localized prostate cancer.

■ Background

Prostate Cancer

The diagnosis of prostate cancer is definitively established by biopsy. The stage of the disease determines the appropriate type of therapy. There are 2 anatomic systems commonly used to classify prostate cancer in the United States—the Jewett system and the American Joint Committee on Cancer (stages A-D) and the International Union Against Cancer (TNM—tumor, node, metastasis).²⁰ World Health Organization grading of prostate tumors is according to the level of cellular differentiation noted in biopsy. The most common

system used for the grading of prostate cancer is the Gleason score.²¹ The Gleason grading system involves rating cancerous prostate tissue from 1 to 5; these scores reflect how much the arrangement of the cancer cells mimics glandular tissue. Two grades are assigned to the most common patterns of cells that appear; these 2 grades (they can be the same or different) are then added to determine the Gleason score (a number from 1–10).^{1,7,20}

Clinical staging is based primarily on the presence or absence of a prostatic nodule on digital rectal examination. Tumors with a Gleason score of 7 or greater are the most aggressive. On the basis of a core-biopsy or a needle-aspiration-biopsy specimen, tumors that are classified as localized (T1–T2, N0, M0), have a Gleason score of less than 6, and are grade 1 or 2 according to World Health Organization criteria are less aggressive tumors.^{22,23} Treatments are determined by stage and grade of disease at diagnosis, prostate-specific antigen levels and the results of digital rectal examination, along with age at diagnosis, functional status, and life expectancy.^{15,24,25}

There is no one best treatment for men with localized prostate cancer. The selection of treatment is based on factors other than survival advantage, such as the effect of therapy on health-related quality of life.^{10,26} Treatment options for localized prostate cancer include discussion of watchful waiting/expectant management, radical prostatectomy, radiation therapy (EBRT and BT), and cryotherapy. Neoadjuvant hormonal therapy is offered to patients with high-risk disease and/or enlarged prostates, or as part of certain protocols before radiation therapy or surgery treatments.^{21,27} The most common approaches to managing localized prostate cancer are watchful waiting, external radiation therapy, BT, and radical prostatectomy.^{1,7,8,28} Watchful waiting is an acceptable alternative for men with low-grade, clinically localized disease and a life expectancy of 10 years.⁷ Radical prostatectomy is another option and provides excellent cancer control for patients with localized prostate cancer. It can be performed through a retropubic approach or laparoscopically.^{1,7,8,28} Radiotherapy can sterilize prostate tumors; the higher the radiation therapy dose administered, the greater the likelihood of obtaining local control.²⁸ Radiation therapy includes EBRT (3-dimensional conformal radiation therapy) and interstitial BT (implanting radioactive seeds into the prostate gland).²⁹ There is lack of consensus among physicians on the outcomes of these different therapies.^{7,8,28}

Prostate cancer can affect the patient differently across phases of the disease. There often are no symptoms for many men with early stage, clinically diagnosed prostate cancer because most prostate cancers arise from the outer peripheral zone of the gland, distant from the urethra.^{7,21} Thus, an elevated serum prostate-specific antigen or abnormal digital rectal examination, or both, is usually suggestive of prostate cancer.²⁷ Symptoms associated with localized prostate cancer include bladder outlet obstructive symptoms (dysuria, dribbling, decreased force of the urinary stream, incomplete bladder emptying), irritating voiding symptoms (urinary frequency, nocturia), hematospermia, decreased ejaculatory volume, or impotence.⁷ Men with localized prostate cancer

experiencing these symptoms, along with those stemming from treatment, report a wide range of symptoms and symptom distress.^{10,14,28,30-32}

Symptoms and Symptom Distress

Incorporating the concept of symptom distress into research is challenging for several reasons. First, the definitions of symptoms and symptom distress lack clarity and consistency. One definition of the term *symptom* is a subjective phenomenon regarded by the individual as an indication or characteristic of a condition departing from normal function, sensation, or appearance.³³ According to the Oxford English Dictionary,³⁴ a symptom is a bodily or mental phenomenon, circumstance, or change of condition arising from and accompanying a disease or affection and constituting an indication or evidence of it; a characteristic sign of some particular disease. According to the National Cancer Institute,³⁵ a symptom is an indication that a person has a condition or disease. Researchers in nursing have defined symptoms as distinctive features of diseases that are used to diagnose a patient's condition and often include signs or objective clinical manifestations.^{12,16,36,37} A symptom is an experience that is perceived and verified only by the individual experiencing the phenomenon; therefore, a symptom is subjective and experiential.³⁸ Symptoms can be viewed also as inevitable side effects of therapy, particularly by the physician.

A second challenge is that the concepts of distress and symptom distress are often used interchangeably. Distress can be defined as a commonly used derivative of the word *stress*.³⁹ When Selye⁴⁰ first defined the term *stress*, he proposed subdefinitions of stress: *eustress* and *distress*. Selye believed that mild, brief, and controllable states of stress positively challenged homeostasis in that they could be perceived as pleasant or exciting stimuli to emotional and intellectual development. Conversely, distress encompassed the more severe, protracted, and uncontrollable situations (both psychologically and physically) that led to frank disease states.⁴¹ Other definitions of distress are the physical or mental suffering or anguish,³³ the amount of upset the sensations cause,⁴² or suffering and upset.⁴³ In the Theory of Unpleasant Symptoms, Lenz et al⁴⁴ defined distress as 1 of 4 dimensions of a symptom that reflects the degree to which the person is bothered by the symptom. The National Comprehensive Cancer Network defined distress as a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.⁴⁵

The definitions of symptom distress vary in the literature in another important way. Symptom distress has been defined as "the degree of discomfort from the specific symptom being experienced as perceived by the patient,⁴⁶ or physical or mental anguish or suffering that results from the experience of symptom occurrence."¹² Researchers defined symptom distress as the degree of physical or mental suffering, discomfort, or bother reported by individuals in relation to their

perceptions of the symptom.^{36,44,46,47} Symptom distress may include thoughts related to the symptom, the degree of attention given to the symptom, and the mood or mental outlook of the person, and the situational context of the symptom occurrence. Rhodes et al⁴⁸ defined symptom distress as an aspect of the symptom experience that includes the human response to symptom occurrence, that is, awareness of the distress and recognition of the degree of upset, strain, and mental anguish.

Bother is another term closely associated with symptom distress.¹⁶ Previous studies evaluated symptom distress by asking subjects "how much a symptom bothered them" or "how much a symptom bothers or distresses them."^{18,49} Distress is synonymous with being upset and is defined as the state of being in great trouble.¹⁶ Other concepts that are related to, but different than, symptom distress are symptom occurrence, symptom experience, symptom awareness, and symptom perception. Symptom distress and symptom occurrence are critical components of symptom experience.^{46,50} Symptom occurrence is frequency, duration, and intensity (severity) of the symptom, whereas symptom distress is the degree of discomfort reported by the patient in response to the specific symptom being experienced.⁵¹

Some researchers posit that symptom distress alters the cancer experience and the quality of life.^{52,53} Symptom distress provides the most useful information about quality of life when using a single symptom assessment measure, with the frequency of the symptom adding significant information about symptom experience.⁵⁴ In several studies of localized prostate cancer, symptom distress has been an indicator of health-related quality of life or outcome indicators of treatment.^{9,14,28,32,55-58} Symptom distress can be an indicator of the disease itself or the adverse side effects of therapy. It also can be one of the outcome measurements of symptom management or one of the causes for symptom management.

■ Method

We conducted a comprehensive search of adult human studies targeting symptoms and symptom distress in men with localized prostate cancer that were reported in English in the MEDLINE, PubMed, CINAHL, and PsychINFO databases from 1996 to 2005. Our 10-year-time framework took into account the tread toward stabilization of the definition of symptom distress over the last decade. To capture the full range of symptom distress and localized prostate cancer, the search included the following keywords: symptoms, symptom distress, bother, symptom experience, and symptom occurrence combined with cancer, malignancy, prostate cancer, and localized prostate cancer/early-stage prostate cancer. Sources of keywords were definitions from the National Cancer Institute and consulting dictionaries.

Studies of symptom distress in prostate cancer are relatively few compared with studies of other cancers. In particular, after carefully reviewing the abstracts of articles and dissertations, there were publications that included content

on symptom distress in localized prostate cancer. Several articles incorporated concepts of symptoms and health-related quality of life along with symptom indexes to represent the concept of symptom distress^{22,23,59,60} or used symptom distress as one of the indicators for health-related quality of life^{10,22,32,57,59,61-64} or as outcome variables of treatments.^{55,65} Health-related quality of life is becoming a widely used concept both clinically and in research, because of the increasing chronicity of illness. For reviews of health-related quality of life in men with prostate cancer, we refer the reader to several excellent articles.^{10,55,66,67}

We reviewed the studies on symptoms and symptom distress in men with localized prostate cancer, first by examining how symptoms and symptom distress had presented in localized prostate cancer patients, and second by exploring how symptom distress was defined and measured in these studies. We critiqued the consistency between the definition and the measurement of symptom distress in each study.

■ Results

On the basis of the literature review, we formulated an alternative definition of symptom distress in localized prostate cancer: the perception of physiological or psychological discomfort resulting from a particular symptom experienced by patients with localized prostate cancer. As so defined, the critical attributes of this concept include the following:

1. presence of physical or mental suffering, anguish, upset, discomfort, or bother;
2. effect of a specific symptom occurrence and/or the perception of subjective states;
3. experiences or reports by individuals regarding their perceptions of the symptom; and
4. the need to alter (restrain or produce) actions in response to a subjective indication of disease.

Symptoms and Symptom Distress in Localized Prostate Cancer

Most studies of symptom distress measured symptom distress without defining it.^{9,14,23,32,57,58,62,68,69} Researchers tended to use symptom indexes representing indicators of health-related quality of life specific to localized prostate cancer. Many studies of prostate cancer focused on health-related quality of life, and the researchers viewed symptoms and symptom distress as indicators or outcome variables of health-related quality of life.^{22,28,61,65,70,71} The Table shows the summary and synthesis of the studies on symptoms and symptom distress in localized prostate cancer. Most studies were focused on health-related quality of life, so within those studies, we pinpointed how the concept of symptom distress was defined and measured.

The 3 most frequently reported symptoms that were of concern to men with localized prostate cancer were urinary problems, sexual dysfunction, and bowel problems. These

major symptoms have been reported in the majority of studies of patients with localized prostate cancer.^{10,14,31,32,56,67,72} Symptoms assessed for urinary function included urinary leakage, urinary urgency, and weak urinary stream. Regarding sexual function, symptoms assessed included sexual desire, erectile capacity, and orgasm/ejaculation, and symptoms assessed for bowel functions included fecal leakage, bowel urgency, and constipation.¹⁰

Men undergoing treatment of localized prostate cancer may experience incontinence, erectile dysfunction, and impotence and report problems with urinary and sexual functioning as their primary concern. For example, men with localized prostate cancer undergoing prostatectomy reported more urinary problems (urinary leakage, incontinence, dribbling, and nocturia) and more sexual dysfunction (erectile dysfunction, dissatisfaction) than men receiving radiation therapy.^{1,7,61} Yarbro and Ferrans⁷³ reported that men treated with radical prostatectomy had a higher rate of physiological impotence (86%) than men treated with external beam radiation (57%). Postoperative patients have reported greater negativity regarding physical appearance, state of health, and sexuality.^{7,74-76} The few men who had watchful waiting as treatment reported problems with impotence (57%). Men undergoing treatments for clinically localized prostate cancer continue to experience difficulty long after treatment.^{7,56,74,75}

Psychological distress after the diagnosis of early-stage cancer includes altered self-perception, anxiety about the effects of treatment, and concerns about treatment decision making.⁷⁷ At the time of diagnosis, 63% of men had higher decision-related distress, and this persisted for 42% of men 12 months after treatment. Also, low-to-moderate psychological distress was most common at diagnosis for men with prostate cancer.⁶⁹

In summary, patients with clinically localized prostate cancer undergo multidimensional distressful symptoms from diagnosis through treatment and beyond.⁴ The most reported physiological distressful symptoms include sexual dysfunction (impotence), urinary problem (incontinence), bowel problem (fecal leakage), and fatigue.^{10,11,62,78,79} The psychological distress in men with localized prostate cancer includes changes in self-perception, distress on decision making, and anxiety.⁶⁹ There has been little research on symptoms and symptom distress in localized prostate cancer; hence, there are few objective indicators for measuring levels of symptom distress.

Measurement of Symptom Distress

Self-report instruments have been developed for the purpose of measuring cancer-related symptom distress in general,³⁶ but no one instrument has focused only on prostate cancer-related symptom distress. Johnson⁴⁹ conducted the first study documenting that symptom distress is not synonymous with symptom intensity. She explored the term "symptom distress" and conceptualized symptoms as consisting of physiological (sensory) and reactive (distress) components of pain sensations in persons with chronic disease and cancer. However, this study did not include men with prostate cancer.

 **Table • Symptoms and Symptom Distress in Localized Prostate Cancer (1996–2005)**

| Authors | Purpose | Methods | Findings | Strengths/Weaknesses |
|------------------------------|--|--|---|--|
| Helgason et al ⁷⁹ | Identify and quantify the most important disease-specific distress | Sample: 431 patients and 435 age-matched controls Measures: 1. The Radiumhemmetts Scale of Sexual Function 2. Four-grade scale—for sexual, urinary, bowel symptoms, and related distress | Majority distressed by waning sexual capacity Urinary and bowel symptoms less common than waning sexual function Decline in sexual function is the most common cause of disease-specific distress | Symptom distress not defined No details of symptom distress measures Defined disease-specific symptoms |
| Litwin et al ³² | Develop and evaluate a self-administered, multi-item, disease-specific measure of health concerns central to QOL | Sample: 255 patients and 273 age- and zip code-matched controls Measures: 1. UCLA-PCI—for urinary function, sexual function, bowel function, urinary bother, sexual bother, and bowel bother (test-retest reliability: 0.66–0.93; internal consistency: 0.65–0.93) 2. CARES-SF sexual function scale 3. SF-36—measures general health domains and emotional well-being | Disease-targeted measures of function and bother in urinary function, sexual function, and bowel function correlated substantially Men undergoing prostatectomy or EBRT showed expected differences in performance on the disease-specific HRQOL Age inversely related to sexual and bowel functions | Symptom distress not defined Addressed specific symptoms and distress as important indicators for HRQOL |
| Lilleby et al ⁶¹ | Assess morbidity, side effects, and QOL | Sample: 154 patients post-EBRT and 108 patients post-RP Measures: 1. EORTC QLQ-C30 2. IPSS subscale—LUTS 3. PAIS—for sexuality 4. Ad hoc constructed questionnaires—for urinary incontinence and bowel distress | 20% of men post-EBRT reported moderate or severe LUTS 35% of men post-RP had moderate to severe urinary incontinence Sexuality moderately or severely impaired in 71% of post-RP group and 50% of EBRT group; 13%–38% of total sample reported moderate to severe bowel distress 9% of EBRT group and 6% of RP group reported moderately or severely impaired QOL In the multivariate analysis, physical and emotional distress and fatigue were significantly correlated with QOL In the univariate analysis, sexuality, lower urinary tract symptoms, and urinary incontinence significantly correlated with HRQOL | Symptom distress not defined Symptoms were indicators of HRQOL Symptom distress not measured |

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| Authors | Purpose | Methods | Findings | Strengths/Weaknesses |
|---------------------------------|---|--|--|--|
| Clark and Talcott ¹⁴ | Develop indexes of urinary, bowel, and sexual function, and related distress | <p>Sample: 184 patients undergoing RP or EBRT</p> <p>Measures:</p> <ol style="list-style-type: none"> Symptom indexes: urinary incontinence; bowel symptoms associated with treatment, and sexual dysfunction <p>Internal consistency $\alpha = .86$ (urinary incontinence), $.67-.89$ (sexual dysfunction), and $.80$ (bowel function)</p> <ol style="list-style-type: none"> SF-36 for HRQOL POMS for total mood disturbance | <p>Symptom and symptom-related distress indexes in each domain highly correlated</p> <p>Symptom indexes accounted for significant proportions of the variance in HRQOL measures</p> <p>Symptom indexes valuable for explaining variation in measures of HRQOL</p> | <p>Defined disease-specific symptoms and related distress</p> <p>Developed multi-item indexes</p> <p>Measured the intensity of physical symptoms and evoked distress</p> |
| Schapira et al ⁶² | Describe the effect of treatment choice on change in HRQOL in men with clinically localized prostate cancer | <p>Sample: 122 patients (42 EBRT, 51 RP, 29 expectant management)</p> <p>Measures:</p> <ol style="list-style-type: none"> UCLA-PCI SF-36 | <p>Treatment choice significantly affects changes in QOL 1 y after treatment</p> <p>Patients with RP group had significantly greater declines in urinary function and sexual function than EBRT and expectant management groups</p> <p>RP group had declines in sexual function; undergoing expectancy management group had no change in disease-specific or general HRQOL 1 y after treatment</p> | <p>No definition of symptom distress</p> <p>Measured specific-disease symptom distress</p> <p>Viewed symptom distress as one of the indicators for HRQOL</p> |
| Wei et al ⁵⁷ | Develop a novel instrument to facilitate comprehensive assessment of prostate cancer-related HRQOL | <p>Sample: 252 patients</p> <p>Measures:</p> <ol style="list-style-type: none"> UCLA PCI EPIC for urinary, bowel, sexual, and hormonal concerns (ie, breast tenderness, hot flash); each of the 4 principal domain summary scores internally consistent ($\alpha \geq .82$ for each); test-retest reliability ($r \geq 0.80$ for each) Validated survey instruments used to assess function and bother across a broad range of possible health states to obtain a comprehensive assessment of | <p>Test-retest reliability and internal consistency were high for EPIC urinary, bowel, sexual, and hormonal domain summary scores and for most domain-specific subscales</p> <p>Correlations between function and bother subscales within domains were high ($r \geq 0.4$ in 47 of 50 items and >0.27 in all)</p> <p>EPIC had weak to modest correlations with SF-12</p> <p>Moderate agreement between EPIC domains relevant to the FACT-P and AUA-SI</p> | <p>Symptoms and symptom distress not defined</p> <p>Viewed symptoms and symptom distress as indicators of HRQOL</p> |

 **Table • continued**

| Authors | Purpose | Methods | Findings | Strengths/Weaknesses |
|------------------------------|---|--|---|---|
| Wei et al ⁶³ | Test whether long-term HRQOL outcomes differ after BT, EBRT, or RP for localized prostate cancer | <p>HRQOL:</p> <p>(a) SF-36</p> <p>(b) FACT-G for general HRQOL</p> <p>(c) FACT-P for prostate HRQOL</p> <p>(d) AUA-SI</p> <p>Sample: 902 patients (84 BT, 147 EBRT, 671 RP, and 112 volunteers as control group)</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. EPIC 2. FACT-P 3. FACT-G 4. SF-36 | <p>All groups reported bothersome sexual dysfunction</p> <p>RP was associated with adverse urinary HRQOL, EBRT associated with adverse bowel HRQOL, and BT associated with adverse urinary, bowel, and sexual HRQOL</p> <p>Long-term HRQOL outcomes less favorable among subjects post-BT than post-EBRT or post-RP</p> | <p>Symptoms, symptom distress not defined</p> <p>Viewed symptom distress as an HRQOL indicator</p> |
| Steineck et al ²² | To evaluate symptoms and self-assessments of QOL in men with localized prostate cancer who participated in a randomized trial comparing RP and watchful waiting | <p>Sample: 376 patients</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. Questionnaires measuring symptom quality, frequency, and intensity 2. Verbal scale of intensity of symptom distress for 7 specific symptoms 3. STAI and the CES-D for anxiety and depression 4. Seven-point visual digital scales—measured psychological symptoms, well-being, and subjective QOL | <p>Frequency of sexual thoughts similar between groups</p> <p>Prevalence of satisfactory erectile function higher in the watchful waiting group</p> <p>56% of the RP groups were distressed (moderately or greatly) by a decline in sexual function as higher than watchful waiting group</p> <p>50% of the RP groups had urinary leakage at least weekly</p> <p>28% of the RP groups and 44% of watchful waiting groups reported a weak urinary stream</p> <p>27% of the RP groups and 18% of watchful waiting group reported moderately or greatly distressed by urinary problems (obstruction and leakage)</p> <p>The RP group had a lower prevalence of psychological symptoms</p> <p>Both groups reported low to moderate subjective QOL</p> | <p>Symptoms or symptom distress not defined</p> <p>Viewed symptoms and symptom distress as HRQOL indicators</p> |
| al-Abany et al ²⁸ | Investigate whether external beam radiation treatment with 3 or 4 fields affect the risk of long-term distressful symptoms | <p>Sample: 158 patients divided into 4 groups by treatment field</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. Questionnaire to measure symptom | <p>Posttreatment with a multileaf collimator: defecation urgency, diarrhea and loose stools more common after 4 fields than 3 fields</p> | <p>Symptom distress not defined</p> <p>Measured symptoms and symptom distress including quality, frequency, intensity, and bother</p> |

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Table • continued

| Authors | Purpose | Methods | Findings | Strengths/Weaknesses |
|-----------------------------|---|---|---|--|
| | | <p>intensity and distress of bowel, urinary, and sexual function</p> <ol style="list-style-type: none"> Quality, frequency, and intensity of symptoms assessed using 6 response alternatives, eg, "no symptom," "once a week," "7 times a week or more" Level of symptom distress was assessed with a "verbal" 4-category scale (none/little/moderate/much) STAT Psychological symptoms, well-being, and the subjective QOL-assessed on 7-point visual digital scales | <p>Fecal leakage and gastrointestinal tract distress less common</p> <p>Fecal leakage symptoms had strongest association with gastrointestinal distress</p> <p>Three fields without a multileaf collimator resulted in a higher risk of defecation urgency than 3 fields with a multileaf collimator</p> | |
| Talcott et al ⁵⁹ | Characterized the time course of treatment complications while adjusting for potentially confounding pretreatment factors, which had hindered other observational studies | <p>Sample: 417 patients</p> <p>Measures:</p> <ol style="list-style-type: none"> SF-36 Symptom indexes for treatment-related symptoms and symptom distress | <p>Patients who underwent EBRT, RP, and BT differed significantly in pretreatment symptom status, especially sexual function</p> <p>Urinary incontinence increased sharply after RP; bowel problems and urinary irritation/obstruction rose after EBRT and BT</p> <p>Sexual dysfunction increased in all patients, particularly after RP, and nerve-sparing surgical technique had little apparent benefit</p> <p>No change in urinaryfunction and little change in overall bowel function after 12 mo; time course of sexual dysfunction varied by treatment and, for bowel function, by symptom</p> | <p>Symptom distress not defined</p> <p>Viewed symptoms and symptom distress as outcome predictors of treatment</p> |
| Visser et al ⁶⁵ | Measure changes in HRQOL (general and prostate specific) 3 mo postdiagnosis | <p>Sample: 23 men with early-stage prostate cancer and 38 BPH</p> <p>Measures:</p> <ol style="list-style-type: none"> EORTC QLQ-C30 IPSS The Sexual Behavior Questionnaire | <p>Decreased QOL (general well-being and the daily activities and social contact) for prostate cancer patients</p> <p>Micturition symptoms diminished in both groups</p> | <p>Symptom distress and psychological distress not defined</p> <p>Symptom distress not measured specifically</p> <p>Viewed symptoms and symptom distress</p> |

 **Table • continued**

| Authors | Purpose | Methods | Findings | Strengths/Weaknesses |
|-------------------------------|---|---|---|---|
| | | <p>4. Coping style for sexual functioning:</p> <p>(a) Shortened Dutch version of the standardized COPE for coping style</p> <p>(b) POMS</p> <p>(c) LES for life events</p> <p>(d) SSQ—measured social support</p> <p>(e) A Dutch version of the Social Desirability Scale—measured social desirability</p> <p>(f) Questionnaires for health behavior</p> | Decline QOL influenced by social support and the active problem solving | as outcome indicators of treatment |
| Rosenfeld et al ²³ | Analyze the relationship between cancer stage and QOL, including measures of physical and psychological well-being | <p>Sample: 341 patients including those with localized (n = 186), locally advanced (n = 92), and metastatic disease (n = 63)</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. FACT 2. UCLA PCI 3. HADS for anxiety and depression | <p>Prostate cancer stage significantly associated with most FACT scales (physical, functioning, social) and summary scores (Treatment Outcomes Index, FACT total score)</p> <p>No significant associations between cancer stage and depression or anxiety</p> | Symptom distress not measured specifically Symptoms represented HRQOL indicator HRQOL not defined |
| Steginga et al ⁶⁹ | Prospective longitudinal study to assess psychological and decision-related distress after diagnosis of localized prostate cancer | <p>Sample: 113 patients (56% had RP; 19% had EBRT; 25% had watchful waiting)</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. UCLA PCI 2. IPSS 3. RIES for psychological response to cancer diagnosis 4. Constructed Meaning Scale for implications of cancer on identity, interpersonal relationships, and the future 5. Satisfaction With Life Scale for global QOL or satisfaction with life 6. Health Care Orientation subscale for adjustment of cancer 7. Decisional Conflict Scale—measured decision-related distress | <p>No significant differences in psychological and decision-related adjustment at baseline or with time</p> <p>Men who were undecided about treatment had greater decisional conflict, more negative healthcare orientation, and less psychological distress than men who had decided</p> <p>At diagnosis, 63% of all participants had high decision-related distress that persisted in 42% 12 mo after treatment</p> <p>At diagnosis, low-to-moderate psychological distress most common, with distress decreasing after treatment</p> <p>Overall QOL similar to community norms</p> | <p>No theoretical or operational definitions of symptom distress, psychological distress, or decision-related distress</p> <p>Measured specific symptom distress related to prostate cancer, psychological distress, and decision-making-related distress</p> |
| Seo et al ⁷¹ | Compared the short-term changes in disease-specific symptoms and symptom bother scores in men who received MB | <p>Sample: 85 patients (63 MB and 22 BT)</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. Symptom Severity and Distress Questionnaires | <p>MB group had a greater increase in urinary obstruction/irritation symptoms and sexual function distress, but not</p> | <p>Symptom distress not defined</p> <p>Measured symptom severity and distress</p> |

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Table • continued

| Authors | Purpose | Methods | Findings | Strengths/Weaknesses |
|-------------------------------|---|--|---|---|
| Galbraith et al ⁷⁰ | Describe HRQOL health status and marital satisfaction of couples up to 5.5 y after treatment of prostate cancer | <p>for sexual, urinary, and bowel complications of treatment</p> <p>2. The Medical Outcomes Study Problems Scale for sexual dysfunction distress</p> <p>Sample: 192 prostate cancer survivors (137 completed) and 126 partner (104 completed)</p> <p>Measures:</p> <ol style="list-style-type: none"> 1. Quality of Life Index for biophysical symptoms, psychological and social factors, and general QOL 2. SF-36 3. Southwest Oncology Group Prostate Treatment-Specific Symptoms Measure (19 items)—symptoms were related to bowel, bladder, and sexual functioning; reliability coefficient = 0.42–0.93 4. Dyadic Adjustment Scale (32 items)—assessed the quality of marriage and other similar dyads and satisfaction with the relationship | <p>sexual dysfunction; BT group reported a small increase in bowel symptoms and bowel distress</p> <p>QOL generally decreased in both survivor and partner groups over the 4 y</p> <p>General health decreased and physical functioning declined overall over the 4 y</p> <p>Men in the low-dose mixed-beam RT group had fewer role limitations caused by emotional problems at 2.5 y than did the men in the watchful-waiting group</p> <p>Men in the low-dose mixed-beam RT group reported fewer gastrointestinal tract symptoms than men in high-dose mixed-beam RT</p> <p>Urinary symptoms increased over time</p> <p>Sexual concerns tended to increase for the high-dose mixed-beam RT groups</p> <p>Participants were more concerned with sexual issues than other prostate cancer treatment-related side effects</p> <p>Couples' HRQOL, marital satisfaction, and health status were partially associated</p> | <p>No measures of symptom distress but measure of symptoms including intensity and frequency</p> <p>Symptom occurrence was viewed as HRQOL indicators</p> |

Abbreviations: AUA-SI, American Urological Association Symptom Index; BPH, benign prostate hyperplasia; BT, brachytherapy; CARES-SF, Cancer Rehabilitation Evaluation System—Short Form; CES-D, Center for Epidemiological Studies Measure of Depression; EBRT, external beam radiotherapy; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer QLQ-C30 instrument; EPIC, Expanded Prostate Cancer Index Composite; FACT-G, Functional Assessment of Cancer Therapy General module; FACT-P, Functional Assessment of Cancer Therapy Prostate module; HADS, Hospital Anxiety and Depression Scale; HRQOL, Health-Related Quality of Life; IPSS, International Prostate Symptom Score; LES, Dutch version of the Life Experience Survey; LUTS, lower urinary tract symptoms; MB, magnetic resonance imaging brachytherapy; PAIS, Psychosocial Adjustment to Illness Scale; POMS, Profile of Mood States; QOL, quality of life; RIES, Revised Impact of Event Scale; RP, radical prostatectomy; RT, radiation therapy; SF-12, Medical Outcomes Study 12-item Short-Form Health Survey; SF-36, Medical Outcomes Study 36-item Health Survey; SSQ, Shortened Social Support Questionnaire; STAI, State-Trait Anxiety Inventory; UCLA PCI, University of California Los Angeles Prostate Cancer Index.

Subjects were asked to mark a sensory scale to reflect the physical intensity of the pain stimulus and a separate distress scale to reflect “the amount of distress the sensations caused” or “how much the sensations bother them.”⁴⁹

In their early work, McCorkle and Young⁴⁶ defined symptom distress as “the degree of discomfort from the specific symptom as reported by patient.” They later modified

this definition to “the degree of discomfort reported by the patient in relation to their perception of the symptoms being experienced.”⁸⁰ The latter definition was applied to the development of the Symptom Distress Scale, which operationalized symptom distress as the sum of responses to symptom intensity and frequency items. It was the first study to determine that symptom distress did not need to be differentiated

according to whether it resulted from the disease itself or from the treatment. Of note, the Symptom Distress Scale has never been used in studies of prostate cancer–related symptom distress.

Three instruments focus on the measurement of symptoms and symptom distress in men with prostate cancer. Two of those specifically target men with early-stage prostate cancer. The UCLA Prostate Cancer Index (UCLA-PCI) is the first disease-targeted measure of function and bother pertaining to 3 domains (urinary, sexual, and bowel).³² These domains are significantly correlated with one another: urinary problems with urinary bother ($r = 0.71$; $P < .0001$), sexual dysfunction with sexual bother ($r = 0.73$; $P < .0001$), and bowel problems with bowel bother ($r = 0.65$; $P < .0001$). Test-retest reliability for the UCLA-PCI is 0.66 to 0.93, and internal consistency is .65 to .93.³² Wei et al.⁵⁷ expanded the UCLA-PCI to develop the Expanded Prostate Cancer Index Composite (EPIC). EPIC is a comprehensive tool for assessing health-related quality of life in patients with prostate cancer. The EPIC contains 4 domains—urinary, bowel, sexual, and hormonal concerns (ie, breast tenderness, hot flash), and each of the domain summary scores has demonstrated robust internal consistency (Cronbach $\alpha \geq .82$ for each) and test-retest reliability ($r \geq 0.80$ for each). Individual items generally yielded high item correlation ($r \geq 0.40$ in 47 of 50 items). The EPIC complements prior instruments by measuring a broad spectrum of urinary, bowel, sexual, and hormonal symptoms.^{57,63}

The Symptom Indexes were developed by Clark and Talcott¹⁴ to focus on patient-reported items that assess symptoms of dysfunction in 4 domains—urinary problems (urinary incontinence, urinary obstruction/irritation), sexual dysfunction, bowel problems, and related distress. These indexes include disease-specific symptoms and symptom distress related to early-stage prostate cancer. The symptom and distress indexes for urinary problems in each domain are highly correlated. The urinary incontinence index had higher internal consistency ($\alpha = .86$), item-index convergence, and divergence from the urinary obstruction/irritation index. The sexual dysfunction index is internally consistent, although item-index convergence correlations varied from $\alpha = .67$ to .89. The bowel function index also had a good internal consistency ($\alpha = .80$).¹⁴

Measuring symptoms and symptom distress in men with prostate cancer is very important both clinically and in research but often neglected. Several other studies have used the UCLA-PCI, Symptom Indexes, or EPIC to measure symptoms and symptom distress to represent indicators of health-related quality of life or outcome indicators of treatments in localized prostate cancer.^{10,14,32,61,62}

■ Discussion

Based on findings reported here, 4 major issues were identified. These issues include prostate cancer treatment–related symptoms, inconsistent definition of symptom distress, measuring symptom distress in men with prostate cancer, and

limited focus on outcome measures and mediating variables and are discussed in the following sections.

Prostate Cancer Treatment-Related Symptoms

Localized prostate cancer is not a trivial condition in that men affected with this disease experience a variety of distressful symptoms from diagnosis through treatment and thereafter. The literature reveals the 3 most commonly experienced symptoms are urinary incontinence, sexual dysfunction, and bowel dysfunction. Studies of symptom clusters such as these are a priority area for nursing research identified by the Oncology Nursing Society.⁸¹ Nurses working with patients with localized prostate cancer have an ideal opportunity to better characterize the distressful nature of these symptoms in this early phase of disease.

Inconsistent Definition of Symptom Distress

Precise and rigorously constructed definitions of concepts improve the development of theory, research, and practice in nursing. Knowledge of symptom distress may aid in clarifying differences between symptom distress and other related concepts, investigating the relationships between symptom distress and related factors, and developing interventions targeting symptom distress. Many studies of symptoms and symptom distress among men with prostate cancer lacked theoretical or operational definitions or had inconsistent definitions between theoretical and operational definitions.^{22,23,61} Unclear definitions of symptom distress and inconsistency among theoretical definitions and operational definitions of symptom distress are important issues for further research. Clarification of the conceptual definition of symptom distress will aid in our ability to measure this important concept and its relation to other factors such as health-related quality of life. Based on this literature review, we defined symptom distress as “the perception of physiological or psychological discomfort resulting from a particular symptom experienced by patients with localized prostate cancer.” This alternative definition of symptom distress is more complete and population focused than other definitions. The alternative definition and critical attributes of symptom distress are more directly applicable to clinical practice in the specific area of prostate cancer.

Measuring Symptom Distress in Men With Prostate Cancer

Accurate measures of symptom distress and symptom occurrence are essential for symptom management and quality of life. A measure of symptom distress should be based on a clear operational definition. Although several instruments are specific for prostate cancer, the lack of a clear definition of symptom distress has continued to exist in reports of symptom distress and health-related quality of life. The majority of established measures of symptoms and symptom

distress do not include disease-specific domains (ie, urinary incontinence, sexual dysfunction, and bowel problem) relevant to men with localized prostate cancer. Using disease-specific domains rather than items on existing measures is another focus for future research. Knowledge of symptom distress may aid in assessment of patients' responses to stress, adverse events of treatments, and perceived healthcare needs or problems. Furthermore, symptom distress may broadly apply to the development of strategies for symptom self-management and the perceived effectiveness of different modes of treatment. Most researchers do not measure both the severity and level of distress associated with a specific symptom. Although researchers have begun to shift attention to the definition and measurements of symptom distress, more work is needed to clarify the variables under study.

Limited Focus on Outcome Measures and Mediating Variables

Symptom distress is used to describe the subjective experience of people in various states of health and illness. Symptom distress hampers self-care, threatens independence, decreases self-esteem, and renders lack of control or power. Symptom distress is related to quality of life, treatment tolerance, and survival in patients with cancer and other illnesses.⁴⁸ Based on the results of this literature review and concept analysis, symptom distress provides important information about quality of life, and it appears to be an indicator of health-related quality of life in most studies of prostate cancer. Previous studies have shown that symptoms and symptom distress were negatively correlated with health-related quality of life in men with prostate cancer. Collective evidence shows that the number of symptoms and level of symptom distress are negatively correlated with quality of life. However, regardless of the definition of symptoms and symptom distress, studies have not yet established a relationship among these concepts and other outcomes (ie, decision regret, decisional control, or treatment satisfaction).

Several studies have also used symptoms and symptom distress as indicators of treatment outcomes in men with prostate cancer. A few studies have investigated the relationships among symptom distress, treatment modalities, stage of disease, and mediating variables (ie, stress or social support group). Therefore, more studies are needed to explore the relationships among symptoms, symptom distress, influential factors, mediating variables, and outcome measures in men with prostate cancer.

■ Implications

A lack of knowledge that helps differentiate symptom distress and related concepts, such as health-related quality of life or symptom experiences, still exists. In particular, relationships among symptom distress, influencing factors, and antecedents and consequences of symptom distress are not well elucidated

in men with localized prostate cancer. Consequences of symptom distress may include stress, symptom self-management, health-related quality of life, or physiological function. Clearly, more research is needed to enhance knowledge of all these factors.

More comprehensive information about symptoms and symptom distress will provide nurses with a better foundation for developing self-management interventions aimed at ameliorating symptom distress and, ultimately, enhancing the quality of life in men with localized prostate cancer.

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