

Evaluating health-related quality of life and priority health problems in patients with prostate cancer: A strategy for defining the role of the advanced practice nurse

by Denise Bryant-Lukosius, Gina Browne, Alba DiCenso, Tim Whelan, Amiram Gafni, Alan Neville, and Jinka Sathya

Évaluation de la qualité de vie liée à la santé et des problèmes de santé prioritaires chez les patients atteints du cancer de la prostate : stratégie de définition du rôle des infirmières en pratique avancée

Abrégé

Un cadre régissant l'institution et l'évaluation des rôles en pratique infirmière avancée (PIA) souligne l'importance de l'adoption d'une approche méthodique dans le développement de rôles basés sur l'évaluation des besoins de santé des patients. Cette étude visait à déterminer la qualité de vie liée à la santé (QVLS) chez les patients atteints du cancer de la prostate afin de comparer les perceptions, de cerner les problèmes de santé les plus graves et les plus fréquents et enfin, de dégager les perceptions des patients, le tout en vue d'éclairer le développement du rôle en matière de soins de soutien des infirmières de formation avancée en oncologie auprès des patients atteints d'un cancer de la prostate avancé.

L'étude a permis de découvrir que la majorité des hommes porteurs d'un cancer de la prostate de stade précoce ou de stade avancé mais hormono-sensible peuvent s'attendre à bénéficier d'une bonne qualité de vie plusieurs années après le diagnostic. Ces deux groupes de patients ont des besoins prioritaires communs sur le plan de l'amélioration de leur état de santé dans les domaines du fonctionnement sexuel, de la fréquence et de l'incontinence urinaires et de l'activité physique. Ces deux groupes pourront tirer parti des interventions liées à un rôle en PIA en oncologie visant à leur fournir des soins de soutien épisodiques relativement aux problèmes de santé survenant à différentes étapes du traitement.

En revanche, on a découvert que les hommes porteurs d'un cancer de la prostate avancé androgéno-indépendant ont une QVLS bien plus mauvaise et de multiples problèmes de santé graves. De même, ces patients ont des besoins prioritaires différents, notamment des problèmes relatifs à la douleur, à la fatigue et à une activité physique réduite. C'est la raison pour laquelle l'orientation des programmes et des interventions en matière de soins de soutien pour les patients atteints de cancer de la prostate avancé diffère de celle des programmes et interventions reliés au cancer androgéno-indépendant. Les patients atteints de ce dernier type tireront meilleur profit d'un rôle en PIA visant à leur fournir des soins de soutien continus plutôt qu'épisodiques afin que puissent être évalué et gérés les multiples problèmes de santé—nouveaux ou s'aggravant—associés à la progression de la maladie.

Abstract

A framework for the introduction and evaluation of APN roles emphasizes the importance of a systematic approach to role development based on the assessment of patient health needs. This study determined the health-related quality of life (HRQL) of patients with prostate cancer. The most frequent and severe patient health problems and their perceptions of priority health problems were identified and compared across five patient groups as a strategy to inform the supportive care role of the advanced oncology nurse for patients with advanced prostate cancer.

The study found that the majority of men with early stage and advanced hormone sensitive prostate cancer can expect to enjoy good quality of life for several years following diagnosis. These two patient groups have common priority needs for improving their health related to sexual function, urinary frequency, urinary incontinence, and physical activity. Both groups may benefit from an advanced practice nursing (APN) role that can provide episodic supportive care for health problems occurring at different treatment stages.

Denise Bryant-Lukosius, PhD, RN, School of Nursing and Department of Oncology, McMaster University. Director, the Canadian Centre of Excellence in Oncology Advanced Practice Nursing (OAPN), Juravinski Cancer Centre.

Gina Browne, PhD, RN, School of Nursing and Department of Clinical Epidemiology and Biostatistics, McMaster University, System-Linked Research Unit on Health and Social Service Utilization.

Alba DiCenso, PhD, RN, School of Nursing and Department of Clinical Epidemiology and Biostatistics, McMaster University, CHSRF/CIHR Chair in Advanced Practice Nursing.

Tim Whelan, BSc, BMBCh, FRCP(C), Department of Oncology, McMaster University, Supportive Cancer Care Research Unit, Juravinski Cancer Centre.

Amiram Gafni, BSc, MSc, DSc, Department of Clinical Epidemiology and Biostatistics, McMaster University, System-Linked Research Unit on Health and Social Service Utilization.

Alan Neville, MB, ChB, MRCP, FRCP(C), Department of Oncology, McMaster University, the Juravinski Cancer Centre.

Jinka Sathya, MD, FRCP(C), Department of Radiation Oncology, CancerCare Manitoba.

Corresponding author: Denise Bryant-Lukosius, Room 3N25D, Faculty of Health Sciences, McMaster University, 1200 Main Street West, Hamilton, ON L8N 3Z5; E-mail: bryantl@mcmaster.ca; Phone: 905-525-9140 ext. 22408; Fax: 905-524-5199

Conversely, it was found that men with advanced hormone refractory prostate cancer experience significantly poorer HRQL and have multiple severe health problems. These patients also have different priority needs including problems related to pain, fatigue, and decreased physical activity. Because of this, the focus of supportive care programs and interventions in advanced prostate cancer will differ for those with hormone refractory disease. They may benefit more from an APN role that can provide ongoing rather than episodic supportive care to assess and manage the multiple, new, and worsening health problems associated with progressive disease.

Introduction

Organizations often fail to conduct a needs assessment when introducing advanced practice nursing (APN) roles. Needs assessments are important for developing new roles and effective health care services because they include patients and families in the planning process (Pallant, 2002). APN roles are most effective when they are designed to complement existing provider roles and services and to address gaps in meeting patient health needs (Bryant-Lukosius, Vohra & DiCenso, 2009). Barriers to role implementation and ability to meet patient needs may occur when the goals of an APN role for improving care delivery are not well defined or understood by the health care team.

Two types of APN roles are recognized in Canada—the clinical nurse specialist (CNS) and the nurse practitioner (NP) (Canadian Nurses Association, 2008). Both roles have distinct and important contributions to cancer care (Canadian Association of Nurses in Oncology, 2001; Cancer Care Ontario, 2009) and decisions about role selection are influenced by patient health needs, goals for improving care delivery, existing human resources, how cancer services are organized and delivered and the required scope of practice.

Little is known about the most effective models of APN care for patients with prostate cancer, especially those with advanced disease. The need to improve supportive and palliative care in prostate cancer has been identified by patients, families, and health care providers (Canadian Cancer Society, 1997). Among Canadian men, prostate cancer is the most frequently diagnosed cancer and the third leading cause of cancer-related death (Canadian Cancer Society, 2008). Prostate cancer is a chronic illness in which 25% to 40% of men who receive curative therapy for local disease will go on to develop advanced disease (Freedland et al., 2005). Supportive care needs may vary with stage of disease, type of treatment, and time since diagnosis. Men with advanced disease may have different needs from the newly diagnosed or those with localized prostate cancer (Butler, Downe-Wamboldt, Marsh & Bell, 2001; Esper & Redman, 1999; Lintz et al., 2003). Organizational factors such as how services are coordinated and the number and mix of health providers across the illness trajectory can impact on patient care and ability to meet health needs. When planning health services for chronic conditions like advanced prostate cancer, examining needs across the care continuum may provide key information about gaps in meeting long-term needs. No studies to date have examined patient priorities for improving prostate cancer care.

This paper describes the first of three studies using a patient-centred approach to conduct a comprehensive needs assessment that will determine the need for, and type of APN role to introduce within a cancer centre for patients with advanced prostate cancer. The PEPPA Framework or a participatory, evidence-based, patient-centred process for APN role development provided the conceptual guide for this needs assessment (Bryant-Lukosius & DiCenso, 2004). In step three of this nine-step framework, assessing health-related quality of life (HRQL) is one strategy for identifying patient health needs. Variations in HRQL may highlight patterns of unmet supportive care needs across patient groups such as those with local

or advanced stage prostate cancer that require new or tailored services to improve patient health (Till, 1994). HRQL has been used as an outcome indicator in clinical trials and other studies of prostate cancer (Dacal, Sereika & Greenspan, 2006; Duke, Treloar & Byles, 2005; Gore, Kwan, Lee, Reiter & Litwin, 2009). Few studies compare HRQL in local and advanced prostate cancer and none of these comparisons include patients with hormone refractory disease (Duke et al., 2005; Lubeck et al., 1999; Rosenfeld, Roth, Gandhi & Penson, 2004). Studies of HRQL in hormone refractory disease are limited to treatment-specific issues (Canil et al., 2005).

The purpose of this descriptive study was to examine patient perceptions of their HRQL and health care needs related to prostate cancer across five stages in the continuum of care from the time of diagnosis through to palliation. More specifically, the study sought to identify and compare: 1) patient perceptions of HRQL, 2) the most frequent and severe health problems affecting HRQL, and 3) patient perceptions of priority health problems.

As the first step in a comprehensive needs assessment process, study results will inform organizational planning to improve the overall model of care for prostate cancer and, more specifically, to develop and evaluate an APN role for patients with advanced prostate cancer.

Methods

Study design and setting

This cross-sectional study was carried out at a university-affiliated regional cancer centre (RCC) in Ontario, Canada. Within its region, there are 1,200 new diagnoses and more than 175 deaths due to prostate cancer each year (Cancer Care Ontario, 2008). Patients are referred to the RCC by family physicians and community urologists primarily for radiation and/or medical treatment.

Definition of study groups

A panel including a clinical nurse specialist, two medical oncologists and a radiation oncologist categorized patients into five groups based on stage of disease and treatment. Patients with T1 to T3 disease according to the Tumour-Node-Metastasis Staging Classification System were categorized into three groups. Early stage newly diagnosed patients (E-NEW) had not yet begun treatment. Early stage on treatment (E-RX) patients were receiving radical radiation therapy. Early stage follow-up (E-FLP) patients were receiving surveillance care more than two months post-radical radiation treatment. Patients with T4 or metastatic disease had advanced disease and were categorized as being hormone sensitive (A-HS) or hormone refractory (A-HR). The A-HS group included newly diagnosed patients prior to treatment and those receiving androgen blockade therapy. Patients in the A-HR group were receiving surveillance care, chemotherapy, palliative radiation, or other symptom management measures.

Sample

Eligible patients were those who gave written informed consent, understood English, and had the physical and cognitive abilities to complete a self-report questionnaire. A minimum of 84 patients per group was required to detect a 2-point difference between groups in HRQL subscale scores and a seven- to 10-point difference in HRQL total scale scores (power = 90%, $p = 0.05$).

Procedure and instruments

The study received ethics approval from the participating RCC and local ethics review board. Research assistants approached patients for study participation during scheduled clinic appointments. Participants completed the questionnaire at this same time, following written,

informed consent. The questionnaires took about 20 minutes to complete. Demographic and health status information were abstracted from patient health records (Table One). PSA levels were documented in patients who completed this test as part of routine care within the two weeks prior to or following completion of the study questionnaire.

Quality of life

HRQL was assessed using the general 27-item Functional Assessment of Cancer Therapy (FACT-G version four) scale and the 12-item prostate cancer specific tool, FACT-P (version four) scale. The FACT-G has four subscales related to physical, social, emotional, and functional well-being (Cella et al., 1993). Both tools utilize a Likert-type scale measuring from 0 to 4, with higher scores representing greater health. The scales have been validated and used in a range of cancer populations (Bonomi et al., 1996; Cella, 1997; Esper et al., 1997; Yu et al., 2000).

Frequency and severity of health problems

Severe health problems were defined as any Total FACT-P item in which patients scored 0 to 1 out of 4 indicating poor HRQL.

Priority health problems

A list of 38 health problem items was developed from several HRQL instruments and the prostate cancer research literature (Borghede & Sullivan, 1996; Davison, Degner & Morgan, 1995; Davison & Degner, 1997; Litwin et al., 1995). From this list, respondents were asked to identify the three most important problems, which, if addressed, would improve their health.

Statistical analysis

Percentages and mean scores were used to describe the data and Cronbach's alpha scores were used to assess the internal consistency of all scales. The primary analysis involved comparisons of HRQL.

Group differences were examined using chi-square for categorical variables and analysis of variance (ANOVA) for continuous variables. When significant differences occurred in the ANOVA, Scheffé's method of post hoc comparison was used to identify the pairs of patient groups involved (Kleinbaum & Kupper, 1978). Based on previous research (Cella et al., 1995; Jaeschke, Singer & Guyatt, 1989; Lee, McQuellon, Harris-Henderson, Case & McCullough, 2000; McQuellon et al., 1997), 2-, 7-, and 10-point differences between groups on FACT subscales, FACT-G, and Total FACT-P scores respectively were defined a priori as clinically important differences in HRQL. Stepwise multiple regression was used to determine if specific patient and prostate cancer-related characteristics were predictors of HRQL, as measured by the Total FACT-P. All subjects met or exceeded the instrument's criteria for completeness of data (Cella, 1997). The Statistical Package for the Social Sciences (SPSS) Version 10.0.0 was used for all analyses (SPSS Inc., 1999).

Results

Sample

Over a four-month period, 631 patients were approached and 551 (87%) participated in the study. Less than 13% declined participation (n = 42) or were unable to complete the questionnaire (n = 35). Three patients had a history of prostate cancer, but were not referred for prostate cancer treatment. The required sample of 84 patients per group was achieved in all but the E-NEW group. Accrual of these patients was hampered by low referrals over the summer months when the study took place. The number of subjects in each group included: E-NEW (69), E-RX (134), E-FLP (128), A-HS (110), and A-HR (110).

Demographic and health data

Participants were mostly elderly and married men living with their spouse or other family members (see Table One). Co-morbidity was

Table One. Characteristics of study sample and comparisons of group differences

Characteristics	Total n = 551	E-NEW n = 69	E-RX n = 134	E-FLP n = 128	A-HS n = 110	A-HR n = 110	Test (df)	P *
Age (years) Mean (SD)	71.47 (6.94)	70.20 (6.80)	68.99 (7.33)	72.14 (5.98)	73.80 (5.81)	72.16 (7.65)	F = 8.94 (4, 446)	< 0.001
Married %	81.9	78.3	88.1	74.2	81.8	85.5	$\chi^2 = 24.32$ (16)	0.03
Live with family %	83.5	82.6	88.8	76.6	82.7	86.4	$\chi^2 = 14.10$ (8)	0.078
Co-morbidity %	87.7	87.0	86.6	87.5	89.1	88.2	$\chi^2 = 0.418$ (4)	0.981
Mental illness %	7.8	5.8	3.7	4.7	9.1	16.4	$\chi^2 = 16.65$ (4)	0.002
Years since diagnosis Mean (SD)	3.07 (3.11)	0.26 (0.23)	0.88 (0.97)	3.02 (2.05)	4.82 (2.80)	5.82 (3.66)	F = 107.60 (4, 446)	< 0.001
Stage at diagnosis %							$\chi^2 = 229.49$ (12)	< 0.001
I	21.3	41.8	23.1	28.1	13.0	5.1		
II	48.6	55.2	56.0	55.5	54.6	18.4		
III	19.3	3.0	20.9	16.4	22.2	28.6		
IV	10.8	0	0	0	10.2	48.0		
PSA ug/L Mean (SD)	66.46 (229.70)	16.61 (26.66)	3.76 (7.10)	2.45 (4.51)	12.34 (40.67)	261.39 (423.18)	F = 29.92 (4, 434)	< 0.001

Note: E-NEW = Early stage new diagnosis, E-RX = Early stage on treatment, E-FLP = Early stage > 2 months post treatment, A-HS = Advanced stage hormone sensitive, A-HR = Advanced stage hormone refractory.

*Significance at p = 0.01, significant values are bold.

Table Two. Comparison of health-related quality of life (HRQL) scores and disease status

HRQL	Total n = 551	E-NEW (n = 69)	E-RX (n = 134)	E-FLP (n = 128)	A-HS (n = 110)	A-HR (n = 110)	F test (df)	P **
Physical 0–28*	24.33 (4.40)	25.94 (3.57)	24.51 (4.28)	25.96 (2.70)	24.28 (3.87)	21.27 (5.45)	23.30 (4, 546)	< 0.001
Social 0–28*	21.63 (5.32)	22.08 (6.05)	21.44 (5.41)	21.75 (5.27)	20.89 (5.36)	22.20 (4.70)	1.043 (4,546)	0.38
Emotional 0–24*	19.18 (4.27)	18.34 (4.20)	19.97 (4.29)	20.53 (2.91)	19.53 (3.64)	16.80 (5.12)	15.169 (4,546)	< 0.001
Functional 0–28*	20.86 (6.16)	22.09 (6.03)	21.95 (5.94)	22.00 (6.42)	20.67 (5.054.9)	17.61 (6.14)	11.298 (4,546)	< 0.001
Prostate Ca 0–48*	33.91 (7.64)	37.16 (6.70)	34.68 (7.96)	35.85 (6.64)	33.05 (6.80)	29.53 (7.72)	16.602 (4,546)	< 0.001
FACT-G 0–108*	85.97 (14.49)	88.30 (14.04)	87.94 (14.47)	90.28 (12.36)	85.42 (12.81)	77.64 (15.42)	14.305 (4,546)	< 0.001
Total FACT-P 0–156*	119.86 (20.39)	125.46 (19.36)	122.63 (20.60)	126.12 (17.13)	118.44 (17.94)	107.10 (20.98)	17.782 (4,546)	< 0.001

Note: E-NEW = Early stage new diagnosis, E-RX = Early stage on treatment, E-FLP = Early stage > 2 months post treatment, A-HS = Advanced hormone sensitive, A-HR = Advanced hormone refractory. FACT-G = Physical + Social + Emotional + Functional Subscale Scores. Total FACT-P = FACT-G Score+ Prostate Cancer Subscale Score. *Score Range, higher scores signify better HRQL. **P significant at 0.007

Table Three. Post hoc comparisons of mean group differences in HRQL (Scheffé Method)

HRQL	Comparison groups	Mean difference (SE)	P **	95% CI around mean difference
Physical well-being	E-NEW and A-HR	4.60 (0.62)	< 0.0001	2.73 to 6.60*
	E-RX and A-HR	3.23 (0.52)	< 0.0001	1.61 to 4.86
	E-FLP and A-HR	4.68 (0.53)	< 0.0001	3.04 to 6.32*
	A-HS and A-HR	3.00 (0.55)	< 0.0001	1.30 to 4.70
Emotional well-being	E-RX and A-HR	3.17 (0.52)	< 0.0001	1.55 to 4.78
	E-FLP and E-NEW	2.18 (0.60)	0.0120	0.31 to 4.06
	E-FLP and A-HR	3.73 (0.52)	< 0.0001	2.09 to 5.36*
	A-HS and A-HR	2.72 (0.54)	< 0.0001	1.03 to 4.41
Functional well-being	E-NEW and A-HR	4.48 (0.91)	< 0.0001	1.66 to 7.30
	E-RX and A-HR	4.34 (0.76)	< 0.0001	1.98 to 6.70*
	E-FLP and A-HR	4.39 (0.77)	< 0.0001	2.00 to 6.77*
	A-HS and A-HR	3.06 (0.80)	0.0060	0.58 to 5.54
Prostate cancer well-being	E-NEW and A-HS	4.10 (1.11)	0.0090	0.66 to 7.54
	E-NEW and A-HR	7.63 (1.11)	< 0.0001	4.19 to 11.06*
	E-RX and A-HR	5.15 (0.93)	< 0.0001	2.27 to 8.03*
	E-FLP and A-HR	6.32 (0.94)	< 0.0001	3.41 to 9.22*
	AHS and A-HR	3.52 (0.97)	0.0120	0.51 to 6.54
FACT-G	E-NEW and A-HR	10.66 (2.12)	< 0.0001	4.09 to 17.22
	E-RX and A-HR	10.30 (1.78)	< 0.0001	4.80 to 15.80
	E-FLP and A-HR	12.64 (1.79)	< 0.0001	7.08 to 18.19*
	A-HS and A-HR	7.76 (1.86)	0.0020	2.00 to 13.53
Total FACT-P	E-NEW and A-HR	18.36 (2.95)	< 0.0001	9.22 to 27.49
	E-RX and A-HR	15.53 (2.47)	< 0.0001	7.88 to 23.18
	E-FLP and A-HR	19.01 (2.50)	< 0.0001	11.28 to 26.75*
	A-HS and A-HR	11.33 (2.59)	0.0010	3.31 to 19.35

Note: *Clinically important differences in HRQL where the lower boundary of CI is greater than cut point for clinically significant difference (mean difference of ≥ 2.0 for subscales; mean difference of ≥ 7.0 for Total FACT-G; and mean difference of ≥ 10.00 for Total FACT-P). **p significant at 0.05

high with frequent reports of hypertension (28.3%), cardiac conditions (25.6%), arthritis (14.3%), and diabetes (11.6%). Except for observation or surveillance, radical radiation and androgen blockade therapy were the most frequently reported current or past treatments. Less than 12% of the sample had undergone prostatectomy, and only 3% had received iridium implants. There were no group differences related to marital status, living arrangements, or the presence of co-morbidity. Except for a history of mental illness, there were also no differences in the types of co-morbid conditions among the groups.

There were statistically significant differences among the five groups related to age, years since diagnosis, stage at diagnosis, and PSA. Post hoc comparisons showed that the E-RX group was younger than E-FLP ($p = 0.007$), A-HS ($p < 0.0001$), and A-HR ($p = 0.01$) groups. The A-HR group also had higher levels of PSA compared to the other groups ($p < 0.0001$). Patients with advanced disease were more likely to have a history of mental health problems compared to those with local disease ($\chi^2 = 12.34$, $df = 1$, $p = 0.0004$). Differences in other disease-related characteristics reflect the continuum of prostate cancer care and confirm that participants were assigned to the correct group and that patients had, or were receiving stage appropriate therapies.

FACT-G and Total FACT-P

The internal consistency of FACT-G and Total FACT-P was high with Cronbach's alpha coefficients for subscale and total scales ranging from 0.72 to 0.90. The data showed that for all early stage and the A-HS groups, mean FACT-G and Total FACT-P scores were relatively high, indicating good HRQL (see Table Two). Apart from social well-being, there were statistically significant differences in all subscale and total scale scores across the five groups.

Table Three summarizes post hoc comparisons of statistically significant ($p \leq 0.05$) differences in HRQL between groups. These

differences in HRQL were also clinically important as mean group differences exceeded the pre-determined cut points for clinical significance.

Variables measuring patient characteristics were regressed on Total FACT-P in a stepwise multiple regression model. Three variables—PSA, disease status (advanced hormone refractory disease), and history of mental health problems were negatively associated with HRQL and contributed to 10%, 5%, and 3% respectively of the variance in Total FACT-P.

Frequency of severe health problems

For each FACT subscale, the most frequent and severe health problems where patients had scored items 0 or 1 out of 4 indicating poor quality of life were identified. Table Four lists severe problems affecting 20% of subjects in at least one patient group. While their frequency among groups varied, similar severe health problems affected patients across all groups.

Severe lack of energy or fatigue was the most common physical problem reported by all groups and especially for the E-RX, A-HS, and A-HR groups. Dissatisfaction with their sex life was a serious concern for more than 36% of patients in all groups. Approximately 20% or more of patients in each group were dissatisfied with how they were coping and E-NEW and A-HR patients were more likely to report severe anxiety or worry that their cancer may get worse. A-HR patients also experienced more severe problems in all aspects of functional well-being. Inability to have an erection was the most frequently reported and severe prostate-specific problem ranging from 37% in the E-NEW group to 94% in the A-HR group. Urinary frequency was a severe problem for a third or more of E-RX and advanced stage patients. The latter group was more likely to mention significant pain and also a decreased sense of male self-image. However, about 20% of patients in all groups were dissatisfied with their current level of comfort. Severe bowel problems occurred less frequently except in the A-HR group.

Table Four. Total FACT-P—Most frequently reported and severe problems (score 0–1)

Subscale items	E-NEW n = 69 %	E-RX n = 134 %	E-FLP n = 128 %	A-HS n = 110 %	A-HR n = 110 %	ALL n = 551 %
Physical Lack energy	10.0	18.7	13.2	20.4	36.1	20.0
Social (Dis)satisfied with sex life	36.7	65.4	55.2	74.7	83.6	64.0
Emotional (Dis)satisfied with own coping Worry about cancer getting worse	26.5 18.8	17.3 9.7	26.0 3.9	19.4 10.0	21.8 30.9	21.8 13.8
Functional Unable to work, even at home (Dis)content with quality of life Enjoy usual fun activities	5.9 10.1 8.7	14.2 11.9 10.4	13.4 9.4 10.3	15.5 10.0 9.2	39.4 27.3 28.2	18.2 13.8 13.5
Prostate Cancer Able to have/maintain an erection Urinary frequency Significant pain (Dis)satisfied with comfort level Feel like a man Pain limits activity Good appetite Bowel problems	37.3 14.5 11.6 18.6 14.5 4.3 13.0 8.7	68.3 33.8 8.7 23.5 17.7 9.8 11.9 9.0	67.2 15.7 17.2 20.2 19.7 11.8 10.2 3.9	87.1 27.1 25.5 21.9 22.1 19.3 8.2 5.6	94.1 37.3 37.6 24.3 30.8 23.6 20.90 19.1	72.8 26.6 22.5 21.9 21.2 14.2 12.7 9.1

Note: E-NEW = Early stage new diagnosis, E-RX = Early stage on treatment, E-FLP = Early stage > 2 months post treatment, A-HS = Advanced stage hormone sensitive, A-HR = Advanced stage hormone refractory. FACT-P = FACT-G (physical, social emotional functional well-being)—Prostate Subscale

Priority problems

The majority of subjects (74%) identified three health problems that were a priority for improvement and less than 8% of subjects identified no priority problems. Table Five summarizes the most frequent priorities for each group and those affecting 15% or more of the entire sample. Most problems were similar, but their importance varied across groups. Sexual function was the top priority for all early stage and the A-HS groups, while improving pain, fatigue, and activity level were a priority for the A-HR patients. Early stage patients identified urinary incontinence as a priority concern, while urinary frequency was important for all but the E-FLP group. Only the E-NEW group identified improving their sense of well-being, the need for more information regarding disease and/or treatment, and changes in their mood as priority concerns.

Discussion

Previous studies report that men with early stage (T0/T1, T2) prostate cancer have better physical, functional and prostate cancer well-being compared to men with advanced (T3/T4) disease (Esper et al., 1997) and experience good quality of life that is similar to age-matched controls with no history of prostate cancer (Litwin et al., 1995; Wei et al., 2002). Our study found that patients with advanced hormone-sensitive disease also experience good HRQL that is similar to those with early stage disease. In contrast, patients with advanced hormone refractory disease had significantly poorer HRQL, more severe health problems, and different perceptions about the importance of health problems compared to those with early stage and advanced hormone-sensitive disease.

This study reinforces previous research indicating that problems related to sexual health and urinary function are common among men with prostate cancer, and provides new insight about the perceived importance of these and other health problems across the continuum of care (Henke Yarbro & Estwing Ferrans, 1998; Ream et al., 2007). Improving sexual function was a top priority for the early stage and advanced hormone-sensitive groups, but this was not the case for the advanced hormone refractory group where alleviating symptoms of pain and fatigue was of greater importance. Urinary incontinence was a priority concern for patients with early stage disease, while urinary frequency was a more pressing issue for those with advanced disease. A notable finding was the importance of physical function for E-RX, E-FLP, and advanced stage patients. Improving their physical activity was identified as priority just as often, or more frequently than other problems commonly associated with prostate cancer.

Study participants were receiving care at a cancer centre and, therefore, the results may not be generalizable to those receiving prostate cancer care in the community. Non-random sampling and difficulty in accruing E-NEW patients may also limit the generalizability of the results. However, the high response rate, relatively large sample size for most patient groups, and completeness of HRQL data are important study strengths that should mitigate these limitations.

The use of health record data may have led to a reporting bias and the greater number of patients with advanced disease who had a history of mental health problems. These patients may be more willing to report, or practitioners may be more likely to assess and document mental health issues in advanced disease compared to early stage disease. Our results likely underestimate the prevalence of mental health problems for all groups. Under-reporting is a common source of bias when subjects have not sought out mental health services (Kessler, 2000). Men also tend to minimize and avoid discussing the negative aspects and psychological impact of their cancer situation (Olliffe, Davison, Pickles & Mroz, 2009; Znajda, Wunder, Bell & Davis, 1999).

Implications for practice

CNS and NP roles have different functions and expertise, but the optimal implementation of both roles requires specific goals and activities to be identified in five areas including clinical practice, education, research, leadership and professional/scholarly development (Cancer Care Ontario, 2009). Our study provides important information about patient health needs in prostate cancer, but it does not determine why unmet needs occur, and specific strategies to address gaps in care delivery are not examined. These issues are the focus of two follow-up qualitative studies involving patients and health care providers, and will complete our planned needs assessment. In subsequent steps, the combined needs assessment data from all three studies will be synthesized to determine the type of APN role (CNS or NP) and specific role activities that will best meet agreed-upon goals for improving patient care for advanced prostate cancer within our organization (Bryant-Lukosius et al., 2004).

However, study results do provide important recommendations for planning and designing new APN roles in advanced prostate cancer. First, it is beneficial for organizations and the APN to view supportive care needs in prostate cancer as occurring across a continuum. Sexual health, urinary function, energy, comfort, coping, and physical function are common patient concerns across the care continuum.

Table Five. Most frequently reported priority health problems

E-NEW (%)	E-RX (%)	E-FLP (%)	A-HS (%)	A-HR (%)	ALL (%)
Sexual function (18.8)	Sexual function (36.6)	Sexual function (39.8)	Sexual function (33.6)	Pain (31.8)	Sexual function (31.0)
Overall well-being (18.8)	Urinary frequency (20.9)	Fatigue (21.1)	Urinary frequency (19.1)	Fatigue (31.8)	Physical Activity (18.5)
Urinary Incontinence (17.4)	Urinary Incontinence (17.2)	Sexual Desire (18.0)	Hot Flashes (15.5)	Physical Activity (30.9)	Fatigue (18.5)
Information About Disease/Treatment (17.4)	Physical Activity (17.2)	Physical Activity (14.8)	Physical Activity (15.5)	Urinary Frequency (20.9)	Urinary Frequency (17.2)
Urinary Frequency (15.9)	Rectal Discomfort (14.2)	Urinary Incontinence (13.3)	Sleeping (15.5)	Sexual Function (19.1)	Urinary Incontinence (14.5)
Mood (14.5)				Sleeping (15.5)	Pain (14.2)

Note: E-NEW = Early stage newly diagnosed, E-RX = Early stage on treatment, E-FLP = Early stage > 2 months post treatment, A-HS = Advanced hormone sensitive, A-HR = Advanced hormone refractory

Most patients with advanced prostate cancer were initially diagnosed with early stage disease and were five to six years post-diagnosis. Conceptualizing prostate cancer care as occurring along a continuum highlights the chronicity of the illness experience and creates new opportunity for health promotion and earlier intervention. Managing common health problems early in the continuum of care may have long-term benefits for patients who later develop advanced disease. For example, early detection and intervention for those at risk for mental health problems at the time of diagnosis may lead to long-term improvements in HRQL.

A main objective of our study was to define, from a patient perspective, targeted priorities for an APN role in advanced prostate cancer. Three primary areas of focus related to prostate cancer health, mental health, and functional capacity are proposed, as a beginning effort to define an APN role. These foci reflect the common and priority unmet needs experienced by men with advanced disease. Figure One illustrates the interdependent relationships among these foci and their impact on HRQL across the continuum of care. For example, severe fatigue or lack of energy was experienced by 20% of the sample and was a priority health need in almost all patient groups. Fatigue and/or emotional distress may also indicate declining function and HRQL, as they often present in combination with clusters of three or more prostate cancer symptoms related to pain and sexual and urinary function (Maliski, Kwan, Elashoff & Litwin, 2008).

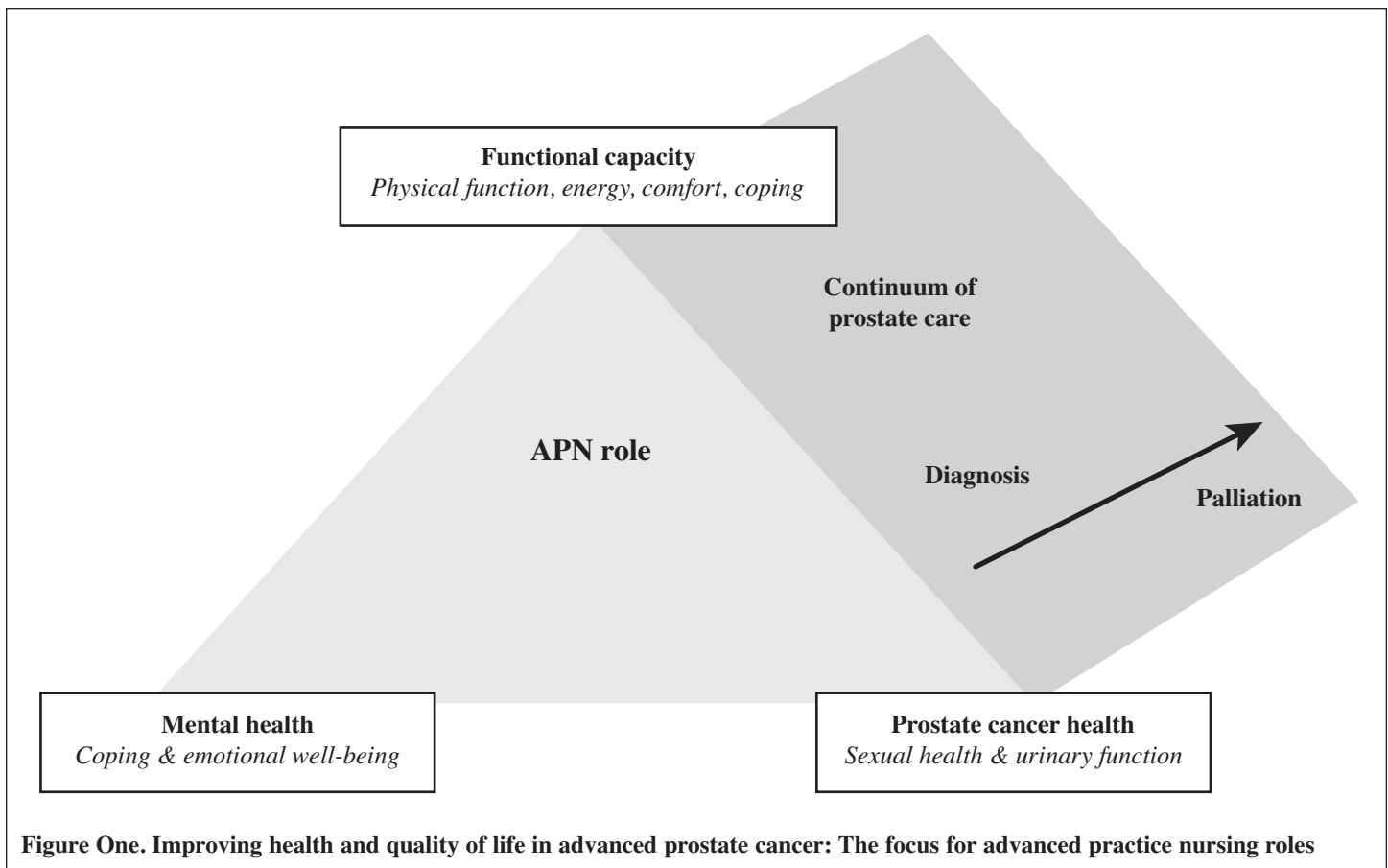
Prostate cancer health

Prostate cancer health includes sexual health and urinary function. Loss of erectile function was almost universal for patients with advanced disease. However, sexual health is more than the absence of dysfunction, but also involves physical, emotional, mental, and social well-being related to sexuality (World Health Organization, 2002). Reducing hot flashes as a physical side effect

of androgen blockade therapy was a priority for patients with advanced hormone-sensitive disease. Social well-being was adversely affected by 75% of men in both advanced stage groups due to dissatisfaction with their sex life. Feelings of masculinity and male self-image were also negatively affected. The adverse effects of prostate cancer on body image, virility, and social relationships have been reported in other studies (Bokhour, Clark, Inui, Sillman & Talcott, 2001; Gray, Fitch, Fergus, Mykhalovsky & Church, 2002; Harrington & Badger, 2009).

Evaluating the impact of advanced prostate cancer on sexual health is an important aspect of the APN role. Patients may be reluctant to volunteer information about their sexual concerns (Butler et al., 2001; Monturo, Rogers, Coleman, Robinson & Pickett, 2001). Thus, establishing a trusting relationship with the patient and his partner is key to exploring sexual health concerns. Patient goals in relation to sexual health should also be determined. While 75% of men in the advanced hormone-sensitive group were dissatisfied with their sex life, only 34% felt sexual function was a priority for improving their health. Men over 74 years of age may be less concerned about sexual function compared to younger men (Fransson & Widmark, 1996). For patients with symptomatic hormone refractory disease, problems such as fatigue, pain, or mood may need to be alleviated before sexual health issues can be addressed.

Urinary frequency and incontinence are challenging issues to resolve in advanced prostate cancer. In addition to urinary obstructive symptoms due to pelvic disease, patients may also have chronic urinary problems from prior surgery and radiation therapy. Urinary problems that disrupt usual activities of daily living contribute to poor HRQL (Rondorf-Klym & Colling, 2003). Thus, a key aspect of the APN role is to assist patients in coping with and managing urinary symptoms and minimizing their impact on day-to-day activities.



Mental health

Patients with advanced stage disease were more likely to have a history of mental health problems. Increased psychological morbidity is associated with declining physical function in advanced cancer such as that experienced by patients with hormone refractory disease (Brietbart, Bruera, Chochinov & Lynch, 1995). The greater proportion of E-NEW patients with severe anxiety is consistent with other reports of psychological distress associated with the uncertainty of a new cancer diagnosis (Ream et al., 2007; Van't Spijker, Trijsburg & Duivenvoorden, 1997; Grassi & Rosti, 1996). In addition, 17% or more of patients in all groups were highly dissatisfied with how they were coping. It may be important to screen for mental health problems at the time of the initial diagnosis of prostate cancer and with changes in stage of disease or treatment status. Declining physical function and uncontrolled pain are associated with increased symptoms of anxiety and depression in prostate cancer (Cliff & MacDonagh, 2000; Heim & Oei, 1993). Aggressive pain and symptom management and interventions to enhance physical function are essential for achieving optimal mental health. Providing education and addressing patient information needs are also key APN interventions for promoting mental health. Information seeking is a coping strategy frequently used by men with prostate and other types of cancer (Gray et al., 2002; Gray, Fitch, Davis & Phillips, 1997; Heyman & Rosner, 1996; Klemm, Hurst, Dearholt & Trone, 1999). Interventions to provide patients with information about their disease and treatment may reduce levels of anxiety and depression, and increase patient involvement in their own care (Davison, Goldenberg, Gleave & Degner, 2003; Lepore, Helgeson, Eton & Schulz, 2003).

Functional capacity

Functional capacity or physical and functional well-being is important for men with prostate cancer. Improving their physical activity was a priority for men with advanced hormone-refractory disease. The importance of sustaining a normal lifestyle and maintaining activities of daily living and social roles is described in qualitative studies of men with prostate cancer (Gray et al., 2000; Gray et al., 2002; Heyman & Rosner 1996). Physical limitations due to prostate cancer are also a source of worry for patients and their partners (Cliff & MacDonagh, 2000).

Common problems such as pain, fatigue, and urinary symptoms may impede activities of daily living and functional capacity. Androgen blockade therapy may cause increased fatigue, loss of voluntary muscle function, and decreased muscle mass that can impair functional capacity (Lubeck, Grossfeld & Carroll, 2001; Stone, Hardy, Huddart, A'Hern & Richards, 2000). APN interventions should aim to reduce fatigue and to promote physical activity, comfort, and coping. For example, exercise may reduce fatigue and improve HRQL for men receiving androgen blockade therapy (Segal et al., 2003). Mobilizing community services and the use of equipment aids may also support patient independence and physical function in their own homes.

Models or approaches to APN care

In studies evaluating advanced or specialized nursing roles for patients with early stage prostate cancer, the nurse-patient interaction was limited to the radiation treatment time period (Faithfull, Corner, Meyer, Huddart & Dearnaley, 2001) or to on-demand patient telephone calls or follow-up calls once every six months (Helgeson et al., 2000). In both studies, patient outcomes in the nurse treatment group were similar to those randomized to medical care, but health care costs in the APN group were reduced by up to 37% (Faithfull et al., 2001). Patients receiving APN care felt they benefited from continuity of care and were more satisfied with their care (Faithfull et al., 2001). Earlier pre-treatment education and interventions may have also led to better baseline symptom scores for patients in the

APN group (Faithfull et al., 2001). These data suggest that access to episodic APN care for health problems occurring before, during and post-treatment may be effective for patients with early and advanced hormone-sensitive prostate cancer. In contrast, patients with advanced hormone refractory disease have more complex, progressive and severe health needs that may require more frequent APN assessment and ongoing management versus episodic care. APN roles that can transition with the patient across health care settings such as the cancer clinic, home, hospital or hospice may also benefit patients with complex care needs such as those with symptomatic hormone refractory prostate cancer (Brooten et al., 2002).

Implications for research

The prevalence of mental health problems in prostate cancer has not been well established. Our study findings suggest that mental health problems contribute to poor HRQL. Further research to determine the extent, risk factors for, and impact of mental health problems on HRQL and other health outcomes across the continuum of prostate cancer care is warranted.

Patient group or disease and treatment status along the continuum of prostate cancer care, PSA level, and history of mental health problems were found to be only modest predictors of HRQL. Future research should continue to identify modifiable patient, disease, and treatment factors that contribute to poor HRQL across the continuum of prostate cancer care.

Patients with early stage prostate cancer have been the focus of nursing research (Butler et al., 2001; Davison et al., 2003; Faithfull et al., 2001; Moore & Estey, 1999; Robinson et al., 1999; Rondorf-Klym & Colling, 2003) and the research evidence documenting the effectiveness of nursing interventions in prostate cancer is limited (Moore & Glazener, 2003; Shell, 2002). There is a paucity of research on nursing interventions in advanced prostate cancer, particularly with respect to patient priority health needs. Research to generate new nursing knowledge and skills will be necessary to significantly improve patient health and quality of life in advanced prostate cancer. Developing the research component of new or current APN roles in advanced prostate cancer should be given high priority. Sufficient time to participate in research, provision of resources, and access to research expertise are necessary to support the development of the APN research role (Bryant-Lukosius et al., 2004).

Conclusions

Patients with advanced hormone refractory prostate cancer experience poorer HRQL and have different priority health needs compared to those with early stage and advanced hormone-sensitive disease. However, common problems related to physical function, energy, comfort, coping, emotional well-being and sexual and urinary function occur across the continuum of prostate cancer care. There is a need for greater emphasis on health promotion and a more comprehensive approach to providing prostate cancer care. Three foci related to prostate cancer health, functional capacity and mental health are proposed to conceptualize patient-focused APN roles for improving health and quality of life in prostate cancer. These foci establish a foundation for directing future research and to develop and evaluate APN roles in new models of care for patients with advanced prostate cancer. ♣

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