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PATIENT AND FAMILY SUPPORTIVE CARE NEEDS IN ADVANCED PROSTATE CANCER: DEVELOPMENT OF AN ADVANCED PRACTICE NURSE ROLE

BY

NANCY M. CARTER,
R.N., B.Sc.N., M.S.

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PATIENT AND FAMILY SUPPORTIVE CARE NEEDS IN ADVANCED PROSTATE CANCER: DEVELOPMENT OF AN ADVANCED PRACTICE NURSE ROLE

By

NANCY M. CARTER, RN, BScN, MS

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Submitted to the School of Graduate Studies

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AUTHOR: Nancy M. Carter, RN, BScN, MS (D'Youville College)

SUPERVISOR: Alba DiCenso, RN, PhD

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Abstract

Patient and Family Supportive Care Needs in Advanced Prostate Cancer: Development of an Advanced Practice Nurse Role

Purpose: The purpose of this study is to further understand the unmet healthcare needs of men with Advanced Prostate Cancer (APC) and their family members, how these unmet needs affect the daily lives of these people, and how the delivery of supportive care services could be improved to meet their needs.

Methods: A needs assessment was designed using a qualitative descriptive method. Focus groups and individual interviews were used to collect data from 29 men with APC and 19 family members in South Central Ontario. A smaller study that explored their experiences of participation in focus groups and interviews was also conducted. Audio-recorded and transcribed data were organized using N-Vivo software. Teams of independent reviewers used content analysis to identify themes regarding unmet health needs and health care services.

Results: Both patients and family members identified information as their priority supportive care need and the men's struggle to maintain their functional capacity as the greatest challenge. Functional issues described by men included urinary and sexual dysfunction, fatigue and the side effects of their treatment. We also identified the patient need for emotional support. Family members were uncertain about the future and some experienced caregiver burden and isolation and needed more practical assistance. Both patients and families recommended providing more opportunities to discuss APC with healthcare professionals and the creation of small support groups.

Conclusion: The design and organization of supportive care services that maximize patient and family resiliency and provide the tools and resources necessary to maintain functional capacity is recommended. This population requires patient focused interventions by Advanced Practice Nurses and other members of the interdisciplinary team to help cope with complex, overlapping supportive care needs that are complicated by advancing age, cancer treatment, and co-morbid conditions.

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CHAPTER ONE

Introduction

This thesis consists of three papers based on a qualitative study that explored the supportive care needs of two groups of men with advanced prostate cancer (APC) and their family members. The three manuscripts, presented in chapters 2, 3, and 4, are being prepared for submission to peer-reviewed journals. This introductory chapter describes the burden of illness of men living with APC and that of their family members, the series of studies of which this is a part, the study objectives and research questions, the theoretical framework and study design, and the outline of the thesis content.

Background: Prostate Cancer in Canada

Prostate cancer is the most prevalent type of cancer in men in Canada. The Canadian Cancer Society and the National Cancer Institute of Canada (2008) have estimated that 24,700 new cases of prostate cancer will be diagnosed in 2008. Furthermore, they estimated that 127,200 cases of prostate cancer currently afflict 0.8% of the Canadian male population. Prostate cancer will account for 11% of all Canadian cancer deaths in 2008. On a more positive note, mortality declined significantly (2.9% per year) between 1995 and 2004, due to earlier detection and improved treatment.

Cancer Care Ontario (2008) has estimated that 10,500 new cases of prostate cancer will be diagnosed in Ontario in 2008. Cancer Care Ontario also reported that in 2004, 992 new cases of prostate cancer were diagnosed and 175 deaths resulted from prostate cancer in the region of the Hamilton Niagara Haldimand Brant Local Health Integration Network (LHIN).

Although most new cases of prostate cancer are diagnosed among men aged 60 to 69, more prostate cancer deaths occur among men aged 80 and older (Canadian Cancer Society & National Cancer Institute of Canada, 2008). This pattern reflects increased cancer screening among younger men and the long natural history of the disease. In many men, the disease will progress from localized to advanced disease as the cancer extends beyond the prostate to lymph nodes, bone tissue, or other organs. As a chronic condition, APC requires extended outpatient care for treatment, symptom management, and palliation. The Hamilton Health Sciences Oncology Program (HHSOP), which is responsible for cancer care in the Central West Ontario Region, is one of the primary healthcare institutions responsible for providing care for men with prostate cancer in Ontario.

Men with APC and their Family Members

Two distinct populations of patients live with APC: those with hormone sensitive (HS) disease and those with hormone refractory (HR) disease. Initially, most men are diagnosed with HS disease and treated with hormone suppression therapy to control the progress of the disease. Eventually, most men diagnosed with HS disease develop HR disease. Palliation is the primary goal of treatment for HR and may involve chemotherapy, radiation and supportive care (McMurtry & McMurtry, 2003). The quality of life of family members of people with cancer is compromised by worry and anxiety for their loved ones and the burden of caregiving. Due to the sexual side effects that often result from prostate cancer and its treatment, this disease particularly affects intimate relationships.

Supportive Care for Individuals Living With APC

In 1997, healthcare providers, researchers, advocacy groups, patients, and their families participated in the National Prostate Cancer Forum (1997) in Toronto to identify priorities and strategies for research and care. Twelve recommendations resulting from the forum set the national framework for prostate cancer control in Canada. Two of these recommendations became the focus of this study: (a) conduct specific research on supportive care to understand the impact of prostate cancer on the individual and his family; and, (b) to improve the delivery of supportive and palliative care. Based on the healthcare community's belief that "patients do not wish merely to survive, they want to *thrive*" (2007, p.10), the Canadian Prostate Cancer Research Initiative's follow-up to this public forum in 2007 highlighted the need for progress in the study of survivorship.

Fitch (1994) defined *supportive care* as:

> the provision of the necessary services as defined by those living with or affected by cancer to meet their physical, social, emotional, informational, psychological, spiritual and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement.

The process of delivering supportive care is complex, particularly for men with APC, who may require care from multiple medical specialties and health professionals, including family physicians, urologists, oncologists, support groups, emergency services, the Canadian Cancer Society, and other community agencies. Regional cancer programs are responsible for developing supportive care services in collaboration with healthcare

consumers and the community. Historically, there has been little collaboration between supportive cancer care and cancer treatment services, or among the organizations that provide supportive cancer care (Brazil et al., 2004).

Brazil, Whelan, O'Brien, and Sussman's (2003) research in Ontario identified problems related to inadequate access, coordination, and integration of supportive and palliative care services. Examining the continuity of cancer care provided by regional supportive care networks, Whelan et al. (2003) found that many cancer patients are unaware of the supportive care services available to them, and those who are aware of such services utilize them at low rates. Although policymakers have encouraged the development of generalized services aimed at meeting a broad range of needs for cancer patients and their families, they have failed to recognize that patients have needs specific to the type of cancer, stage of disease, type of treatment, and prognosis.

Series of Studies to Address Supportive Care

The study described in this thesis is one of three studies planned to systematically identify and understand the factors that influence the regional healthcare system's ability to meet the reported supportive care needs of patients and families affected by APC. Previous work by Bryant-Lukosius (2003) summarized trends in patient use of cancer program services, identified priority patient healthcare needs, examined the impact of unmet mental healthcare needs on quality of life, and described the use of healthcare services among patients with APC in the Hamilton region. Based on her work, she made recommendations for the development of an Advanced Practice Nurse (APN) role across

the continuum of prostate cancer. She recommended an APN intervention focused on prostate cancer health, mental health, and functional capacity.

In Bryant-Lukosius' first study (2003), the health needs of men with prostate cancer who attended the regional cancer centre were examined. A total of 551 men participated in the study and were administered the Functional Assessment of Cancer Therapy-Prostate (FACT-P) scale to understand health related quality of life (HRQL) and the types and importance of health problems. Men with HS APC experienced good HRQL that was similar to men with early stage disease. Men with HR APC had significantly poorer HRQL and more severe health problems. For men with HR APC, alleviating pain and fatigue were the priority, which was different from the top priority of improving sexual function reported by the early stage and HS APC groups. Analysis of prostate cancer related variables revealed that higher levels of Prostate Specific Antigen (PSA), advanced hormone refractory disease and a history of mental health problems were modest predictors of poor HRQL.

The second study by Bryant-Lukosius (2003) focused on the prevalence of mental health problems in advanced stage disease and the health care costs associated with these problems. Ninety-nine men with APC were administered a questionnaire via telephone which assessed mental health, HRQL and health care costs. Anxiety or affective disorder were reported by 19% of the patients. Patients with a mental health disorder had significantly poorer HRQL than those with no mental health problems. Health care costs reported by patients with a mental health disorder were twice as high as those patients with no mental health problems.

Although patient perceptions of the importance and frequency of prostate cancer related health problems were reported, the impact of these problems on daily life and overall quality of life was not explored (Bryant-Lukosius, 2003). The purpose of the study reported in this thesis is to further understand the unmet healthcare needs of men with APC, how these unmet needs affect their daily lives, and how the delivery of supportive care services could be improved to meet their needs.

This study expands on the previous work done through the use of qualitative methods. Qualitative data collection methods provided the opportunity to contextualize patient and family needs and the extent to which the health care system addresses them. The methods also allowed exploration of concepts with individual participants. The target population under study was expanded to include both men with APC who are cared for in the community and family members of men with APC. The two previous studies were restricted to men who attended the regional cancer centre for their care, limiting the generalizability of results. Family members are included in the sample to confirm patient supportive care needs, to identify their own supportive care needs, and to understand the impact of prostate cancer on the patient and family life. Because family members have caregiving responsibilities, their suggestions for care delivery improvement are important.

Study Objectives and Research Questions

Study Objectives

The study objectives were to:

1. Gain further understanding of patient supportive care needs.

2. Identify patient and family perceptions of unmet priority supportive care needs.
3. Identify strategies to improve the delivery of supportive care services to meet those needs.

Research Questions

The study objectives were achieved by addressing the following research questions:

1. What are patient and family perceptions of the met and unmet supportive care needs of men with HS APC and HR APC and their families?
2. What are the priority perceived supportive care needs of APC patients and their families?
3. What are the strengths and limitations of the current delivery of supportive care services in meeting the needs of APC patients and their families?
4. What strategies should be implemented to improve the delivery of supportive care services in order to meet the priority healthcare needs of APC patients and their families?

Theoretical Framework and Study Design

Study Framework

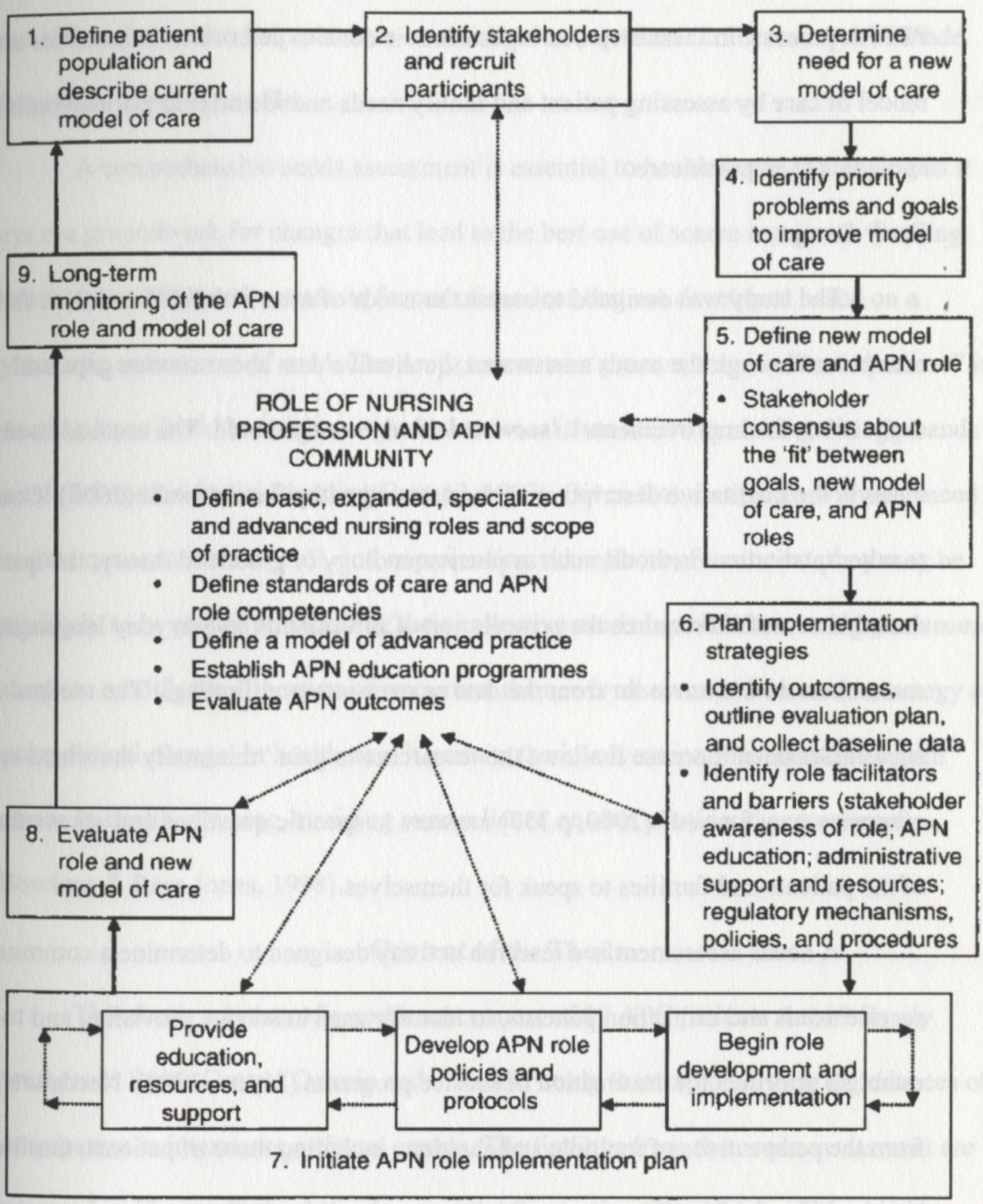
Based on her work, Bryant-Lukosius recommended the development of an APN role to focus on prostate cancer health, mental health, and functional capacity. The study described in this thesis was designed to learn more about the unmet healthcare needs of men with APC and how the delivery of services could be improved to meet these needs. The participatory, evidence-based, patient-focused process for advanced practice nursing role development, implementation and evaluation (PEPPA) framework as described by

Bryant-Lukosius and DiCenso (2004) was selected as the framework for this study because it emphasizes the need to examine the current model of care for meeting patient health needs in order to fully inform what additional health services are needed and who should deliver them. While the PEPPA Framework is a systematic, health care planning guide used to minimize or prevent commonly known barriers to the effective development, implementation, and evaluation of APN roles, its early stages are important in determining whether an APN role is needed at all and if not, what role, if any, is needed.

The principles of participatory action research (PAR) informed the development of the PEPPA Framework. PAR empowers consumers through their involvement in project planning, study design, choices of data collection and analysis and use of outcome data (Bourke, 2002). PAR involves both a commitment to honoring the experiences and knowledge of participants and a commitment to an authentic collaboration in the research (Wong & Chow, 2006). Gray and colleagues (2000) discuss the challenges of PAR and suggest that most participatory research lies in the middle of a continuum between the ideal of equality between participant and the practical reality of token participation from selected community representatives. In keeping with PAR's approach, engagement of patients and other key stakeholders as participants in the healthcare planning process is a central feature of the framework.

The PEPPA Framework involves a nine-step process (Figure 1). Steps One to Six focus on health care decision-making and planning for developing and implementing a new model of care that may include an APN role. Step Seven involves initiating the

Figure 1. The participatory, evidence-based, patient-focused process for advanced practice nursing role development, implementation and evaluation (PEPPA) framework



implementation plan. Steps Eight and Nine include the short and long-term evaluation of the APN role and the new model of care to determine progress and sustainability in achieving pre-determined goals and outcomes. This study focused on Steps 3 and 4 of the PEPPA process. In these steps, an assessment is done to determine the need for a new model of care by assessing patient and family needs and identifying priority problems and goals to improve care.

Study Design

The study was designed to assess the needs of men with APC and their family members. Through the needs assessment, qualitative data about service gaps and suggestions for improvements to service delivery was gathered. The method used in this thesis is the qualitative descriptive method described by Sandelowski (2000). Compared to other qualitative methods, such as phenomenology or grounded theory, the qualitative descriptive method requires the presentation of information in everyday language; researchers do not move far from the data or over-interpret findings. The method suits a needs assessment because it allows the researcher to gain "minimally theorized or otherwise transformed" (2000, p.337) answers to specific questions and allows the words of the patients and families to speak for themselves.

A needs assessment is a research activity designed to determine a community's service needs and utilization patterns, to identify gaps in service provision, and to establish priorities for the creation of service programs (Myers, 1988). Needs are assessed from the perspectives of multiple stakeholders, including those of patients, families and health care providers. It is a systematic process for discovering more about needs and

who has them, as well as examining why needs exist and the possible solutions for meeting them (Edmonton Social Planning Council, 1993). Determination of the gaps between need and health service can inform subsequent program modifications and evaluation. It can also help planners establish priorities when choices need to be made about what services to offer.

A comprehensive needs assessment is essential to health services planning as it lays the groundwork for changes that lead to the best use of scarce resources. Funding decisions are likely to be made in favour of services that are developed based on a systematic assessment of need. The needs assessment process serves as an "equalizer" in securing input from those who might be less vocal than others in making their demands heard (Edmonton Social Planning Council, 1993). Given that many men with advanced prostate cancer are elderly, ill, and experiencing side effects of treatment, they may be less likely to be proactive in having their collective needs heard. When used by consumer groups to modify the allocation of resources, the needs assessment becomes a strategy of sociopolitical change. In healthcare, it permits the involvement of users of the health service in health planning, avoiding over-reliance on care providers' perceptions (Bowling & Rees Jones, 1998).

Content of the Thesis

This thesis consists of a needs assessment of 29 APC patients and 19 family members in South Central Ontario and a smaller study that explored their experiences of participation in interviews or focus groups. The findings from the needs assessment are presented in Chapter 2, An Assessment of the Supportive Care Needs of Men with

Hormone Sensitive and Hormone Refractory Advanced Prostate Cancer. Findings from the focus groups and interviews with family members are reported in Chapter 3, The Long Slow Dance: The Experiences of Family Members Living with Men with Advanced Prostate Cancer.

This thesis proved to be an opportunity to explore the challenges of engaging consumers in research for health care planning purposes. Collecting data from the two patient populations and their family members was difficult. Because we wanted to hear the experiences of patients with the greatest needs, we needed to be flexible in the types of methods we used and therefore, we used interviews and focus groups to collect data. Uncertainty and concern regarding the use of both focus groups and individual interviews influenced the data and findings led to further exploration of the use of methods. Chapter 4, Different Strokes for Different Folks: Individualizing the Use of Focus Groups or Individual Interviews within a Single Study Based on Study Participant Circumstances and Preferences, describes the findings from the study of participant experiences embedded in the needs assessment study. The objectives of this study were to explore the subjects' experiences as participants in focus groups or individual interviews. The chapter begins by reviewing, synthesizing, and critiquing the literature exploring the use of focus groups and interviews. It then reports on the exploration of the participants' experiences with focus groups and interviews as data collection methods and provides recommendations for their use in future studies. This chapter provides an important contribution to what we know about the pragmatics of collecting data in health care planning research.

Chapter 5 describes the major findings reported in the previous three chapters, and then discusses the contributions of this research to understanding the needs of men with APC and their family members, as well as patient and family priorities for improving care for men with APC. A discussion about the challenges of engaging patients and families in the health care planning process, and recommendations for using focus groups and in-depth interviews to collect data from patients and family members in future studies follows. The chapter concludes with the study's implications for nursing practice, education, policy, and research.

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CHAPTER TWO

An Assessment of the Supportive Care Needs of Men with Hormone Sensitive and Hormone Refractory Advanced Prostate Cancer

Key Words: supportive care, needs assessment, advanced prostate cancer, focus groups, interviews

Nancy Carter

Denise Bryant-Lukosius

Jennifer Blythe

Alan Neville

Alba DiCenso

Faculty of Health Sciences, McMaster University, Hamilton, Ontario

Abstract

Background: There is a need to develop more efficient and effective models of care delivery to meet the rising demands for cancer and supportive care services for patients with advanced prostate cancer (APC).

Objectives: To better understand the priority supportive care needs of men with hormone-sensitive (HS) and hormone-refractory (HR) APC and to gather data about suggestions for improvements to service delivery.

Methods: This qualitative descriptive study used focus groups and interviews to collect data from a purposeful sample of 12 men with HS disease and 17 men with HR disease in South Central Ontario. The men were asked to identify their priority needs, and the strengths and limitations of the current model of care delivery for meeting them. They were also asked for recommendations for improving health services for men with advanced-stage prostate cancer. Audio recorded and transcribed focus group discussions and interviews were organized using N-Vivo software. Teams of independent reviewers used content analysis to identify themes from the transcribed data regarding unmet patient health needs and health care services.

Results: Participants identified APC specific information and support to maintain their ability "to do what they want to do" as priority needs. Both HS and HR patients cited problems with urinary function, the side effects of their treatment, fatigue, and sexual issues as major functional issues. They experienced emotional distress related to their diagnosis and treatment. Participants recommended increasing the availability of prostate-specific antigen (PSA) testing for the general population, vigilant assessment of

prostate cancer to prevent the development of advanced disease, and small-group meetings facilitated by a health professional to address information and coping needs.

Conclusion: Our results show that a priority health need for men with APC is to improve or maintain their functional abilities. In addition to this, men need support to meet their stage specific informational needs and emotional support to reconcile feelings about their diagnosis and past treatment decision making.

Background

Prostate cancer is the most prevalent type of cancer in men in Canada, affecting approximately 127,200 Canadians, or 0.8% of the Canadian male population. The Canadian Cancer Society and the National Cancer Institute of Canada (2008) have estimated that 24,700 new cases of prostate cancer will be diagnosed in 2008. Prostate cancer will account for 11% of all Canadian cancer deaths in 2008.

The majority of men (over 85%) diagnosed with prostate cancer are older than 65 years of age. Despite improvements in early detection and treatment, many men progress from localized to advanced disease. Advanced prostate cancer (APC) extends beyond the prostate to lymph nodes, bone tissue, and other organs. It is a chronic condition requiring extended outpatient care for treatment, symptom management, and palliation. Two distinct populations of patients live with APC: those with hormone-sensitive (HS) disease and those with hormone-refractory (HR) disease. Treatment for HS disease involves controlling disease growth through hormone-suppression therapy by medical or surgical castration. Eventually, most patients develop hormone "resistant," or HR disease, 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, even after the development of advanced disease, facing the challenges of living with a chronic illness (Levy, Gibbons, Collins, Perkins, & Mao, 1993; Maxwell, 1993; Stephenson, 2002). Common problems associated with APC include deteriorating levels of function related to cancer and aging; and problems related to sexual and urinary function, fatigue, and pain (Jakobsson,

Hallberg, & Loven, 1997; Maxwell, 1993; 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 (Kornblith, Herr, Ofman, Scher, & Holland, 1994). Physical symptoms related to the androgen deprivation and chemotherapy for metastatic disease exacerbate disease-related problems (Penson & Litwin, 2003). There also are less urgent, but no less important, needs related to information, treatment decisions, side-effect management, and coping (Gray et al., 2002; Gray, Fitch, Phillips, Labrecque, & Klotz, 1999).

Services designed to meet the non-medical needs of patients are considered supportive care services. According to Fitch (2000), *supportive care* is

> the provision of the necessary services, as defined by those living with or affected by cancer, to meet their physical, social, emotional, informational, psychological, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement. (Fitch, 2000, p.40)

Regional cancer programs in collaboration with health care recipients and the community are responsible for supportive care services. Health care restructuring, poor access to supportive care expertise, and limited funding opportunities have hindered the development of services. The Canadian Strategy for Cancer Control (2002) identified several factors contributing to the lack of progress in developing supportive care programs: insufficient data about the types of supportive care and rehabilitation that

patients need, as well as a lack of information about how patients actually use health services at various stages of the disease.

Delivering supportive care involves multiple health professionals that work in various agencies throughout the community, including regional cancer centres. Further complicating supportive care delivery is the large number of nonmedical services that may be involved such as home care, nutritional support, social services and financial planning. Nurses provide supportive care at many stages in the cancer continuum. For patients with APC, nursing support is provided in outpatient cancer treatment programs, hospitals, and through community care. Bryant-Lukosius (2003) described use of an advanced practice nursing (APN) role to care for men with APC. She developed a preliminary model articulating the supportive care role of the APN for patients with APC across a continuum from diagnosis to palliation (Appendix A).

Literature Review

Historically, there has been little coordination between treatment services and supportive cancer care and little coordination among the organizations that provide supportive cancer care (Brazil et al., 2004). Problems are related to inadequate access, coordination, and integration of supportive and palliative care services (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 centres, hospitals, and community agencies. Whelan and colleagues (2003) examined the continuity of cancer care provided by regional networks of supportive care and identified that many cancer patients were unaware that supportive care services were

available while others made little use of them. While 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. Three reviews and other research have 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 advanced HR disease report significantly poorer health-related quality of life (HRQL) than other groups (Bryant-Lukosius, 2003; Curran et al., 1997; Kornblith et al., 1994).

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, 2003; Fitch, Gray, Franssen, & Johnson, 2000; Jakobsson et al., 1997), as well as a desire for support and information (Boberg et al., 2003). The needs of men with prostate cancer depend on their stage of illness and treatment (Bryant-Lukosius, 2003; Lintz et al., 2003; 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). Bryant-Lukosius (2003) found urinary frequency and incontinence, and other treatment side effects affected men with HS disease, whereas men with advanced HR disease 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. Wallace and Storms (2007) used focus groups to explore the psychosocial and educational needs of men with prostate cancer using a previously developed cancer model. They found needs included patient and family education, patient and family psychosocial support, and connection with survivors.

Few studies focus solely on APC or distinguish between the needs of men with HS APC and the needs of men with HR APC. The few published studies that did so used quantitative methods, and did not allow for exploration of men's priority needs or their thoughts about better health care delivery. Qualitative methods give participants opportunities to share information about their experiences during difficult times in their lives (Woodward & King, 1993). Further qualitative research is needed to discover why unmet needs for supportive care services persist, 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 explore the supportive care needs of men affected by APC and to determine whether or not the current model of care responds to these needs. The study is a component of a comprehensive assessment of APC patient and family needs in the Hamilton region initiated by Bryant-Lukosius (1999). Previous work by Bryant-Lukosius (2003) with patients with APC in the Hamilton region summarized trends in patient use of cancer program services, identified priority patient

healthcare needs, examined the impact of unmet mental healthcare needs on quality of life, and described the use of healthcare services. Based on her work, she made recommendations for the development of an Advanced Practice Nurse (APN) role across the continuum of prostate cancer. She recommended the focus of an APN intervention be prostate cancer health, mental health, and functional capacity.

Although patient perceptions of the importance and frequency of prostate cancer related health problems were reported, the impact of these problems on daily life and overall quality of life was not explored (Bryant-Lukosius, 2003). The purpose of this study is to further understand the unmet healthcare needs of men with APC, how these unmet needs affect their daily lives, and how the delivery of supportive care services could be improved to meet their needs.

This study expands on the work previously done through the use of qualitative methods. Qualitative data collection methods provided the opportunity to contextualize patient and family needs and the extent to which the health care system addresses them. The methods also allowed exploration of concepts with individual participants. The target population under study was expanded to include men with APC cared for in the community. The two previous studies were restricted to men who attended the regional cancer centre for their care, limiting the generalizability of results.

The *P*articipatory, *E*vidence-based, *P*atient-focused *P*rocess for *A*dvanced practice nurse roles (PEPPA) framework, as described by Bryant-Lukosius and DiCenso (2004) guided this study. Specifically, the study focused on Steps 3 and 4 of the

framework – determining the need for a new model of care by assessing patient and family needs and identifying priority problems and goals to improve care.

The study builds on the evidence that men with APC have unmet needs and that men with HS disease may have needs different from men with HR disease. The research questions were as follows:

1. What are the supportive care needs of men with HS and HR APC and are the needs of these two groups different?
2. What are the strengths and limitations of the current delivery of health care services in meeting the supportive care needs of these patients?
3. What are the recommended strategies and priorities to improve the delivery of health care services to meet the priority supportive needs of these patients?

Brazil and colleagues (2003) examine the construct of "need" in their systematic review of the supportive care needs of people with cancer. The definition of need varies from study to study, and ranges from an impaired health state to a need or problem that requires a service. The construct includes the concepts of health problem, need/desire for service, and satisfaction with service. Bryant-Lukosius and colleagues (2004) suggest that patient health needs are "subjective expressions of goals or of something missing that is important for well being" (p. 534) and should be distinguished from health problems.

Methods

A needs assessment was designed to determine service needs and utilization patterns, to identify gaps in service provision, and to establish priorities for the creation

of service programs for men with APC. A needs assessment is a systematic process for discovering who has needs, why they exist and which solutions might meet them (Edmonton Social Planning Council, 1993). Needs assessments in health care often involve users as a means to circumvent reliance on provider perceptions of consumer need (Rees Jones, 1998). Given that many men with APC are elderly, ill, and experiencing side effects of treatment, they might not ordinarily be proactive in articulating their collective needs. A thorough understanding of needs allows health care teams working with patients with advanced disease to provide appropriate interventions. Nurses must not only care for the physical aspects of the disease and treatment, but also support the psychosocial, practical, and spiritual consequences as the disease progresses and dying from the cancer becomes a reality (Fitch, 2005).

This study uses the qualitative description method outlined by Sandelowski (2000) to attain a comprehensive description of the supportive care needs of men with APC and their suggestions for improving supportive care. Qualitative description is a method which allows a summary of participant experiences without in-depth level of interpretation (Milne & Oberle, 2005). This method is suitable for health services research because it allows the presentation of patient data close to its original form, and because it allows health care planners to receive answers to specific service related questions.

The Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board and the St. Joseph's Healthcare Research Ethics Board approved all study procedures (Appendices B and C).

Sample

The study was designed to collect information from HS and HR patients separately due to differences in their health (Bryant-Lukosius, 2003; Bryant-Lukosius & DiCenso, 2004; Lintz et al., 2003; Rosenfeld et al., 2004). Eligible patients with APC were defined as men with stage T4 disease by the Tumour-Node Metastasis (TNM) staging system, or D1 or D2 disease by the Whitmore-Jewitt classification system. HS patients included those receiving androgen-suppression therapies (orchiectomy or Luteinizing Hormone-Releasing Hormone [LHRH] analogues with or without anti-androgens). Men with HR disease had reached a PSA nadir on hormone-suppression therapy and had three consecutive rises in PSA.

Participants were recruited from various settings. HS patients were identified through urologists' offices, newspaper and community television advertisements, university and interest group web site notices, and local prostate cancer support groups (Appendix D). The nurse in the urology clinic used a screening tool to assist with identifying eligible participants (Appendix E). Some HR patients were also recruited through community advertising, but most were recruited from a Central West Ontario Cancer Centre. Using the same screening tool to identify potential participants, clinic nurses approached HR patients during their appointments, explained the study to them and asked if they would participate. Interested patients were asked if their name and phone number could be given to the primary investigator. Nurses were asked to record the reasons a patient refused to participate, but not all nurses did this. The primary investigator used a telephone script when contacting interested patients (Appendix F). In

the study proposal, it was estimated that six focus groups would be held (three of HS patients, and three of HR patients).

Data Collection and Analysis

The original plan was to collect all data through focus groups; however, the different treatment settings for HR and HS patients influenced ease of recruitment. Recruitment at the regional cancer centre proceeded quickly, due to the large number of potential participants. Although some men at the regional cancer centre refused to participate in focus groups, there were enough willing participants to organize focus groups. Reasons for not participating included not wanting to be part of focus groups, not feeling well enough to participate or not having the time. One man had a laryngectomy and was not comfortable communicating in a group. Recruitment of HS patients through urologists' offices and in the community was slow and led to the decision to conduct individual interviews to ensure recruited participants did not lose interest before focus groups could be organized. Consent was obtained prior to data collection (Appendices G and H).

Focus groups involve organized discussion with select groups of participants and are useful in getting several perspectives on the same topic. They differ from individual interviews because "dynamic and interactive exchange among participants" leads to "multiple stories and diverse experiences" (Brown, 1999, p.115). Focus groups have been used previously with patients with prostate cancer and their families (Clark et al., 2001; Harden et al., 2002; Sanders, Pedro, Bantum, & Galbraith, 2006). Individual, in-depth interviews permit collection of information about needs and potential health care

solutions but do not permit interaction among individuals experiencing the disease. Individual interviews have been used with patients and with patient-partner dyads previously (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2001). The data collection methods will be discussed further in Chapter 4.

In total, 17 men each participated in one of five focus groups lasting 90-120 minutes. The number of participants in each focus group ranged from 2 to 5. Eleven men participated in one-to-one, in-depth, semi-structured interviews lasting 30-60 minutes. Spouses of the men were present during some of the interviews. Participants were asked how APC had affected their lives, problems they were experiencing, and whether their needs were being met (Appendix I). They also were asked what the priorities should be for improving care for men with APC. At the end of the focus groups and interviews, major themes were recapitulated to validate and clarify the information given (member checking). A research assistant observed the focus group interaction and made notes about verbal and nonverbal communication among the men during the focus-group sessions. After each focus-group session, the researcher and the research assistant reflected on the group interaction and content. All focus-group discussions, interviews, and reflections were audiotaped and transcribed verbatim. Data were collected until saturation occurred, meaning no new information was obtained (Morse, 1995).

Content analysis is the most common form of analysis used in the qualitative descriptive method and involves systematically reducing the data into coded units that are clustered into categories (Milne & Oberle, 2005; Sandelowski, 2000). Data analysis occurred concurrently with data collection. The research team read initial transcripts and

developed a coding scheme. Using N-Vivo software, the coding system, and thematic content analysis as described in the framework suggested by Burnard (1991), the research team and two research assistants with oncology nursing experience reviewed all transcripts. They developed core categories and codes were clustered into these categories. From these categories, significant themes emerged. The researcher and research assistants who reviewed the transcripts discussed data saturation and agreed when data collection could stop.

Triangulation is a process where multiple methods are used to help clarify meanings or verify observations or interpretations (Denzin & Lincoln, 2003; Sandelowski, 1995). Triangulation strategies in this study included the comparison of study results with those of the previous studies conducted on this patient population (Bryant-Lukosius, 2003) and attendance at five prostate cancer support groups held by the Canadian Cancer Society to listen to the issues raised by men and their wives. The issues raised at these meetings were noted and compared to those raised by the study participants.

The credibility or truth value of qualitative research depends on its internal validity (Sandelowski, 1986). A critical technique for establishing credibility is member checking, which seeks participant views of findings or interpretations (Cresswell, 1998). A summary of the information provided by participants was reviewed at the end of each focus group and individual interview to ensure clarity. The themes generated were also shared with stakeholders such as nurses, physicians and other members of the health care team at the regional cancer centre, at nursing academic seminars and at research

conferences to see if they were "recognizable" or credible to them (Koch, 1994). Using a second researcher with oncology nursing expertise to assist with coding also supported truth value by ensuring the codes reflected the data (Morse, 1994).

Fittingness or transferability refers to the applicability of the findings to the outside world, also known as external validity (Sandelowski, 1986). Those who read study results determine the meaningfulness of the findings to their own experiences (Davies & Dodd, 2002). To assist in determining fittingness, detailed demographic information about study participants was provided so that readers can assess whether findings can be transferred because of "shared characteristics" of the study sample (Cresswell, 2003). Direct quotes from patients have been included in the reporting of the findings as examples of patient data that provide a rich and detailed description of their experiences.

A study and its findings are auditable when another reader can follow the "decision trail" used by the researcher (Sandelowski, 1986). To promote the auditability of this study, a journal was kept to document steps and rationale for decisions made. Included were details about literature searches, data collection, data coding and analysis. After most focus groups, the primary investigator and research assistant "debriefed" about participant interaction and these debriefings were audiotaped and transcribed. The researcher also used peer review or debriefing with other members of the research team and other nurses with oncology expertise as an external check of the research process (Cresswell, 2003). This was done at research team meetings and with fellow graduate students during graduate student meetings.

The term "verification" corresponds to "validity" in quantitative studies and Cresswell (2003) recommends that researchers use at least two verification procedures in a study. In addition to the verification procedures listed above (member checking, the use of rich description, and peer debriefing), the researchers attempted to clarify biases that might influence interpretation of the data. These may include past experience or prejudices. The primary investigator conducted all focus groups and interviews and analyzed data. She is not an oncology nurse or cancer expert and entered the study without preconceived ideas about patient need or supportive care services. She had no previous relationship with participants and no employment relationships with the regional cancer centre, urology clinics or any health care agencies. The triangulation strategies listed previously also verify the study findings.

Findings

Twenty-seven men participated in this study. The majority of HR patients (16 of 17) participated in a focus group and one was interviewed in his home. In contrast, 10 of the 12 HS patients were interviewed individually. Two HS patients were interviewed together. The ages of men in the HS and HR groups were similar (mid 70's), as were the lengths of time since diagnosis (7-8 years). The majority of participants were married and retired from work. HS participants had more health problems, including cardiac disease, hypertension, diabetes, arthritis, and hearing and vision loss (Table 1).

Table 1

Participant Demographic Information

	Hormone sensitive $n = 12$	Hormone refractory $n = 17$
Mean age (range)	76 years (59-88 yrs)	75 years (61-85 yrs)
Mean time since diagnosis (range)	7 yrs (1-13 yrs)	8 yrs (1-16 yrs)
Marital status (n, %):		
Married	10 (84%)	13 (76%)
Widowed	1 (8%)	4 (24%)
Divorced	1 (8%)	
Employment status (n, %):		
Self-employed	1 (8%)	
Part-time	1 (8%)	1 (6%)
Disabled		2 (12%)
Retired	10 (83%)	14 (82%)
Mean number of other medical problems (range)	3 (0-5)	1 (0-5)

In keeping with the qualitative descriptive method described by Sandelowski (Sandelowski, 2000), a descriptive summary of the content of the data is presented in this section. The data have been clustered into categories according to the research questions,

and then grouped by shared characteristics. The results from the focus groups and interviews are reported under four sections.

In the first section, titled *Living with Prostate Cancer,* men describe their daily lives with prostate cancer. Although this does not answer any of the research questions directly, it provides relevant background information and helps to ensure attention to the context of the conversations, which is essential in a qualitative descriptive study (Milne & Oberle, 2005).

The next sections are organized according to the study research questions and include patient data related to (a) *Supportive Care*, (b) *Strengths and Limitations of the Care Delivery System* and (c) *Recommended Strategies to Improve the Delivery of Health Care Services*. Men shared information about the coping strategies they utilized to meet their needs, and these data are included in the section about Supportive Care Needs.

Living with Prostate Cancer

At the beginning of focus groups or interviews, men often shared information about their diagnosis and their various procedures and treatments since that time. They discussed their daily lives, and how things had changed for them. The theme, *Living with Prostate Cancer,* has four subthemes, including *losses, living longer than expected, feeling fortunate to have prostate cancer*, and *feeling fine.* This information provides a background to the discussion of needs and care delivery.

Men reported that while living with prostate cancer they experienced many "ups and downs," but that they had become accustomed to living with the disease. Many men with HS described how they lived their lives as they had previously, feeling little

difference. Men with HR disease experienced greater challenges, having progressed to a later stage of the disease. Many shared the difficulties of coping with chemotherapy treatments, the spread of cancer throughout their bodies, and the experience of living with the disease for long periods. One man with HR disease said, "My cancer doesn't seem to want to go anywhere."

Both men with HS and men with HR described the emotional effects of having prostate cancer and their feelings during the progression of their disease, including fear and anger at the time of diagnosis, and fear and uncertainty of living with the disease. Men also described the worry they live with.

> Yeah you can't escape the worrying, the thinking, you know?" (Patient, HS disease).

> I guess in a way I've been going uphill all the way because it was 1990 when I was diagnosed with prostate cancer and at that point I had a PSA of 244 and the first inkling that I had anything wrong with me. At that point in time I was given maybe 6 months to 2 years survival time and I, this is . . . will be 16 years this October. So you sort of live on the edge for a long period of time, which, I think, has a bearing on your mental attitude towards a lot of things. (Patient, HR disease)

Men discussed the anxiety related to the changing treatments that came with cancer recurrence or spread.

> Then my PSA started creeping up again. And I go into the cancer clinic one day and the doctor says, well obviously this isn't working anymore, so take you off this and you go back home and come back in 6 months and we'll take a look then.

> Now if what they're giving you has stopped working, and they're telling you to go home and come back in 6 months, it leaves you with a pretty rotten feeling. You can just see the handwriting on the wall. (Patient, HR disease)

Men expressed their frustration with new problems that constantly arose while living with prostate cancer.

> Not another. I went through this, oh, I guess about 8 or 9 years ago, you know, where you just seemed to be, you just finish one thing and boom, you've got another one, and what the hell, you know what I mean? (Patient, HR disease)

Losses

Men with HS and men with HR experienced various losses as a result of the cancer and some the result of treatment.

> I had just finished building a home up North on about three acres of land and with something like this coming along, you're on a septic tank, you're on a well, you've got gardens to tend, and so on and so forth, so 2 years later I had to give that up and come back to the city where I can be closer to a doctor. (Patient, HS disease)

> "I've got property down in Florida which I haven't seen for about 15 years" (Patient, HR disease).

Living Longer Than Expected

HS and HR men reported living longer than they had expected after diagnosis.

> "I've been with cancer about 16-18 years. At this point there's nothing about prostate cancer that I'm concerned about anymore. I'm more

concerned about what I'm going to cook for dinner tonight" (Patient, HR disease).

"Like I consider myself pretty fortunate actually. I was diagnosed in 1996 and I think the prognosis was 5 or 6 years. Well it's closer to 10 now, but that's what I told myself at the time anyway" (Patient, HS disease).

Feeling Fortunate to Have Prostate Cancer

Often, men described other people they knew with different cancers, the short length of time those people lived, and how prostate cancer was one of the "better" cancers to have.

Now I think . . . if I can suggest this . . . we're fortunate that we have prostate cancer. My younger brother had liver cancer; he was gone in 2 weeks. My accountant had liver cancer; he was gone in 3 weeks. So at least we're fortunate to say that we have one cancer maybe that isn't as severe as maybe we're just . . . or I know I feel I'm very lucky that's what I have instead of something else. (Patient, HR disease)

Feeling Fine

Most of the men reported feeling fine, despite having advanced disease. Very few men reported feeling unwell, and they described their complaints of pain or fatigue as "minor" or a "nuisance."

"But anyway, I'm supposed to be sick, but I don't feel anything yet, you know" (Patient, HS disease).

> And you know I feel fine. I get pain in my back and so forth but . . . I'm in a holding pattern, as I understand it. They keep saying I have a very aggressive form of cancer and I have maybe 1½ years to maybe 3½ years, depending on who you talk to, but I feel fine. (Patient, HR disease)

The researcher conducting focus groups and interviews observed a noticeable difference in physical appearance between the two groups of men. Most of the HS patients had the typical body type associated with those who receive androgen deprivation. They were overweight with rounded abdomens and hips, enlarged breasts, thick heads of hair, and red cheeks and they were often perspiring. The primary investigator noted that one man looked "vibrant." Men with HR disease, on the other hand, generally looked unwell. Based on their appearance, they would be described as slim, frail looking, pale, and older, and this appearance was likely due to the chemotherapy treatments and progressing disease.

Supportive Care

Men were asked what needs they had as a result of their prostate cancer, and they provided both explicit and implicit descriptions of needs. Men clearly articulated some of the things they needed, such as information. More often however, men articulated their needs indirectly and instead described the problems or issues they were experiencing. As per the construct of need described by Brazil and colleagues (2003), both explicit needs for service and problems and issues are presented under the grouping of supportive care need.

The supportive care needs identified both directly and indirectly by participants are described in this section. Because most of the problems, issues and needs identified were shared by both groups, the results from both HS and HR participants are combined. Similarities and differences between the groups are identified within each theme. Men had some stage specific needs related to the progression of illness (for instance, HR patients had more pain and discomfort) and their treatments differed (androgen deprivation versus chemotherapy).

Analysis of focus-group and interview data revealed three groups of themes related to supportive care: (a) *functional problems - "not being able to do what I want to do",* (b) *informational needs,* and (c) *emotional distress*. The similarities and differences between the two groups of men are listed in Table 2.

Functional Problems –"Not Being Able to Do What I Want to Do"

Men with HS and HR disease complained about the changes in their functional capability and the problems associated with this. Although some men related their inability to carry out some activities to "getting old," they felt that many of the changes were a result of the advancing disease, such as pain and fatigue, or side effects of treatment such as urinary issues and loss of sexual function.

> 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 it's . . . but like I say, I can't do it. (Patient, HS disease)

Table 2

Comparison of Themes and Subthemes Related to the Supportive Care of Men Living With HS and HR APC

	HS disease	HR disease
Functional Problems – "Not being able to do what I want to do"		
• Loss of sexual function	•	•
• Urinary and incontinence issues	•	•
• Fatigue	•	•
• Side effects of androgen deprivation	•	
• Pain and discomfort		•
• Side effects of chemotherapy and treatment		•
Informational Needs		
• Need for information about treatments, side effects	•	•
• Need for information about available services	•	•
• Need for information about prognosis and the future	•	•
• Need for assistance to access information	•	•
• Need for assistance to understand health related information	•	•
Emotional Distress		
• Unresolved feelings about diagnosis and treatment decisions	•	•

Similar Functional Problems

Loss of Sexual Function.

Both men with HS disease and men with HR disease reported the loss of sexual function and acknowledged that the androgen deprivation left them with no desire for sex. One man was not given any information about the sexual side effects of androgen deprivation and the change in sexual function became an issue in his marriage.

> There's no desire, either. You know it might come back, I don't know. And we, my wife and I, we both sat down and we talked about it and we came to the conclusion that it's better than being in a pine box, right [laughing]? (Patient, HS disease)

Many men joked about their sexual issues, particularly about the impact it had on their spouses.

> "Dr. X said to me, my wife was sitting there, and he said, now you realize that so many percentages of men will be impotent after this surgery. So what? That'll make two of us not interested [laughing]" (Patient, HS disease).

For some men, living with the serious illness brought them closer to their spouses, and the loss of sexual function was not as important in their relationship.

> "Anyway, that aspect of our life, it really, if anything, the fact that I had a serious illness brought us closer together. I would say as far as our life was concerned" (Patient, HR disease).

Urinary and Incontinence Issues.

Both groups reported problems related to changes in their urinary function since having prostate cancer. For men with HS disease, this was a priority issue affecting their daily lives. 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.

> I always got to be aware of where, you know, where I can go. And do I have the appropriate equipment with me? You know, after 8 years of wearing a pad every damn day for 8 years. My whole life is predicted on where's the nearest toilet and whether I got a pad in my pocket. We went to a restaurant last night and thought that I had one and I didn't, okay, so I drove home thinking, I hope nobody invites us in tonight. (Patient, HS disease)

Men with HR disease also experienced urinary issues. Although it was a big problem for a few men, it did not seem to be a priority issue for men with HR disease.

> Well my prostate cancer isn't really . . . hasn't affected me that much up until the last year or so. I had 37 treatments of radiation and it didn't bother me a bit. I got through that real good and then radiation has scarred my bladder and I wasn't able to urinate so I have a catheter permanently installed and that is more annoying than any other part of the, of taking chemo now that I've got this that affected me except I'm losing my hair but physically it's not bothering me that much. Seems

to be my catheter, that's my biggest problem. It's something I could still live with. (Patient, HR disease)

Leakage issues interfered with one man's ability to do his household chores.

And, ah, leakage seems to occur when I'm more active. Like if I go cut the grass or walking, then I get more leakage, but if I'm sitting down, I don't get any at the moment and when I'm in bed I don't get any, any leakage. It's when I'm active. (Patient, HR disease)

Fatigue.

Fatigue and lack of energy were reported by both groups of men and may be related to side effects of androgen deprivation, chemotherapy, progression of disease, and age. These issues affected the ability to function in their daily lives, to do common activities such as chores around the house and yard, and to participate in social events. Fatigue was one of the main concerns for men with HR disease.

"I think I get a little bit more tired. I like going outside but . . . I get more tired, yeah" (Patient, HS disease).

One man wanted to find out more about what he could do for his fatigue.

As far as the fatigue is concerned I, they've never offered any suggestions as to how I can overcome it, which when you get through the chemo like 4 or 5 days after . . . you can hardly move it's so bad. So like what can you do? (Patient, HR disease)

Many men reported that fatigue restricted their daily activities.

> You have to consider . . . it really begins to restrict what you can do, where you can go and when you could go and that sort of thing. And you realize, of course, that your health is not what, what it has been when you're full of vim and vigour, you know. So that you have to watch your health as well and you also find that there's a fatigue factor that comes through it all the time, particularly related to the chemotherapy aspect. (Patient, HR disease)

Men needed regular rest periods when they were receiving their chemotherapy treatments to deal with fatigue.

> Well, yeah, there is a period of 2 or 3 days after each chemotherapy treatment where you really do feel, you spend a lot of time just lying down having a rest, you know. (Patient, HR disease)

Different Functional Problems

Side Effects of Androgen deprivation.

Men with HS disease reported that the side effects—including hot flashes, sweating, breast soreness, weight gain, fatigue, and weakness—of androgen deprivation interfered with their daily lives.

> Then all of a sudden I just, I just started to sweat like mad and it was warm in there and it was uncomfortable in the first place and then I get a hot flash and then just so I had to get out and everybody gets upset and everything else and . . . you get a cold rag on me you feel better. (Patient, HS disease)

These men used words like "nuisance" and "bothersome" to describe the problems and many acknowledged that these were minor concerns associated with fighting the cancer.

> Well, I'm not as physically active as what I was before. I get tired more easily. I think more because of the weight I think. I experience problems doing up shoes and whatnot. In some cases, bending down and getting back up again is difficult…but basically that's about all right now. (Patient, HS disease)

Pain and Discomfort.

Many of the men with HR disease reported discomfort 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 sort of thing. So I take painkillers 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 [laughing]. (Patient, HR disease)

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. Many men denied any discomfort or pain.

> Yes, it's in the middle of the back in the lower spine and the ribs. He says I've got a couple spots. And now it's gone to another two areas, he said. I was on Tylenol 3 for a while, a good while, and that took the pain away, but it also gives me terrible constipation. (Patient, HR disease)

Side Effects of Chemotherapy and Treatment.

The side effects of treatment, particularly chemotherapy, were problematic to men with HR disease.

> Really the main problem, the biggest problem, was the reaction to the initial chemo. 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 or the disease advancing, I'm not sure. One thing I haven't had is any significant pain. (Patient, HR disease)

They described issues with loss of appetite, nausea, extreme fatigue, and reactions to certain medications.

> Well, I was okay for roughly 10 years is when I started to get bone pain and I got into the chemo part. That kind of messed up my life. 'Cause now I'm always tired and once I got into the, the chemo routine, it completely changed. Now I can't really take a trip because I have no idea what will happen if I go on a trip and like my health plan will say if you're under active treatment you're not covered. (Patient, HR disease)

Informational Needs

Both groups of men consistently and directly reported a need for information. During focus groups and interviews, participants asked questions of the interviewer or of other men in the focus group, seeking information. Both HS and HR patients reported a need for information related to their diagnosis, treatment, and future.

Need for Information about Treatments and Side Effects

Men reported needing more information about treatments, medications and side effects, and alternative therapies.

> It was never really fully explained what would happen if I didn't take the chemo. Or if there's an alternative to doing that route. (Patient, HR disease)

One man described wanting more information about treatment options and how he felt when he did not get information.

> An urologist said, "I would suggest that you have radiation". He said, "I wouldn't recommend a radical prostectomy" or whatever it's called. He said "that's a very serious operation". Well that's about as much as I found out about it. The situation you're in is, once again, I say you're sort of numb. Your mind hasn't grasped this thing completely so you're more or less in your doctor's hands and when he says radiation, why what are you gonna say? You're not gonna argue with him. He's the guy. But I didn't get to the bottom of it. I didn't ask the questions that would tell me well you're . . . you know this is the problem at your age. And it wasn't volunteered, either, at that time. I just felt that I was sort shunted off to one side because . . . I think it was inferred that I didn't qualify for the radical. (Patient, HS disease)

Men also wanted to know more about new treatment developments they heard about from people outside their health care team.

> Like I hear there's an injection they put right into your bones rather than go through the chemo for the type of cancer that I have now. But I never heard about it until I spoke to somebody, you know, other than a hospital employee. A driver for the cancer people, he told me his brother-in-law is getting that now. (Patient, HR disease)

One man read about a novel treatment in the newspaper and described what it was like to discuss the information with his oncologist.

> You just want to go by what you read in the paper and then you tackle your oncologist about it and you find that it's years away. That's just the beginning of a study and you don't really know quite how authentic some of these things are. Like when we read about the injection of vitamin C. You think that's an incredible breakthrough! But then you see there's no one here in this centre that's enthusiastically running around pumping Vitamin C into patients. (Patient, HR disease)

Some patients 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" (Patient, HR disease).

Need for Information about Available Services

Patients lacked information about services available to them and were unsure of the services offered at the cancer centre where they were being treated or by the Cancer Society.

> There's uncertainty. I have no idea. You know, 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. (Patient, HR disease)

Need for Information about Prognosis and the Future

Both HS and HR men had difficulty getting information about their prognosis and what to expect in the future.

> We're all grown-ups so the information whether it be good or bad . . . I think we should be given some indication at what stage we might be at. (Patient, HS disease)

Some men understood that it would be difficult for doctors to provide that information.

> This is one thing that does concern you is you sort of live a life in limbo. You don't really hear what your prospects are. You sort of guess at them and your guesses might be good might be bad, but I don't think anybody is in a position to really say what your real position and what your life expectancy might be at any particular time or which way your cancer is going to develop. (Patient, HR disease)

One man wanted to know more information to make concrete plans for his care and the care of his wife when his condition got worse.

> But it's sort of the ongoing, you know sooner or later, you're going to become disabled or relatively disabled. So what's there? I don't think that's ever been explained to me and I think a lot of people that I've talked to have the same kind of problem. What is available? My wife's 85. She certainly can't look after me if I'm disabled. What are the options? I think that's very important. (Patient, HS disease)

Need for Assistance to Access Information

Men reported getting information from various sources. HR patients not only received information from oncologists, urologists, and nurses; they also used friends, family members, and acquaintances as sources. Other sources of information included Cancer Society publications and the Internet. The main source of information for HS patients was the urologist. Publications at the urologists' offices and articles in the newspaper were also mentioned as sources of information.

Some men used the Internet, but others did not have access to it.

> Well I don't have a computer so I can't go on the Internet and mostly I rely on my doctors (Patient, HR disease).

> I go on the Internet and there's a couple of places there where you can get a lot of information. Well, a friend put me onto a guy who she knows; I think it was in Mississauga. I contacted him by email. He's much in the same boat I am but he's gone down to the States. (Patient, HS disease)

Some men were dissatisfied with general cancer information and sought out information specific to their disease.

> I didn't go to the Cancer Society for information. The Cancer Society is respected and whatnot, but they're dealing with more than just one cancer. Man to Man deals with prostate cancer. So you go toward the source. (Patient, HS disease)

Men also needed assistance to ask the right questions to get the information they wanted.

> People don't know the questions to ask. The only way you learn the questions is by looking at the disease and talking to people and whatnot and what they've gone through and get rid of the fallacies that are out there. (Patient, HS disease)

Some patients attended local prostate support groups to get information, but not all reported them to be useful. Some of the men who had had cancer for long periods of time had stopped going to them because they were not finding out any new information.

> And people can just stand up and ask a question and whoever's the guest speaker will try to answer it. But I think once you get beyond the early stages of prostate that it probably doesn't help much because you're sort of assigned, you know, what's going to happen with it. You're going to be on hormone therapy for a number of years until that wears out and then something else is tried. So when I was first diagnosed I went to quite a few meetings. It was interesting but then after a while I didn't bother going. (Patient, HR disease)

Need for Assistance to Understand Health Related 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 them.

> I was on the placebo for about 2 years and now I'm on the real thing, and I'm still here, I'm still alive so something's working but exactly what, who knows. And it's very difficult to tie anybody down with an answer on anything (Patient, HR disease)

Some men asked the interviewer specific questions or asked other members of the focus group questions.

> What are they measuring anyway? If your prostate's removed, right, PSA is a measurement of cancer germs or something in your prostate, right? What are they measuring, if your prostate is gone? (Patient, HR disease)

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. (Patient, HS disease)

Emotional Distress

In the focus-group discussion and interviews, men expressed various intense emotions, including sadness, anger and frustration. Men with both HS and HR APC were coping with the consequences of APC and their uncertain future.

Men were frustrated that they did not know more about the services currently available to them. One man was frustrated that no one had helped him to decide how to treat his pain and he had to make the decision with his wife.

> But . . . the part that bothers me is that nobody's really told me what kind of painkiller to take or how strong. It's just my wife and I and we just decided to use Advil 400 and I take one about every 4 hours. (Patient, HR disease)

Another man was very angry when he found out from other focus-group participants about the driving service offered by the Canadian Cancer Society.

> I've been coming up here for 5 years. I knew there were drivers but I didn't know that it was for free. And I'm like you, my wife works and it's hard. She's got a

hard time 'cause I don't feel good when I've got to drive back home. (Patient, HR disease)

Unresolved Issues about Diagnosis and Treatment Decisions

A subtheme of the need for emotional support was unresolved issues related to diagnosis and treatment decisions. Many of the men in our study had been diagnosed with prostate cancer over 10 years ago, 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 they 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.

"I should have found out earlier! Something missed along the line" (Patient, HR disease).

One man described the conversation he had with a physician while preparing for a heart investigation.

I went there and he said to me "Well we're going to do an angiogram but you have another major problem." He said "Your PSA is 12.65" and he said "Nothing is being done about it" and then I said "I don't know nothing about it". He said "You'd better go with your doctor and ask all your questions of all your PSA tests and you'd better see an urologist."(Patient, HS Disease)

Another man shared how the casual relationship with his doctor may have prevented him from being diagnoses sooner.

> I used to go to a family doctor who was a flyer like I was a flyer. I'd go to my annual examination and we'd talk about flying for an hour and then he'd be relaxed and I'd go home. He never did a digital 'til one day in 1997. He did a digital and he said, hey, you've got a problem. (Patient, HR disease)

One man was very angry that he did not have enough information prior to his surgery.

> They cut me here [pointing to groin]. And if I had known what was gonna happen, they'd have never done it. I'd have died first. I would have preferred to have the cut here [pointing to perineum]. The reason being . . . getting cut down here I couldn't walk. I used to be very strong - my legs and that. Not anymore. I've got no strength at all there. They must have cut whatever they cut, muscles and everything else. And I'll tell you, your sex life is gone. Not 99%. 100%. I don't know about you. I should have been filled in on cutting here and I should have been filled in on cutting here. (Patient, HR disease)

An HS patient was angry that he was not given information that had an impact on the relationship with his wife.

> Yeah, I think there's some issues, and one of the problems I have, as a physician everybody assumes I know what's going on. Well, I have certainly a better general knowledge, but I think there's a lot of information that people don't get. I think from my point of view, I realized that starting on the hormone was going to be a major problem with sex life and that was never really brought up at all. (Patient, HS disease)

Men expressed concern about not being able to get enough information from their physicians and continued to question their physician's motives.

> Why wouldn't they fill you in on that? Why wouldn't they fill you in on that here? Is it a secret? (Patient, HR disease)

> Well, the doctor should have told me in the first place that it had metastasized and he didn't. I have no idea. I know a doctor friend that told me afterwards. He was disgusted with him for not telling me. (Patient, HR disease)

One man described why he would not question the information from the doctor.

> It's the old story, isn't it? The patients are afraid to literally cross-examine the doctor, they're afraid to do it. I guess the older you are the more that applies because we always think, looked upon a doctor as God, you might say, and you don't question it. (Patient, HR disease)

Coping Strategies Utilized

Men with HS and HR APC have both stage specific and common supportive care needs, and these are likely due to the treatments they undergo and the progression of disease (Figure 1). Despite having advanced cancer and other comorbidities, many of the men in both groups described coping well with their disease. Although this information is not directly related to the study objectives it is included because it adds to our understanding of how APC affects men's daily

Figure 1. Stage specific and common supportive care needs of men with APC.

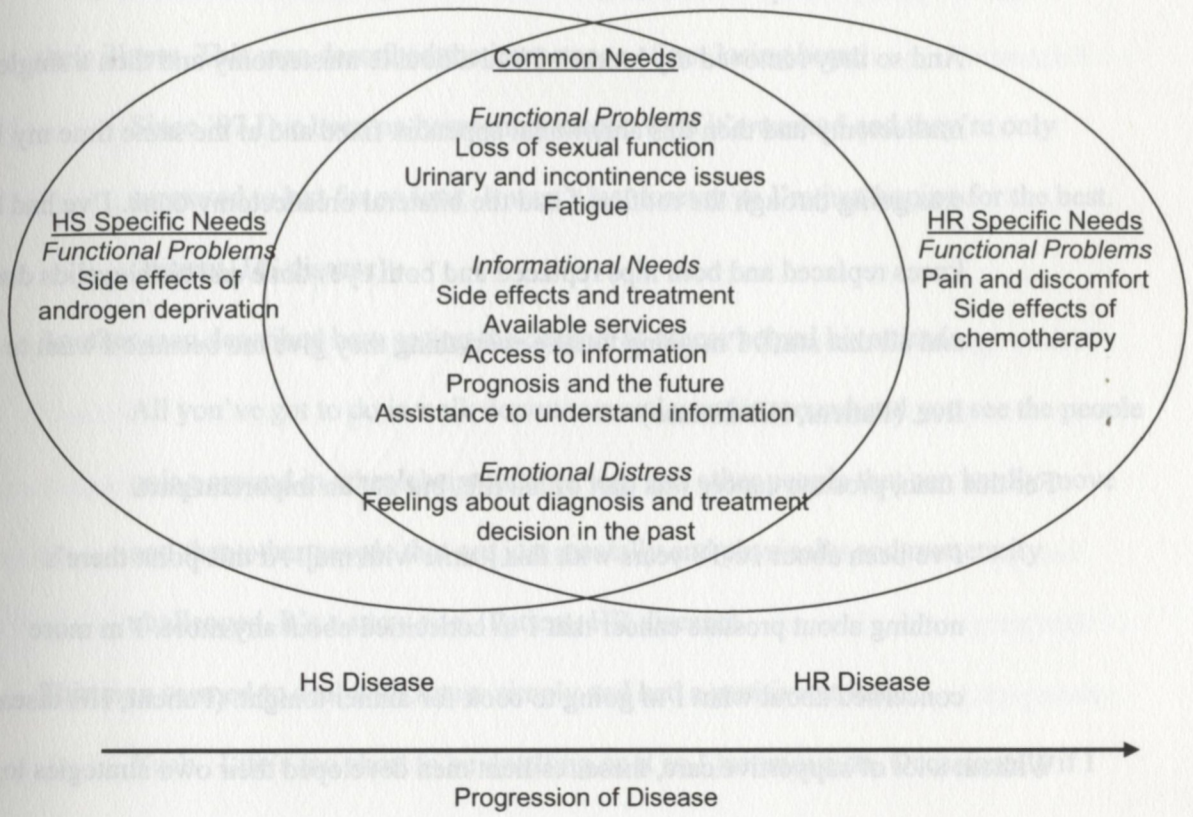

Figure 1. This diagram depicts the overlap of patients' supportive care needs as they move along the continuum of disease progression.

lives. It also gives us insight into the potential strategies that could be developed. Most of the men described many years of different treatments, procedures and surgeries related to their prostate cancer. Their stories described their survival.

This man described the various surgeries he had over the years, many of which were a result of treatment for prostate cancer.

> And so they removed my breasts. I had a double mastectomy and then a single mastectomy and then this abdominal appendix fixed and at the same time my PSA was going through the roof, so I had the bilateral orcadectomy done. I've had both knees replaced and both hips replaced and both eyes done and both eyelids done and all that stuff. I'm going to take everything they give me because I want to live. (Patient, HR disease)

For this man, prostate cancer was part of his life, but not an important part.

> I've been about 16-18 years with this [same with me]. At this point there's nothing about prostate cancer that I'm concerned about any more. I'm more concerned about what I'm going to cook for dinner tonight. (Patient, HR disease)

Without a lot of supportive care, these resilient men developed their own strategies to meet unmet needs. For instance, many men described how they got their work done despite suffering from fatigue.

> I go out to cut the grass. I have a lot of grass to cut and it takes me about 2 hours to cut it. But if I cut for a half hour, then I have to go for a rest for half an hour then I go back later and I do that for another half an hour or something like that. You have to pace yourself. (Patient, HR disease)

This man also talked about the importance of resting.

> I rest a lot. Whenever I feel like it, I just, I go and lie down. Maybe doze off for a half an hour or hour. (Patient, HR disease)

Positive Attitude

Many men described the importance of having a positive mental attitude to cope with their illness. This man described the importance of not losing hope.

> Since '97 I've been on hormone therapy. Well it's worked and they're only supposed to last for so long. It won't last forever so I'm just hoping for the best. (Patient, HS disease)

Another man described how seeing the despair of others helped his attitude.

> All you've got to do is walk downtown and wander around and you see the people going around in wheelchairs with no legs and other people that can hardly move and then other people that are just mentally and physically and monetarily challenged. It's a sorry site. (Patient, HR disease)

This man seemed to deal with issues simply and had a positive attitude.

> Yeah. Life's too short to be dwelling on it so I just move on. Occasionally if I don't get to the Jon in time, than I change my shorts. That's what it boils down to. (Patient, HS disease)

This man described his efforts to take care of himself, and the problem with relying on others.

> Try and keep yourself mentally alert. Try and do something that gives you some reasonable living and some bit of happiness in the life and be prepared to help yourself. Because that's where you're going to get your most help - from yourself. (Patient, HS disease)

The Use of Humour

Many research team members commented on the apparent humour in the transcripts. As demonstrated in previous quotations and below, men downplayed or trivialized their problems and joked about many things, including the feminization of their bodies, their lost sex lives, and their uncertain future.

> They gave me five years or something that I might make it [laughing] and I went on these female hormones for 4.5 years and I grew the nicest pair of breasts you ever saw in your life. (Patient, HR disease)

> I had an orcadectomy, double orcadectomy and oh gosh I guess that was about 8 or 9 years ago. And after I did that I went on a drug and I had the same problem as you. After about another 9 or 10 months I looked like a beautiful little girl! So I had a double mastectomy. (Patient, HR disease)

This man was able to joke about his incontinence issues.

> I want to be able to do things without having to worry about peeing in my pants is really what it boils down to. Pisses me off daily. [laughing] (Patient, HS disease)

Another man joked about his children and their attitude towards his cancer.

> Well the kids were both out of the house at that stage of the game or almost out. They are still in university. They're pretty good people actually. I'm not suffering, so I don't think they are. Of course I'm worth more dead than alive anyway, so they may be just waiting [laughing]. (Patient, HS Disease).

This man also joked as he discussed his attitude towards his cancer.

> You know you play the hand you're dealt. If you win, you win. If you lose? Well wait for the next time maybe. When I get up in the morning, if I wake up and see the grass is green and I'm looking down - that's good [laughing]. (Patient, HS Disease)

Strengths and Limitations of the Care Delivery System and *Recommended Strategies to Improve the Delivery of Care*

Patients were asked about the care they were receiving and how things could be improved. Participant suggestions for change to care delivery included (a) education and support for early detection and diagnosis, (b) increased 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 health professional. For both HS and HR groups, the priority for improved care was increased information.

As noted previously, HS patients were not satisfied with the amount of information they received. Otherwise, the HS patients were satisfied with the care they received for their prostate cancer and felt caregivers would be responsive if they required help. Most of these men received hormone injections at an urologist's office and were not treated at the regional cancer centre.

> I've just been on treatment and so I rely on the professionals to treat me because I know nothing about the situation except the way it affects me, myself. So as far as advancement is concerned, it's through people like you studying the situation and maybe some day, you know, science will come up with something. But, you

know, I'm satisfied with our health care system. I've heard a lot of people knock it, but I applaud it. (Patient, HS disease)

Patients were asked for suggestions to improve the delivery of care for themselves and for other men with prostate cancer. Many men recommended increased PSA testing as a way to diagnose prostate cancer sooner.

"PSAs should be given sooner. They argue about whether it's worth it or not and all the rest of it, but I think if I'd had it found it sooner, it wouldn't have metastasized." (Patient, HS disease)

One HS participant had participated in "Man to Man" support groups in Toronto and thought they were helpful to him.

"The main thing would be more discussion groups" (Patient, HS disease).

Despite their dissatisfaction with the amount of information they received, men with HR disease were satisfied with care delivery and with physicians, nurses, and other caregivers. However, HR patients who received care at the cancer centre complained about wait times in the chemotherapy unit.

Local prostate support groups organized by the Cancer Society were given mixed reviews because getting stage specific information was difficult. These large groups (often 25 or more in attendance) were perceived as too large for some HR patients, and expressed anger that men newly diagnosed with the disease dominated the discussions. They did, however recognize that when men were first diagnosed, they had the greatest need for assistance.

> Well, my suggestion would be when a person first finds out they have prostate cancer, that's when they need the advice and the help and the support and everything else. And it's the people who are just getting it; it scares the hell out of you. (Patient, HR disease)

One man suggested peer support for newly diagnosed men.

> It comes back to the beginning. I think in the beginning if you had five or six of the new patients come in and somebody like us who've been through the journey for several years able to come in and tell them about our experiences and what happens so that they have an idea of the things that they're going through are kind of normal or whatever, or not normal. (Patient, HR disease)

Another man recommended small sessions that gave information about treatment options.

> Well, you could have a little session, where you're saying, now I want to explain to you what this is all about. And we wouldn't suggest this treatment for this reason, and you get the details as to why, for example, at a certain age they wouldn't recommend a radical. (Patient, HR disease)

One focus-group participant recommended a group similar to the focus group used for data collection as a way to provide support and information to men with advanced disease.

> A group like this I could live with without any trouble at all. That was just about the right size that was. Well, if people with the same sort of mindset, too. It's different than some people who want to dominate all the time, and I didn't find any domination here, which is nice. (Patient, HR disease)

Discussion

This qualitative descriptive study explored the supportive care needs of men with APC and their ideas to improve the current model of care. Participants identified both the problems they were experiencing and the needs that resulted because of certain problems. Some of the identified unmet needs were implied from the problems men discussed, and some were validated through clear articulation. For example, one man experienced erectile dysfunction because of androgen deprivation and shared his anger because he was not warned about this. His problems of sexual dysfunction and not knowing enough about it informs us about his need for information.

Some of the data collected was the result of men reflecting back on as many as 10 years living with prostate cancer. Participants identified unmet priority needs related to information and problems associated with maintaining their ability "to do what they want to do." Functional issues shared by HS and HR patients included problems with urinary function, the side effects of their treatment, fatigue, and sexual issues. For men with HS disease, urinary function was a priority issue. For men with HR disease, avoiding fatigue was the priority for functional ability. Consistently, men identified information as their 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. We identified the emotional distress men were experiencing and suggest they need support to deal with their unresolved feelings about diagnosis and treatment decisions. Generally, participants were 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 health professional to address information and coping needs.

There is limited literature with which to compare these APC-specific findings, and few studies distinguish between HS and HR APC. For the purposes of this discussion, studies that include only men with advanced disease or studies that report and distinguish the findings according to disease stage are used. When no studies that report on APC exclusively were available, studies of men with all stages of prostate cancer were included.

Men in this study described periods that were difficult emotionally and physically, usually around the time of diagnosis. This is consistent with the findings of Wallace and Storms (2007) who reported on the myriad of emotions related to the prostate cancer diagnosis. A summary of studies on depression in men with prostate cancer revealed that men with prostate cancer most at risk of depressive symptoms included those with advanced disease, prominent cancer symptoms, and side effects of treatment (Bennett & Badger, 2005). Yet many of the men in this study reported feeling fortunate to have prostate cancer as opposed to other cancers. Lindqvist and colleagues (2006) described having APC as living with bodily problems in cyclical movements between experiencing wellness and illness. The men in this study also described uncertainty about their prognosis, treatment, and the future, which is a common experience in chronic illness (Mishel, 1999).

Both groups reported problems relating to urinary function, a finding consistent with previous studies (Bryant-Lukosius, 2003; Fitch et al., 2000). Problems with frequent

urination and incontinence were unmet priority needs for HS patients. The loss of sexual function as a result of androgen deprivation was often described as a trade-off to fighting the cancer. Lindqvist and colleagues (2006) reported a similar finding. Our findings were inconsistent with other studies, most involving surveys, which reported sexual function as a priority for men with HS disease (Bryant-Lukosius, 2003; Fitch et al., 2000; Herr, Kornblith, & Ofman, 1993; Lintz et al., 2003; Navon & Morag, 2003). The reason for this discrepancy might have been men's reluctance to discuss sexuality with the investigator or the way in which the questions were asked. Despite more HS patients participating in interviews and not focus groups, they may have been reluctant to discuss issues related to sexuality. Focus groups may have provided a "safer" atmosphere for men to discuss sexuality if other members brought up the subject and participants saw they were not alone with the problem.

Both groups of men reported fatigue related to their treatments and its impact on their daily lives. Fatigue was one of the main concerns of the HR group, a reaction that is consistent with the literature (Bryant-Lukosius, 2003; 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, which is the most common cancer in men. Additionally, they found few studies that focused on patients with metastatic cancer. Pain

control was also an unmet need for some men with HR APC, a finding that has been reported previously (Bryant-Lukosius, 2003; Fitch et al., 2000).

Because of their advanced disease, we expected the men to have more physical complaints. However, most of them reported feeling fine, consistent with the findings of Lindqvist and colleagues (2006). This may have been a result of the men not wanting to complain or appear unwell, or we may have heard only from those who felt well enough to attend a focus group or an interview. Men who had many physical complaints and felt sicker may not have volunteered. A man with HR disease who did not feel well enough to attend a focus group agreed to be interviewed, and he had several severe physical complaints, including pain and constipation.

The study findings support the assertion that men with these two types of APC have different problems, which appears to be due largely to the different 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. There is a progression of illness within both disease groups which adds complexity and dimension to their problems and needs.

Men with HS disease more often reported feeling well, with few complaints, as opposed to men with HR APC, who had more physical complaints. Men with HR APC have worse outcomes than men with HS APC in physical function, role function, and HRQL (Curran et al., 1997). Urologists practicing in hospital or in the community cared for most HS patients, and, in most cases, HS men had little or no contact with a nurse or other health care providers. Most HR patients, however, received care at a regional

cancer centre and had access to oncologists, primary nurses, an APN, social workers, and other allied health professionals.

It became evident early in the data collection that a priority for both HS and HR participants was the need for information. Men talked about unresolved information needs regarding diagnosis, treatment, side effects, prognosis, the future, and services available. 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 APC want include information on treatment, side effects, and the future (Davison et al., 2002; Davison, Degner, & Morgan, 1995; 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 groups reported satisfaction with the care they received, despite having problems related to functional ability and a need for information. It appeared that the men were receiving good medical care but not adequate supportive care. Both HS and HR participants expressed dissatisfaction and sometimes anger about the lack of information they received. HS and HR 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, especially 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. We 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 and colleagues (2000) also found anger was expressed as men shared unresolved issues regarding their diagnosis of prostate cancer and lack of information.

A priority for both groups was help in interpreting information about APC, treatment options, and supportive care services. Patients with cancer have similar information needs. One team of researchers report the "paradox" of patients wanting more information about treatment, but having difficulty absorbing and retaining information that was presented (Skalla, Bakitias, Furstenberg, Ahles, & Henderson, 2004). At many points during the focus groups and interviews, it was evident 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 was and tumour-grading scores. In their survey of 965 Canadian men with prostate cancer, Gray and colleagues (1997a) also found that many men did not understand information. The older age of the participants in our study likely contributed to information needs. Fitch (2006) used a tool specific to cancer information to study the information topics and satisfaction with information in 352 patients over 65 years old in an ambulatory setting. She found the barriers to receiving information included the hectic nature of the surroundings, the speed with which health professionals talk, the medical language used, and the overwhelming amount of information presented.

We found that support groups run by the Canadian Cancer Society were a source of information for some men, yet others did not attend them. Weber and colleagues (2000) suggested that the 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 and colleagues (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; Gray, Fitch, Davis, & Phillips, 1996; Steginga et al., 2001; Thaxton, Emshoff, & Guessous, 2005); however, this literature is not specific to men with APC. One man in our study had participated in the "Man to Man "self help groups, which are an extension of a self-help group supported by the American Cancer Society. Arrington and colleagues (2005) reported on their observational study of "Man to Man" groups over a fourteen month period. They reported that the groups offered and discussed informational support, but altogether avoided discussing emotions.

Despite little interest in the larger prostate support groups in the community, the men who participated in the HR focus groups suggested that similar small-group meetings at the cancer centre consisting of men with the same diagnosis would be helpful. Other researchers (Fitch et al., 2000; Thaxton et al., 2005) also recommended stage-specific cancer support. In addition, both groups recommended that services could be improved by earlier diagnosis and prevention of the development of APC through increased PSA testing and more vigilant assessment of prostate-cancer-related symptoms.

Limitations and Strengths of the Study

The limitations of this study include the inconsistency in data collection methods. Some data were collected from patients through focus groups and some from other patients through interviews. Most (10 of 12) HS patients participated in the interview; most HR patients (16 of 17) participated in a focus group. However, the use of interviews did allow us to gather data that we would not have otherwise if we had only used focus groups. Additionally, this recruitment issue sheds light on the differences in delivery of treatment to the two patient populations and the absence of supportive care services offered to those cared for in urologist or community settings. It is unclear if findings would have differed if the same data collection method had been used. This issue will be examined in Chapter 4.

Another limitation of the study is that we report on data from participants, but do not understand the needs of non-participants in the study. The non-participant group of patients with APC could include those who are well and do not use supportive care services. But more importantly, there is likely a group of patients who are vulnerable and may suffer from multiple other problems, including mental health issues and lack of social support. We need to discover new ways of engaging the neediest and most vulnerable patients with cancer to ensure their needs are also addressed. This issue will be discussed in more detail in Chapter 5.

The focus groups may have limited the amount of sharing of sensitive or embarrassing information and may have promoted group bias (the tendency to agree with the group even if the participant had different views). In addition, the experiences of HR

patients who declined to participate in the focus groups may have been different from those who attended. As mentioned previously, a man not well enough to participate in a focus group was sought out and individually interviewed. Men who were interviewed also may have been reluctant to share sensitive information. All men who participated in the study were given contact information so they could share information after their scheduled appointment.

This study is one of the relatively few studies that provide information about the needs of men with APC exclusively and that compare men with HS and HR APC. Qualitative methods of data collection using focus groups and in-depth interviews were effective for capturing unmet health needs that are important to patients. This study more comprehensively identified the priority needs related to information than did the larger quantitative survey (Bryant-Lukosius, 2003). The study also captured information about why some supportive care services were not used and about the need to ensure that patients have the required information to access those services.

Implications

A more proactive approach to planning for the needs of men with APC 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 are often left trying to manage the impact of many side effects, including urinary incontinence, without adequate resources, information or health professional support (Butler et al., 2001). Maliski, Clerkin, and Litwin (2004) report on the interventions used by nurse case managers in the home-based care of low-income men

with prostate cancer in the United States. Categories of interventions included coordination, advocacy, facilitation, teaching, support, collaborative problem solving, and support and these interventions were individualized and combined to meet the needs of patients with varying degrees of problems.

Both HS and HR patients need supportive care services delivered by a interprofessional team that includes nurses. Complex issues such as urinary problems, pain, and fatigue, which do not respond to nursing interventions alone, often require multifaceted interventions. Nurses' greatest contribution to meeting the needs of men with APC would be to focus on nonmedical interventions, addressing men's information needs. Lack of information causes anxiety and emotional distress and leads to uncertainty. Gebhard describing his own experience with prostate cancer, said, "I can honestly say there is never enough information; a situation that fills me with such despair that I feel like screaming and shouting at those responsible" (2001, p.56). Butler and colleagues (2001) suggest that many information issues, such as the availability of community resources, post-operative 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 informational needs must be designed, implemented, and evaluated. Davison and Degner (1997) reported that men newly diagnosed with prostate cancer had lower levels of anxiety six weeks after receiving assistance to get the information they wanted compared to men who did not receive this. The resources needed to implement new information interventions could be minimized by the development and provision of care through informational modules for

small groups. Small-group sessions optimize resource use and peer support. Lepore, Helgeson, Eton, and Schulz (2003) used a randomized controlled trial (RCT) design to evaluate two different group-education interventions for men treated for localized prostate cancer. Both educational interventions had a positive influence on knowledge about the disease, health behaviours, physical functioning, and employment when compared to the control group. James et al. (2005) report on the establishment of a prostate support group led by clinical nurse specialists (CNSs) in the UK. It included men at all stages of prostate cancer and offered guest speaker sessions, peer discussion and time for one-to-one support from the CNS. A library of cancer related publications was available to members. Nine months after the first meeting, members rated the group as "excellent" but wanted more time to talk with the CNS on an individual basis and ask questions in confidence. Based on the data from our participants, small groups must be specific to APC and dynamic enough to ensure they continue to meet the changing informational needs of men as the disease progresses. Empowering men to identify their needs and make decisions may increase acceptance and attendance. Processes must also be put into place to prevent individuals from monopolizing group time.

Methods to meet the informational needs of men with prostate cancer that have been evaluated include the use of telephone support (Scura, Budin, & Garfing, 2004) and also 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 to meet informational needs must include both the information itself and assistance to patients and families with interpreting information about APC, treatments, and side effects. Sessions planned on a regular basis at cancer centres, 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 groups sessions still receive support, the services could be delivered through print or electronic media. Face-to-face or telephone counseling would assist with interpretation and provide individual support. Templeton and Coates (2004) conducted an RCT to evaluate the impact of an educational package for men with prostate cancer receiving androgen deprivation. 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 study was limited by a small sample size.

Nursing interventions should also focus on strengthening patients' ability to seek out information. Although the focus of interventions is often on the health care 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 health 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 oncology patients provide opportunity for the development of APN roles (Cunningham, 2004). An APN working with men with APC and their families would utilize both clinical and nonclinical aspects of their role (Bryant-Lukosius, DiCenso, Browne, & Pinelli, 2004). The provision of clinical care to elderly men with APC who suffer from metastatic cancer, treatment-related side effects and other health problems requires advanced knowledge and educational preparation, in addition to clinical expertise. The research experience and expertise of an APN are required to evaluate models of care or nursing interventions for men with APC. Organizational leadership provided by an APN is needed to advocate for the redesign of care.

Bryant-Lukosius' (2003) preliminary model outlines three priority areas for APN intervention: (a) prostate cancer health (sexual health and urinary function), (b) mental health (coping and emotional well-being), and (c) functional capacity (physical function, energy, comfort, and coping) (Appendix A). The findings of this qualitative study are consistent with this model, yet they highlight the extent and importance of unmet information needs. A fourth priority area for APN intervention is information and education. In this study, many patients with HR disease received supportive care from an APN. Examining patient needs through focus groups and interviews has provided valuable information that can contribute to the evolution of the APN role and model of care she proposed.

Bryant Lukosius' APN role in prostate cancer was developed to provide care to patients from diagnosis to palliation. The study results confirm the need for intervention at different stages of the disease process. These findings have implications for APNs and the health care system. It is clear there is a need 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.

Our findings are consistent with the preliminary model of the needs of men with prostate cancer developed by Wallace and Storms (2007). This model, based on a model of breast cancer survivors, suggests that men go through three stages during their prostate cancer experience related to diagnosis, the cancer experience, and cancer survival. Similar to our recommendations, they propose nursing support throughout all of the stages. They too advocate for the employment of nurses or nurse practitioners in urologists' offices to enhance the level of knowledge and enhance physician-patient communication. Physicians do not have the time to meet the informational and emotional needs of these patients. APNs can provide the emotional support and education that patients need and could provide an opportunity to calm patients so they can hear and understand needed information. Development of the model of care for the APN role will be discussed further in chapter 5.

The PEPPA framework (Bryant-Lukosius & DiCenso, 2004) was a valuable guide for defining the research question for this study. The framework advocates the purposeful gathering of data from patients and stakeholders to learn about patient needs and gaps in the current system of care. We asked patients to identify unmet needs and to provide

suggestions for improved care. To ensure the needs of men living with APC can be fully understood, the input of family members is also essential. Like all cancers, prostate cancer affects not only individuals but also families. In the next chapter, we report on the needs of family members.

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CHAPTER THREE

The Long Slow Dance: The Experiences of Family Members Living with Men with Advanced Prostate Cancer

Key Words: advanced prostate cancer, family members, focus groups, interviews

Nancy Carter, RN, MScN

Denise Bryant-Lukosius

Jennifer Blythe

Alan Neville

Alba DiCenso

Faculty of Health Sciences, McMaster University, Hamilton, Ontario

Abstract

Background: Men with advanced prostate cancer can live for long periods with the disease and often suffer from the consequences of both the progress of the disease and advancing age. Like all cancers, prostate cancer affects families, and in particular the nature of treatment may have a profound effect on social and intimate relationships. It is unclear what the supportive care needs are of family members of men with APC.

Objectives: To explore the supportive care needs of family members of men with hormone sensitive (HS) and hormone refractory (HR) APC and to elicit family members' suggestions for improvements to health care delivery in order to meet their identified needs.

Methods: We conducted a qualitative study using focus groups and interviews to collect data from a purposeful sample of 8 family members of men with HS APC and 11 family members of men with HR APC residing in South Central Ontario. In HR APC focus groups, and HS APC individual interviews, the family members of patients with APC were asked to identify their needs, discuss the strengths and limitations of the current model of care delivery for meeting their unmet priority health needs, and provide recommendations for improving health services for patients with APC and their families. We audiotaped and transcribed the focus group discussions and interviews and organized the data using N-Vivo software. Teams of independent reviewers used content analysis to identify from the transcribed data themes related to unmet family health care needs and recommendations for improving health care services.

Results: Content analysis revealed both groups of family members had problems and unmet needs arising from a lack of information, which left them uncertain about future courses of action. HR family members lived with the burden of caregiving for their loved ones and experienced isolation.

Conclusion: Participants suggested providing more opportunities for discussing APC with health care professionals and other families and recommended the development of family support groups and family resource centres.

Introduction

As with any serious illness, prostate cancer affects the entire family, particularly the spouse or partner of the patient (Maliski, Heilemann, & McCorkle, 2002). Patient partners often experience stressors that affect their roles as partners and informal caregivers (Giarelli, McCorkle, & Monturo, 2003). Prostate cancer generally occurs in older men, adding to the challenges associated with advanced age (Harden, 2005). As caregivers, partners must cope with the effects of the illness and its treatment.

Advanced prostate cancer (APC) is a form of cancer that extends beyond the prostate gland to nearby tissue, lymph, or bone. The two distinct APC populations are men with hormone sensitive disease (HS) and men with hormone refractory disease (HR). Initial treatment for HS is the control of disease growth by hormone suppression through surgical castration or medical castration using androgen suppression therapy. The side effects of androgen deprivation include breast growth, weight gain, hot flashes, insomnia, and other menopausal symptoms that together comprise the *feminization effect*. Eventually, most of these patients will develop hormone resistant or refractory disease (McMurtry & McMurtry, 2003), at which point the focus of treatment shifts to palliative treatment with chemotherapy, radiation, and supportive care.

Prostate cancer and its treatment affect intimate relationships. The development of advanced or metastatic disease often compounds urinary problems, pain, and other age-related health concerns. The feminization effect of hormonal therapy, including erectile dysfunction, compounds the psychosocial effects associated with a loss of masculinity and sexuality. Treatments associated with HR disease often exacerbate fatigue and induce

nausea, anorexia, and other chemotherapy-related symptoms. The sexuality-related side effects of treatment impact intimate relationships and increase the stress of coping with a loved one's illness.

Literature Review

The literature was reviewed to understand more about family members of men with APC, but there was limited research specific to this group. Studies that explore issues for family members of men with other stages of prostate cancer or other types of cancer have been included in this review.

Partners of patients with breast and prostate cancer have a good understanding of the patients' experience (Carlson, Ottenbreit, Pierre, & Bultz, 2001). Although partners are often included in studies that examine the effect of the cancer on the patients' quality of life (QOL) (Galbraith, Arechiga, Ramirez, & Pedro, 2005; Knight et al., 2001; Kommer, Sneeuw, Albertsen, & Aaronson, 2001), relatively few studies have considered the impact of the disease on partners or their relationships with the patients (Boehmer & Clark, 2001b).

In their integrative review of the literature on partner responses to diagnosis, treatment, and side effects after prostatectomy, Resendes and McCorkle (2006) found the partner participants to be more distressed than the patients. The reasons for their distress included lack of information, fear of the unknown, fear of the future, and concerns related to treatment. Another review of the research (Couper et al., 2006) that directly studied the partners of men with prostate cancer from 1994 to 2005 categorized studies into those focusing on the (a) psychosocial distress of partners; (b) coping patterns of partners; (c)

impact of prostate cancer on the relationship; and, (d) psychosocial interventions for the partners. The review found that although the partners reported more distress than did the patients, the partners believed the patients to be more distressed than were the partners. Because of such discrepancies between patient and partner reports, researchers have suggested that eliciting the input of both partners in the relationship is needed to gain greater understanding of living with prostate cancer.

Harden (2005) used a developmental perspective in reviewing the literature and exploring the relationship between couples' developmental age and prostate cancer specific issues that might impact QOL. She concluded that wives experience distress related to worry and role strain resulting from changes in socialization patterns and additional responsibilities. She identified a gap in the literature regarding the difficulties faced by spouses caring for prostate cancer patients. Butler and colleagues (2000) used interviews to explore the experiences of wives after their husbands' radical prostatectomy. Women reported the diagnosis of prostate cancer had a profound and direct impact on their lives. Problems experienced by these women included a lack of information on catheter and incontinence care, communication issues between partners, and changes in their relationship.

In an influential article on the quality of life (QOL) of partners of men with prostate cancer, Kornblith, Herr, Ofman, Scher, and Holland (1994) used the validated European Organization for Research and Treatment of Cancer (EORTC) Prostate Cancer Quality of Life Questionnaire to assess the experiences of 83 partners and 172 patients, approximately two thirds of whom had metastatic disease. The authors found that patients

with advanced disease experienced greater pain, fatigue, urinary problems, and deteriorating function than their partners realized. The partners frequently reported the symptoms of decreased sexual interest and enjoyment, fatigue, worry, tension, insomnia, and depression. The authors correlated patient symptoms with partner QOL, showing that as patient fatigue and frequency of urination increased, partner QOL decreased.

Partners of men with prostate cancer have often reported difficulties with intimacy and sexuality (Couper et al., 2006; Crowe & Costello, 2003; Sanders, Pedro, Bantum, & Galbraith, 2006) and communication with their partners (Boehmer & Clark, 2001b; Hawes et al., 2006; Lavery & Clarke, 1999). Partners need support to manage the daily impact of the disease and treatment side effects (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Harden et al., 2002; Hawes et al., 2006; Ka'opua, Gotay, Hannum, & Bunghanoy, 2005; Ka'opua, Gotay, & Boehm, 2007; Malcarne et al., 2002) as well as more information related to caregiving (Feltwell & Rees, 2004; Harden et al., 2002; Rees, Sheard, & Echlin, 2003). Davison and colleagues (1995) report that some men rely on their wives to get necessary information about self-care.

For the purpose of planning appropriate interventions to assist family members, Couper et al. (2006) suggested that studies that specified stage of cancer and treatment modality were superior to those that did not address stage of cancer of participants. However, in many prostate cancer studies that include partners, stage of illness is not identified in the analysis (Crowe & Costello, 2003; Feltwell & Rees, 2004; Harden, Northouse, & Mood, 2006; Manne, Babb, Pinover, Horwitz, & Ebbert, 2004; Rees et al., 2003). While developing an intervention to enhance problem solving for prostate cancer

patients and their spouses, Hawes and colleagues (2006) gathered data from the spouses about their problems. Their study included 66 patients and their partners and 14% of the patients had metastatic disease. The participants were asked to prioritize problems needing attention from among the categories related to treatment and side effects, patient issues, family issues, and spousal issues. The couples most frequently wanted to address spousal issues with a focus on developing strategies for maintaining a balanced life and emotional wellness. The researchers found that the types of problems that the men and their spouses chose to work on were similar at all stages of prostate cancer. The researchers concluded that interventions aimed at helping the partner cope and create balance would support the patient because of the frequency with which both patients and partners desired to work on spousal issues.

Boehmer and Clark (2001b) conducted focus groups and interviews with 20 married men with APC and 7 of their wives to explore communication in the marital relationship. They found it surprising that the couples claimed that there had been little change in their lives despite a lack of communication about the disease and the loss of sexual relations. The authors suggested that couples with metastatic disease may be at risk for distress and poor adjustment when the men downplay their illness and spouses collaborate by hiding their fears and despair. The researchers admitted that a limitation of their study was the collection of data from wives about the men's needs with little focus on the needs of the wives. In the same study, Boehmer and Clark (2001a) reported on their examination of diagnosis and treatment decision making of 7 of the men and their wives. They found that the couples experienced difficulties with communication,

particularly because most of the men hid their symptoms from their wives and did not involve them in decision-making. The results of this two-part study suggested that the stresses on the wives of men with APC are intensified by the disease's impact on their relationship.

Findings from these studies indicate that the partners of men with prostate cancer are affected by disease and treatment factors that impact their relationships and QOL. However, few studies have been specifically designed to understand the needs of partners of men with APC and no studies were identified that distinguish between the partners of men with HS and HR disease. Moreover, no studies were found that elicited information about priority interventions or suggestions for improving care delivery.

Study Purpose and Research Questions

The aim of this qualitative descriptive study was to further develop our understanding of the supportive care needs of those affected by APC by seeking out family members to share their experiences and suggestions for improving supportive care services. The findings of two previous studies were limited by the collection of data from patients who attended the regional cancer centre for their care (Bryant-Lukosius, 2003). Family members are included in the sample of this study to understand the impact of prostate cancer on patient and family life. Because partners are often a major source of social support for people with cancer (Carlson et al., 2001), it is important to understand the impact that prostate cancer has on partners.

The study addressed the following research questions:

1. What are the supportive care needs of the family members of men with HS and HR APC?
2. Are the needs of the families of these two groups different?
3. What are the strengths and limitations of the current model of care in meeting the supportive care needs of these family members?
4. What are the recommended strategies for improving the current model of delivery of care to meet the supportive needs of family members?

Methods

The methods for this study have been described in detail elsewhere (Carter, Bryant-Lukosius, Blythe, Neville, & DiCenso, 2008). Briefly, this study was a needs assessment using a qualitative descriptive method outlined by Sandelowski (2000) to explore and understand the supportive care needs of family members of men with APC and their suggestions for improving supportive care. Data were collected through focus groups and interviews. The Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board and the St. Joseph's Healthcare Research Ethics Board approved all study procedures (Appendices B and C).

Sample

We collected information from the HS and HR family members separately because of reported differences in the health care needs of men with different forms of APC. Eligible family members included wives, partners, and children of patients with APC. The participants were recruited from various settings. Many participants were identified by patients with APC who had participated in the patient arm of the study

(Carter et al., 2008), however not all participants were family members of men who participated in the patient study. Family members were also recruited through urologists' offices and at local prostate support groups as well as through newspaper advertisements, community television commercials, and university and interest group Web site notices (Appendix D). Several were also recruited from a Central West Ontario Cancer Centre. Participant recruitment continued until no new information was heard in the interviews or focus groups, and data saturation occurred (Sandelowski, 1995).

Data Collection and Analysis

Data were collected through indepth interview and focus groups. Consents were obtained prior to data collection (Appendices J and K). Interviewees took part in one 40-90 minute in-depth semi-structured interview. Participants were asked how APC had affected their lives, the problems they were experiencing, and whether their needs were being met. They were also asked to prioritize future efforts to improve the care of patients and families with APC. At the end of the interviews, the investigator summed up the priority needs and the suggested strategies (member checking). Focus group participants participated in one 60-90 minute focus group facilitated by the principal investigator. The same semi-structured interview guide was used for both interviews and focus groups (Appendix L). At the end of the focus groups, the investigator recapped the major themes to validate and clarify the information (member checking). A research assistant wrote notes about the interaction among participants during the focus groups, and after each group, the investigator and research assistant reflected on the group interaction and content. All focus groups, interviews and reflections were audiotaped and transcribed

verbatim. Recruitment of study participants continued until no new information emerged and data saturation had occurred (Morse, 1995).

The strategy for data analysis has been reported elsewhere (Carter et al., 2008). Briefly, a team of nurse researchers, including the investigator, analyzed data concurrently with data collection and used N-Vivo software and thematic content analysis as described in Burnard's (1991) framework.

Strategies to establish the rigor of the study have been reported previously (Carter et al., 2008). Briefly, the researcher who was responsible for all data collection and who analyzed data had no previous relationship with participants and had no employment relationships with the regional cancer centre, urology clinics or any health care agencies. In addition to member checking, triangulation strategies included the comparison of study results with other published oncology studies involving family members and attendance at five local prostate cancer support groups held by the Canadian Cancer Society to listen to the issues raised by men and their wives. A summary of the participant data was reviewed at the end of each focus group and individual interview to ensure clarity. The themes generated were also shared with stakeholders such as nurses, physicians and other members of the health care team at the regional cancer centre to see if they were "recognizable" or credible to them (Koch, 1994). Using other researchers with oncology nursing expertise to assist with coding of data also supported truth value by ensuring the codes generated were present in the data (Morse, 1994).

A journal was kept by the researcher that included information about data collection to support the auditability of this study. The researcher also discussed methods and

decisions with other members of the research team and fellow graduate students as an external check of the research process and to clarify any issues with bias which could have affected interpretation of the data (Cresswell, 2003).

Findings

Data were collected from nineteen family members through both focus groups and in-depth interviews. Not all family members who participated in the study were related to men in the patient study. Table 1 shows a descriptive overview of the participants. The term "wife" is used to describe women who are married or living common law with a man with APC.

Table 1

Description of Family Participants

	Hormone Refractory	Hormone sensitive
	$n = 11$	$n = 8$
Number of Wives	10	6
Mean age of wives (range)	71 years (53-85 yrs)	69 years (63-85 yrs)
Number of Adult Children	1	2
Ages of Adult Children	56 yrs	32 yrs, 52 yrs

There were eleven family members of men with HR disease. Ten HR family members participated in three focus groups. Of these 10 focus group participants, there were 9 wives and one daughter who attended with her mother. One HR family member

was interviewed at home with her husband. The ages of wives of men with HR APC ranged from 53-85 years. The daughter who attended with her mother was 56 years old and a retired health care professional. Three of the 10 wives worked outside the home (2 full time, 1 part time) and 7 reported being homemakers. Seven of the ten wives reported having health problems of their own, including high blood pressure (4/7), arthritis, vision problems, and circulation issues.

Eight family members of men with HS disease were interviewed (6 wives, 1 son, and 1 daughter). The ages of these wives of men ranged from 63-85 years. Two of the six wives worked outside the home. The interviewed son was 52 years old and worked full time. His mother was not a study participant. The daughter who participated in the study was 32 years old and worked full time. Her stepmother was a study participant. Some wives reported health problems including vision problems and arthritis. One wife and the son reported suffering from depression.

There were no focus groups with HS family members. The inability to recruit HS family members was related to slow recruitment and the fear that recruited participants would lose interest before participating. Differences in data collection methods will be discussed further in Chapter 4 (Carter, Blythe, Bryant-Lukosius, Neville, & DiCenso, 2008)

In keeping with the qualitative descriptive method described by Sandelowski (Sandelowski, 2000), a descriptive summary of the content of the data is presented in this section. The data have been clustered into categories according to the research questions, and then grouped by shared characteristics.

Analysis of data revealed eight major themes. During data collection, family members described what life was like *(1) living with prostate cancer* and how they were *(2) dealing with the cancer together*. Major themes related to supportive care included *(3) informational needs, (4) uncertainty about the future, (5) the burden of caregiving, (6) need for practical assistance* and *(7) isolation.* Family members also described *(8) coping with prostate cancer*. These themes are described in more detail below.

In the first sections, titled *Living with Prostate Cancer* and *Dealing with the Cancer Together,* family members described the impact of cancer on their lives. Wives described the impact prostate cancer had on their relationship. Although this does not answer any of the research questions directly, it provides relevant background information and helps to ensure attention to the context of the conversations, which is essential in a qualitative descriptive study (Creswell, 2003). In the last section of the findings, family members describe how they are *coping with cancer*. Similarly, this section is included to increase our understanding of the context of the participants' lives. After the reporting of supportive care needs, the family members' description of coping and their suggestions for improving supportive care are reported.

Background – Living with Prostate Cancer

Prostate cancer had been part of the lives of most of the family members for many years. Wives of men with HS disease described their partners as feeling generally well, having some physical complaints such as fatigue, low energy levels, and urinary problems, and the side effects of androgen deprivation (hot flashes and weight gain). A few women reported that their partners were irritable and anxious due to frustration with

not being able to do what they previously could do as a result of fatigue or weakness. Together, these couples fought to go on with a normal life.

In the following statements, several family members described the challenges faced by the APC patients. Family members describe a range of issues men with APC face. For example, one woman described both minor issues such as ambulation as well as the emotional suffering her husband experienced living with cancer.

> Still has a little bit of trouble getting out of chairs and what not. He has bigger problems that he worries about, and that's incontinence. He gets totally anxious when he has blood in his urine even though he's been kind of reassured on that by the doctors that this is what you expect with this particular kind of cancer that you will get bloody urine every so often. He thinks it's the cancer moving on and invading other parts and breaking apart other tissues and what not. So it bothers him.
>
> (HS family member)

Many family members described how lack of energy and fatigue affected men's ability to do what they wanted to do.

> Less energy with the treatment, yes. And the sweating. He sweats a lot but it's hot too, you know. So it's a combination you know. (HS family member)
>
> He comes in the house and says, "Oh I just can't do what I used to." (HS family member)

One woman described how the prostate cancer and issues with incontinence and erectile dysfunction affected her husband.

> It takes quite a while to get back mentally. It's really devastating for a man to have this kind of a problem. It's not something that they've ever experienced before and they find it very hard to talk about and it's very demoralizing for them. (HS family member)

Many family members described how the activities men participated in changed.

> He don't enjoy himself like he used to. Because he don't feel like sitting down and drinking like he used to and enjoying. He can't seem to enjoy his life as well as what he did. (HS family member)

Most HR family participants felt their family members were coping well emotionally, describing the time around diagnosis as having been the most difficult. They reported that the men suffered from physical problems such as fatigue, pain, urinary problems (i.e., incontinence and/or catheter problems), sleeping problems, and other side effects of treatment (i.e., nausea and loss of appetite). Chemotherapy treatments seemed to be a milestone in their illness, as these treatments caused fatigue.

> He's losing his get up and go. He wants to. He tries but he just tires so quickly. And I don't know whether it's the disease or the chemo or the combination. (HR family member)

Some women described the pain their husbands experienced and the struggle to get adequate pain control.

> He had a bad patch of pain and we considered going on disability but then we tossed the odds about. I said, "This is going to kill him more than the cancer if

he's off from his work." With him being relatively young, he's got so much that he wants to do. (HR family member)

There were several descriptions of how men fought to do difficult things they once found easy.

Prior to the kidney infection, he was walking 2 miles a day and now he's gradually getting back to that because I don't think he wants to give in to not doing it. (HR family member)

Frequently, women described how men with APC refused to give up activities.

He thinks he can do anything, but physically he can't. (HR family member)

Well sometimes the mind is willing but the body isn't and my husband is a dairy farmer and worked hard 7 days a week. (HR family member)

Some men were reluctant to accept assistance, such as pain killers.

He's reluctant to take any pain killers. He's not on a prescription pain killer at all yet. And I've said, "Why don't you call the doctor and see if you can get a prescription?" And he says, "Oh it's not that bad. You know I don't want to take anything too strong." He tends to put up with it and you can tell he's in pain just by guarding the way he walks and that kind of stuff. (HR family member)

Wives described the ways they supported men's need to function as they had previously.

He cut the grass yesterday and then he slept in the afternoon. But he fights to do these things. But I don't stop him because I think it's good for his mentality. (HR family member)

Many family members were frustrated by the men's inability to acknowledge their physical limitations, reporting that the patients only reluctantly gave up such activities as playing with grandchildren, yard work, and socializing with friends. Family members described how other people noticed a change in the men's level of wellness.

> But other people worry too. They'll say, "Oh he looks so white" or ask if he should be here. At the pancake breakfast, he's standing there serving, and honestly, I'm dying. I said to him, "We've got to go home." He's so white and he barely can stand and people are just saying to me, "Why is he doing that?" I said, "Because he wants to!" (HR family member)

Background - Dealing With the Cancer Together

The majority of the wives of HS and HR patients reported that living with prostate cancer for many years brought them closer to their partners as they dealt with the disease together. One woman described that dealing with the cancer was like "a long slow dance". They often commented that the communication shared between them led them to gain insight into their relationship. Wives depicted prostate cancer as one of the "good cancers" to get. They described how they were thankful for the time they had together, which often included long periods of relative wellness.

> I'm not such a scaredy cat as I used to be. We've been living with this for 8 years and nothing's happened and every time he has a bone scan it's clear. You know it hasn't spread so that brings you up. And we don't dwell on it every day. (HR family member)

One woman described the intimate relationship she continued to have with her husband, despite treatment related erectile dysfunction.

> Well of course he's impotent, which is accepted, but it really isn't important because we love each other and that's just one thing that you accept. I've got him! He's here! I have so many friends that have lost their husbands. But no, at our age it's not that important. You know we have a very loving relationship. (HS family member)

Another woman described how she and her husband dealt with the problems they experienced together.

> We talk about stuff here fairly openly between us and we've got children too. We sit down and if there's an issue we make sure they're aware of the issue that's here and that we're dealing with. And we just deal with it. (HS family member)

Communicating about the prostate cancer made one of the participants feel closer to her husband.

> He used to really just confide at the beginning in one friend and then as the years went by, especially recently, he's really opened up. It's just wide open now and he just chats about it and just about everything, which is, it's really nice. I like it when they talk about it. I think it's much better. (HR family member)

Another woman used the term "we" when asked how she was coping.

> But so far we're doing okay. We're together. (HR family member)

Supportive Care of Family Members of Men with HS and HR APC

In this section, the problems and supportive care needs of family members are described. Some family members clearly described their needs, while others described the problems and issues they were experiencing. All these problems, issues, and needs have been reported in this section of supportive care.

Analysis of focus group and interview data revealed that the HS and HR groups had many problems and needs in common. Because most of the problems and needs identified by family members were shared by both groups, the results from both groups are combined and are reported according to themes. First, similar problems and needs are reported. Both HS and HR family members had *informational needs* and *uncertainty about the future.* Family members of men with HR disease had additional problems and needs related to the progression of the illness. HR family members also reported the *burden of caregiving, a need for practical assistance and isolation* (Table 2).

Similar Problems and Needs of HS and HR APC Family Members

Informational Needs

Both HS and HR family members expressed the need for more information regarding treatments and side effects, available supportive care services, and the future course of the disease.

> From where I'm sitting, it's just a lack of information. A lack of what's available out there. So unless you specifically ask, you don't find out. Sometimes you just don't know what question to ask because you don't know what's out there. (HR family member)

Table 2

Supportive Care of Family Members of Men with HS and HR APC

	HS family members	HR family members
Informational needs	■	■
Uncertainty about the future	■	■
The burden of caregiving		■
Need for practical assistance		■
Isolation		■

> I think more information through the years would have been helpful. (HR family member)

The focus group participants took the opportunity presented by the study to engage in frequent information sharing. Most wives reported that their physicians were their main sources of information, but the information they received at appointments was either overwhelming or difficult to understand. They also described feeling rushed during physician appointments.

> I still find the doctor is the main person for answering specific questions, and you always feel that you're taking up his time or you can't phone him in between your monthly appointments. No, sorry it's not monthly appointments, its 3-month appointments. (HR family member)

> If a caregiver wants to know, there needs to be a comfortable place to hear those kinds of things and when you're in the appointment together it just doesn't happen always. (HR family member)

Women also seemed reluctant to ask questions at doctor's appointments, unsure if doing so was their prerogative.

> I have different questions than he does and I don't want to upset him, you know. (HS family member)

> Every 6 months we would go and we were in and out in a minute and didn't seem to give us much time to talk. Sometimes there were things I wanted to say but it's hard. I know they're busy. (HS family member)

When describing their strategies for collecting and remembering information, several older family members stated that their hearing loss often exacerbates the frustration they experience at the doctor's office.

> Both mum and dad are a bit hard of hearing and that's increasing with age. (HR family member)

> Sometimes I find myself trying to listen so hard that I'm a sentence behind in what they're saying. (HR family member)

Another woman had developed a strategy to help her keep track of information.

> I write everything down. I have a lot to keep track of. I keep a little journal just to keep myself straight. (HS family member)

Younger family members reported accessing the Internet, but many of the older participants did not.

> I don't know that we have accumulated all that much information. I haven't joined the younger generation with the Internet and don't expect I ever will. (HR family member)

Several family members shared the difficulties that could arise with receiving *too much* information:

> I have often withheld test results from him because I knew that giving it to him today was not a good idea. (HR family member)

Having *too much* information was often a result of searching the Internet.

> I tell him, "Don't surf the net." I'll do the surfing because there's bad stuff there. There's poor stuff and if you stumble on it, it might just upset you. Let me filter it and then I'll give you what you need to know. Once I've narrowed it down to something that you should see then I'll give it to you and you go and look at it. That's how we do it. (HR family member)

> That's the danger of a little bit of information or a little bit of knowledge. It's very powerful. Knowledge is very powerful but don't mistake it because sometimes just that little bit, if you don't know how to put the pieces together, can be very terrifying. We've stopped looking at the Internet because of that. (HR family member)

Uncertainty about the Future

Both HS and HR family members discussed their feelings of uncertainty about the future, particularly their frustration with not knowing what to expect as the prostate cancer progressed.

> Basically he's just as he was before, except with a little PSA signpost hanging over his head. Like, okay, when's the count going to change? (HS family member)

One woman was frustrated by the reluctance of her husband's physician to discuss his prognosis.

> Perhaps it's our doctor. For a doctor who deals with cancer patients I find it funny because it's so difficult for him to dish out bad news. Even this prognosis, we had to tease it out. I see the MRIs. I see the progression from one MRI to the other. How can you say this? But okay, you shut up. But that's hard. I think they have to be more realistic. (HR family member)

Uncertainty about the future also affected one couple's decision making about treatment options. It also showed the woman's concern for her husband's quality of life.

> That's the next choice. My husband has to decide whether he wants chemo or not and of course he has to make the decision. But I'm reluctant for him to start it because it not only kills the bad cells, it certainly kills the good. Is it worth your quality of life to be sick for the length of time they're going to be sick? (HR family member)

One woman shared how difficult it was to talk about the future.

> I think it's making me a little more anxious. I'm sure it is. Probably because I want to do what's right for him and I'm not always sure what it is. I don't know whether to broach the subject. "Oh, so you've got prostate cancer you know and where does this leave us?" (HR family member)

This woman shared how they were dealing with the cancer at the present time.

> I don't know what the future holds but you know we're okay right now. (HR family member)

The family members were anxious about both their loved ones and themselves, often wondering how they would cope when their loved ones' conditions worsened.

> During those last 3 days its like, oh my God, I feel so fragile. What am I doing? I can't imagine if there's future crisis or if things get worse or I see my dad suffering. (HS daughter)

> I don't know if he suddenly became ill. He one day said, "Don't ever try to keep me home," and I said, "Well I know I couldn't cope. I just couldn't." (HS family member)

Frequently, family members worried how the future progression of the cancer would impact their loved one.

> What the future holds? Nobody has a crystal ball or so no one actually tells you. Hopefully we can go on for a couple of years like this. I just don't know. But I don't want to see him live and suffer. (HS family member)

Different Problems and Needs of HS and HR APC Family Members

Family member of men with HR APC experienced different problems and had different needs, and this was likely due to the progression of their husband's illness. These women experienced *the burden of caregiving, had* a *need for practical assistance,* and experienced *isolation.*

The burden of caregiving

Most family members were reluctant to discuss their own needs, tending to downplay the effect that living with an APC patient has had on them personally. Several

HR family members described the burden of being the primary caregiver, which included supporting the men's physical, functional, and emotional needs.

> It is a constant battle trying to give them the positive end. (HR family member)

One woman described the burden of providing emotional support to her husband and at the same time not disclosing to family and friends how sick he was.

> But he's had this cancer since 1997 and you would never know it because he would tell everybody he's fantastic. His favorite saying if he is asked, "How are you?" "Oh I'm fantastic!" I'm the only one that really knows." (HR family member)

An adult daughter described how her father's poor appetite was putting a strain on her mother.

> I think mom's at the point where she's tired of cooking. I think it's a real chore. When dad wasn't feeling well in March, nothing appealed, and then that's really difficult because you know that he needs to eat and you want to give to him. So that's a lot of added pressure. (HR daughter)

Need for Practical Assistance

Women need practical assistance to help them care for their husbands. They described the work involved in organizing care for her husband, including the task of keeping medications straight.

> I have his medication in a spreadsheet [group laughter] to give out when we see the doctor. I say, "This is what he's taking now" because it's not simple. It's a complex list. I counted one day. I bought him the mother of all pillboxes you

know. It was 100 pills a week at one point. I mean that's including vitamins and supplements and stuff, but it's a lot of meds. So even little things, like how to organize medication, you have to figure out on your own. If you get into it, that's fine. But if you haven't dealt with this before, it's kind of hard. (HR family member)

Very few of the women described the implications that caring for their husbands had on their own health. But some women did describe being tired.

I'm still able to do everything I did before and I always go with him. Wherever he wants to go, I go. We go shopping and everything together. I always come up here (the Cancer Centre) with him and nothing is really changed. So it hasn't affected me in any way. Not yet. But some days, I get tired, that's all. I'm older than he is. I'm 5 years older than he is but so far it hasn't bothered me in any way. (HR family member)

This woman did describe her concerns about her own health.

I don't want to feel that I'm indispensable, but I just wonder sometimes what he would do if I wasn't there, you know? And I do worry about my own health. (HR family member)

Many women described their inability to keep up with household chores because they no longer had the help of their husbands and were also doing jobs previously done by their husbands.

> Well, it's different, I will admit. I'm finding it a little more difficult to keep on top of everything, but we're coping. Maybe the corners in the house aren't quite as clean as they might be but anyway we're coping. (HR family member)

This family member appeared to be in need of assistance with housekeeping.

> I'm very happy to have this time to get everything spring cleaned before the family comes. Not that they care, but they've always known it to look kind of nice. And you don't want them to see that mother can't do it. But you also don't want them to see mom half dead either. (HR family member)

Isolation

For some HR family members, the burden of caregiving led to feelings of isolation. They reported that the men often did not want to go outside of the home because of incontinence and fatigue.

> My husband likes people to come over. He doesn't like to go visit anybody and he loves it if someone, anybody, comes over. He tries to make them stay a bit longer. But we don't go out. We don't go out much, because he can't really walk so much. (HR family member)

> I just accept it. We can't go out as much as we did but I'm getting older too. I tell him he's lucky he hasn't got a 21 year old because I'm 85. So I'm not out there dancing. I guess the fact that I'm older and ready to sort of slow up is making it easier for him. (HS family member)

An adult daughter was very concerned about the isolation her mother was experiencing.

> Mom needs more activities. She needs to get out and socialize more but she doesn't want to leave him. I think he enjoys seeing family. But he wants to stay at home. That's where he wants to be. That's not necessarily where Mom wants to be or needs to be and so we've got these needs that are just totally opposite right now. (HR daughter)

One woman described how her husband's constant fatigue prevented her from having visitors to her home.

> Well we live in a one-bedroom apartment and I have the bed in the bedroom and he has a single pull-out in the front room so he can just collapse whenever he wants. Our lives have changed a lot. Most of his friends were his working buddies and then most of our friends, you know, they were couples, which is fine but I find with the bed out and him sleeping so much, we really don't do things like we used to. (HR family member)

Although many acknowledged their need to get out and socialize, they were reluctant to do so, often because they did not want to leave their husbands.

> It affects your social life as well. Because it's hard to plan anything and then I don't really want to be out gallivanting having a wonderful time and he's at home suffering. So when social things come up for work that wouldn't normally include him, I have started to decline those invitations. It just doesn't feel good to be out enjoying yourself and he's at home suffering. Occasionally, I know I need to go out. But I know he'd do the same for me if the table was turned. (HR family member)

> I'm always thinking of him when I'm away you know. What will I find when I open that door? Is he going to be all right? (HR family member)

Coping with Prostate Cancer

The family members reported using various ways of coping, including the use of humor, sharing experiences with family and friends, and purposively taking time for them. Some of the younger wives continued to work. One woman described how she kept her place of employment separate from her life dealing with prostate cancer.

> The one thing I've done—at work I don't talk about it very much. There's obviously people who need to know, but I think out of their caring and kindness, it's too much everybody coming in and asking, "Well how's everything?" It's the one place I've kept to myself that I don't have to deal with it every minute, every hour. (HR family member)

Women coped by participating in activities with friends and families outside of the home.

> I'm cranky if I don't get out there to do my exercise. So I have to, even when he's in the middle of pain. I mean obviously when it's very bad I'd get somebody to cover for me or I'd tell him, "All it is—it's an hour," you know? I say, "Look, if things get bad, ring the pool and they'll get me out of the water." He hasn't had to do that. You know you've got to, because it's hard enough caring. (HR family member)

As the disease progressed, the coping strategies used by some family members changed.

> We used to joke about it a lot at one point because we thought that was the best way to handle it. It was quite funny at times. But then it's not been too funny lately. (HR family member)

This family member described how the possibility of new medications in the future helped her to cope.

> My girlfriend, her husband is in pharmaceuticals. So I've talked to her and she said that they feel that the future is going to be in new drugs that are coming up. She said they're feeling that a lot of the pharmaceutical companies have is that people will have cancer and they will be living with cancer but there will be medications that will kind of tide them over until the next … [pause] … thing. Their lives will be pretty well a lot longer and a lot healthier more or less, by maintaining the drugs. So that kind of helps as well when you kind of know someone in the industry that's willing to kind of tell you that. (HS family member)

Another woman described how her faith helped her to cope.

> You know I got faith in some doctors. We go in there and I got great faith the medication works. We come home and try to continue the same thing because we feel comfortable with each other. Try to cook, cook for him, to do my best, to have the medications in the right moment and not to forget anything. It's all you can do. Pray God they work that's all. (HS family member)

This woman describes how avoiding the issue sometimes helped her cope.

> Sometimes I don't want to think anymore and you know I want to think its okay and everything is okay, you know? (HS family member)

Differences between the Supportive Care Problems and Needs of HS and HR APC Family Members

Although both HS and HR family members had similar issues and experiences *living with prostate cancer*, there were some notable differences related to the level of wellness and advancing burden of illness of the HR patients (Figure 1). Both HS and HR family members described how they *deal with the cancer together*, which often brought them closer. Both HS and HR family members expressed a *need for information* and *uncertainty about the future*. Different treatment regimens, particularly chemotherapy, resulted in more supportive care needs for the HR family members. HR family member data revealed issues related to *the burden of caregiving, the need for practical assistance and isolation*.

Strengths and Limitations of the Current Delivery of Supportive Care Services and Recommended Strategies for Improvement

Most family members were satisfied with the care the patient was receiving. The majority of their suggestions for improvement were related to access to information, more specifically increasing their access to and time with informed health care providers. Most family members were very clear about what they needed when asked how things could be improved.

> Information. Once I understand what the condition is my anxiety rate goes down. (HS family member)

Figure 1. Stage specific and common supportive care needs of family members of men with APC

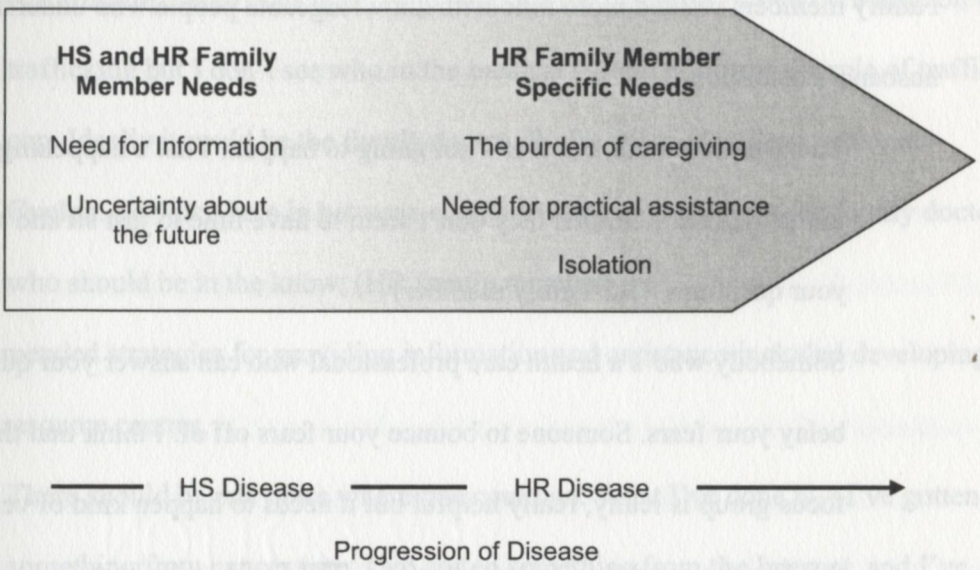

Figure 1. This diagram depicts the overlap of family members' supportive care needs as patients with APC move along the continuum of disease progression.

> I guess I'm from a different generation than the spouses that are here and I'm from the generation where information is power. So I want to know everything that I can about what my dad has. So it's very hard. (HR daughter)

One woman wanted to be able to access support for herself, without her husband present.

> If a caregiver wants to know, there needs to be a comfortable place to hear those kinds of things and when you're in the appointment together it just doesn't happen always. Because I have different questions than he does and I don't want to upset him and start pressing all the buttons here and things start getting said that he doesn't even want to hear. But yet I still need a place to be able to ask

without taking people's time on the telephone and messages back and forth. (HR family member)

Family members wanted more time with knowledgeable people who understood their husband's condition.

To have more time, but that's not going to happen. That's happening everywhere in the medical field that they don't seem to have time to just sit and answer all your questions. (HS family member)

Somebody who's a health care professional who can answer your questions and belay your fears. Someone to bounce your fears off of. I think that this kind of focus group is really, really helpful but it needs to happen kind of very close to the diagnosis and then follow ups after. (HR family member)

A few spouses commented on the challenges of having to get information from the physician, and made suggestions to change this.

The doctor is just not available. If there was another way of getting information specifically related to my case for the men, that they could phone up one day and say, "Can I talk to you about this?" If there was sort of like a second in command or like a nurse practitioner who had access to the charts. I don't know if that's possible. (HS family member)

You don't have that personal connection with the doctor and as you get into the extended family you don't have a connection at all. Personally I would like to see some printed information whether it's a question/answer sheet, so that you can have a discussion with the doctor based on where my dad is. (HR family member)

One woman described the need for someone to help her coordinate her husband's care, and recommended the family physician.

> A traffic cop. Who does that? Who supports the caregiver? I will do a little bit of trafficking but I don't see who in the medical system performs the role of traffic cop. Ideally it could be the family doctor. We're not in Hamilton, we're in Guelph. So when he's in between chemo treatments, really it's our family doctor who should be in the know. (HR family member)

Recommended strategies for providing information and assistance included developing family resource centres.

> There should be one place where one could go. What I've done is—I've gotten something from cancer care, I've gotten something from the Internet, and I've talked to a family doctor. Why am I having to do this? Why can't I go to one place? (HR family member)

> A family resource centre for patients with cancer. It is so interesting to hear they do have a pain clinic here because that's one of the things we could have used. (HR family member)

Both HS and HR family members suggested family support groups.

> A family support group would be good for families to figure out and to get some ideas. (HS family member)

> I think the focus group was a great experience for my father because he got to talk with other people and see that he's not as bad off as he thought he was. As you know, everybody's experience is different. I think that was a really very positive

> experience for him. If something like that could be instituted for everybody I think that would be a tremendous support. (HR family member)

Many women emphasized the need for support that was relevant to the stage of cancer their husbands had.

> It would be good if when people get into an advanced stage, to have a thing where you talk to the caregiver and say, "These are the things that are important." Because what happens is you get bits and pieces of information. (HR family member)

Some family members had participated in prostate support groups offered by the Canadian Cancer Society and commented on how support groups could be improved.

> Sometimes the information they're talking about isn't relevant to where you are. If it's topics that are relevant, than it's certainly helpful. But I think the smaller groups are a lot more helpful. (HR family member)

Only one woman requested support for herself at home, but then seemed to trivialize her request.

> Well sometimes I just wish I had somebody to come in every, say, every 2 weeks, and just vacuum through the whole house. I find vacuuming is hard. And there's always something else I've got to do today, that it will wait until tomorrow [laughing]. But there are worse things. (HR family member)

Another woman suggested their care needs might change in the future.

> Well right now everything's going along fine. It's when something happens that you need something extra. (HR family member)

The family members participating in the focus groups engaged in frequent interaction and information sharing. The women listened intently to each other's stories, frequently nodding their heads to signal approval and understanding. They also frequently exchanged information regarding supportive care services.

Discussion

The purpose of this qualitative descriptive study was to explore the needs of two groups of family members caring for patients with APC and elicit their suggestions for improvements for care delivery. Analysis of the data revealed that the family members of men with HS and HR APC have similar experiences related to dealing with the cancer together. The family members of HR patients described the burdens associated with caregiving and isolation. Both HS and HR family members reported informational needs were a priority, particularly because they felt uncertain about the future. To our knowledge, there is no literature that distinguishes the differences between HS and HR family members with which we can compare our findings. For the purposes of discussion, studies that include family members of men with prostate cancer and distinguish disease stage are used if available. We also compare our findings with studies of family members living with other forms of cancer.

Couples living with prostate cancer face long-term challenges to their relationships as they adapt to the chronicity of the disease. The spouses of APC patients described various ways that living with prostate cancer had affected their relationships. Consistent with the findings of Lavery and Clarke (1999) the spouses in the current study reported that their relationships had improved, several stating that they had become

closer because of the prostate cancer. Two other research groups confirmed that spouses consider both the patient and the marital relationship to be a source of support in their health care problem-solving efforts (Fergus, Gray, Fitch, Labrecque, & Phillips, 2002; Giarelli et al., 2003). Some spouses described how maintaining communication with their husbands about the disease was an important part of coping. In their study using separate focus groups of metastatic prostate cancer patients and their wives to explore their communication patterns, Boehmer and Clark (2001b) found that the couples talked little about their worries and fears, leading to concern that a lack of communication put them at risk for poor adjustment to the cancer.

The priority supportive care need identified by both groups of family members in the current study was the need for additional information. When Resendes and McCorkle (2006) examined the literature on the responses of spouses whose husbands had been diagnosed with prostate cancer and undergone prostatectomy, they identified a lack of information to be a source of distress. A review of the literature of the information needs of men with prostate cancer and their partners found that although there is evidence suggesting partner needs are not being met, many studies had methodological limitations due to small sample sizes and poor response rates (Echlin & Rees, 2002). When Harden et al. (2002) conducted focus groups of men with prostate cancer, 59% of whom had advanced disease, and their partners, the participants reported an overwhelming need for information.

The family members in the current study expressed the need for more information about treatments and side effects, available supportive care services, and the future course

of the cancer. This need is consistent with that found in other studies (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2000; Davison et al., 2002; Finney Ruttin, Squiers, & Treiman, 2006; Giarelli et al., 2003). Most of the family members in the current study reported that they relied on health care professionals as their primary sources of information. This finding is somewhat inconsistent with the results of a study of Canadian men and their partners by Davison et al. (2002). In Davison et al.'s study, the partners reported that their main sources of information (from most to least accessed) were friends or relatives, other men with prostate cancer, reading material in doctor's offices, physicians, and the Internet. Few family members in the current study accessed the Internet, and those who did found doing so to be stressful because the availability of a large amount of detailed information confused them and increased their anxiety.

Prior research has identified a conflict between seeking and avoiding information. In their study of the information-seeking behaviours of partners of men with prostate cancer, Feltwell and Rees (2004) found that information needs are individualistic, with some seeking large amounts of information and others wishing to avoid receiving information. Wong et al. (2002) found that the use of the Internet was the least-favoured method of obtaining information in their survey of Canadian patients with advanced cancer and their caregivers.

In the current study, hearing difficulties, difficulty processing medical information, and insufficient access to and time with physicians were some of the problems compounding family members' ability to receive information from health care professionals. Fitch (2006) found barriers to receiving cancer-related information for

older adults included the hectic nature of the health care environment as well as the rapid rate at which health professionals spoke, their use of medical terminology, and the overwhelming volume of information they presented.

During this study's focus groups, the family members used each other as resources to learn about various supportive care services, such as the pain program and home care. Such action is consistent with Maliski et al.'s (2002) finding that women seek out other wives of men with prostate cancer to gather information. After the focus groups concluded, many participants commented on the benefits they had experienced by participating in the study, supporting the researchers' decision to use focus groups because of the interaction they permitted among participants.

Participants in both the HS and HR groups reported feeling uncertain about what the future would hold for both their loved ones and for themselves and desired more information regarding the next treatment/health care steps and their consequences. The presence of such a concern is consistent with the literature. Shaha and colleagues (2008) explored the literature to discover key aspects of uncertainty expressed by patients with breast, prostate and colorectal cancer. They suggest three different sources may cause or reinforce feelings of uncertainty in cancer patients: 1) information-related issues after diagnosis, 2) decision about treatment, and 3) the effect of cancer related uncertainty and its effects on the lives of patients and families over the disease trajectory. This is particularly challenging in prostate cancer because of the various treatment options about which couples must make decisions. Based on discussions of life expectancy with terminal cancer patients and their family members, Clayton, Butow, Arnold, and

Tattersall (2005) found that the participants wanted general information regarding the life expectancy of other patients with their specific illness, but did not want details specific to their situation. When Ka'opua et al. (2005) used grounded theory to describe partner adaptation to long-term prostate cancer survival, they found that the women emphasized continuous learning as a way to cope with uncertainty. Based on this finding, they suggested the use of psychoeducational interventions for wives.

In their review of the psychosocial responses of spouses of men who had undergone prostatectomy, Resendes and McCorkle (2006) found fear of the unknown and fear of the future to be sources of distress. Our study findings confirm these results as family members described how a lack of information about the future resulted in distress. In a study examining patient and family experiences of living with prostate cancer, Germino and colleagues (1998) found uncertainty was inversely related to positive affect regarding patient illness, QOL at home, and psychological distress. In their qualitative study using focus groups to explore the experiences of couples living with prostate cancer, Harden and colleagues (2002) found one of the emerging themes to be enduring uncertainty, which included struggling with choices and feeling as if one's life were interrupted and one were on an emotional roller coaster.

HR family members but not HS family members reported experiencing isolation. Various aspects of prostate cancer contributed to this isolation, particularly changes in participants' social activity due to their family members' physical problems such as incontinence and fatigue. Harden's (2005) exploration of the relationship between developmental age and disease-specific issues in couples experiencing prostate cancer

found changes in normal patterns of socialization led to loneliness for caregivers. Butler and colleagues (Butler et al., 2000) reported some wives of men who experienced radical prostatectomy experienced isolation related to their husband not including them in decisions related to treatment or care. Some of the isolation experienced by participants in the current study seemed self-imposed, several women explaining that they had decreased their social activity because they did not want to leave their spouse alone. One daughter poignantly described the needs of her father and mother as opposing, with her mother needing activity away from her father.

Boehmer and Clark (2001b) described how couples often isolate themselves from each other by avoiding both communication and working through their feelings together. They also reported that men's communication was often restricted to their wives, many disclosing their diagnosis to their wives only. This was poignantly confirmed by one study participant who reported, "I am the only one who really knows." Another family participant shared how she felt embarrassed in social situations because her husband looked so unwell. In their QOL study of men and their spouses, Kornblith et al. (1994) found that urinary problems were more strongly related to the spouse's distress than to the patient's distress. They suggested that spousal distress may arise from the limitations that urinary problems put on the couple's social life and/or fears of social embarrassment related to incontinence.

Harden (2005) noted that caregivers often have multiple role responsibilities at home and work as a result of their spouses' fatigue and ill health. For older spouses, these additional responsibilities add to their own health issues and increase their own need for

support (Hawes et al., 2006). The family members in the current study found it very difficult to discuss their own needs, particularly those related to the burden of caregiving. Appearing reluctant to ask for help, HR family members quietly mentioned the added workload that came with their spouse's prostate cancer. Such reluctance was illustrated when one daughter insisted that her elderly mother needed help caring for her father as her mother tried to downplay the situation. Kornblith et al. (1994) suggested that the advanced age of the majority of men with prostate cancer required their spouses to assume new responsibilities and roles that led to feelings of hopelessness.

Despite their requests for more information and support, most family members reported being satisfied with the care they were receiving from physicians and nurses. However, they reported having to go out of their way to obtain information about available services or arrange for supportive care. Previous research found that caregiving families were consistently unaware of available support services despite the presentation of such information by health care professionals (Hardwick & Lawson, 1995). Grobe, Ahmann and Ilstrup (1982) suggested that the reason for this lack of awareness might be that family members are not ready to hear this information when it is related or forget information presented during a time when they believe that they are coping well and do not need additional support.

The participants also reported the lack of coordination and various physical locations of available services to be other limitations of the health care system. Several participants recommended developing family resources centres as a means of consolidating available services and increasing access to health care professionals. In

their survey of 71 Canadian patients with advanced cancer and 73 caregivers to gain understanding of their informational needs, Wong et al. (2002) found that most participants preferred receiving information in a "one-on-one" situation with a health professional.

The participants in the current study also suggested the formation of small support groups in which they could both receive information and interact with other family members, a suggestion previously made by Harden and colleagues (2002). The use of small groups to provide education and support to wives of men with prostate cancer has been evaluated by Manne et al. (2004). They used a randomized controlled trial (RCT) design to test the effects of a 6-week group psychoeducational intervention led by health care professionals. The intervention included sessions on: (a) prostate cancer and treatment; (b) nutrition; (c) stress management; (d) communication; (e) intimacy and sexual concerns; and, (f) survivorship issues. The researchers found no difference in the reduction of psychological distress between the intervention and control groups. They did find the interventions had a positive impact on two coping strategies used by the wives to deal with the cancer experience. These two coping strategies were positive reappraisal (adjusting priorities and expectations for uncontrollable cancer stresses) and denial coping (coping strategies such as avoidance). Few of the participants in this study were living with advanced stage cancer and the authors suggest the intervention should be tested with those experiencing significant distress.

Although many participants in the current study had experience with support groups, most of these were the prostate support groups offered by the Canadian Cancer

Society. These groups do not provide support specific to family members. These meetings are often large and not disease stage specific. A Canadian study of prostate cancer support groups found the major motivation for women to attend these groups was to help them understand and manage their own experience of prostate cancer (Bottorff et al., 2008). Arrington, Grant, and Vanderford (2005) evaluated 20 meetings of the "Man to Man" self-help group for men with prostate cancer and 14 meetings of the auxiliary "Side-to-Side" self-help group for spouses. As a framework for their study, they considered three broad types of social support: (a) tangible or practical support; (b) informational support; and, (c) emotional support. The authors were surprised to find that during both types of meetings, information dominated the discussion, with no practical support offered and emotional support was actively discouraged. They suggested that such action or lack of action leads spouses to seek support outside of the group from their husbands, family, and friends, consistent with the findings of the current study.

Comparison of Data from Patients and Family Members

As part of the overall study, we also collected data from men with HS and HR APC to learn about their supportive care needs (Carter et al., 2008). Both men and family members described the time around diagnosis as being the most difficult. Men in our study continued to express anger and frustration about their diagnosis, and the family members also recalled difficulty coping during that time.

Consistent with the reports of the family members, informational needs were found to be the priority needs for both groups of patients. Specifically, the patients needed information about treatments, side effects, and available services. The patients

also recommended changes to the model of care delivery that would provide for additional assistance in interpreting information and the formation of small group sessions specific to men with advanced disease led by a health care professional.

Men reported the impact that prostate cancer and treatments had on their daily function, or their ability to do what they wanted to do. Urinary and incontinence issues were problematic symptoms for the HS group and fatigue was a problematic symptom for the HR group. The results from this study reaffirm patients' need to maintain life as it is "now", which includes functional capacity and independence. But the men's fight to do things and reluctance to "give in" or accept help was stressful to family members. The women's descriptions paint a picture of "stoicism", which could be a source of conflict for the family members who wanted to protect, support and care for the men. This was not easy for family members, and one woman described "the constant battle" of trying to provide the positive side. Some women provided examples of how they supported this stoicism, by helping to hide the truth from friends and family. This combination of men downplaying their illness and spouses collaborating by hiding their fears and despair was reported by Boehmer and Clark (2001b).

Consistent with the results from the patient study, wives discussed how dealing with cancer brought couples closer together. Patients specifically described this when discussing sexual issues. One of the noticeable differences found between the data collected from patients was a clear lack of discussion about the needs of their wives, except when discussing erectile dysfunction. This may be because we asked the family members about their husbands, but did not explicitly ask the patients about their family

members' needs. It was surprising, however, that men did not discuss their wives role in supporting them throughout their illness.

Limitations and Strengths of the Study

The limitations of this study included the inconsistency in data collection methods. The majority of HR family members participated in focus groups and HS family members participated in individual face to face interviews. The decision to use both methods allowed us to gather information from individuals who might not have participated otherwise. Additionally, one HR family member was interviewed in the presence of her husband, and this may have changed the nature of the data provided given the husband was present.

Because the researchers recruited participants from various locations (regional cancer centres, local urologist offices, and through community advertising), the results reflect the experiences of a spectrum of family members living with APC patients. In addition, collecting information concurrently from family members and patients allowed the researchers to reflect on the unique needs of men, their family members, and the couple as a unit. This issue is described in more detail in a subsequent chapter (Carter et al, 2008a).

The majority of prior studies of family members of men with APC include partners or spouses only (Couper et al., 2006). Although the original intent was to explore the needs of wives of men with APC, our study included adult children in the study sample (3 of the 19 participants). Analysis of the data from adult children was limited by the small sample size. Despite this limitation, the insights of the children were valuable

and provided a glimpse of the challenges faced by the spouses that were not disclosed by the wives or patients. Further exploration of the experience of adult children of men with APC is needed. Because adult children often assume the role of caregiver for an elderly parent living with prostate cancer, they could provide practical information into both patient and spouse needs.

To the best of the researchers' knowledge, this is the first needs assessment that identifies and compares the needs of family members of men with HS and HR APC. Discriminating for stage of prostate cancer strengthens the transferability of the study findings to readers.

Implications

This study suggests there is evidence on which to create supportive care services for partners of men with advanced prostate cancer who play a vital role in caring and supporting patients. For spouses of men with HR APC, this is urgent, as this group is overburdened by the demands of caregiving and feelings of isolation. Supportive care services developed for patients with APC must recognize and plan for the increased burden on elderly wives. Wives need support in their homes because of additional caregiving work they must do. Treatment related fatigue and decreasing function results in increased household responsibilities for spouses. We have found that couples try hard to go on with their lives and deal with the cancer together, and spouses also need assistance to support their husband's emotional needs. But men's needs to maintain their functional capacity and "normalcy" may be a source of conflict for family members who are concerned with caring for their loved ones. In this study, family members expressed

frustration resulting from men's stoicism in the face of fatigue and pain. Family members also need emotional support to help them cope with their own fear, uncertainty and feelings associated with conflicts with their partners.

Services should be organized to provide support to these families in their homes or community, as progressive disease limits the ability of family members to leave the home and their ill loved ones. It is also imperative to understand more about the utilization of current services, as our study discovered that there is both a lack of knowledge about availability of services and difficulty accessing supportive care. Exploration of the reluctance of some family members and patients to ask for assistance is also needed to fully understand the match between what is currently available and what is utilized.

The family members of cancer patients require information that helps them care for their loved ones as well as cope personally (Finney Ruttin et al., 2006). A critical review of the empirical literature examining cancer patients' communication with health care providers suggests that family members should be the target of future intervention studies because of their supportive role (Parker, Davison, Tishelman, & Brudage, 2005). We recommend the development and evaluation of small stage-specific peer support groups led by health care professionals for both HS and HR family members. Focused support group interventions have been found effective in helping spouses cope in other patient populations, including victims of acute cardiac event (Gerwick, 1999) and spinal cord injury (Sheija & Manigandan, 2005). Although Manne et al. (2004) did not find that their structured psychoeducational group intervention for spouses with prostate cancer

resulted in decreased distress, they did find that the intervention improved various coping strategies used. The positive comments provided by the participants in the current study regarding their interaction and sharing in the focus groups suggest that a less structured approach might have been more effective. Mannion and colleagues (1994) found that attendance at psychoeducational support groups for spouses of persons with serious mental illness developed by a "spouse task force" with spouse-specific content and co-facilitated by trained spouses was better than was attendance at general family support groups.

The participants in the current study desire more time and interaction with health care professionals who understand APC. The HS family members had access to physicians only and increased support from nursing was recommended for emotional and informational needs. Some HR family members had contact with primary nurses and an APN through the regional cancer centre. In our study, we did not ask participants about the APN role. The purpose of this study was not to evaluate specific health care provider roles or interventions, but to identify unmet needs of the men with APC and their families. One family member suggested that having access to a nurse practitioner with knowledge of her husband's condition would be helpful to meet her informational needs. Further exploration using questions specific about the APN role in APC is an area for additional research.

Advanced prostate cancer is a complex, chronic disease and APNs have the skills, expertise, and educational preparation needed to assess patient and family supportive care needs and to plan and evaluate interventions. Bryant-Lukosius' (2003) conceptual model

for the development of an APN role in prostate cancer should be explicit about the important component of family participation in patient care, as well as the family as a potential focus of APN intervention (Appendix A). Family members influence the experience of men with prostate cancer, and the disease also significantly affects their own lives. Therefore, they should be included in supportive care interventions.

A number of APN interventions for family members have been evaluated. Giarelli et al. (2003) evaluated an APN intervention for spouses of men with prostate cancer that was part of a larger RCT investigating the effectiveness of a standardized nursing intervention protocol (SNIP) on QOL outcomes for men postprostatectomy. The APN assessed the spouses' knowledge of prostate cancer and their comfort with caregiving procedures before providing information on pain and addressing concerns related to their own health and well-being. The APN also identified sources of support for the caregiver and continued to answer questions and guide the participants throughout the intervention. The results of the intervention were evaluated at 3 months and 6 months post-prostatectomy. The spouses who had participated in the APN intervention had fewer information needs at 3 months than the control group and no information needs at 6 months. Spouses in the intervention group also reported receiving enough information and support to resolve practical problems in a timely manner.

Important insights into APN intervention planning emerged from the study by Larson et al. (2005) who used a similar longitudinal RCT design to test the effectiveness of a specialist nurse-led support and educational program for the spouses of stroke patients. They found no significant difference in perceived QOL, general well-being, and

state of health between the intervention and control group. They suggested that the results of their study may have been limited by poor attendance, as over 50% of the intervention group participants did not attend the required six sessions. Our results that show family members' reluctance to access service and/or leave their spouses might be a reason for poor attendance.

It is unclear from the study by Larson and colleagues if the specialist nurse was familiar to the family members and if this had an impact on attendance at sessions. The Quality Cost Model of APN Transitional Care developed by Brooten and colleagues (Brooten, Youngblut, Deatrick, Naylor, & York, 2003) is based on the premise that comprehensive discharge planning and home follow up by an APN affects costs and outcomes for high-risk, high-volume, high-cost patient groups. Although the model has not been tested with prostate cancer patients, it did decrease health care costs with older adults following hospitalization for heart failure (Naylor et al., 2004). The authors suggest the success of the model with an elderly population with multiple comorbid conditions was related to the continuity of care provided by the same APN in the hospital and the home, and the holistic approach that addressed the complex needs of patients and caregivers. Our results suggest that family members would welcome consistent APN support in both the ambulatory clinic and in the home. HR family members reported being overburdened with care and both HS and HR family members had difficulty meeting informational needs in the hectic clinic environment.

Based on their findings, Larson and colleagues (2005) recommended the use of an "empowerment approach" that involved spouses in the development of intervention

program content. We support the need for user specific content, and a needs assessment similar to the one we conducted would be useful for developing the content of information and education interventions. Further exploration of the resources needed to support wives to actually get out of the home and attend sessions is also needed.

Involving patients and families in the assessment of current services and seeking their input for the redesign of supportive care services were the focus of this research. By exploring patient and family needs and eliciting suggestions for care delivery, the researchers were able to identify the priorities of the study population. The use of focus groups and interviews allowed a more indepth exploration with participants than previous quantitative methods had provided, and allowed us to explore the context of patient and family needs. Collecting this information through qualitative methods was not without challenges, however. In another paper (Carter et al, 2008b), we describe our experiences collecting data through two data collection methods and propose preliminary guidelines for other researchers who are making decisions about whether to use focus groups, individual interviews or both methods to collect data. The use of both methods in this study enabled us to get a better understanding of the experiences of two groups of family members living with APC cancer in the community and provided insights for those responsible for planning care for this vulnerable population.

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CHAPTER FOUR

Different Strokes for Different Folks: Individualizing the Use of Focus Groups or Individual Interviews within a Single Study Based on Study Participant Circumstances and Preferences

Key Words: focus groups, interviews, qualitative data collection,

Nancy Carter

Jennifer Blythe

Alba DiCenso

Denise Bryant-Lukosius

Alan Neville

Faculty of Health Sciences, McMaster University, Hamilton, Ontario

Abstract

Background: As part of an assessment of the supportive care needs of men with advanced prostate cancer (APC) and their families, we planned to collect data through focus groups. However, difficulty recruiting focus group participants led to the decision to conduct individual interviews with those individuals unable to attend focus groups. This led us to search the literature to explore the use of these two methods of data collection within the same study.

Objectives: The objective of this paper is to identify and explore issues related to the use of the two methods in the same study.

Methods: We searched the literature to find research evidence that compared the use of focus groups and interviews. In addition to this, we asked those who participated in the APC needs assessment study in person or by telephone to describe their experiences of participating in focus groups or individual interviews. The participant responses were audiotaped, transcribed, and organized using N-Vivo software.

Results: Focus group participants reported that interaction with other members allowed them to meet others like them, receive information and contribute to research. Interviewed participants had various reasons for preferring an individualized interview, including not feeling well, inconvenience and communication issues.

Conclusion: There is a paucity of literature that compares the nature of data obtained within the same study when data are collected from some participants through focus groups and from others through interviews. Based on consideration of the research question and participants, there are circumstances under which a researcher may decide

to offer study participants either method of data collection. However, further study is required to identify the full implications of this approach.

Introduction

Qualitative research methods are ideally suited to capture the perceptions of individuals and families about their healthcare needs. The integration of qualitative methods into health services research has been facilitated by the adoption of a paradigm that emphasizes the patient's perspective (Lehoux, Poland, & Daudelin, 2006).

Most qualitative research involves the collection of data through interviews with individuals or groups (Britten, 1995), with the selection of the type of interview depending upon the purpose of the study and resources available. *In-depth individual interviews* (IDI) are described by Fontana and Frey (2000) as "one of the most common and powerful ways in which we try to understand our fellow human beings" (p. 645). They allow researchers to explore topics in-depth. Interviews ranging from the structured and controlled to the unstructured and fluid, can elicit a rich body of data regarding personal experiences and perspectives (Russell, Gregory, Ploeg, DiCenso, & Guyatt, 2005). IDIs also allow for spontaneity, flexibility, and responsiveness to individuals (Patton, 2002a). However conducting, transcribing and analyzing individual interviews takes considerable time

Focus groups (FGs), on the other hand, elicit data from multiple participant interviews in which participants can hear each others' responses and provide additional comments that they might not have made individually (Patton, 2002b). Participant interaction that stimulates the identification and sharing of various perspectives on the same topic is central to the success of FGs (Morgan, 1996). Although FGs are often initially less costly in terms of time and money than are IDIs, the time needed to analyze

the complex data elicited from FGs may ultimately cancel out any time savings (Mansell, Bennett, Northway, Mead, & Moseley, 2004) .

Brown (1999) explained that FGs differ from IDIs in that the "dynamic and interactive exchange among participants" in FGs leads them to produce "multiple stories and diverse experiences" (p. 115). Although participant interaction is often described as the distinguishing feature of FGs, several authors have pointed out that researchers rarely report or discuss this phenomenon (Clayton, Butow, Arnold, & Tattersall, 2005; Duggleby, 2005; Kitzinger, 1994; Lehoux et al., 2006; Sandelowski, 2000; Sandelowski & Barroso, 2003; Webb & Kevern, 2001; Zorn, Roper, Broadfoot, & Weaver, 2006). For example, Kitzinger (1994) found no discussion of conversations among participants and very few quotations from more than one participant at a time in her review of over 40 studies that used FGs. Such findings led Duggleby (2005) to conclude that although FG interactions are considered a source of data, these data are underused and underreported. Other researchers have argued that FGs are not the only method that generates interaction, pointing out that the interaction between interviewer and subject in IDIs provides negotiated, contextually-based results (Fontana & Frey, 2000).

Some of the disadvantages of FGs include difficulty with recruitment (Freeman, 2006; Howatson-Jones, 2007; Lehoux et al., 2006; MacDougall & Fudge, 2001; Mansell et al., 2004; Morgan, 1995), difficulty with developing the skills needed to moderate the groups (Mansell et al., 2004), and the risk that participants with viewpoints different from those of the majority may not express their views (Patton, 2002b). It has also been

suggested that focus group discussion is more superficial than the in-depth discussion generated by IDIs (Powell & Single, 1996).

Recent reviews have raised issues regarding the use of FGs in nursing research. When Webb and Kevern (2001) evaluated and critiqued nursing studies published between 1990 and 1999 in which data were collected using FGs, they found that only 16 of the 124 reports retrieved using the search keywords *focus group* and *research* formally used FGs to collect data, and of these, most described nursing education or management projects. After thoroughly reviewing the data-analysis stage of these articles in an attempt to understand how and why FGs were used, the authors concluded that the principle reason was their ability to generate interaction among participants. However, the nature of the interaction was rarely discussed. After reviewing the published nursing literature from 1985 to 2004, Happell (2007) reported that although references to FGs had increased between 2000 and 2004, most were guides for planning or conducting FGs or discussions of the advantages and disadvantages of using FGs. The finding led Happell to conclude that until the time of his study, little nursing research had utilized FGs for data collection.

Regardless of whether data are collected through FGs, IDIs, or both, researchers often ask participants to share their experience of painful events or times in their lives (Morse, 2005). Because IDIs are often chosen for sensitive topics, recalling and responding to questions about unpleasant experiences might put IDI participants at greater risk for unintended harm than FG participants. On the other hand, IDI participants could potentially benefit through the catharsis, empowerment, and healing provided by

disclosure (Hutchinson, Wilson, & Wilson, 1994). As the use of FGs in the social sciences began to increase in the early 1980s, discussion papers that addressed their merits compared to other qualitative methods suggested that combining FGs with other methods encouraged triangulation in research (Morgan & Spanish, 1984). Based on their belief that conducting FGs prior to conducting IDIs could increase the effectiveness of interviewing, Morgan and Spanish advocated using multiple methods.

In this chapter, we first describe a needs assessment that used both individual interviews and focus groups. We had originally intended to collect all data via FGs but for various reasons, extended invitations to participate in IDIs to those who could or would not attend a FG. We then review, synthesize, and critique the literature relevant to the use of these data collection methods. Next, we describe the perceptions of participants in the APC needs assessment about their decision to attend a FG or an IDI. We conclude by presenting recommendations informing the decision to use IDIs and FGs within the same study, based on the literature review and our research experience.

Background

The overall aim of this qualitative descriptive study was to understand the supportive care needs of men with APC and their family members and identify the improvements needed in the current model of care delivery (Carter, Bryant-Lukosius, Blythe, Neville, & DiCenso, 2008b; Carter, Bryant-Lukosius, Blythe, Neville, & DiCenso, 2008a). This study was part of a larger research program examining the role of an advanced practice nurse (APN) in prostate cancer.

APC is a form of cancer that extends beyond the prostate gland to nearby tissue, lymph, or bone. The two distinct APC populations are men with hormone sensitive disease (HS) and men with hormone refractory (HR) disease. Initial treatment for HS involves controlling disease growth by hormone suppression through surgical or medical castration using androgen-suppression therapy. The side effects of the androgen deprivation include breast growth, weight gain, hot flashes, insomnia, and other menopausal symptoms that together comprise the *feminization effect*. Eventually, most patients develop hormone-resistant or refractory disease (Penson & Litwin, 2003), at which point the therapy shifts to palliative treatment with chemotherapy, radiation, and supportive care.

Bryant-Lukosius' (2003) large survey of men at all stages of prostate cancer in the Hamilton region revealed that although both HS and HR patients had common needs, these populations also had different needs. We therefore designed a qualitative study to explore the stage-specific needs of these two groups of men and their families. Our decision to use qualitative methods was based upon our knowledge that such methods are used when information on a subject is inadequate or more in-depth data are required (Curtis & Redmond, 2007), as well as to gain understanding of individuals' perspectives within the context of their circumstances and setting (Freeman, 2006).

Qualitative methods have been used extensively in studies of men with prostate cancer and their partners. More specifically, IDIs have been used to explore men's experiences living with cancer (Hedestig, Sandman, & Widmark, 2003), treatment decision-making (Bailey, Wallace, & Mishel, 2007), functional health status and quality

of life (Jakobsson, Hallberg, & Loven, 1997a; Korfage, Hak, de Koning, & Essink-Bot, 2006) and supportive care needs (Jakobsson, Hallberg, & Loven, 1997b; Templeton & Coates, 2003). IDIs have also been used specifically with APC patients to explore living with bodily problems (Lindqvist, Widmark, & Rasmussen, 2006), fatigue (Lindqvist, Widmark, & Rasmussen, 2004), and coping strategies (Navon & Morag, 2003). Interviews of men and their spouses have been used to explore living with prostate cancer (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000b; Malcarne et al., 2002), treatment decision-making (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2000; Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2001; Maliski, Heilemann, & McCorkle, 2002), managing the impact of illness (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000a), coping and marital adjustment (Lavery & Clarke, 1999), and support for spouse caregivers (Fergus, Gray, Fitch, Labrecque, & Phillips, 2002). However, research studies involving IDIs with spouses have only focused on how they adapted to the long term survival of their husbands despite having cancer (Ka'opua, Gotay, Hannum, & Bunghanoy, 2005) and the use of spiritual resources (Ka'opua, Gotay, & Boehm, 2007).

Prostate-cancer researchers have conducted FGs of men with APC to collect data on their information needs (Maliski, Connor, Fink, & Litwin, 2006) and decision-making (Ross, Kohler, Grimley, Green, & Anderson-Lewis, 2007). They have also conducted FGs of both men and their spouses to explore quality-of-life issues (Harden et al., 2002), treatment decision-making (Boehmer & Babayan, 2005), perceptions of treatment (Boehmer & Clark, 2001a), the wife's role in treatment (Boehmer & Clark, 2001b), and intimacy needs (Sanders, Pedro, Bantum, & Galbraith, 2006). These studies suggest that

researchers believe that qualitative methods are useful in exploring prostate cancer and that the subject is not too sensitive a topic for a FG discussion.

We chose to conduct FGs to collect data in our study because we believed that the potential interaction among members would lead to the generation of richer data. We also thought that conducting FGs would be less resource intensive than conducting IDIs. Because we wished to collect data from the two patient groups separately as well from family members, we organized a total of four sets of FGs: (a) men with HS, (b) men with HR, (c) families of men with HS, and (d) families of men with HR. We experienced challenges with recruitment for a number of reasons including: accessing the HS population through the regional cancer centre, urologists' offices, and the community; the poor health and advanced age of some of the potential study participants; and the sensitive nature of the questions that we intended to ask. To expedite recruitment and complete data collection, we decided to use IDIs almost exclusively with two of the groups—men with HS and the families of men with HS—as well as one man with HR whose poor health prevented him from attending a FG.

Difficulty with recruitment led us to reflect upon our experience and question whether we had chosen the best data-collection methods and if any methodological concerns would arise when using both methods in one study. To address our concerns, we developed a strategy that included (a) searching the literature to learn from the experience of other researchers, (b) interviewing participants to learn from their experience, and (c) reflecting upon our own experience.

Literature Review

We researched the nursing literature to gain understanding of the merits of using FGs or IDIs within the same study and to identify any sources that might inform our ultimate choice of method(s). Although using the keywords *focus group* and *in-depth interview* generated numerous citations, it quickly became clear that most referred to discussion papers addressing the advantages and disadvantages of the methods, as well as several reviews of the use of these methods. When we expanded our search to include the social sciences and business literature, it led to the identification of very few empirical studies comparing the methods.

In the following section, we report on the findings from our search that informed our understanding of the use of the two methods in the needs assessment of men with APC and their family members. We classified the literature into (a) empirical studies comparing FGs and IDIs and (b) researcher reports of experiences using FGs, IDIs or both methods.

Empirical Studies Comparing FGs and IDIs

We were unable to identify any published papers in the nursing literature comparing the use of FGs and IDIs. We found that exploration of the differences between FGs and IDIs has been limited to the communications, marketing, and urban planning fields. These empirical studies tested common beliefs about the utility of using FGs or IDIs. In one marketing study, Fern (1982) explored the following common assumptions about the use of FGs and IDIs for idea generation: (a) group output is better than individual output, (b) moderators are crucial to the FG process, (c) FGs should be

composed of 8 to 12 members, and (d) FG participants should be strangers to one another. To explore these assumptions, he compared the mean number and quality of ideas of seven different group configurations: (a) a group of individuals working alone who were not interviewed, (b) a group of individuals who participated in IDIs, (c) an unmoderated FG composed of 4 strangers, (d) an unmoderated FG composed of 8 strangers, (e) a moderated FG composed of 4 strangers, (f) a moderated FG composed of 8 strangers, and (g) a moderated FG composed of 8 acquaintances. Finding that the individuals working alone generated more ideas than did those participating in unmoderated FGs and that individuals participating in IDIs generated more ideas than did those participating in any of the moderated FGs, Fern concluded that IDIs might be a better alternative for exploratory research than are FGs.

In professional communication, reader feedback on draft documents is often obtained through IDIs and FGs. In a study in the Netherlands, DeJong and Schellens (1998) compared the use of IDIs and FGs to evaluate the text in a brochure (a pretest) encouraging young people to take a moderate approach to the consumption of alcoholic beverages. They did so by examining a number of discussions and focusing on forms of interaction. Although they found no significant differences between the number of problems identified in IDIs and FGs in the pretests, they found that FG participants focused upon the primary subject matter and overall picture presented by the text whereas IDI participants were more inclined to attend to the finer details of the text. The interaction among the FG participants provided the researchers with insight into problems with the brochure; specifically, when one participant offered a criticism, others would

provide additional evidence. They concluded that the two methods produced different results, leading them to suggest that the interaction among group members affected the results.

Kaplowitz (2000; 2001) and Kaplowitz and Hoehn (2001) described their attempts to compare FGs and IDIs in research exploring participants' use of a shared mangrove ecosystem in two communities in Mexico. In the first paper, Kaplowitz (2000) tested the null hypothesis that FGs and IDIs yield similar information sets regarding *socially sensitive topics*, which he defined as those topics that concern difficulties in and between communities and community members. Kaplowitz coded and transformed the qualitative data into summary variables to allow for the statistical analysis and testing of his hypothesis. He found that although sensitive topics were raised during both FGs and IDIs, only 1 of 12 participants raised them during FGs whereas 12 of 19 participants raised them during IDIs. Based upon his findings, he calculated that IDI participants were 18 times more likely to raise a sensitive topic than were FG participants and asserted that the two methods produced complementary rather than different data.

Likewise, Kaplowitz and Hoehn's (2001) further analysis demonstrating that information and ideas regarding the use and nonuse of the ecosystem revealed in FGs and IDIs provided different perspectives on the range of resource services, values, and issues, leading them to conclude again that one method was not better than the other but rather that the two approaches were complementary. Furthermore, they suggested if they had used only one method, they would have obtained different impressions of the relative importance of the ecosystem services.

After conducting a Pearson chi-square test of the homogeneity of FG and IDI data to determine whether the data from FGs and IDIs were truly different, Kaplowitz (2001) concluded that the data were significantly different. Although both methods produced information dominated by discussion of one particular topic (snail collection), the other ecosystem topics discussed using each method were different. Kaplowitz suggested that IDIs provided an opportunity for participation by individuals who do not wish to share information in a group setting. Describing his experience with the study, during which he had relied on the same discussion guide, probes, equipment, and facilitator training for the IDIs and FGs, he reported that his greatest challenges had been the recruitment of participants, the logistics of the sessions, and group dynamics.

In conclusion, researchers who have used quantitative methods to empirically investigate the use of FGs and IDIs have found that using the different methods leads to different results. Although Fern (1982) found that IDIs generated more ideas than did FGs, DeJong and Schellens (1998) did not find this. However, they did find that the results obtained from FGs and IDIs were different, as did Kaplowitz (2000; 2001) and Kaplowitz and Hoehn (2001). A limitation of these studies is that the researchers were interested in idea generation versus the purpose of this needs assessment, which was to explore participants' experiences and needs. Another limitation of all these studies is that the researchers retrospectively reviewed data from FGs and IDIs, which weakened the strength of their results. A stronger design would have been a prospective study, where participants were randomized into either FGs or IDIs. This would allow a more rigorous examination of the data collection techniques.

However, even if a more rigorous design were put into place, FGs and IDIs would be difficult to compare because of the theoretical underpinnings of qualitative and quantitative research designs. One would question if it is possible to use empirical observation and measurement (a post positivist approach) with data that are collected based on understanding and multiple participant meanings (a constructivist approach) (Creswell, 2003). Kaplowitz (2001) described how although he had used the same moderator/interviewer, interview guide, and probes in his efforts to control certain elements of the process, his efforts had not been sufficient to control the various complexities that arose during qualitative data collection. These complexities include but are not limited to the uncontrollable variables associated with the participants, moderator, and setting. For instance, even if the same moderator facilitated both the IDIs and FGs, this moderator may behave differently during each session, which could affect the results. The interactions among the participants and between the moderator and the participants could also differ during each session, producing different results. Unless they are randomly assigned to participate in either an FG or IDI, the participants will likely self-select one group for a reason that could impact the context.

Although many of the studies identified in our literature review support the suggestion that FGs and IDIs produce different results, we argue that different results cannot be entirely attributed to the use of different data-collection technique. Still, the results of these studies provide some insight by challenging previous assumptions regarding the use of a particular method and encouraging researchers to question the use of one or both methods.

Researcher Experiences using FGs and IDIs

We classified the second group of studies identified during our literature search as those that used both FGs and IDIs as data-collection methods. Although many of these studies did not explicitly address the issues associated with using both methods in one study, their authors provided insights from their experiences. Because of the large number of these studies, the following section does not review all of them but instead provides some examples and highlights how the authors described their use of both methods and the resulting data.

Very few studies have accounted for the use of both methods or provided details regarding the differences in the data collected when using the methods. In his ethnographic study of adolescent boys' thoughts and talk about sex in which he used observation, FGs, and IDIs to collect data, Wight (1994) noted differences between what the boys said during FGs and subsequent IDIs. He noted that whereas the boys expressed greater sensitivity and were more open when participating in IDIs, they displayed stronger expressions of masculinity and were more guarded when participating in FGs.

Many researchers have provided few details regarding their use of both methods in the methods or discussion sections of their qualitative studies. Indeed, it is rare for researchers to report on the use of either data-collection method within the same study, particularly those that collect data from some study participants via FGs and others via IDIs. Several researchers have used the two data-collection methods sequentially for the purpose of triangulation. In their attempt to triangulate the data from FGs and IDIs to elicit a richer data set, Mkandawire-Valhmu and Stevens (2007) developed an IDI guide

from FG results and used IDI data to probe for specific details regarding issues raised during FGs. However, they neither discussed the differences in the nature of the data collected through the two methods nor addressed how the use of both methods influenced their results. In a study investigating quality of primary care for diabetic patients, Khunti (1999) concluded that his use of multiple data-collection methods—brainstorming, FGs, and IDIs— benefited his results and allowed a complete depiction that may not have been achieved had only one approach been used.

One of the most widely reported reasons for using both IDIs and FGs is difficulty with the logistics of conducting FGs. Although nurse researchers have reported using IDIs as substitutes for FGs when they encountered difficulties with recruitment (Clayton et al., 2005; Reed, 2005), they have not discussed the impact of this substitution on study results. In one of the few examples in the prostate-cancer literature, Feltwell and Rees (2004) described the use of "mini focus-group" discussions or couple interviews rather than FGs due to the inability of the participants to travel to the FG setting. They identified this use of different data-collection methods within the same study as a methodological limitation and recommended repeating the study using one common data-collection strategy. This is one of the few studies where the researchers have taken a "stance" and made a recommendation to use only one data collection method based on the results of using both IDIs and FGs.

There appears to be a contradiction within the published literature regarding the use of FGs. Although the nursing literature often promotes the use of FGs for a variety of reasons (Happell, 2007; Webb & Kevern, 2001), it provides no accounts of researchers'

reactions to their unsuccessful use of FGs and subsequent decision to use IDIs. It is unclear why the researchers did not more explicitly discuss their combined use of these methods in their studies. Potential reasons could include publisher restrictions on the length of papers or even that the issue had not been considered worthy of discussion. We also wonder if researchers considered the need to use IDIs in addition to FGs as a concession that reflected a failure in their study design, and did not wish to elaborate upon this supposed failure. Other critics provide support for this conclusion by noting that published research presents a "sanitized view of the research process" that gives incorrect impressions about the actual process to the novice researcher (MacDougall & Fudge, 2001, p.117).

It would be informative if researchers were to disclose their reasons for using both methods in their studies and any impact this combined approach may have had on their results. For example, if researchers were to disclose more information regarding why certain participants chose to participate in IDIs rather than FGs, this information could help other researchers determine which method is more suitable for participants in their studies. Gaining understanding of how researchers combine FG and IDI data to inform study results might ease data collection for those experiencing challenges with FG recruitment, particularly for researchers who might potentially lose recruited subjects or valuable data from subjects who do not want to participate in FGs.

Exploring Participant Experience

There is limited empirical research on the experience of those who participate in either FGs or IDIs, although researchers often report participants enjoyed the experience.

In a marketing study, Tuckel, Leppo and Kaplan (1992) conducted two telephone surveys of 673 focus group participants to explore the reasons for their participation. One of their major findings was that compared to first-time participants, those who had previous experience in FGs attached greater weight to the opportunity to offer opinions than they attached to a monetary reward, suggesting that their first experience had been positive. In an attempt to empirically study the perceptions of atmosphere in FGs, Bristol and Fern (1996) compared the views of participants who participated in FGs, a nominal group technique, and an open-ended survey. They found that FG participants perceived their experience as more stimulating and exciting than those who participated in the other approaches to data collection.

To further inform our understanding of the use of both FGs and IDIs in our research, APC patients and their family members who had participated in the needs assessment were asked about their experiences participating in FG or IDI. For the initial needs assessment, *eligible patient participants* were defined as men with stage T4 disease according to the Tumour-Node Metastasis (TNM) staging system or D1 or D2 disease by the Whitmore-Jewitt classification system. *Eligible family members* were defined as wives, partners or children of APC patients.

Data about participants' experience in a FG or IDI were collected either in person at the conclusion of a FG or IDI or by telephone interview after participation in the FG. Patient and family member participants were asked to describe their experience of providing data through the FG or IDI in which they participated. All responses were audiotaped and transcribed. A coding scheme was developed based upon review of the

initial transcripts and the application of N-Vivo software and thematic content analysis as described in Burnard's (1991) framework. Based on the coding scheme, core categories were developed and codes clustered into these categories, which led to the identification of significant themes. The findings were shared with the research team and qualitative researchers at a research conference to validate and clarify the findings.

Three groups of patients and two groups of family members were asked at the end of their FG about their experience. In cases where the FG had already been held, we interviewed five people by telephone. Of the 20 patients and family members who participated in IDI, eleven were asked to comment on participation. Although some participants responded at length about their participation, most provided brief answers. When FG participants were asked about participation in the group, not all responded.

Overall, the participants expressed positive feelings about their participation in the study. Analysis of the data from FG participants identified the theme *interaction,* with the subthemes of *there are others like me, receiving information* and the theme of *wanting to contribute.* Themes from interview participants included *no interest in focus groups, not feeling well, inconvenience* and *communication issues.*

Focus-Group Participants

Interaction - There are others like me

FG participants frequently commented on how the novel experience of being in a group with patients and/or family members with similar issues contributed to their increased comfort level.

> Oh, it was an interesting experience. It was interesting to find that there are some other people in Hamilton who have problems with this like I have problems with it. At times you think, well maybe you're the only one around with this type of problem. But no, you learn that there are other people that have survived for a long time and each one of them has their own sort of set of problems that they have to face to keep going. Focus group patient participant (FGPP)

One gentleman shared his feelings about participation with his family.

> Oh yeah, as I said I was completely, I was really happy with it. I came back and I said to my daughter, "You know that was really great." Great to talk to people who you know have walked the same mile in the same type of shoes [laughing]. (FGPP)

Family participants also commented on the therapeutic effects of the FG and the benefits of interacting with others.

> It's spiritually uplifting—sharing. It's more comfortable to talk here because everybody here is going through exactly the same thing and you don't have to explain, or to your friend and say, "Well, this is like because of this," you know? You just know if I say to you, "Okay he's having trouble walking"—you know, and that's it. Focus group family participant (FGFP)

Another man appreciated having the opportunity to interact with others with APC.

> I think it's good to talk to other chaps who have…I've always wanted to do that and probably the group could be a little larger. (FGPP)

One man articulated how focus group participation benefited people in different ways.

> And like I said before, sometimes people get satisfaction from discussing a problem and knowing they're not alone. Their situation, they're not alone in this situation and psychologically it may do more for some people than others. (FGPP)

A participant seemed both surprised and disappointed that the research session was not a regular meeting.

> This was our only meeting? Oh! I was looking forward to coming. (FGPP)

Interaction - Receiving information

Many FG participants, particularly those who participated in family member groups, reported learning new things and getting needed information from the focus groups. The individual interview participants did not comment on this because the moderator did not have the ability to provide any information requested by participants.

> Well, I found this quite informative . . . and it's nice to know there are other people out there worse off than you and with the same problem. Only everybody's different. (FGPP)

This family member was very positive about her experience and received concrete information that she would use to help her husband.

> For me, it was like one of the best things that has happened. I found out so much because of that one lady in our group. She has so many resources and information and I just found that so wonderful. (FGFP)

Another family member felt meeting others helped her to get needed information.

> I think this networking piece of what we're doing here today is quite an important part of finding that knowledge. (FGFP)

This participant was able to articulate how being part of a group of people with similar diagnoses facilitates information sharing.

> Focus groups are good in the sense that you learn from other people at least and you'll become more comfortable. You'll ask more questions of somebody who's gone through it than you would of someone who was a total stranger and not gone through it. (FGPP)

Interaction - Wanting to contribute

When asked about their FG participation, many reported that their desire to help others and contribute was one of the reasons they participated.

> Well if I can help somebody I'm glad. It's a little bit I can do to help somebody else. (FGPP).

> And I found I'm very open to talk about it. Very easy to talk about it, about my cancer and I think that helped me to be honest and maybe you can help other people at the same time. (FGPP).

This participant was unsure if his participation made any contribution when asked about his FG experience.

> I felt I could say anything and I think I told you practically everything that's happening to us. Yes I think that certainly we're free to talk. I don't know how much we contribute, that's all. (FGPP)

Another participant commented that he felt focus groups were the best way to collect data for the current research study.

Well I, I think from whichever way you approach this you're going to get quite a cross-section of answers. I have complications with mine that I don't think any of them have. Questionnaires only hit the points that you ask, where a group like that I think you have better chance of uncovering some maybe different sides to the equation. (FGPP)

Interviewed Participants

No interest in FG participation

Some interviewed participants preferred not to participate in focus groups. It is unclear if these participants were more introverted by nature or whether the focus of the group discussion led to their preference to be interviewed individually.

Yea, some people like it's you know, stay and company and talk and share – whatever. But he prefers to get a good book and read. Interviewed Family Participant (IFP)

Another man did not elaborate on the reasons for not wanting to participate, and was apologetic.Not interested. Sorry. Interview Patient Participant (IPP)

Not feeling well

Many men declined participation in focus groups because they were not feeling well. Some of these men agreed to be interviewed in their homes. For one of these men, even the interview was difficult because of the discomfort he was experiencing.

Interviewer: I can imagine it would have been hard for you to come to a focus group.

Patient participant: Yes. You know when you're not feeling good [crying].

Inconvenience

For some participants, their choice to be interviewed had more to do with the logistics of the focus group meeting, such as the time and location, as opposed to the actual focus group process.

One woman talked about her difficulty getting to the regional cancer centre.

> It's the parking. You see, I had a hip replaced and it's not satisfactory. So I can't walk very far. So when we go to the Cancer Clinic it's funny he lets me out at the door and parks. So, I don't know. (IFP)

Communication issues

Issues related to participants' ability to communicate affected their preference to be interviewed. During recruitment, one man declined focus group participation because he had a laryngectomy. Another man's hearing problems seemed to be an issue when I asked him and his wife about focus group participation:

> I don't know if I will or not. (IPP – Husband)
>
> He's liable to go in there and not hear 'em. (IFP – Wife)

Because of the paucity of literature exploring participant experience of taking part in focus groups and individual interviews, comparing this study's findings to those of past studies proved to be difficult. Interaction was the central theme for FG participants. As participant interaction is the foundation of FGs, it is not surprising members commented upon it. The benefit of interacting with others who share similar issues was previously reported in a feminist study of rural women that suggested that focus groups were empowering to women who had not shared their stories previously (Pini, 2002). It

appears that an unintended result of the FG was that some family participants addressed their unmet needs. Isolation and the need to interact with others were identified as priority needs for family members in the needs assessment (Carter et al., 2008a) .

Some men and family members preferred not to participate in FGs. Two participants' ill health prevented them from attending and one man was too emotionally distressed to participate in a group. The majority of individually interviewed men suffered from HS. For those who requested to be interviewed individually, it is unknown if their desire to not participate in a group may have been related to the side effects of androgen deprivation and the feminization effect. Previous studies have suggested that these side effects can lead to body self-image issues and low self-esteem (Herr, Kornblith, & Ofman, 1993; Korfage et al., 2006; Lindqvist et al., 2006; Navon & Morag, 2003; Navon & Morag, 2004).

Many focus-group participants commented on the information received from other members. In the supportive care needs assessment studies, informational needs were a priority for both patients and family members (Carter et al., 2008b; Carter et al., 2008a). Therefore, the acquisition of knowledge from focus group participation is clearly an advantage of this method for the participant. Studying how knowledge is shared, acquired, and contested led one group of researchers to identify various knowledge roles in FGs (Lehoux et al., 2006). They suggested that participants either establish themselves as: a) experienced and knowledgeable, b) vulnerable and/or in search of information and advice, or c) challenging or validating claims of knowledge. However, FGs are not without risk for their participants who are seeking information. Information may be

inaccurate or the moderator may lack the ability to correct incorrect information (Hyde, Howlett, Brady, & Drennan, 2005). In this study, many of the participants had more knowledge of supportive care services than did the moderator. Both patients and families recommended small information groups, and reports from participants confirm that it was a satisfactory vehicle for delivering and sharing information. Facilitation of these groups by knowledgeable health professionals could prevent the sharing of misinformation.

Although we found our exploration of the experiences of patients and families who had participated in FGs and IDIs to be informative, it is unclear whether our results will be informative to other researchers faced with making decisions regarding data-collection methods for their studies. Although the primary intent of our study was not to provide an opportunity for APC patients and their family members to interact and receive information or therapeutic benefits, the participants reported enjoying many aspects of FG participation, including interaction with other participants and receiving information. Similar to the findings of DeJong and Schellens (1998), we found that their interaction data among group members informed our results. The utility of our findings are also limited because not all participants in the needs assessment had the opportunity to "debrief". We are unsure what these participants would say about their experience in FGs or IDIs.

A key discovery of our exploration of participant experiences is that there is a range of reasons why individuals prefer to participate in one technique rather than another that are related to both the participant's individual preferences and how that preference interfaces with the data-collection technique. For example, FG participation

was preferable for those who wanted information and the opportunity to meet with others in a similar situation and in contrast, IDI participation was preferable for those who did not want to interact with others.

Another key discovery is the importance of the overall characteristics of the study population; specifically, participants' characteristics impact their ability to participate. In our study, the participants were men of advanced age living with advanced cancer and other chronic conditions and family members who served as their caregivers, many of whom were also frail and living with their own health issues. Poor health often affected the participants' ability to contribute to the study. For example, a family member's inability to drive to the FG setting and park her car may have influenced her preference to be interviewed at home. Our exploration of participant experiences offers insight into the barriers to using FGs with vulnerable populations and why proactively planning to use FGs and IDIs can ensure timely and comprehensive data collection.

Discussion

Problems with recruitment and other logistical issues required us to alter our original plan to use FGs exclusively to collect data from a population largely composed of older men and women with chronic health issues. Although we initially believed that the sensitive nature of the topic of prostate cancer might limit access to and recruitment of participants, the inability to recruit quickly enough was ultimately the greatest challenge. In order to collect data from men with HS disease and their family members, we found it necessary to conduct IDIs, a method that, in hindsight, proved to have both advantages and disadvantages. IDIs were advantageous in that they allowed the needs

assessments to be conducted much more comprehensively and completely by permitting the collection of data from those who would not have participated otherwise. These data provided insight into the needs of men with HS disease and their family members and other valuable information that will help shape service delivery. The study results would have differed had input not been obtained from men with HS disease and their family members. The use of interviews was disadvantageous because of the time involved collecting, transcribing an analyzing individual data.

The synthesis of relevant literature and exploration of participant feedback have informed our understanding of the implications of using both FGs and IDIs in our study and how doing so may have impacted our results. Next, we formulate an initial set of recommendations for researchers to inform their decision making about whether to use IDIs or FGs exclusively or in combination.

Recommendations

The use of IDIs and FGs within the same study can be an effective data collection strategy when researchers understand the potential benefits and challenges. In our study, the use of both methods provided findings that were complementary and were not "at odds". The use of both methods allowed us to hear from a broad spectrum of participants and we would recommend being flexible to allow contributions from various patient and family participants. Based upon our experience, we conclude that decisions regarding the use of a data collection method should not be based on which method is better but rather what each can contribute to the study. Specifically, researchers should consider two main

components of their research design when deciding whether to use FGs or IDIs exclusively or in combination: the research question and the research participants.

The Research Question

The necessity to strictly adhere to a chosen data-collection technique may depend upon the overall focus of the study. If the study's underlying philosophical assumptions are related to the methodology, combining data-collection methods may not be desirable. For example, researchers would likely choose to use IDIs exclusively when attempting to collect data from personal accounts of a phenomenon in a phenomenological study. On the other hand, researchers might choose to use FGs to create social-interaction data in a study of information sharing using a participatory action-research approach. However, researchers whose objective is to gather information from a certain population to understand its point of view may find that using IDIs and FGs in combination permits them to make contact with an array of participants who represent the diversity within the study population. Researchers seeking to strike a balance between breadth and depth may find that using both IDIs and FGs allows them to do so.

In some studies, some participants may not want to participate in FGs because of the sensitive nature of the research questions. Kaplowitz (2000; 2001) found that sensitive issues were more likely to be raised during IDIs than during FGs. In this study of men with APC, we found sensitive subjects such as therapy-induced feminization and sexuality issues were raised during both FGs and IDIs. Although some men were reluctant to share embarrassing issues with a female interviewer during IDIs, the presence of other men in the FGs with similar experiences created a more comfortable atmosphere

for discussing these issues. Researchers investigating sensitive topics should give careful consideration to whether IDIs or FGs would increase the participants' comfort level.

The Research Participants

It is essential to gain a thorough understanding of the research participants to inform the choice of data-collection techniques. In this study of men with APC and their family members, the primary nurses who cared for the men at the regional cancer centre were responsible for participant recruitment. During early meetings to discuss the study, the nurses' familiarity with the population under study led them to raise many questions regarding our initial plan to use FGs exclusively to collect data. The nurses understood that the preference for IDIs among some of the population would have led to faster participant accrual.

The functional limitations of individuals may influence the ability to use FGs exclusively. Age-related factors, such as hearing loss or other communication problems, may deter participation. Persons with advanced-stage cancer or other serious illnesses may be experiencing pain, fatigue, or other treatment-related effects that could limit their ability to leave the comfort of their home and sit at ease within a group. Because the health status of these individuals can change quickly, their ability to participate may change between the date of recruitment and the date of the FG session. Individually interviewing these participants at home contributes to a more accurate and real understanding of their experiences by allowing the researcher to capture information from participants at varying stages of illness in their own environments.

Certain individuals prefer FGs or IDIs based on their personality factors. IDIs are more appropriate for participants unwilling to reveal or share information with others and/or those who are shy, as well as participants who may present challenges for the FG moderator. For example, a participant who has unresolved issues and anger due to negative experiences with healthcare delivery might be disruptive during an FG session. Although it is often difficult to determine participant characteristics prior to data collection, it may be helpful to screen participants before the FG session to gauge their feelings about the FG topic. If the researcher is unfamiliar with the community or population under study, enlisting the help of other healthcare professionals who have a better understanding of the individual participants can help determine which method is better suited for each participant. Rejecting willing participants who do not wish to participate in FGs because of health and/or personality factors may lead to a loss of valuable data. The researcher should therefore strive to conduct IDIs with these participants.

Some studies may require the collection of data from different populations. For example, a study of the provision of care in a long-term setting might require the participation of staff nurses, charge nurses, physicians, and administrators. Although FGs may be an efficient method of collecting data from a large number of staff nurses, IDIs may be more appropriate for the few charge nurses or physicians and the one administrator. The geographical scope of the study must also be considered. Several researchers have suggested that qualitative research is often conducted in urban areas simply because it is more convenient to do so (Twohig & Putnam, 2002). Whereas it may

be desirable to conduct FGs for populations living within small geographical boundaries, drawing participants from remote distances for FG participation is impractical and resource intensive. Conducting either face-to-face or telephone interviews with participants living in remote areas may be more feasible than conducting FGs.

Time considerations related to both researcher and participant issues influence the choice of study methodology. Researchers must be realistic about the amount of time needed to recruit participants, particularly those from vulnerable populations (Owen, 2001). If time is an important factor and researchers are experiencing difficulty recruiting a sufficient number of participants to form FGs, they may decide to conduct IDIs instead of FGs. Researchers must also consider that recruited participants may lose interest if an extended period elapses between initial recruitment and the FG meeting, as well as the fact that participants with advanced-stage cancer or other illnesses may experience declining health or die before FGs can be organized. These factors may lead to the decision to collect data from willing participants through more timely IDIs.

Conclusion

Exploring participants' experiences of and preferences for participation in IDIs and FGs was not part of the original design of this study of men with APC and their families. Difficulty recruiting HS patients alerted us to the value of exploring participant experiences to gather data about an area that few researchers have addressed. Although the results of our exploration did not provide a definitive answer regarding which methods participants prefer, they did provide insight into participant experiences. Despite its limitations, this study fills a research gap in the nursing literature regarding participant

experiences and the combined use of IDIs and FGs to collect data from patients and their families.

Increasing patient participation in the design of cancer care services will require researchers to develop new ways of engaging patient and families. As patients increasingly become partners in research for the purposes of health care planning, it becomes more important to understand their participation from their perspective (Abma, 2005). The results of this small exploratory study indicate that further research is needed to understand the experiences of patients and families who participate in FGs and IDIs. Although participants in qualitative studies are often asked to comment on study results, gaining a greater understanding of their personal experiences through additional inquiry will help nurse researchers make the most of their experiences and prevent feelings of participation burden.

There is a gap in the nursing literature regarding the implications of using FGs and IDIs in combination in one study to collect data. This gap is of particular concern to nurse researchers, who often study vulnerable populations and can benefit from the use of both methods. Although researchers have reported on the use of both IDIs and FGs, they have rarely discussed the implications of their combined use on data analysis or study results. The two data-collection methods are different and thus likely produce different and complimentary results.

This study explored the experiences of men with APC and their families after participation in a needs assessment study. The IDI and FG participants reported different experiences related to interaction and the benefits of participation. The two different data-

collection methods impacted the final results of the study both positively and negatively. Although conducting IDIs allowed inclusion of participants unable or unwilling to participate in FGs, their participation in IDIs did not permit the interaction with other participants that often leads to different results and a gratifying experience for the participants.

Careful consideration of the research question and study population will help researchers determine whether using IDIs, FGs, separately or combined is an appropriate data-collection strategy. This non standard approach of individualizing the decision to use IDIs or FGs within the same study based on the preferences and circumstances of potential study participants may provide the most comprehensive and complete approach to data collection with populations experiencing chronic health issues.

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CHAPTER 5

THESIS CONCLUSIONS

CHAPTER FIVE

Thesis Conclusions

The number of men living with advanced prostate cancer (APC) will increase in Canada as the population ages and as new treatments prolong their lives. Men with APC and their families have unique supportive care needs related to the progressive disease, the effects of aging, and the presence of co-morbid conditions. This thesis consists of three papers that report the findings from a needs assessment of men with APC and their family members using qualitative data collection techniques. The purpose of the study was to explore and understand unmet patient and family supportive care needs and obtain suggestions for improvement to supportive care service delivery.

The study was designed to use qualitative methods, which complemented the previous quantitative research design used by Bryant-Lukosius (2003). The findings we obtained from men with APC and their families using focus groups and interviews allowed us to explore in more detail the unmet needs identified of the population identified previously. The inclusion of family members in the sample was essential to gaining understanding of men's needs as well as the impact of the disease on family members and family relationships.

While the original plan was to collect data through focus groups only, difficulty with recruitment led to the use of interviews in instances when focus group attendance was not possible. The unanticipated use of focus groups and interviews prompted a search of the literature to understand the implications of using both data collection methods within one study and this literature was summarized in a manuscript

documenting our experience with this combined approach. Some of the study participants agreed to a subsequent interview in which they reflected on their experience of participating in a focus group or interview.

This unplanned examination of patient and family participation in our research study led to serendipitous findings, and provides us the opportunity to expand the discussion from our participants' experiences to the larger issue of engaging patients and families in cancer care redesign. This issue is explored further in this chapter.

The study methods and results are presented in detail in Chapters 2, 3, and 4. This final chapter presents and then applies a summary of study findings to Bryant-Lukosius' (2003) preliminary model of the role of the advanced practice nurse (APN) in APC care and treatment. The chapter concludes by outlining the strengths and limitations of the study and recommendations for APN practice, education, policy, and further research.

Summary of Findings

Chapter 2 describes the unmet needs of men with HS and HR APC. The participants identified their priority need as a desire for APC-specific information that supports their ability "to do what they want to do." Functional issues described by both HS and HR patients included urinary and sexual dysfunction, fatigue, and the side effects of their treatment. We also identified patient need for emotional support to resolve past issues related to their diagnosis and treatment decision-making. Patients recommended small-group meetings facilitated by a healthcare professional to address their informational and coping needs. They also recommended increased prostate-specific antigen (PSA) testing and vigilant assessment of prostate cancer to prevent the

development of advanced disease. Consistent with the results of the previous quantitative study of this population (Bryant-Lukosius, 2003), the results from this study indicate that APC patients require the provision of stage-specific information that helps them maintain their functional abilities and emotional support to help them reconcile their feelings about their diagnosis and past treatment decision-making.

Chapter 3 describes the unmet needs of family members of HS and HR APC patients. Content analysis revealed both groups of family members had unmet needs arising from a lack of information, which left them uncertain about future courses of action. Family members of patients with HR APC, who experienced caregiver burden and isolation, stated that they needed more practical assistance. Many family participants suggested providing more opportunities for discussing APC with healthcare professionals and several recommended the creation of family support groups and family resource centres.

When patient and family member needs were compared in Chapter 3, there was much consistency; both patients and their families identified information as their priority supportive care need and the men's struggle to maintain their functional capacity as the greatest challenge. Analysis of the findings indicated a conflict between the men's need to continue to perform usual actions and their family members' concern for their well-being and need to care for them. Whereas the men spoke little about their family members in relation to coping with their disease, their family members described how they dealt with the cancer together and the burdens associated with their caregiver role.

Chapter 4 describes the focus group and interview data collection methods, specifically, the advantages and disadvantages of interviewing study participants who are not able or willing to attend a focus group. Although the original intention had been to collect both patient and family data through focus groups alone, difficulty with recruitment led to the complementary use of individual interviews. A search of the literature revealed no sources from nursing or other disciplines that would have aided in determining the most appropriate method for the proposed research. Data regarding the focus group and interview participants' descriptions of their experiences, as well as our own experience using both methods were used to build on the relevant literature. We have proposed recommendations for researchers who are making decisions about which method to use. We recommend that a clear understanding of the research question and the research participants helps to make this decision. Flexibility in the use of interviews and/or focus groups may be an important consideration for fostering participation by a broad spectrum of patients.

Engaging Patients and Families in Cancer Care Research

Involvement of patients with cancer is difficult, and some patients may be unwilling to become involved when they are undergoing treatment and unsure if they can commit time and energy (Stevens, Wilde, Hunt, & Ahmedzai, 2003). Thornton (2008) suggests that the ability of patients with cancer to participate in research may be limited by their general fitness and level of debilitation. Qualitative methods may prove to be more difficult for patients than quantitative methods such as surveys, because of the time and personal effort required of participants.

A new emphasis on gaining the patient's perspective has paved the way for the incorporation of qualitative methods into health services research (Lehoux, Poland, & Daudelin, 2006). Our exploration of patients and family experiences participating in either focus groups or individual interviews has shown us there are no easy answers or rules to use to decide which method is better – for the researcher or the participant. Better ways of engaging patients and families to participate need to be developed and evaluated. Oliver and colleagues (2001) suggest that the way in which consumers are involved and the impact they have on research are related. They suggest attention to the setting, timetable, resources and language are a beginning to make fundamental changes to how we involve consumers. In retrospect, using a participatory action research (PAR) study design in full partnership with of patients may have facilitated increased recruitment of the HS population. Patient engagement at the beginning of the study may have permitted increased access to and the ability to identify patients where they worked and lived.

Our results only report on the patients and families we engaged, but what about the missing voices we did not hear? In our study, those missing voices likely represent two categories of patients and families: 1) those who had their needs met, and 2) a more vulnerable group who was unable to participate due to more unmet or severe health needs or disability, and/or a lack of social support. It is this second group of participants that researchers need to focus on to understand how we can engage them in designing better care delivery services. Stevens and colleagues (2003) suggest that only a minority of users who belong to advocacy groups represent consumers in research, and the majority of consumers who do not belong to these groups have no way of articulating their needs.

Those underrepresented people are likely to be from an ethnic minority, have advanced disease, the frail elderly, or live in rural areas.

In our study, patients and families often had trouble articulating their needs. They often discussed problems and issues they were having, but could not directly or clearly tell us what they needed to solve their problems. Our sample was from an older generation that may not be as likely to understand and exercise their right to ask for what they need. There is currently a shifting paradigm to "patient centred" care and new ways of involving patients and families in health services research will likely evolve because of this shift. In the United Kingdom, policy initiatives have pushed the involvement of cancer patients in the prioritization of research questions, coordination of research, and dissemination of findings (Stevens et al., 2003).

Patient-centred care has many definitions but commonalities are *respect for patients' needs and/or wants and/or preferences and/or values* (International Alliance of Patients' Organizations, 2007). A systematic review of nine models and frameworks of patient-centred care reported that the following components were identified most frequently: a) education and shared knowledge; b) involvement of family and friends, c) collaboration and team management, d) sensitivity to non-medical and spiritual dimensions of care, e) respect for patients needs and preferences, and e) free flow and accessibility of information (Shaler, 2007). Participatory research is a means of incorporating patient-centred components into a research design. Involving both patients and their families throughout the research process strengthens the significance and suitability of the research findings (Wright, Corner, Hopkinson, & Foster, 2006). As part

of their commitment to a patient-centred approach, APNs and other health services researchers must advocate not only for a suitable method of collecting data from patients and families, but include them in the entire research process. A true PAR approach would have also increased shared learning between patients, researchers and health care providers in a way that would have aided patients in articulating their concerns and ability to formulate concrete recommendations for improving care delivery.

Relating Findings to a Framework for the APN Role in Prostate Cancer

Bryant-Lukosius (2003) developed a framework to inform the role of the APN in APC care and treatment (Appendix B). The framework evolved from a study of supportive care needs of patients at all stages of the disease and included an in-depth exploration of the mental healthcare needs of these men. Study findings led to the identification of three foci for APN care: *functional capacity, mental health,* and *prostate cancer health*. The framework has been re-examined and revised based on the findings of the current study.

Consistencies between Current Study Findings and the Framework

Chinn and Kramer's (1999) guide for the critical analysis of theory was adapted to aid in revisions to the initial framework. The authors suggest reflecting upon the clarity, simplicity, generalizability, accessibility and importance of a theory to determine its value. The findings of the current study confirm the three priority areas for APN intervention depicted in the framework.

With respect to prostate cancer health, both groups of men experienced incontinence issues and sexual dysfunction. For men with HS disease, urinary and

incontinence issues were particularly troublesome. Sexual dysfunction was described by both groups of men and both groups of family members.

Both patients and their family members described the challenges of trying to maintain their functional capacity. For men with HS disease, functional capacity was related to the side effects of androgen deprivation, urinary and incontinence issues, loss of sexual function, and fatigue. Men with HR disease were further compromised by pain and discomfort and the side effects of chemotherapy. Both groups of men also identified the need for emotional support because their mental health was compromised by unresolved issues related to their diagnosis of prostate cancer and past treatment decisions. Family members of both groups of men experienced uncertainty related to the future and family members of men with HR disease also experienced isolation.

Consistent with the framework, the findings from the current study indicated the importance of understanding the supportive care needs of men with prostate cancer across the continuum from diagnosis to palliation. A surprising finding was the strong emphasis that men placed on past experiences related to their diagnoses, treatment decisions, and interactions with physicians. They spent a great amount of time describing these even when for some men, these events occurred over 10 years ago. Despite living with the consequences of advanced disease at the current time, the priority suggestions from participants were improved prostate cancer screening and supportive care services for newly diagnosed men.

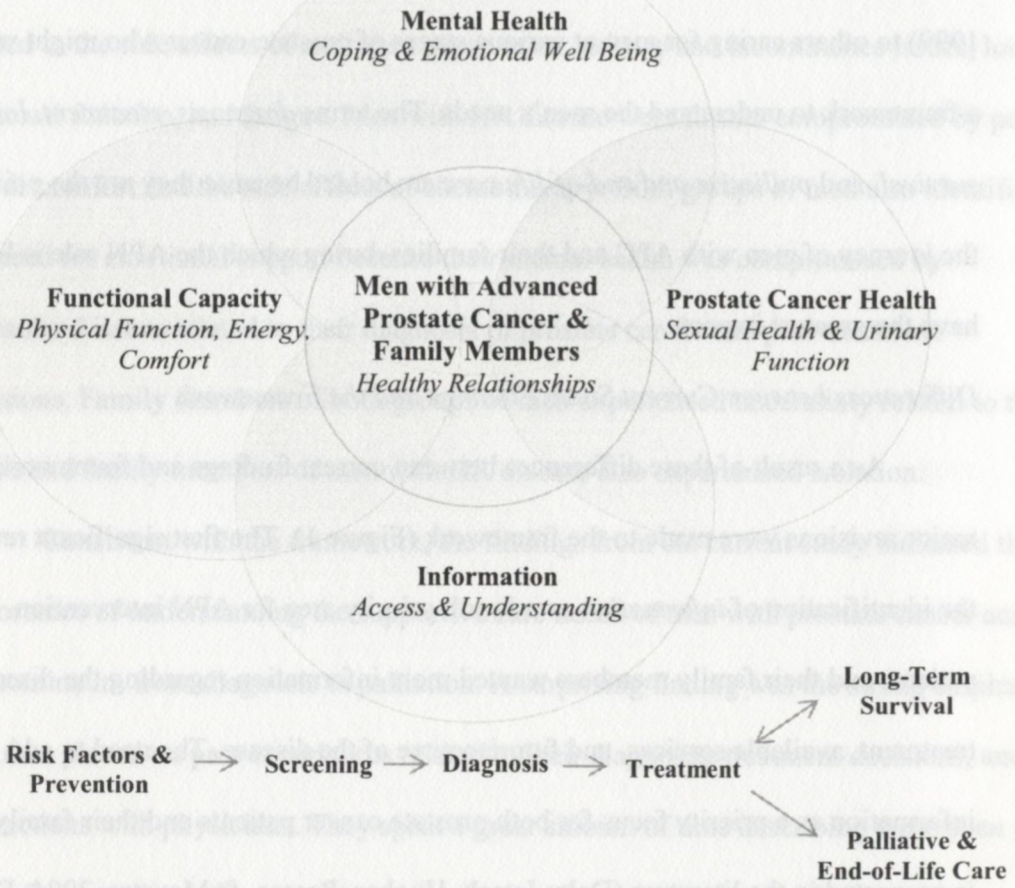
In the revised version of the framework, the continuum of care is illustrated more prominently by adopting the terms that Cancer Care Ontario (CCO; 2008) uses to

describe the patient journey (Figure 1). The use of these terms makes the framework more relevant to CCO, a key stakeholder and decision maker in oncology APN role development, as well as to APNs working in Ontario cancer treatment facilities. Showing the continuum also makes the framework more general and accessible (Chinn & Kramer, 1999) to others caring for men at various stages of prostate cancer who might want to use a framework to understand the men's needs. The terms *diagnosis, treatment, long-term survival,* and *palliative and end-of-life care* are bolded because they are the points along the journey of men with APC and their families during which the APN role is likely to have the greatest impact.

Differences between Current Study Findings and the Framework

As a result of these differences between current findings and framework, three major revisions were made to the framework (Figure 1). The first significant revision is the identification of *information* as a fourth priority area for APN intervention. Both the patients and their family members wanted more information regarding the disease, treatment, available services, and future course of the disease. The need to add information as a priority focus for both prostate cancer patients and their family members is supported in the literature (Dale, Jatsch, Hughes, Pearce, & Meystre, 2004; Davison et al., 2002; Echlin & Rees, 2002; Feltwell & Rees, 2004; Finney Ruttin, Squiers, & Treiman, 2006; Giarelli, McCorkle, & Monturo, 2003; Gray et al., 1997a; Gray et al., 1997b; Harden et al., 2002; Lintz et al., 2003; Resendes & McCorkle, 2006; Templeton & Coates, 2003; Wong et al., 2000).

Figure 1 The focus for advanced practice nursing roles in APC.



The second major revision is the situation of the patient and family in the centre of the model because their needs pertain to each of the four priority areas, not just information and education. Prostate cancer is a disease that affects families and its

associated sexual side effects impact intimate relationships. The burden of caregiving and need for practical assistance described by families affects their ability to function. Finally, family members' mental health is a priority, as they struggle with anxiety and concerns about the men's treatment and prognosis, and their uncertainty about the future. The third major revision is that the four priority areas for APN role intervention (functional capacity, mental health, prostate cancer health, and information) are positioned in the framework to overlap depicting interrelationships among the areas. Study findings indicate that many patient needs do not exist in isolation but rather intersect with other needs. For instance, a lack of information about available support services can create uncertainty and emotional stress among family members. Another example is the overlap between prostate cancer health, functional capacity, and mental health. For men with HS disease, the daily struggle with incontinence issues affects their ability to function and is a constant source of stress.

The interrelationships among the four priority areas and the focus on both the patient with APC and his family depict the complexity of the needs of this patient population. This complexity further supports the need for advanced nursing skills to care for this population. Although the APN role domains (clinical practice, education, research, organizational leadership, and professional development) continue to shape the supportive care an APN would provide, these are no longer specifically itemized in the revised framework. Since the development of the framework in 2003, there has been further discussion and analysis of APN roles in the nursing literature (Bryant-Lukosius, DiCenso, Browne, & Pinelli, 2004; Gardner, Chang, & Duffield, 2007; Scarpa, 2004).

Internationally, it is accepted that the role is multifaceted and includes many domains (International Council of Nurses, 2008). More importantly, removal of the APN role domains simplifies the framework and shifts the focus to patients and families (Chinn & Kramer, 1999). Simplification of the framework is advantageous because it facilitates its use as a general guide for APN practice that can then be tailored for individualized patient care. It is important that a theory be reflected upon to help make decisions about its usefulness (Chinn & Kramer, 1999). A recent survey of administrators in oncology in Ontario suggested that at least 150 new oncology APN positions will be required over the next 5 years and some will focus on patients with prostate cancer (Bryant-Lukosius, 2008). The revised framework based on findings from patients and their families can guide implementation of new APN roles in prostate cancer and help new APNs prioritize the care and treatment they provide.

Strengths and Limitations of the Study

While strengths and limitations of each facet of the study were outlined in their respective chapters, the following discussion addresses the strengths and limitations of the needs assessment in its entirety.

This qualitative study complements the quantitative study conducted by Bryant-Lukosius (2003), which collected data from patients with APC regarding their health problems and co-morbid conditions. The qualitative data confirmed the findings of the quantitative study. However, in the qualitative study, when discussing unmet supportive care needs face-to-face with the investigator, men often downplayed their health problems. Instead, they focused on their need for more information and the emotional toll

related to a lack of information over the course of their disease. This allowed us to more accurately understand patient priorities, and also understand how the lack of supportive care services shaped their care priorities. By combining the results of the quantitative and qualitative studies, greater understanding was gained regarding the severity of health problems, their impact on daily life, the manner in which patients cope with their problems, and which needs they consider the most important. Additionally, the results of this study confirmed and refined the initial framework developed to guide the development of an APN role.

The principal investigator who performed both data collection and analysis does not have a background in oncology nursing and had not previously worked with the population under study, which contributed to an objective view of the area of study. Additionally, the leadership support provided by an interdisciplinary team, which consisted of medical oncologists, a radiation oncologist, an urologist, and an APN who worked with the study population, strengthened the research project. Their leadership not only provided entry into the system but also guidance when difficulty with participant recruitment was encountered. The assistance and cooperation provided by healthcare providers at the regional cancer centre and urology offices, as well the volunteers at the Canadian Cancer Society and two local prostate cancer support groups, was an additional strength of the study. Healthcare providers at the regional cancer centre assisted with the recruitment of subjects and participated in interpretation of the study results.

Information was collected from two different groups of men with APC and their family members to better understand their supportive care needs and solicit suggestions

for changes to the delivery of supportive care services. Collection of data from healthcare providers, in addition to the patients and family members, would provide a more complete picture of the current delivery of supportive care services from both users and providers. To address this limitation, the researcher has begun to collect data regarding patient needs and service delivery from healthcare providers in the community, at local urologist offices, and at the regional cancer centre.

A limitation of this study is the unanticipated need to use interviews in addition to focus groups to collect data from the patients and their families. While this introduced inconsistency in data collection, it did permit the inclusion of study participants who for various reasons, could not or would not attend a focus group. The complementary nature of study findings suggests that the use of these methods enhanced overall study results.

Recommendations

Recommendations for Practice

These populations of men with APC and their family members have demonstrated remarkable resilience in living with prostate cancer and coping with treatments, surgeries, and associated losses over the years. We recommend the design and organization of supportive care services to build on and maximize this resilience by giving them tools and resources necessary to maintain their functional capacity and cope on their own. Most of the issues and problems identified by men with APC and their family members related to how well they could live and cope with their cancer as opposed to issues related to medical care.

As demonstrated by the results of our study and the framework developed to focus the APN role, men with APC and their family members have complex overlapping supportive care needs that are complicated by advancing age, cancer treatment, and co-morbid conditions. There are no easy solutions to meeting the supportive care needs of this population and multiple interventions delivered by various providers must be designed. Simple patient centred initiatives are not effective to address the multiple dimensions of patient health concerns and have significant and meaningful clinical effects (Lauver et al., 2002). We recommend that interventions delivered by APNs, nurses, and other healthcare providers with expertise in supportive care become more effectively integrated into overall medical treatment.

There are some unmet needs of men with APC that may best be addressed by the services of an interdisciplinary team. For example, occupational therapists, physical therapists, and home care nurses have important expertise in assessing and managing health problems that limit functional capacity. Social work is required to support men and can play an important role in addressing emotional, psychosocial, family and practical health needs. The effective use of health care teams requires clear goals, communication, innovative practices and better organization of services (Grumbach & Bodenheimer, 2004). Current access to care is often defined by a pre-set schedule to receive routine hormone injections and/or disease monitoring every three months. Increasing patient awareness and ability to access a broad range of integrated cancer support services when and where they need it may increase patient control of their care and ability to earlier address and meet patient health needs. Perhaps a variety of services could be provided in

one location that also house informational resources and provide space for patients to meet with peers. Expert clinicians could then address identified needs such as relief of fatigue, management of weight loss or weight gain, and most importantly, provision of information and education. New models of care that permit the delivery of services and interaction with healthcare providers, volunteers and peer supports are required. In this study, both the patients and their families requested opportunities to discuss their prostate cancer with healthcare providers and peers, and many suggested that a clinic or resource centre could be an appropriate venue in which to do so. Any attempt to meet patient and family needs through the use of a resource clinic or centre would require the involvement of stakeholders in the planning, because current similar resources are underutilized (Brazil et al., 2004).

The APN is positioned to provide leadership to an interdisciplinary team focused on men with APC and their families. The APN could act not only to support the team at the regional cancer centre, but also help to bridge the gap between the regional oncology services and supportive care services offered in the community. APN support should also be offered to men and their families in their homes. Similar to the transitional APN model developed by Brooten and colleagues (2002; 2003), we recommend that APNs "transition" with patients to whatever setting in which they find themselves. This would be particularly beneficial to wives of advanced age, who tend to be overburdened by their caregiving role. Specialized home care services provided by an APN have been found to improve survival and quality of life for elderly patients with cancer post surgery, compared to patients who received standard care alone (McCorkle et al., 2000). In their

RCT, Faithfull and colleagues (2001) found that nurse-led care that included home follow up and telephone support for men treated with radical radiotherapy for prostate and bladder cancer resulted in increased patient satisfaction related to continuity of care and cost benefits.

The findings of our qualitative study suggest that particular attention should be paid to the informational needs of wives of advanced age. Recent studies that explored the manner in which older adults perceive information in cancer settings suggested that the current methods of providing patient information are not effective (Fitch, 2006). Ways to assess patient and family informational needs and their understanding of information need to be developed and evaluated, so they can become a regular component of the care that they receive during outpatient visits with the oncology team. Maliski et al. (2001) found that both patients and spouses reported decreased anxiety and an enhanced ability to care for themselves after receiving APN-delivered transitional care following radical prostatectomy.

Stacey et al.'s (2002) work with women with breast cancer suggested that APNs can facilitate proactive planning to identify individualized informational, self-care, and decisional support needs. A preventative approach might also help manage the effects of prostate cancer and its treatment on men's functional capacity. The results of recent studies suggest lifestyle interventions, such as providing structured diet and exercise programs, may play a role in preventing fatigue and improving quality of life for men with prostate cancer (Carmack Taylor et al., 2006; Demark-Wahnefried et al., 2006; Monga et al., 2007).

Patient and family identification of a priority need for information has direct implications for the interprofessional team. Our study results identified several factors that may have contributed to unmet information needs including: lack of provider time and "rushed" appointments, physical disability such as fatigue and hearing loss which may impair ability to process information, and patient access to multiple information sources but lack of opportunity to understand how information relates or is relevant to their health.

Strategies that should be considered include the development of new models and approaches to care that permit the time and provide information in forms that aid in patient understanding. Some possible examples include structured education programs and resources, peer and health care professional facilitated support groups and treatment decision aids. Case management by an APN or other specialized oncology RN roles may provide increased access to a central health care professional with intimate knowledge of the patient's experiences and may increase patient access to information when they need it. Additionally, follow up and reinforcement of prior learning and education is needed.

We recommend that all of the team members, including physicians and nurses, should attempt to allow adequate time for patients and their families to communicate and receive information, adequate support to understand the information, and the opportunity to ask questions. Development and evaluation of a more structured educational program is needed for men and family members at diagnosis. This study's results indicate that patients and families are still struggling with the emotional consequences of their diagnosis years after receiving information regarding their diagnosis and making

treatment decisions. The men in this study continued to "second guess" themselves and wonder if they had made the right choices and received the best treatment. Addressing informational needs early in the patient's journey may have implications for patients and families at later stages of the disease continuum and could reduce anxiety and feelings of uncertainty.

Recommendations for Education

As discussed previously, APNs can assume important roles in aiding men with APC and their families in dealing with the complexity of the condition and providing for their resulting supportive care needs. Although APNs need to have specialized training in oncology to provide such care, there is currently no master's degree program in specialty oncology nursing offered in Canada. The development of such a program is needed to ensure APNs are adequately prepared to treat and care for oncology populations. The findings of this study suggest a need for interprofessional education to ensure that all members of the healthcare team understand the supportive care needs of men and families living with prostate cancer. As this study found that patients and families rely on physicians for most of their information, medical students should receive better training in providing information and assessing patient informational needs.

Recommendations for Policy

Cancer Care Ontario (2006), the agency responsible for the organization of supportive cancer care services, has taken the initiative in planning for an increase in advanced practice roles in cancer care. We recommend that CCO continues this work and provides funding to prepare APNs for their role in caring for men with APC and their

families. Other agencies and institutions, including universities, need to be involved to ensure that there is an adequate number of RNs with master's degrees in specialty oncology training available to provide care and treatment.

Additionally, we recommend that CCO, hospitals, and community agencies collaborate to create practice environments that allow APNs to transition from inpatient areas to ambulatory clinics to patient homes. In Ontario, providing leadership to facilitate the easy intersection of different care delivery sectors in the regions is also the responsibility of the new Local Health Integration Network (LHIN).

Recommendations for Research

Future studies could involve community stakeholders (patients, families, health care providers) in all aspects of the research process. Examples of true community or participant based oncology research have been reported (Bourke, 2002; Gray, Fitch, Davis, & Phillips, 2000; Halbert, Weathers, & Delmoor, 2006). As mentioned previously, stakeholder involvement in the development and evaluation of new services is essential to ensure utilization.

The next step is to examine the perceptions of healthcare providers treating men with APC and their families. This researcher is currently analyzing the data gathered from urologists, nurses, community providers, and members of the interdisciplinary team at the regional cancer centre.

A framework for the focus of an APN role in APC is depicted in Figure 1. Future studies should examine the utility and application of this framework with patients and families at different stages of prostate cancer, or perhaps even with patients with other

types of cancer. Three of the four priorities (functional capacity, mental health and information) could be related to the needs of other patients living with other types of cancer, with the fourth priority relating to needs specific to cancer type. We suggest exploration of how the APN can make a difference in the lives of patients and families to validate the model.

The literature examining outcomes of care provided by oncology APNs suggests that a priority for oncology APN research is the assessment of outcomes (Cunningham, 2004). The results of this study could inform the development of APN interventions for men with APC and their families and the revised framework could be useful in structuring APN outcome research. APNs have the knowledge, skill, and expertise to care for this vulnerable population. Future studies should identify the circumstances in which they are most valuable in providing care and treatment to their patients.

Dissemination of the results of this study has already begun. Results from patients and family have been presented to the interprofessional staff at the regional cancer centre, and patient results were presented at a nursing research conference. The results of our exploration into the use of focus groups and interviews were presented at an international conference of qualitative research methodology. Next, manuscripts from chapters two to four will be developed for publication in relevant oncology nursing and qualitative research journals. Finally, the results of the patient and family study will be combined with the data from healthcare providers to provide a more complete picture of the current delivery of supportive care services from both users and providers. An ideal way to

present this information would be at a community forum including patients and families, health care providers, community stakeholders, and local media.

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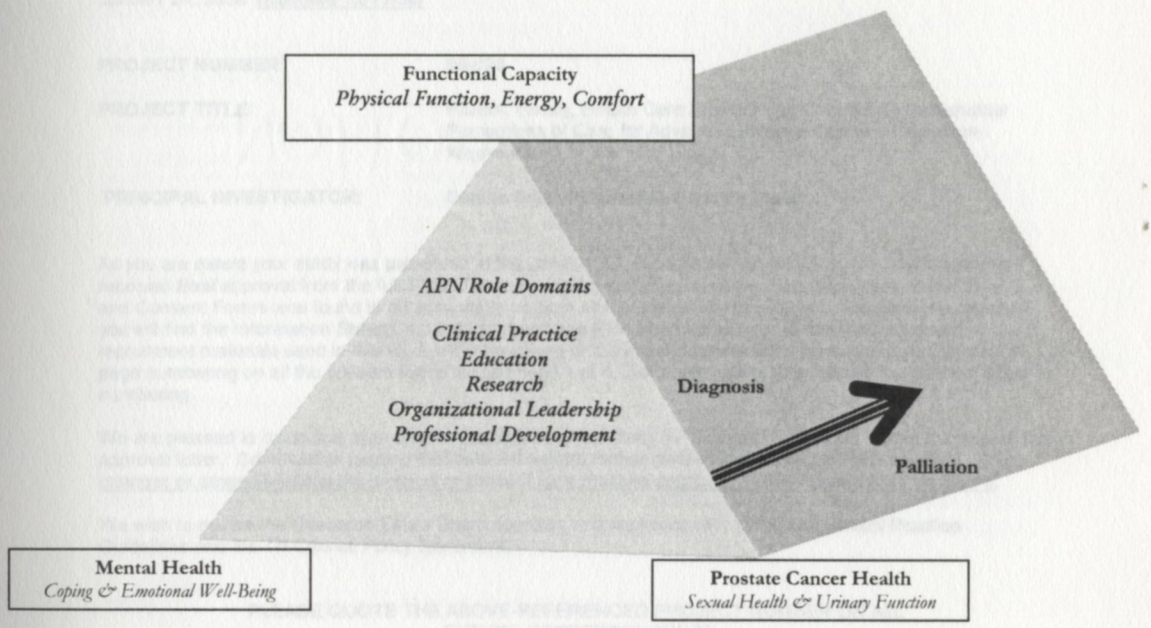
APPENDICES

Appendix A

Preliminary Model for APN Role in Prostate Cancer



Appendix B

Hamilton Health Sciences Research Ethics Board Approval

McMaster University

Hamilton Health Sciences
EXEMPLARY CARE • ACADEMIC EXCELLENCE

RESEARCH ETHICS BOARD

January 24, 2006 ***(Revised 12/17/08)***

PROJECT NUMBER: **06-028**

PROJECT TITLE: Patient, Family, Health Care Provider and Community Stakeholder Perceptions of Care for Advanced Prostate Cancer in Hamilton-Wentworth

PRINCIPAL INVESTIGATOR: **Denise Bryant-Lukosius & Nancy Carter**

As you are aware your study was presented at the January 17, 2006 Research Ethics Board meeting where it received ***final*** approval from the full REB. The submission, including all of the Participant Information Sheets and Consent Forms was found to be acceptable on both ethical and scientific grounds. ***Please note*** attached you will find the Information Sheet/Consent forms with the REB approval affixed; all consent forms and recruitment materials used in this study must be copies of the attached materials—we suggest you revise the page numbering on all the consent forms to read page 1 of 4, 2 of 4, etc. rather than having the protocol page numbering.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of this approval letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board.

We wish to advise the Research Ethics Board operates in compliance with ICH Good Clinical Practice Guidelines and the Tri-Council Policy Statement.

PLEASE QUOTE THE ABOVE-REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Sincerely,

J. Holland, MD

F. Jack Holland, MD, FRCP, FRCP(C)
Chair, Research Ethics Board

/dm

All correspondence should be addressed to the REB Chair and forwarded to:
REB Coordinator, Hamilton Health Sciences, REB Office
1057 Main Street West, Suite 1
Hamilton ON L8S 1B7
Telephone: 905-521-2100, Ext. 42013
Fax: 905-577-8379

Appendix C

St. Joseph's Healthcare Hamilton Research Ethics Board Approval

St. Joseph's Healthcare Hamilton

McMaster University

50 CHARLTON AVENUE EAST, HAMILTON, ONTARIO, CANADA L8N 4A6

RESEARCH ETHICS BOARD

Tel. (905) 522-4941 ext. 3537 Fax: (905) 521-6092

Research Ethics Board Membership

Raelene Rathbone, MB, BS, MD, PhD, Interim Chairperson

Alistair Ingram, BSc, MD, FRCPC, ABIM, Nephrology

Peter Bieling, BSc, MA, PhD - Psychology

Lisa Dolovich, BscPhm, PharmD, Pharmacy

Susan Goodman, BA, MA (Community)

Marc Townsend, BA, MBA Research Administration, McMaster University

Anil Kapoor, MD, FRCS(C) Urology & Renal Transplantation

Marie Lynch, BScN, MHA Administration

Astrid Petsch, PhD - Laboratory Services

Rory McDonagh, MSc, MD, FRCSC Obstetrics & Gynecology

Lehana Thabane, BSc, MSc, PhD Biostatistics

Peter Tice, LLB (Community)

Parameswaran Nair, MD, PhD, FRCP, MNAMS – Respirology

Valerie Taylor, MD Psychiatry

Deborah Cook, MD Medicine

Mary Jane Sayles, RN, CCRC Clinical Trials Research Nurse

Kevin Smith, DPhil President/CEO (Ex officio)

The St. Joseph's REB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the Health Canada / ICH Good Clinical Practice Consolidated Guidelines (E6); and the applicable laws and regulations of Ontario. The membership of this REB also complies with the membership requirements for REBs as defined in Canada's Food and Drug Regulations (Division 5: Drugs for Clinical Trials Involving Humans Subjects).

March 15, 2006

Dr. Anil Kapoor
Dept. of Surgery
St. Joseph's Healthcare Hamilton

Dear Dr. Kapoor:

RE: R.P. #06-2621: Patient, family, health care provider and community stakeholder perceptions of care for advanced prostate cancer in Hamilton-Wentworth - **Protocol dated January 27, 2005 – stamped Jan 27 2006 by REB, Appendix A: A research program to assess patient & family needs related to advanced prostate cancer in Central West Ontario, Appendix B: Providers of supportive care: external/internal to regional cancer centre, Appendix C: Providers of supportive care, Appendix D: Study participants, Appendix E: Focus groups, Appendix F: Patient screening tool for primary nurses, Appendix G: Telephone scripts, Appendix H: Confirmation letters for study participants dated March 2006, Appendix I: Recruitment poster with REB stamp Mar 15 2006, Appendix J: Demographic tools, Appendix K: Interview guides, Appendix L: Information sheets/consent forms dated March 2006 with REB stamp Mar 15 2006, REB approval from HHS/McMaster University**

The Research Ethics Board's Subcommittee reviewed R.P. #06-2621 at its meeting on February 27, 2006 and approved it with some conditions. Those conditions have now been met.

You have final approval to commence your research.

This approval will be for a one-year period **ending March 15, 2007.** We will request a progress report at that time.

If your project is terminated, it is your responsibility to notify the REB. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board prior to implementation.

Please ensure that all study personnel are familiar with the REB requirements on the appended page.

.../2

Dr. Anil Kapoor March 15, 2006

Please reference R.P. #06-2621 in any future correspondence.

We wish you well in the completion of this research.

Sincerely yours,

Raelene Rathbone

Raelene Rathbone, MB, BS, MD, PhD
Interim Chairperson, Research Ethics Board

RR:ah

cc: Marnie Fletcher - Gail Gray - Dr. Lisa Dolovich

Append.

cc: Nancy Carter

Appendix D

Community Advertising

Do you or a loved one have Advanced Prostate Cancer?

Hamilton Health Sciences/McMaster
MAR 1 0 2006
Research Ethics Board

We are conducting a study to understand the health needs of men with advanced prostate cancer and their family members. We also want advice on how to improve health services for those affected by advanced prostate cancer.

We are looking for people who:

- Have advanced prostate cancer
- Are the spouse, partner or family member of men who have advanced prostate cancer
- Are able to participate in a discussion group for 60 to 90 minutes

FOR MORE INFORMATION,
PLEASE CALL AND SPEAK WITH
A RESEARCH NURSE AT
905-525-9140 EXT 26251

Hamilton Health Sciences

Appendix E

Patient Screening Tool for Primary Nurses

Eligible patients with advanced prostate cancer are defined as men living in Hamilton-Wentworth with documented metastatic or stage IV disease.
Advanced Hormone Sensitive patients are those on androgen suppression therapy (orchidectomy or Luteinizing Hormone-Releasing Hormone (LHRH) agonist with or without anti-androgens) with a demonstrated response to treatment (decline in Prostate-Specific Antigen (PSA) and no consecutive rises in the last three PSA levels.
Advanced Hormone Refractory Patients include those who had 3 consecutive rises in PSA following an initial response to hormone suppression therapy.

Additional eligibility criteria include the ability to speak and understand English and the physical and cognitive ability to participate in a 90 minute meeting outside the home.

Type of Advanced Prostate Cancer:

Advanced Hormone Sensitive☐ Advanced Hormone Refractory☐

Current Treatment: (Check all that apply)

Hormone Therapy ☐ Radiation ☐

Chemotherapy ☐ Other ☐

_____ (describe)

Year of Birth: _____

Year of Prostate Cancer Diagnosis _____

Patient agrees to be contacted by the research assistant regarding the study:

No ☐

Yes ☐ If yes, provide the following information:

Patient Name _____ **Phone Number** _____

Source of patient referral for study:

Patient ☐ Rad. Onc Team☐ Med. Onc. Team☐ Urology Team☐

Other ☐ _____ (describe)

Appendix F

Telephone Script for Contacting Patients with Advanced Prostate Cancer

My name is Nancy Carter. I am a Registered Nurse and Doctoral student in the School of Nursing at McMaster University. I am working with researchers and health care providers from the Juravinski Cancer Centre, St. Joseph's Hospital and McMaster University to conduct a study about advanced prostate cancer.

We would like to invite you to participate in this research study that has been funded by the Juravinski Cancer Centre Foundation. One purpose of the study is to learn more about the health needs of men with advanced prostate cancer. We also want to learn more from patients, families, health care providers and community stakeholders about how they think cancer services could be improved to better meet the health needs of men with advanced prostate cancer in Hamilton-Wentworth.

The results of this study may be used by health care providers and managers to help them plan and provide cancer care services that are important for patients and families who are affected by advanced prostate cancer.

If you agree to be a part of this study, you will participate in a group discussion with other men who have advanced prostate cancer. You will also be asked to complete a very brief survey about you and your prostate cancer treatment just prior to the group discussion. Completion of the survey will take about 5 minutes. During this group discussion, I will ask participants to talk about the kinds of health problems they have experienced, how well the health system is able to meet these needs, and to provide suggestions about how to improve cancer care services for men with advanced prostate cancer. The group discussion will last for about 1 to 1.5 hours. The group discussion will be audiotaped and later transcribed into written notes.

Participation in the study is completely voluntary and your cancer care will not be affected in any way should you choose not to participate. You may also choose to withdraw at any time during your participation in the study. It is also important to know that your participation in the study is confidential and that any information you provide will not be shared with your health care providers. You and your family members will not be identified in the reporting of the study results.

Thank you for your consideration of our request. Do you have any questions at this time?

If you have any further questions or concerns about this study at a later time, you can call me at (905) 525-9140 x 26251. Or you could also speak to the Principal Investigator of this study, Dr. Denise Bryant-Lukosius at (905) 525-9140 x 22245.

If you have any questions regarding your rights as a research participant, please contact the office of the Chair of the Research Ethics Board, St. Joseph's Healthcare Hamilton, at 905-522-1155 Ext. 3537.

Appendix G

Informed Consent – Patient – Hamilton Health Sciences

St. Joseph's Healthcare Hamilton

McMaster University Health Sciences

Hamilton Health Sciences

INFORMATION SHEET/CONSENT FORM FOR MEDICAL RESEARCH

PARTICIPANT INFORMATION SHEET (Patients)

Title of Study: Linking with the Community: Patient, Family and Health Care Provider Perceptions of Care for Advanced Prostate Cancer in Hamilton-Wentworth

Locally Responsible Investigator and Principal Investigator, Department/Hospital/Institution:
Denise Bryant-Lukosius, RN, PhD, Assistant Professor and Nancy Carter, PhD Student, Faculty of Health Sciences (Nursing), McMaster University

Co-Investigator(s), Department/Hospital/Institution:
Alba DiCenso, RN, PhD
Professor, School of Nursing, Clinical Epidemiology and Biostatistics, McMaster University

Jennifer Blythe, PhD
Associate Professor, School of Nursing, Faculty of Health Sciences, McMaster University
Senior Scientist, Nursing Health Services Research Unit, McMaster University

Alan J. Neville, MBChB, M Ed, MRCP, FRCP(c)
Assistant Dean, Undergraduate MD Program, McMaster University
Professor, School of Medicine, McMaster University

Ian Dayes, MD, MSc, FRCP(C)
Radiation Oncologist, Juravinski Cancer Centre
Assistant Professor, Dept. of Medicine, McMaster University

Sebastien Hotte, MD, FRCP(C)
Medical Oncology and Head Phase 1 Program, Juravinski Cancer Centre
Assistant Professor, Dept. of Medicine, McMaster University

Anil Kapoor, MD, FRCS(C)
Director, Urological Research, McMaster Institute of Urology, St. Joseph's Health Care
Assistant Professor, Dept. of Medicine, McMaster University

Carol Rand, MSc, MA
Director, Regional, Systemic and Supportive Care Programs, Juravinski Cancer Centre
Tim Whelan, MD
Director, Supportive Cancer Care Research Unit, Juravinski Cancer Centre
Professor, School of Medicine, McMaster University

You are being invited to participate in a research study conducted by Denise Bryant-Lukosius, RN, PhD and Nancy Carter, RN, who is a PhD Student because you have advanced prostate cancer.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision.

WHY IS THIS RESEARCH BEING DONE?

Men with advanced prostate cancer may experience a number of health needs or problems that result from the cancer and from treatment. In previous studies, our research has found that men with advanced prostate cancer have different health needs and concerns compared to men with other stages of prostate cancer. Our research also suggested that some of these health needs were not always well met within the current health system.

WHAT IS THE PURPOSE OF THIS STUDY?

This study is being done to find out more about the health needs of men with advanced prostate cancer and their families. We also want to learn from men, their families, and health care providers about ways in which the delivery of health care services can be improved to better meet the health needs of people affected by advanced prostate cancer.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

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WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

It is possible that you may experience some emotional upset when describing the health problems and concerns you have experienced as a result of having advanced prostate cancer.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

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WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you from your participation in this study. However, you may benefit from experiencing the satisfaction of knowing you have contributed to the research that increases what we know about the needs of men with advanced prostate cancer and improving health care delivery. Your participation may help other people with cancer in the future. There are no medical benefits to you from taking part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

It is important for you to know that you can choose not to take part in the study. Choosing not to participate in this study will in no way affect your care or treatment. If you choose to take part in this study, we will tell you if we make any changes to the study, so you can decide if you want to continue to be part of it.

WHAT INFORMATION WILL BE KEPT PRIVATE?

No information that you provide in the focus group will be shared with health care providers involved in your care without your permission. To prevent you from being personally identified in the audiotapes or typed notes, you will be asked to use a "nickname" of your choice during the focus group discussion. We will also ask but cannot guarantee that all focus group members keep the information shared in the group confidential. Only the typist and members of the research team will listen to audiotapes. The audiotapes will be destroyed after 1 year. Only the researcher and another team member will read and analyze the typed notes.

Your name or information that could identify you or your family member will not be used in any presentations or publications of the study results.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you agree to be in this study, you may withdraw or decide to stop participating at any time. Any information collected from you, up until you withdraw, will be included in the final study results. Withdrawal from the study will in no way affect the quality of care you or your family members receive at this institution.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

If you agree to take part, we will reimburse you for any parking costs during the focus group. You will also receive refreshments at the focus group.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact:

Nancy Carter at (905) 525-9140 ext. 26251 or the Principal Investigator for this study, Denise Bryant-Lukosius, RN, PhD at (905) 525-9140 ext 22245.

If you have any questions regarding your rights as a research participant, you may contact Hamilton Health Sciences Patient Relations Specialist at 905-521-2100, ext. 75240.

CONSENT STATEMENT

SIGNATURE OF RESEARCH PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form

_____

Name of Participant

_____

Name of Legally Authorized Representative (if applicable)

_____ _____

Signature of Participant or Legally Authorized Representative Date

Consent form administered and explained in person by:

_____
Name and title

_____ _____
Signature Date

Signature of Witness to Consent Interview

My signature as witness, certifies that I witnessed the "Consent Interview" for the research study named above in this document. I attest that the information in this Information Sheet and Consent Form was explained to, and apparently understood by, the participant (or the participant's legally authorized representative).

_____ _____
Signature Date

Signature of Witness to Participant's Signature:

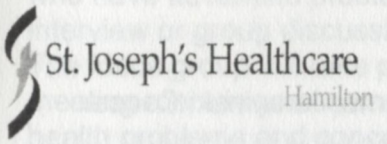
My signature as witness, certifies that I witnessed the participant (or the participant's legally authorized representative) voluntarily sign this consent form in my presence.

_____ _____
Signature Date

May 2005

Appendix H

Informed Consent – Patient – St. Joseph's Healthcare Hamilton







INFORMATION SHEET/CONSENT FORM FOR MEDICAL RESEARCH

PARTICIPANT INFORMATION SHEET (Patients)

Title of Study: Linking with the Community: Patient, Family and Health Care Provider Perceptions of Care for Advanced Prostate Cancer in Hamilton-Wentworth

Locally Responsible Investigator and Principal Investigator, Department/Hospital/Institution:

Anil Kapoor, MD, FRCS(C)
Director, Urological Research, McMaster Institute of Urology, St. Joseph's Health Care
Assistant Professor, Dept. of Medicine, McMaster University

Denise Bryant-Lukosius, RN, PhD,
Assistant Professor, School of Nursing, McMaster University
Nancy Carter, RN, PhD Student
Faculty of Health Sciences (Nursing), McMaster University

Co-Investigator(s), Department/Hospital/Institution:

Alba DiCenso, RN, PhD
Professor, School of Nursing and Clinical Epidemiology and Biostatistics
McMaster University

Jennifer Blythe, PhD
Associate Professor, School of Nursing, Faculty of Health Sciences, McMaster University
Senior Scientist, Nursing Health Services Research Unit, McMaster University

Alan J. Neville, MBChB, M Ed, MRCP, FRCP(c)
Assistant Dean, Undergraduate MD Program, McMaster University
Professor, School of Medicine, McMaster University

Ian Dayes, MD, MSc, FRCP(C)
Radiation Oncologist, Juravinski Cancer Centre
Assistant Professor, Dept. of Medicine, McMaster University

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Medical Oncology and Head Phase 1 Program, Juravinski Cancer Centre

Assistant Professor, Dept. of Medicine, McMaster University

Carol Rand, MSc, MA
Director, Regional, Systemic and Supportive Care Programs, Juravinski Cancer Centre

Tim Whelan, MD
Director, Supportive Cancer Care Research Unit, Juravinski Cancer Centre
Professor, School of Medicine, McMaster University

You are being invited to participate in a research study conducted by Denise Bryant-Lukosius, RN, PhD and Nancy Carter, RN, who is a PhD Student because you have advanced prostate cancer.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision.

WHY IS THIS RESEARCH BEING DONE?

Men with advanced prostate cancer may experience a number of health needs or problems that result from the cancer and from treatment. In previous studies, our research has found that men with advanced prostate cancer have different health needs and concerns compared to men with other stages of prostate cancer. Our research also suggested that some of these health needs were not always well met within the current health system.

WHAT IS THE PURPOSE OF THIS STUDY?

This study is being done to find out more about the health needs of men with advanced prostate cancer and their families. We also want to learn from men, their families, and health care providers about ways in which the delivery of health care services can be improved to better meet the health needs of people affected by advanced prostate cancer.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

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WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

It is possible that you may experience some emotional upset when describing the health problems and concerns you have experienced as a result of having advanced prostate cancer.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

About 25 – 50 men with advanced prostate cancer, and 25-50 family members will participate in this study. There will be approximately 4-7 other people in your focus group. We are hoping to hold at least 6 focus groups of men with advanced prostate cancer, and another 6 focus groups with family members. We are also conducting focus groups with health professionals working at the Juravinski Cancer Centre, St. Joseph's Hospital and in the community.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you from your participation in this study. However, you may benefit from experiencing the satisfaction of knowing you have contributed to the research that increases what we know about the needs of men with advanced prostate cancer and improving health care delivery. Your participation may help other people with cancer in the future. There are no medical benefits to you from taking part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

It is important for you to know that you can choose not to take part in the study. Choosing not to participate in this study will in no way affect your care or treatment. If you choose to take part in this study, we will tell you if we make any changes to the study, so you can decide if you want to continue to be part of it.

WHAT INFORMATION WILL BE KEPT PRIVATE?

No information that you provide in the focus group will be shared with health care providers involved in your care without your permission. To prevent you from being personally identified in the audiotapes or typed notes, you will be asked to use a "nickname" of your choice during the focus group discussion. We will also ask but cannot guarantee that all focus group members keep the information shared in the group confidential. Only the typist and members of the research team will listen to audiotapes. The audiotapes will be destroyed after 1 year. Only the researcher and another team member will read and analyze the typed notes.

Your name or information that could identify you or your family member will not be used in any presentations or publications of the study results.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you agree to be in this study, you may withdraw or decide to stop participating at any time. Any information collected from you, up until you withdraw, will be included in the final study results. Withdrawal from the study will in no way affect the quality of care you or your family members receive at this institution.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

If you agree to take part, we will reimburse you for any parking costs during the focus group. You will also receive refreshments at the focus group.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact:

Nancy Carter at (905) 525-9140 ext. 26251 or the Principal Investigator for this study, Denise Bryant-Lukosius, RN, PhD at (905) 525-9140 ext 22245.

If you have any questions regarding your rights as a research participant, you may contact Hamilton Health Sciences Patient Relations Specialist at 905-521-2100, ext. 75240 or you may contact the Office of the Chair of the Research Ethics Board, S. Joseph's Healthcare Hamilton, 905-522-1155, Ext. 3537.

CONSENT STATEMENT

SIGNATURE OF RESEARCH PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form

_____
Name of Participant

_____
Name of Legally Authorized Representative (if applicable)

_____
Signature of Participant or Legally Authorized Representative

_____
Date

Consent form administered and explained in person by:

_____
Name and title

_____ _____
Signature Date

Appendix I

Interview Guide - Patients

Patients

1. How has having prostate cancer affected your life?
2. What needs, problems, or concerns have you experienced since your diagnosis of prostate cancer?
3. How well have your needs, problems and concerns been met or resolved?
4. What are the helpful and unhelpful strategies that you have utilized to assist you in coping with these needs, problems, or concerns?
5. How has the health care system, such as your doctors, nurses, the Cancer Centre, and other health care services or community agencies been helpful/unhelpful in meeting your needs, problems, or concerns?
6. Based on your experiences, how could the delivery of health care services be improved to better meet your needs?
7. What needs would you identify as priorities for the focus of future efforts to improve the care of patients and families affected by prostate cancer?

Appendix J

Informed Consent – Family – Hamilton Health Sciences

St. Joseph's Healthcare Hamilton

McMaster University Health Sciences

Hamilton Health Sciences

INFORMATION SHEET/CONSENT FORM FOR MEDICAL RESEARCH

PARTICIPANT INFORMATION SHEET (Family Member)

Title of Study: Patient, Family, Health Care Provider and Community Stakeholder Perceptions of Care for Advanced Prostate Cancer in Hamilton-Wentworth

Locally Responsible Investigator and Principal Investigator, Department/Hospital/Institution: Denise Bryant-Lukosius, RN, PhD, Assistant Professor and Nancy Carter, PhD Student, Faculty of Health Sciences (Nursing), McMaster University

Co-Investigator(s), Department/Hospital/Institution:

Alba DiCenso, RN, PhD
Professor, School of Nursing and Clinical Epidemiology and Biostatistics, McMaster University

Jennifer Blythe, PhD
Associate Professor, School of Nursing, Faculty of Health Sciences, McMaster University
Senior Scientist, Nursing Health Services Research Unit, McMaster University

Alan J. Neville, MBChB, M Ed, MRCP, FRCP(c)
Assistant Dean, Undergraduate MD Program, McMaster University
Professor, School of Medicine, McMaster University

Ian Dayes, MD, MSc, FRCP(C)
Radiation Oncologist, Juravinski Cancer Centre
Assistant Professor, Dept. of Medicine, McMaster University

Sebastien Hotte, MD, FRCP(C)
Medical Oncology and Head Phase 1 Program, Juravinski Cancer Centre
Assistant Professor, Dept. of Medicine, McMaster University

Anil Kapoor, MD, FRCS(C)
Director, Urological Research, McMaster Institute of Urology, St. Joseph's Health Care
Assistant Professor, Dept. of Medicine, McMaster University

Carol Rand, MSc, MA
Director, Regional, Systemic and Supportive Care Programs, Juravinski Cancer Centre
Tim Whelan, MD
Director, Supportive Cancer Care Research Unit, Juravinski Cancer Centre
Professor, School of Medicine, McMaster University

You are being invited to participate in a research study conducted by Denise Bryant-Lukosius, RN, PhD and Nancy Carter, RN, who is a PhD Student because your family member has advanced prostate cancer.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

WHY IS THIS RESEARCH BEING DONE?

Men with advanced prostate cancer may experience a number of health needs or problems that result from the cancer and from treatment. In previous studies, our research has found that men with advanced prostate cancer have different health needs and concerns compared to men with other stages of prostate cancer. Our research also suggested that some of these health needs were not always well met within the current health system.

WHAT IS THE PURPOSE OF THIS STUDY?

This study is being done to find out more about the health needs of men with advanced prostate cancer and their families. We also want to learn from men, their families, and health care providers about ways in which the delivery of health care services can be improved to better meet the health needs of people affected by advanced prostate cancer.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

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men and families affected by advanced prostate cancer. The focus group discussion will be recorded using an audiotape recorder and then typed out.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

It is possible that you may experience some emotional upset when describing the health problems and concerns you have experienced as a result of having a family member with advanced prostate cancer.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

About 25 – 50 men with advanced prostate cancer and 25-50 family members will participate in this study. There will be approximately 4-7 other people in your focus group. We are hoping to hold at least 6 focus groups of men with advanced prostate cancer, and another 6 focus groups with family members. We are also conducting focus groups with health professionals working at the Juravinski Cancer Centre, St. Joseph's Hospital and in the community.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

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IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

It is important for you to know that you can choose not to take part in the study. Choosing not to participate in this study will in no way affect your care or the treatment of your family member. If you choose to take part in this study, we will tell you if we make any changes to the study, so you can decide if you want to continue to be part of it.

WHAT INFORMATION WILL BE KEPT PRIVATE?

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WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

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Nancy Carter at (905) 525-9140 ext. 26251 or the Principal Investigator for this study, Denise Bryant-Lukosius, RN, PhD at (905) 525-9140 ext 22245.

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CONSENT STATEMENT

SIGNATURE OF RESEARCH PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form

_____

Name of Participant

_____

Name of Legally Authorized Representative (if applicable)

_____ _____

Signature of Participant or Legally Authorized Representative Date

Consent form administered and explained in person by:

_____

Name and title

_____ _____

Signature Date

Signature of Witness to Consent Interview

My signature as witness, certifies that I witnessed the "Consent Interview" for the research study named above in this document. I attest that the information in this Information Sheet and Consent Form was explained to, and apparently understood by, the participant (or the participant's legally authorized representative).

_____ _____

Signature Date

Signature of Witness to Participant's Signature:

My signature as witness, certifies that I witnessed the participant (or the participant's legally authorized representative) voluntarily sign this consent form in my presence.

_____ _____

Signature Date

Appendix K

Informed Consent – Family – St. Joseph's Healthcare Hamilton

St. Joseph's Healthcare Hamilton
McMaster University Health Sciences
Hamilton Health Sciences

INFORMATION SHEET/CONSENT FORM FOR MEDICAL RESEARCH

PARTICIPANT INFORMATION SHEET (Family Member)

Title of Study: Patient, Family, Health Care Provider and Community Stakeholder Perceptions of Care for Advanced Prostate Cancer in Hamilton-Wentworth

Locally Responsible Investigator and Principal Investigator, Department/Hospital/Institution:
Anil Kapoor, MD, FRCS(C)
Director, Urological Research, McMaster Institute of Urology, St. Joseph's Health Care
Assistant Professor, Dept. of Medicine, McMaster University

Denise Bryant-Lukosius, RN, PhD,
Assistant Professor, School of Nursing, McMaster University
Nancy Carter, PhD Student,
Faculty of Health Sciences (Nursing), McMaster University

Co-Investigator(s), Department/Hospital/Institution:
Alba DiCenso, RN, PhD
Professor, School of Nursing and Clinical Epidemiology and Biostatistics, McMaster University

Jennifer Blythe, PhD
Associate Professor, School of Nursing, Faculty of Health Sciences, McMaster University
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Carol Rand, MSc, MA
Director, Regional, Systemic and Supportive Care Programs, Juravinski Cancer Centre

Tim Whelan, MD
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Professor, School of Medicine, McMaster University

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WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

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IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

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treatment of your family member. If you choose to take part in this study, we will tell you if we make any changes to the study, so you can decide if you want to continue to be part of it.

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CONSENT STATEMENT

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_____

Name of Participant

_____

Name of Legally Authorized Representative (if applicable)

_____ _____

Signature of Participant or Legally Authorized Representative Date

Consent form administered and explained in person by:

_____

Name and title

_____ _____

Signature Date

_____ _____

Signature Date

Appendix L
Interview Guide - Family

Family Members

1. How has your life and that of your family member been affected by his diagnosis of advanced prostate cancer?

2. What needs, problems, or concerns have you and your family member experienced since his diagnosis of advanced prostate cancer?

3. How well have these needs, problems and concerns been met or resolved?

4. What are the helpful and unhelpful strategies you and your family member have used to cope with these needs, problems, or concerns?

5. How has the health care system, such as your doctors, nurses, the Cancer Centre, and other health care services or community agencies been helpful/unhelpful in meeting these needs, problems, or concerns?

6. Based on your experiences, how could the delivery of health care services be improved to better meet these needs?

7. What needs would you identify as priorities for the focus of future efforts to improve the care of patients and families affected by advanced prostate cancer?

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