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# The Supportive Care Needs of Men With Advanced Prostate Cancer

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**P**rostate cancer is the most common type of cancer in Canadian men and accounts for 27% of all cancer cases (Canadian Cancer Society and National Cancer Institute of Canada, 2010). Despite improvements in early detection and treatment, many men progress from localized to advanced disease. Advanced prostate cancer is a chronic condition requiring extended outpatient care for treatment, symptom management, and palliation. Two distinct patient populations live with advanced prostate cancer: those with hormone-sensitive cancers and those with hormone-refractory cancers. Treatment for hormone-sensitive prostate cancer involves controlling disease growth through androgen-deprivation therapy by medical or surgical castration. Eventually, most patients develop hormone-resistant prostate cancer, at which point the focus is on palliative treatment with chemotherapy, radiation, and supportive care (McMurtry & McMurtry, 2003).

Men with prostate cancer may live for long periods of time even after the development of advanced disease and, therefore, face many challenges living with a chronic illness (Stephenson, 2002). Common issues associated with advanced prostate cancer include deteriorating levels of function related to cancer and aging and issues related to sexual and urinary function, fatigue, and pain (McMurtry & McMurtry, 2003; Penson & Litwin, 2003). Aggressive supportive care is needed to manage symptoms, including pain, spinal cord compression, fatigue, cachexia, and bowel and urinary obstruction, related to bone metastasis and soft tissue disease (Khafagy et al., 2007; Lindqvist, Rasmussen, & Widmark, 2008). Physical symptoms related to androgen deprivation and chemotherapy for metastatic disease exacerbate disease-related issues (Penson & Litwin, 2003). Less urgent but no less important needs related to information, treatment decisions, side-effect management, and coping also exist (Gray et al., 2002; Gray, Fitch, Phillips, Labrecque, & Klotz, 1999). For Canadian patients with advanced prostate cancer, nursing support is provided in outpatient cancer treat-

**Purpose/Objectives:** To better understand the priority supportive care needs of men with advanced prostate cancer.

**Research Approach:** Qualitative, descriptive study.

**Setting:** Outpatient cancer center and urology clinics in central western Ontario, Canada.

**Participants:** 12 men with hormone-sensitive prostate cancer and 17 men with hormone-refractory prostate cancer.

**Methodologic Approach:** Patients participated in focus groups and interviews that examined their supportive care needs, their priority needs, and suggestions for improvements to the delivery of care. Tape-recorded focus group discussions and interviews were organized using NVivo software.

**Main Research Variables:** Patients' supportive care needs.

**Findings:** Participants identified prostate cancer-specific information and support to maintain their ability "to do what they want to do" as priority needs. Both hormone-sensitive and hormone-refractory groups cited problems with urinary function, the side effects of treatment, fatigue, and sexual concerns as major functional issues. Participants experienced emotional distress related to diagnosis and treatment.

**Conclusions:** A priority health need for men with advanced prostate cancer is to improve or maintain functional abilities. In addition, men require support to meet their stage-specific information needs and to address concerns about the diagnosis and ambivalent feelings about past treatment decisions.

**Interpretation:** Nurses could play an important role in addressing men's information needs and providing emotional support. The complex care needs of men with advanced prostate cancer provide opportunity for the development of advanced practice nurse roles that would use the clinical and nonclinical aspects of the role.

ment programs, hospitals, and through care delivered by healthcare professionals in the community in which patients live. However, restructuring of health care in Canada, poor access to supportive care expertise, and limited funding opportunities have hindered the development of supportive care services.

## Literature Review

In Ontario, little coordination has historically existed between treatment services and supportive cancer care and the organizations that provide supportive cancer care (Brazil et al., 2004). Inadequate access, coordination, and integration of supportive and palliative care services are all factors (Brazil, Whelan, O'Brien, & Sussman, 2003). Accessibility to supportive care programs and services requires coordinating care among a multitude of services, including those in regional cancer centers, hospitals, and community agencies. Whelan et al. (2003) examined the continuity of cancer care provided by regional networks of supportive care and identified that many patients were unaware that supportive care services were available and others who knew of them made little use of them. Although generalized services are available to meet a broad range of needs for patients and their families, individuals experience specific needs depending on the type of cancer, stage of disease, type of treatment, and prognosis.

Limited research has focused on men with advanced prostate cancer. The literature has identified that symptomatic advanced-stage prostate cancer and its treatment have a negative impact on patient quality of life (Clark, Wray, & Ashton, 2001; Lindqvist, Widmark, & Rasmussen, 2006; Navon & Morag, 2003; Penson, Litwin, & Aaronson, 2003; Rosenfeld, Roth, Gandhi, & Penson, 2004; Trask, 2004). Men with hormone-refractory prostate cancer report significantly poorer health-related quality of life than other groups or men with prostate cancer (Bryant-Lukosius et al., 2010). Bryant-Lukosius et al. (2010) found urinary frequency and incontinence and other treatment side effects affected men with hormone-sensitive prostate cancer, whereas men with hormone-refractory prostate cancer had priority needs related to pain, fatigue, decreased physical activity, and urinary frequency. The prevalence of depression in men with advanced disease was comparable to that in people with other cancers and higher than in the general population.

Studies designed to explore the needs of men with all stages of prostate cancer found that they have unmet physical and psychosocial needs (Bryant-Lukosius et al., 2010; Fitch, Gray, Franssen, & Johnson, 2000) as well as a desire for support and information (Boberg et al., 2003). The needs of men with prostate cancer depend on the stage of illness and treatment (Bryant-Lukosius et al., 2010; Lintz et al., 2003; Northouse et al., 2007; Rosenfeld et al., 2004). Patients with advanced disease are most likely to report needs related to psychological, health system and information, and sexuality domains (Lintz et al., 2003). Wallace and Storms (2007) used focus groups to explore the psychosocial and educational needs of men with prostate cancer. Patient participants identified three main needs related to patient and family

education, patient and family psychosocial support, and connection with other survivors.

Few studies focus solely on advanced prostate cancer or distinguish between the needs of men with hormone-sensitive advanced prostate cancer and the needs of men with hormone-refractory advanced prostate cancer. Published studies that did use quantitative methods and did not allow for exploration of men's priority needs or thoughts about better healthcare delivery. Qualitative methods give participants opportunities to share information about their experiences during difficult times in their lives. Additional qualitative research is needed to discover why unmet needs for supportive care services persist in Canada, despite calls by national and provincial cancer organizations to improve the delivery of supportive and palliative care (Whelan et al., 2003).

## Study Purpose and Research Questions

The purpose of this study was to further understand the unmet healthcare needs of men with advanced prostate cancer, how these unmet needs affect their daily lives, and how the delivery of supportive care services could be improved to meet their needs. As part of a larger program of research to determine the role of the advanced practice nurse in the care of patients with advanced prostate cancer, this study was guided by the PEPPA framework, a participatory, evidence-based, patient-focused process for introducing and evaluating advanced practice nursing roles (Bryant-Lukosius & DiCenso, 2004). This nine-step framework emphasizes the importance of assessing patient and family needs and identifying priority issues and goals to fully inform what additional healthcare services are needed and who should deliver them.

In this article, the authors focus on the needs of men with advanced prostate cancer. Specifically, the authors address the following research questions: What are the supportive care needs of men with advanced hormone-sensitive and hormone-refractory prostate cancer and how do they differ? What are the recommended strategies for improving care to meet the supportive needs of these men?

## Methods

This study used the qualitative description method outlined by Sandelowski (2000) to attain a comprehensive description of the supportive care needs of men with advanced prostate cancer and their suggestions for improving supportive care. The Hamilton Health Sciences and McMaster University Faculty of Health Sciences research ethics board and the St. Joseph's Healthcare research ethics board approved all study procedures.

## Sample

The study was designed to collect information from men with hormone-sensitive and hormone-refractory prostate cancer separately because of differences in their health (Bryant-Lukosius et al., 2010; Lintz et al., 2003; Rosenfeld et al., 2004). The authors recruited participants through urologists' offices, newspaper and community television advertisements, local prostate cancer support groups, and a central western Ontario cancer center.

## Data Collection and Analysis

The original plan was to collect all data through focus groups; however, slow recruitment of men with hormone-sensitive prostate cancer led to the decision to conduct individual interviews as well. The authors experienced challenges with recruitment for a number of reasons. Men with hormone-sensitive prostate cancer receive care in a variety of settings in the community, such as urologists' offices and at cancer centers and, therefore, were more difficult to identify and recruit. To expedite recruitment and complete data collection, the authors decided to use individual interviews almost exclusively with the hormone-sensitive prostate cancer group, as well as with one man with hormone-refractory prostate cancer whose poor health prevented him from attending a focus group. In contrast, men with hormone-refractory prostate cancer were more likely to require care at a regional cancer center and, therefore, were easier to identify and recruit and were more willing to participate in focus groups that could be conveniently scheduled on the same day as clinic visits.

In total, 17 men participated in one of five focus groups lasting 90–120 minutes. Twelve men participated in one-to-one, in-depth, semi-structured interviews lasting 30–60 minutes. At the end of the focus groups and interviews, the authors summarized major themes to validate and clarify the information provided with participants (member checking). All focus-group discussions, interviews, and reflections were tape recorded and transcribed. The authors collected data until no new information was obtained (data saturation) (Morse, 1994).

Data analysis occurred concurrently with data collection. The research team read initial transcripts and developed a coding scheme. The primary investigator and two research assistants with oncology nursing experience used NVivo software to review all transcripts. The authors developed core categories and clustered codes into these categories. From these categories, themes emerged. Triangulation strategies included the review of summaries of information with focus group and interview participants, and the comparison of study results with those of the previous studies

conducted on this patient population (Bryant-Lukosius et al., 2010) and with comments made at prostate cancer support groups held by the Canadian Cancer Society.

## Findings

### Participants

Twenty-nine men participated in this study. The majority of men with hormone-refractory prostate cancer (16 of 17) participated in a focus group and one man was interviewed in his home. In contrast, the authors individually interviewed 10 of the 12 hormone-sensitive participants, with two hormone-sensitive participants being interviewed together.

The hormone-sensitive and hormone-refractory groups were similar in age (mid 70s) and length of time since diagnosis (7–8 years). The majority of participants were married and retired. Hormone-sensitive participants had more health issues, including cardiac disease, hypertension, diabetes, arthritis, and hearing and vision loss. Demographic data are shown in Table 1.

### Supportive Care

Analysis of focus group and interview data revealed three themes related to supportive care: functional problems, with a patient's example of "not being able to do what I want to do;" information needs; and emotional distress.

**Functional issues:** Men with hormone-sensitive and hormone-refractory prostate cancer complained about changes in their functional capability because of the advancing disease and reported experiencing pain and fatigue or side effects of treatment, such as urinary

**Table 1. Participant Demographic Characteristics**

Characteristic	Hormone-Sensitive Prostate Cancer (N = 12)		Hormone-Refractory Prostate Cancer (N = 17)	
	$\bar{X}$	Range	$\bar{X}$	Range
Age (years)	76	59–88	75	61–85
Years since diagnosis	7	1–13	8	1–16
Number of other medical problems	3	0–5	1	0–5
Characteristic	n	%	n	%
<b>Marital status</b>				
Married	10	84	13	76
Widowed	1	8	4	24
Divorced	1	8	–	–
<b>Employment status</b>				
Self-employed	1	8	–	–
Part-time	1	8	1	6
Disabled	–	–	2	12
Retired	10	84	14	82



incontinence and loss of sexual function. According to one hormone-sensitive participant,

It's things that I used to do myself, you know, and I've got to get somebody else to help me. That's what bugs me, you know! I want to do it myself. Now, I can't do it.

Both groups reported urinary function issues, and this was a priority issue for men with hormone-sensitive prostate cancer. The men reported the "nuisance" of urgency, leakage, and the need to wear incontinence pads. Urinary and incontinence issues affected their ability to function daily, including doing daily chores, participating in sports activities, and attending social events. A hormone-sensitive participant said,

My whole life is predicted on where the nearest toilet is and whether I have a pad in my pocket. We went to a restaurant last night and I thought that I had one and I did not. So I drove home thinking, "I hope nobody invites us in tonight."

Both groups of men reported fatigue and lack of energy related to side effects of androgen deprivation, chemotherapy, progression of disease, and age. Many men reported that fatigue restricted their daily activities and they needed regular rest periods to do common activities, such as chores around the house and yard, and to participate in social events. One hormone-refractory participant wanted to find out more about what he could do for his fatigue.

As far as the fatigue is concerned, they've never offered any suggestions as to how I can overcome it, which, when you get through the chemo[therapy] like four or five days after . . . you can hardly move it's so bad. So, like, what can you do?

Men with hormone-sensitive prostate cancer reported that the side effects of androgen deprivation, including hot flashes, sweating, breast soreness, weight gain, fatigue, and weakness, interfered with their daily lives. These men used words like "nuisance" and "bothersome" to describe the issues and many acknowledged that these were minor concerns associated with fighting the cancer. The side effects of chemotherapy were problematic for men with hormone-refractory prostate cancer.

The biggest problem was the reaction to the initial chemo[therapy]. I could hardly get around. It cleared up after I stopped it. I think I'm getting slowly physically weaker, and whether it's the chemo[therapy] or the disease advancing, I'm not sure.

Hormone-refractory participants described issues with loss of appetite, nausea, extreme fatigue, and reactions to certain medications. Many of the men with hormone-refractory prostate cancer also reported dis-

comfort related to their cancer. They described the pain as sporadic and often said it was related to activity.

My pain started just after January. Started with some pain in my back, in my hips . . . [that] sort of thing. So I take pain killers for that . . . Advil® or whatever. Still play golf and cut the grass and everything, but playing golf isn't so hot because it hurts when I hit the ball.

Pain was described as bone pain or pain in the hips or pelvis, and many participants were unsure if the pain was related to their cancer or to age-related issues such as arthritis. On the other hand, many men denied any discomfort or pain.

**Information needs:** Both groups of men consistently and directly reported a need for information about treatments, medications and side effects, and alternative therapies. During focus groups and interviews, participants asked questions and some sought information from the interviewer or from other men in the focus group. Both hormone-sensitive and hormone-refractory participants reported a need for information related to their diagnosis, treatment, and future. One hormone-sensitive participant described wanting more information about treatment options and how he felt when he did not get information.

But I didn't get to the bottom of it. I didn't ask the questions and it wasn't volunteered either at that time. I just felt that I was sort of shunted off to one side.

Men also wanted to know more about new treatment developments they had heard about from people outside their healthcare team. Some men, such as this hormone-refractory participant, regretted not asking more questions and seeking out more information.

That was my own fault. I didn't ask enough questions. But in the other stages, I think that was the big problem—the lack of information.

Patients lacked information about services available to them and were unsure of the services offered at the regional cancer center or by the Canadian Cancer Society. One hormone-refractory participant said,

There's uncertainty. For instance, I came up here to supportive care today and all the time I've been coming here, which is a long time, I don't know what supportive care does for us or what services are available for people in my boat.

If was difficult for hormone-sensitive and hormone-refractory participants to get information about their prognosis and what to expect in the future. One hormone-sensitive participant wanted to know more information to make concrete plans for his care and the care of his wife when his condition worsened. "What is

available? My wife is 85. She certainly can't look after me if I'm disabled."

Men received information from various sources, including oncologists, urologists, and nurses; they also accessed friends, family members, and acquaintances for information. Other sources of information included Canadian Cancer Society publications and the Internet. Some men were dissatisfied with general cancer information and sought information specific to their disease. Some patients attended local prostate support groups to get information, but not all reported groups to be useful. Some of the men who had had cancer for long periods stopped going to support groups because they were not learning any new information.

Many men reported not understanding information about their prostate cancer, diagnosis, or treatment. One man did not understand how the treatments actually worked and had difficulty getting anyone to explain it to him. Some men asked specific questions of the interviewer or focus group participants, such as this one from a hormone-refractory participant.

What are they measuring anyway? [Prostate-specific antigen] is a measurement of cancer germs or something in your prostate, right? What are they measuring if your prostate is gone?

A hormone-sensitive participant asked a similar question.

But then there's something called a Gleason score. I never did figure out what the hell they were talking about and I have no idea what it meant.

**Emotional distress:** In the focus group discussion and interviews, men expressed various intense emotions including sadness, anger, and frustration. Men with hormone-sensitive and hormone-refractory prostate cancer were coping with the consequences of advanced prostate cancer and their uncertain future.

Related to the need for emotional support were the unresolved issues around diagnosis and treatment decisions. Many men in this study were diagnosed with prostate cancer more than 10 years earlier and they continued to express unresolved feelings about their diagnosis and the decisions made about their initial treatment. They expressed anger, frustration, and regret and were dissatisfied with the information they received at various stages of their illness. Many men felt if they or their doctor had been more informed, they would have been diagnosed sooner and would have had better outcomes. One hormone-refractory participant said, "I should have found out earlier! Something was missed along the line." Another hormone-refractory participant was very angry that he did not have enough information prior to his surgery.

If I had known what was gonna happen, they'd have never done it. I'd have died first. I used to be very strong. Not anymore. I've got no strength at all there. They must have cut muscles and everything

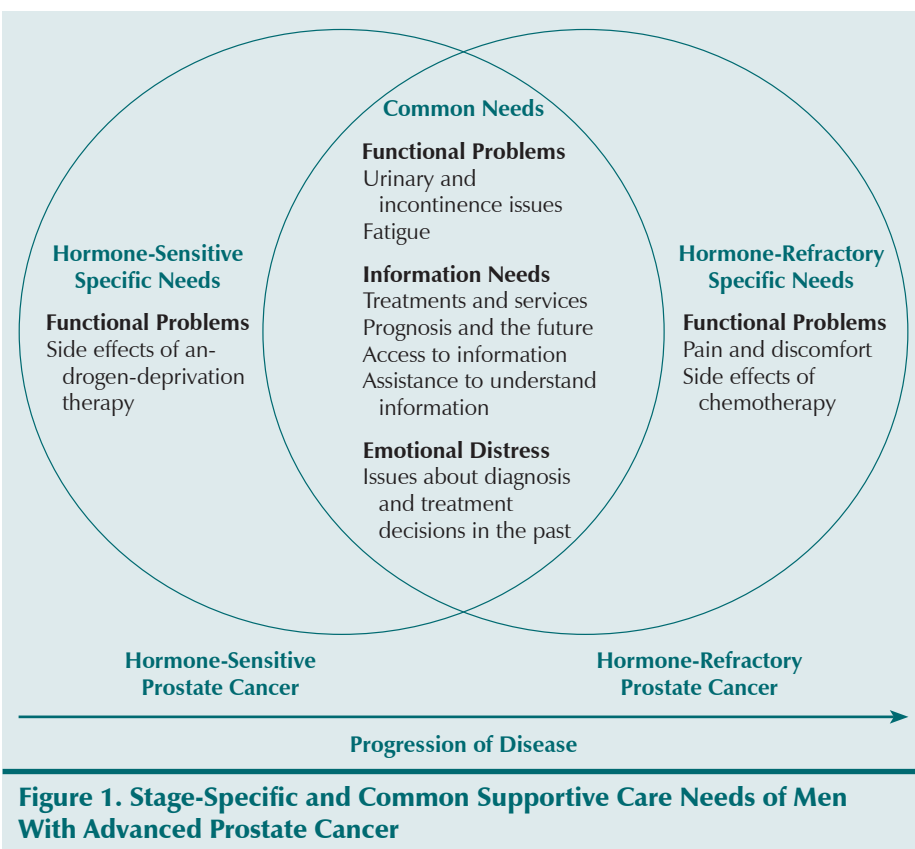
else. And I'll tell you, your sex life is gone. Not 99%, 100%. I should have been filled in.

**Recommended strategies to improve the delivery of care:** The authors asked participants about the care they received and suggestions for improvement. The suggested changes to care delivery included (a) education for patients about early detection and diagnosis, (b) increased prostate-specific antigen (PSA) testing, (c) increased disease-related information for newly diagnosed men, (d) increased information and assistance interpreting information, and (e) small group sessions specific to men with advanced disease led by a healthcare professional. For hormone-sensitive and hormone-refractory groups, the priority for improved care was to address information needs.

## Discussion

This qualitative descriptive study explored the supportive care needs of men with advanced prostate cancer and their ideas to improve the current model of care. Men with hormone-sensitive prostate cancer and men with hormone-refractory prostate cancer have stage-specific and common supportive care needs, and these are likely a result of the treatments they undergo and the progression of disease (see Figure 1). Participants identified unmet priority needs related to information and issues associated with maintaining their ability "to do what they want to do." Functional issues shared by hormone-sensitive and hormone-refractory participants included problems with urinary function, the side effects of their treatment, fatigue, and sexual issues. For men with hormone-sensitive prostate cancer, urinary function was a priority issue whereas, for men with hormone-refractory prostate cancer, avoiding fatigue was the priority. Both groups consistently identified information as a priority need. The lack of information about their original diagnosis of prostate cancer, past and current treatments, and prognosis led to many emotions including anger, frustration, fear, and uncertainty. Participants were generally satisfied with the care they received, but recommended increased PSA testing, vigilant assessment of prostate cancer to prevent the development of advanced disease, and small-group meetings facilitated by a healthcare professional to address information and coping needs.

Men in this study described periods that were difficult emotionally and physically, usually around the time of diagnosis. This information is consistent with the findings of Wallace and Storms (2007), who described the myriad of emotions related to the prostate cancer diagnosis. However, many of the men in the current study reported feeling fortunate to have prostate cancer as opposed to other cancers. Lindqvist et al. (2006) described having advanced prostate cancer as living with bodily problems in cyclical movements between experiencing



**Figure 1. Stage-Specific and Common Supportive Care Needs of Men With Advanced Prostate Cancer**

also was an unmet need for some men with hormone-refractory prostate cancer, a finding that has been reported previously (Bryant-Lukosius et al., 2010; Fitch et al., 2000; Lindqvist, Rasmussen, Widmark, & Hyden, 2008).

The study findings support the assertion that men with these two types of advanced prostate cancer have different problems that appear to be the result largely of the side effects of treatment and the progression of their disease. Although the reported differences between the two groups of men appear to be distinct, this is likely oversimplified. A progression of illness exists within both disease groups, which adds complexity and dimension to their problems and needs. Men with hormone-sensitive prostate cancer more often reported feeling well, with few complaints, as opposed to men with hormone-refractory prostate cancer, who had more

wellness and illness. The men in the current study also described uncertainty about their prognosis, treatment, and the future, which is a common experience in chronic illness (Mishel, 1999).

Both groups reported issues relating to urinary function, a finding consistent with previous studies (Bryant-Lukosius et al., 2010; Fitch et al., 2000). The authors' findings were inconsistent with other studies, mostly those involving surveys that reported sexual function as a priority for men with hormone-sensitive prostate cancer (Bryant-Lukosius et al., 2010; Fitch et al., 2000; Lintz et al., 2003; Navon & Morag, 2003). The reason for this discrepancy might have been men's reluctance to discuss sexuality with the female investigator.

Both groups of men reported fatigue related to their treatments and its impact on their daily lives, and this has been previously reported (Jonsson, Aus, & Bertero, 2009). Fatigue was one of the main concerns of the hormone-refractory group, a reaction that is consistent with the literature (Bryant-Lukosius et al., 2010; Lindqvist, Widmark, & Rasmussen, 2004; Lintz et al., 2003). Fatigue is one of the most common symptoms experienced by patients with metastatic disease and also one of the most challenging for cancer-care providers. In their systematic review of cancer-related fatigue interventions, Jacobsen, Donovan, Vadaparampil, and Small (2007) found few studies that had been conducted on men with prostate cancer and few studies that focused on patients with metastatic cancer. Pain control

physical complaints. Men with hormone-refractory prostate cancer have worse outcomes than men with hormone-sensitive prostate cancer in physical function, role function, and health-related quality of life (Curran et al., 1997). In most cases, hormone-sensitive participants had little or no contact with a nurse or healthcare providers other than their urologists. Most hormone-refractory participants, however, received care at a regional cancer center and had access to oncologists, primary nurses, an advanced practice nurse, social workers, and other allied healthcare professionals.

It became evident early in the data collection that a priority for hormone-sensitive and hormone-refractory participants was the need for information. Previous studies have shown that men want information during all stages of prostate cancer (Boberg et al., 2003; Dale, Jatsch, Hughes, Pearce, & Meystre, 2004; Lintz et al., 2003; Wong et al., 2000) and that the types of information men with advanced prostate cancer want include information on treatment, side effects, and the future (Davison et al., 2002; Echlin & Rees, 2002). Men in this study sought out information from a variety of sources, including physicians, friends, and acquaintances, and this is consistent with previous studies (Davison et al., 2002; Wallace & Storms, 2007).

Both hormone-sensitive and hormone-refractory participants expressed dissatisfaction and sometimes anger about the lack of information they received, and this has been reported previously (Sinfield et al., 2009). Hormone-



sensitive and hormone-refractory participants reported that physicians were their main source of information and that they were dissatisfied with the amount of time physicians spent answering their questions. Many men thought that doctors were not informed or that information was withheld from them, particularly as their disease advanced. Templeton and Coates (2003) found that men with all stages of prostate cancer considered physicians to be the main source of information. The authors sensed an underlying anxiety or mistrust of the information they received, and some men were concerned they did not make the correct treatment decisions based on information available to them. Fitch et al. (2000) also found that anger was expressed as men shared unresolved issues regarding their diagnosis of prostate cancer and lack of information.

A priority for both groups was the need for help in interpreting information about advanced prostate cancer and treatment options. One team of researchers reported on the paradox of patients wanting more information about treatment but having difficulty absorbing and retaining information they received (Skalla, Bakitias, Furstenberg, Ahles, & Henderson, 2004). At many points during the focus groups and interviews, it was evident that men did not have information or that they misunderstood the information they had received. For example, in two focus groups, participants questioned the meanings of PSA and tumor-grading scores. Gray et al. (1997a) also found that many men with prostate cancer did not understand presented information. The older age of the participants in the current study likely contributed to their information needs. Fitch (2006) examined the perspectives of older adults about cancer information and identified the following barriers to receiving information: the hectic nature of the surroundings, the speed with which healthcare professionals talk, the medical language used, and the overwhelming amount of information presented.

The authors found that support groups run by the Canadian Cancer Society were a source of information for some men; however, others did not attend them. Weber, Roberts, and McDougall (2000) suggested that embarrassment and shame related to sexual dysfunction and incontinence prevent many men from attending prostate cancer support groups. In a cross-sectional survey of 965 Canadian men with prostate cancer, Gray et al. (1997b) found that men reported considerable benefit from attending self-help groups. The literature on prostate support groups indicates that the primary reason men attend support groups is to get information, as opposed to obtaining psychosocial support (Fitch et al., 2000; Steginga et al., 2001; Thaxton, Emshoff, & Guessous, 2005); however, this literature is not specific to men with advanced prostate cancer.

Despite little interest in the larger prostate support groups in the community, the men who participated in the hormone-refractory focus groups suggested

that similar small-group meetings at the cancer center consisting of men with the same diagnosis would be helpful. Other researchers (Butow et al., 2007; Fitch et al., 2000; Thaxton et al., 2005) also recommended stage-specific cancer support. In addition, both groups recommended that services be improved to promote the earlier diagnosis of prostate cancer through increased PSA testing and more vigilant assessment of prostate cancer-related symptoms. They also called for improved treatments and services to prevent prostate cancer.

## Limitations and Strengths of the Study

The limitations of this study include the inconsistency in data collection methods. Most (10 of 12) hormone-sensitive participants were interviewed; almost all hormone-refractory participants (16 of 17) took part in a focus group. However, the use of interviews did allow the authors to gather data that would not have otherwise been obtained if only focus groups had been used. Whether findings would have differed if the same data collection method had been used is unclear. Another limitation of the study is that the authors report on data from participants but do not understand the needs of nonparticipants in the study. The nonparticipant group of patients with advanced prostate cancer could include those who are well and do not use supportive care services. But, more importantly, the authors may not have captured the needs of more vulnerable patients who may not have participated in the study because of multiple health issues, lack of social support, or mental health problems. Discovering new ways of engaging the neediest and most vulnerable patients with cancer to ensure their needs are addressed is a priority.

This study is one of the relatively few that provide information about the needs of men with advanced prostate cancer exclusively and that compare men with hormone-sensitive and hormone-refractory advanced prostate cancer. Qualitative methods of data collection using focus groups and in-depth interviews were effective for capturing unmet health needs that are important to patients.

## Implications

Study results validate similar unmet patient health needs identified in an earlier quantitative survey (Bryant-Lukosius et al., 2010) but provide a more comprehensive examination. The current qualitative approach was effective for identifying new and priority patient needs related to disease and treatment information. Study participants also experienced considerable emotional distress and required additional support to deal with their unresolved feelings about past diagnosis and treatment decisions.

A more proactive approach to planning for the needs of Canadian men with advanced prostate cancer is needed.

Given that most care is delivered on an outpatient basis, community program planners should consider increasing supportive care services to this group in their homes. Patients and families often are left trying to manage the impact of many side effects, including urinary incontinence, without adequate resources, information, or healthcare professional support (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2001). Both men with hormone-sensitive and hormone-refractory prostate cancer need supportive care services delivered by an interprofessional team. Nurses could play an important role in addressing men's information needs. Butler et al. (2001) suggested that many information issues, such as the availability of community resources, postoperative teaching, and assessment of knowledge, present an opportunity for nurses to personalize care for men with prostate cancer.

Evidence-based interventions to meet men's information needs must be designed, implemented, and evaluated. The resources needed to implement new information interventions could be minimized by the development and provision of care through information modules for small groups. Small-group sessions optimize resource use and peer support. Lepore, Helgeson, Eton, and Schulz (2003) used a randomized, controlled trial to evaluate two different group-education interventions for men treated for localized prostate cancer. Both education interventions had a positive influence on knowledge about the disease, health behaviors, physical functioning, and employment when compared to the control group. Based on the data from the current study's participants, small groups must be specific to advanced prostate cancer and dynamic enough to ensure they continue to meet the changing information needs of men as the disease progresses. Empowering men to identify their needs and make decisions may increase acceptance and attendance. Methods to meet the information needs of men with prostate cancer that have been evaluated include the use of telephone support (Scura, Budin, & Garfing, 2004) and the provision of audiotapes of treatment consultation (Hack, Pickles, Bultz, Ruether, & Degner, 2007). However, both of these interventions were tested on newly diagnosed men and may not be appropriate for men with advanced disease.

Interventions also are required to assist patients and families with interpreting information about advanced prostate cancer, treatments, and side effects. Sessions planned on a regular basis at cancer centers, at urologists' offices, and in the community to coincide with medical oncology or urology clinic times will minimize travel costs for patients. To ensure individuals who prefer not to attend group sessions still receive support, the services could be delivered through print or electronic media. Face-to-face or telephone counselling would assist with interpretation and provide individ-

ual support. Templeton and Coates (2004) conducted a randomized, controlled trial to evaluate the impact of an education package for men with prostate cancer receiving androgen-deprivation therapy. The intervention consisted of an information booklet supplemented by verbal teaching by a urology nurse. The intervention had a significant effect on knowledge, quality of life, and satisfaction with care, but not on coping. The small sample size of this study may not have permitted identification of small but important improvements in patient coping.

Nursing interventions also should focus on strengthening patients' abilities to seek out information. Although the focus of interventions often is on the healthcare provider's role, the process of communicating information is a reciprocal one (Salmon, 2005). A review of the literature on interventions to help patients communicate with healthcare providers during medical visits reveals that studies focus primarily on either helping patients to ask for information or helping patients to remember what was discussed (Parker, Davison, Tishelman, & Brudage, 2005). Boxhall and Dougherty (2003) reported that the intervention of a specialist nurse to provide information, emotional support, and practical assistance with managing side effects was useful to older men with prostate cancer.

The complex care needs of patients with cancer provide opportunity for the development of nursing roles at various stages of the cancer experience in various settings, including advanced practice nurse roles (Cunningham, 2004). The provision of clinical care to older men with advanced prostate cancer who suffer from metastatic cancer, treatment-related side effects, and other health issues requires advanced knowledge and educational preparation, as well as clinical expertise. Examining patient needs through focus groups and interviews has provided valuable information that can contribute to the evolution of nursing roles, and the study results confirm the need for tailored interventions at different stages of the disease process across the continuum of prostate cancer care. These findings have implications for nurses and the Canadian healthcare system. A clear need exists to provide information and support at the time of diagnosis, at the time of treatment decision making, post-treatment to deal with side effects, and after the active treatment phase. Effective management of patient health needs at earlier stages of the care continuum may lead to improved health outcomes and quality of life for patients who go on to develop advanced disease.

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## References

- Boberg, E.W., Gustafson, D.H., Hawkins, R.P., Offord, K.P., Koch, C., Wen, K., . . . Sainer, A. (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counseling*, 49, 233–242. doi: 10.1016/S0738-3991(02)00183-0
- Boxhall, S., & Dougherty, M. (2003). An evaluation of a specialist nursing role for men with prostate cancer. *Urologic Nursing*, 23, 148–152.
- Brazil, K., Whelan, T., O'Brien, M.A., & Sussman, J. (2003). *Coordinating supportive cancer care in the community*. Hamilton, Ontario, Canada: Supportive Cancer Care Research Unit.
- Brazil, K., Whelan, T., O'Brien, M.A., Sussman, J., Pyette, N., & Bainbridge, D. (2004). Towards improving the co-ordination of supportive cancer care services in the community. *Health Policy*, 70, 125–131. doi: 10.1016/j.healthpol.2004.02.007
- Bryant-Lukosius, D., Browne, G., DiCenso, A., Whelan, T., Gafni, A., Neville, A., & Sathya, J. (2010). 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. *Canadian Oncology Nursing Journal*, 20, 5–14.
- Bryant-Lukosius, D., & DiCenso, A. (2004). A framework for the introduction and evaluation of advanced practice nursing roles. *Journal of Advanced Nursing*, 48, 530–540. doi: 10.1111/j.1365-2648.2004.03235
- Butler, L., Downe-Wamboldt, B., Marsh, S., Bell, D., & Jarvi, K. (2001). Quality of life post radical prostatectomy: A male perspective. *Urologic Nursing*, 21, 283–288.
- Butow, P.N., Kirsten, L.T., Ussher, J.M., Wain, G.V., Sandoval, M., Hobbs, K.M., . . . Stenlake, A. (2007). What is the ideal support group? Views of Australian people with cancer and their carers. *Psycho-Oncology*, 16, 1039–1045. doi: 10.1002/pon.1172
- Canadian Cancer Society and National Cancer Institute of Canada. (2010). *Canadian Cancer Society/National Cancer Institute of Canada: Canadian cancer statistics 2010*. Toronto, Ontario, Canada: Author.
- Clark, J.A., Wray, N.P., & Ashton, C.M. (2001). Living with treatment decisions: Regrets and quality of life among men treated for metastatic prostate cancer. *Journal of Clinical Oncology*, 19, 72–80.
- Cunningham, R.S. (2004). Advanced practice nursing outcomes: A review of selected empirical literature. *Oncology Nursing Forum*, 31, 219–232. doi: 10.1188/04.ONF.219-232
- Curran, D., Fossa, S., Aaronson, N., Kiebert, G., Keuppens, E., & Hall, R. (1997). Baseline quality of life of patients with advanced prostate cancer. *European Journal of Cancer*, 33, 1809–1814. doi: 10.1016/S0959-8049(97)00187-1
- Dale, J., Jatsch, W., Hughes, N., Pearce, A., & Meystre, C. (2004). Information needs and prostate cancer: The development of a systematic means of identification. *BJU International*, 94, 63–69. doi: 10.1111/j.1464-410X.2004.04902.x
- Davison, B.J., Gleave, M.E., Goldenberg, S.L., Degner, L.F., Hoffart, D., & Berkowitz, J. (2002). Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nursing*, 25, 42–49. doi: 10.1097/00002820-200202000-00009
- Echlin, K.N., & Rees, C.E. (2002). Information needs and information-seeking behaviors of men with prostate cancer and their partners: A review of the literature. *Cancer Nursing*, 25, 35–41.
- Fitch, M. (2006). Perspectives of older adults about the cancer information they receive. *European Journal of Oncology Nursing*, 10, 216–217. doi: 10.1016/j.ejon.2006.04.010
- Fitch, M.I., Gray, R., Franssen, E., & Johnson, B. (2000). Men's perspectives on the impact of prostate cancer: Implications for oncology nurses. *Oncology Nursing Forum*, 27, 1255–1263.
- Gray, R.E., Fitch, M.I., Phillips, C., Labrecque, M., & Klotz, L. (1999). Presurgery experiences of prostate cancer patients and their spouses. *Cancer Practice: A Multidisciplinary Journal of Cancer Care*, 7(3), 130–135. doi: 10.1046/j.1523-5394.1999.07308.x
- Gray, R.E., Fitch, M.I., Phillips, C., Labrecque, M., Klotz, L., & Fergus, K.D. (2002). Prostate cancer and erectile dysfunction: Men's experiences. *International Journal of Men's Health*, 1, 15–29. doi: 10.3149/jmh.0101.15
- Gray, R.E., Klotz, L., Iscoe, N.A., Fitch, M.I., Franssen, E., Johnson, B.J., & Labrecque, M.M. (1997a). Prostate cancer patients' satisfaction with medical information. *Canadian Journal of Urology*, 4(2, Suppl. 1), 83–87.
- Gray, R.E., Klotz, L., Iscoe, N.A., Fitch, M.I., Franssen, E., Johnson, B.J., & Labrecque, M.M. (1997b). Results of a survey of Canadian men with prostate cancer. *Canadian Journal of Urology*, 4, 359–365.
- Hack, T.F., Pickles, T., Bultz, B.D., Ruether, J.D., & Degner, L.F. (2007). Impact of providing audiotapes of primary treatment consultations to men with prostate cancer: A multi-site, randomized, controlled trial. *Psycho-Oncology*, 16, 543–552. doi: 10.1002/pon.1094
- Jacobsen, P.B., Donovan, K.A., Vadaparampil, S.T., & Small, B.J. (2007). Systematic review and meta-analysis of psychological and activity-based interventions for cancer-related fatigue. *Health Psychology*, 26, 660–667. doi: 10.1037/0278-6133.26.6.660
- Jonsson, A., Aus, G., & Bertero, C. (2009). Men's experiences of their life situation when diagnosed with advanced prostate cancer. *European Journal of Oncology Nursing*, 13, 268–273. doi: 10.1016/j.ejon.2009.02.006
- Khafagy, R., Shackely, D., Samuel, J., O'Flynn, K., Betts, C., & Clarke, N. (2007). Complications arising in the final year of life in men dying from advanced prostate cancer. *Journal of Palliative Medicine*, 10, 705–711. doi: 10.1089/jpm.2006.0185
- Lepore, S.J., Helgeson, V.S., Eton, D.T., & Schulz, R. (2003). Improving quality of life in men with prostate cancer: A randomized controlled trial of group education interventions. *Health Psychology*, 22, 443–452. doi: 10.1037/0278-7133.22.5.443
- Lindqvist, O., Rasmussen, B.H., & Widmark, A. (2008). Experiences of symptoms in men with hormone refractory prostate cancer and skeletal metastases. *European Journal of Oncology Nursing*, 12, 283–290. doi: 10.1016/j.ejon.2008.03.003
- Lindqvist, O., Rasmussen, B.H., Widmark, A., & Hyden, L. (2008). Time and bodily changes in advanced prostate cancer: Talk about time as death approaches. *Journal of Pain and Symptom Management*, 36, 648–656. doi: 10.1016/j.jpainsymman.2007.12.013
- Lindqvist, O., Widmark, A., & Rasmussen, B.H. (2004). Meanings of the phenomenon of fatigue as narrated by four patients with cancer in palliative care. *Cancer Nursing*, 27, 237–243. doi: 10.1097/00002820-200405000-00010
- Lindqvist, O., Widmark, A., & Rasmussen, B.H. (2006). Reclaiming

- wellness—Living with bodily problems, as narrated by men with advanced prostate cancer. *Cancer Nursing*, 29, 327–337. doi: 10.1097/00002820-200607000-00012
- Lintz, K., Moynihan, C., Steginga, S.K., Norman, A., Eeles, R., Huddart, R., . . . Watson, M. (2003). Prostate cancer patients' support and psychological care needs: Survey from a non-surgical oncology clinic. *Psycho-Oncology*, 12, 769–783. doi: 10.1002/pon.702
- McMurtry, C.T., & McMurtry, J.M. (2003). Metastatic prostate cancer: Complications and treatment. *Journal of the American Geriatrics Society*, 51, 1136–1142. doi: 10.1046/j.1532-5415.2003.51367.x
- Mishel, M.H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing*, 17, 269–294.
- Morse, J.M. (1994). Designing funded qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220–235). Thousand Oaks, CA: Sage.
- Navon, L., & Morag, A. (2003). Advanced prostate cancer patients' ways of coping with hormonal therapy's effect on body, sexuality and spousal ties. *Qualitative Health Research*, 13, 1378–1392. doi: 10.1177/1049732303258016
- Northouse, L.L., Mood, D.W., Montie, J.E., Sandler, H.M., Forman, J.D., Hussain, M., . . . Kershaw, T. (2007). Living with prostate cancer: Patients' and spouses' psychosocial status and quality of life. *Journal of Clinical Oncology*, 25, 4171–4177. doi: 10.1200/JCO.2006.09.6503
- Parker, P.A., Davison, B.J., Tishelman, C., & Brudage, M.D. (2005). What do we know about facilitating patient communication in the cancer care setting? *Psycho-Oncology*, 14, 848–858. doi: 10.1002/pon.946
- Penson, D.F., & Litwin, M. (2003). The physical burden of prostate cancer. *Urologic Clinics of North America*, 30, 305–313. doi: 10.1016/S0094-0143(02)00187-8
- Penson, D.F., Litwin, M.S., & Aaronson, N.K. (2003). Health related quality of life in men with prostate cancer. *Journal of Urology*, 169, 1653–1661. doi: 10.1097/01.ju.0000061964.49961.55
- Rosenfeld, B., Roth, A.J., Gandhi, S., & Penson, D.F. (2004). Differences in health-related quality of life of prostate cancer patients based on stage of cancer. *Psycho-Oncology*, 13, 800–807. doi: 10.1002/pon.797
- Salmon, P. (2005). Patient interventions to facilitate communication. *Psycho-Oncology*, 14, 859–860. doi: 10.1002/pon.971
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334–340. doi: 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
- Scura, K.W., Budin, W., & Garfing, E. (2004). Telephone social support and education for adaptation to prostate cancer: A pilot study. *Oncology Nursing Forum*, 31, 335–338. doi: 10.1188/04.ONF.335-338
- Sinfield, P., Baker, R., Camosso-Steinovic, J., Colman, A.M., Tarrant, C., Mellon, J.K., . . . Agarwal, S. (2009). Men's and carers' experiences of care for prostate cancer: A narrative literature review. *Health Expectations*, 12, 301–312. doi: 10.1111/j.1369-7625.2009.00546.x
- Skalla, K.A., Bakitias, M., Furstenberg, C.T., Ahles, T., & Henderson, J.V. (2004). Patients' needs for information about cancer therapy. *Oncology Nursing Forum*, 31, 313–319. doi: 10.1188/04.ONF.313-319
- Steginga, S.K., Occipinti, S., Dunn, J., Gardiner, R.A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer. *Psycho-Oncology*, 10, 66–75. doi: 10.1002/1099-1611(200101/02)10:1<66::AID-PON493>3.0.CO;2-Z
- Stephenson, R.A. (2002). Prostate cancer trends in the era of prostate-specific antigen. An update of incidence, mortality, and clinical factors from the SEER database. *Urologic Clinics of North America*, 29, 173–181. doi: 10.1016/S0094-0143%2802%2900002-2
- Templeton, H., & Coates, V. (2003). Informational needs of men with prostate cancer on hormonal and manipulation therapy. *Patient Education and Counseling*, 49, 243–256. doi: 10.1016/S0738-3991(02)00181-7
- Templeton, H., & Coates, V. (2004). Evaluation of an evidence-based education package for men with prostate cancer on hormonal manipulation therapy. *Patient Education and Counseling*, 55, 55–61. doi: 10.1016/j.pec.2003.07.005
- Thaxton, L., Emshoff, J.G., & Guessous, O. (2005). Prostate cancer support groups: A literature review. *Journal of Psychosocial Oncology*, 23, 25–40. doi: 10.1300/J077v23n01\_02
- Trask, P.C. (2004). Quality of life and emotional distress in advanced prostate cancer survivors undergoing chemotherapy. *Health and Quality of Life Outcomes*, 2, 37. doi: 10.1186/1477-7525-2-37
- Wallace, M., & Storms, S. (2007). The needs of men with prostate cancer: Results of a focus group study. *Applied Nursing Research*, 20(4), 181–187. doi: 10.1016/j.apnr.2006.08.008
- Weber, B.A., Roberts, B.L., & McDougall, G.J. (2000). Exploring the efficacy of support groups for men with prostate cancer. *Geriatric Nursing*, 21(5), 250–253. doi: 10.1067/mgn.2000.110836
- Whelan, T., Grunfeld, E., Sussman, J., Abelson, J., Willan, A., & Sellick, S. (2003). *An evaluation of continuity of care through regional supportive care networks*. Ottawa, Ontario, Canada: Canadian Health Services Research Foundation.
- Wong, F., Stewart, D.E., Dancey, J., Meana, M., McAndrews, M.P., Bunston, T., & Cheung, A.M. (2000). Men with prostate cancer: Influence of psychosocial factors on informational needs and decision making. *Journal of Psychosomatic Research*, 49, 13–19. doi: 10.1016/S0022-3999(99)00109-9