UNMET SUPPORTIVE CARE NEEDS OF PATIENTS WITH COLON CANCER

THE UNMET SUPPORTIVE CARE NEEDS
OF
PATIENTS
WITH NEWLY DIAGNOSED ADVANCED COLON CANCER

By

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ABSTRACT

The Unmet Supportive Care Needs of Patients with Newly Diagnosed Advanced Colon Cancer

Purpose

Colorectal cancer (CRC) is the fourth most common cancer and the second leading cause of cancer death among Canadians. Little is known about the types of supportive care needs (SCNs) that patients with colon cancer experience during the diagnostic phase or whether these needs are met. To inform the development of population specific healthcare services, a needs assessment of patients with newly diagnosed advanced colon cancer was conducted to identify the types, prevalence, severity, and importance of unmet SCNs, as well as to identify any gaps between patient priority needs and their use of supportive care services.

Patients and Methods

A descriptive cross-sectional survey was conducted. Over one year, all newly diagnosed patients with colon cancer at the Juravinski Cancer Centre were screened for eligibility. Sixty-two of 80 eligible patients completed a self-report written questionnaire prior to starting treatment (response rate = 77.5%). The questionnaire included the Supportive Care Needs Survey-Short Form, Functional Assessment of Cancer Therapy-Colorectal and Health Service Utilization Questionnaire.

Results

‘Fears about the cancer spreading’ was the most prevalent unmet SCN (n = 52/62 or 84%). Unmet SCNs experienced by 65% or more of participants related to lack of control about treatment outcomes, the uncertain future, and concerns about family member well-being. Patients also rated these needs as being most severe.

The two most severe CRC-specific concerns were related to ‘body appearance’ (Mean = 1.77, SD = 1.37) and ‘bowel control’ (Mean = 2.28, SD = 1.37). The most important or priority unmet needs were related to uncertainty about the future (43.5%), fatigue (24.2%), and information (22.6%). Less than 12% of participants had used existing supportive care services in the community.

Conclusion

Prevalent and priority unmet needs were related to psychosocial support and information. Recommendations for designing colon cancer-specific services are provided along with strategies to improve patient use of existing resources.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

List of Figures

Chapter 4

List of Tables

CHAPTER 1

Colorectal cancer (CRC) is the fourth most common cancer and the second leading cause of cancer death among Canadians (Canadian Cancer Society [CCS] & National Cancer Institute of Canada [NCIC], 2011). The incidence of CRC has risen at an average of 2% per year since 1997 (Cancer Care Ontario [CCO], 2004). Growing public awareness about the importance of CRC screening has led to the increased diagnosis of colon cancer (CCO, 2004). Ontario's incidence of CRC is among the highest in the world (CCO, 2004) with 8,300 new cases reported in 2010 (CCS & NCIC, 2010). Low CRC screening rates (29%) in Ontario contribute to the high proportion of adults being diagnosed with advanced stage CRC (CCO, 2010b). Despite improvements in the early detection of CRC using a population-based screening program (ColonCancerCheck), about 56% of Canadians have advanced stage CRC at the time of diagnosis (National Cancer Institute [NCI], 2007). In Central West Ontario region, over 650 new cases of CRC were diagnosed in 2007/2008 and 60% of these cases had colon cancer. Of those diagnosed with CRC, over half (59%) had advanced disease which includes stages III and IV (CCO, 2008a).

The treatment for advanced CRC has improved markedly in the last decade with the availability of new chemotherapy agents (American Cancer Society, 2005; Shah, 2008). As a result, there has been a steady increase in the overall survival rate for patients with advanced CRC (CCS & NCIC, 2011; CCO, 2004; Shah, 2008). In addition to medical treatment, patients with advanced CRC require supportive care services for symptom control, dietary advice, psychosocial support, and palliation. Young and Rhea

(2000) recommend that the initial contact for supportive care services among patients with advanced CRC should be made at the time of diagnosis, rather than at a crisis point later in the disease trajectory.

The diagnosis of cancer is associated with various psychological and emotional reactions, including shock, anger, anxiety, confusion, and depression. These reactions may be heightened by an advanced cancer diagnosis (Manne, 1998; Maughan, Heyman, & Mathews, 2002). In addition, patients recently diagnosed with cancer may have significant needs related to existing co-morbidity, uncertainty about their prognosis, and the stigma associated with cancer (Shaha, Cox, Taman, & Kelly, 2008; Whelan et al., 1997). The CCS's (2003) study on the needs of Ontarians with cancer identified major gaps in the coordination and integration of supportive and palliative care services. These gaps have contributed to significant unmet needs for both patients and family caregivers across the continuum of care from diagnosis through to rehabilitation and palliative care.

Regional cancer programs in Ontario are responsible for developing integrated and needs-driven supportive care services in collaboration with key informants, other service agencies, and the community (CCO, 2010a). As will be discussed in Chapter 2, the paucity of data about the patterns of supportive care needs (SCNs) and levels of service use have contributed to slow progress in developing comprehensive supportive cancer care programs in Ontario (Fitch, 2000). Limited research has focused on SCNs of patients with CRC, and most studies have employed qualitative data to describe patient experiences across the illness continuum. In this thesis, the literature review illustrates that significant gaps exist in understanding the priority SCNs of newly diagnosed patients with colon cancer and in particular those with advanced disease.

The conduct of a systematic needs assessment is the first step in healthcare planning (Myers, 1988) and is essential for developing relevant regional supportive care services for specific patient populations that may have unique SCNs.

The ultimate goal of this thesis was to quantify the prevalence and severity of the met and unmet SCNs of patients with newly diagnosed advanced colon cancer (ACC) (stage III or IV) who were referred to the Juravinski Cancer Centre (JCC) in Hamilton, Ontario, Canada. The information derived from the findings is an essential first step in identifying key patient priorities. These findings, in turn, may provide directions for improving the current services, thereby better meeting patients' SCNs.

Contextual Background

Colorectal cancer.

Colorectal cancer refers to any cancer that occurs in the large intestine (colon) or the rectum. In Canada, it is estimated that there will be 22,200 new cases of CRC (56% male) and 8,900 associated deaths in 2011 (CCS & NCIC, 2011). Cancer Care Ontario (2004) reports that 64% of Ontarians with CRC are diagnosed with colon cancer of both right and left colon combined. Despite a slight increase in the 5-year survival rates in the last decade for North America and Western Europe to 65% and 54% respectively (Parkin et al., 2005), its relatively poor prognosis maintains colon cancer as a major cause of death worldwide.

If colon cancer spreads beyond the colon to nearby lymph nodes and/or to distant organs, such as the liver or lungs, it is termed as advanced cancer. For the purpose of this study, ACC is defined as stage III or IV, according to the tumor, node involvement, and metastasis (TNM) staging system of the American Joint Committee on Cancer (AJCC) (Greene et al., 2002). Advanced colon cancer treatment aims to control disease progression and to provide symptomatic relief and palliation. Adjuvant chemotherapy (drug therapy after primary surgical resection) is the recommended medical treatment for patients with ACC (Shah, 2008; Young & Rhea, 2000).

For decades, 5-fluorouracil (5-FU) was the sole adjuvant chemotherapy agent for CRC. In the modern era, the availability of new active agents, such as irinotecan, oxaliplatin, and three humanized monoclonal antibodies (bevacizumab, cetuximab, and pantumumab) has significantly improved outcomes for patients with CRC (Shah, 2008). A Cochrane database review on the supportive care of patients with advanced gastrointestinal (GI) cancers (stomach, gastric, and colorectal cancers) reports that chemotherapy, along with supportive care, improves survival, quality of life (QOL), and median time to disease progression (Ahmed, Ahmedzai, Vora, Hillam, & Paz, 2004). The United States (US) population-based estimates for five-year relative survival rates are 55% and 5% for AJCC stage III and IV CRC respectively (Ries et al., 2000).

Theoretical framework - supportive care needs.

Supportive care services are those designed to meet the non-medical needs of patients. Fitch (2000) denotes supportive cancer 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 prediagnostic, diagnostic, treatment and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement (p. 41).

The Supportive Care Framework for Cancer Care described by Fitch (2008) was utilized as the theoretical framework for this study. This framework builds on many constructs, one of which is human needs. According to Fitch (2008), "…supportive care must be based upon, and matched with, an individual's needs within the context of his or her unique situation" (p. 11).

The diagnosis of cancer may interfere with an individual's usual approach to meeting physical, emotional, psychological, social, and spiritual needs (Fitch, 2000; Fitch, 2008; Frank-Stromberg & Wright, 1984). The nature of these needs differ from one person to another and may change for the same person over time. Supportive care needs also are individualized based on factors related to age, gender, socio-economic status, education, religion, language, culture, and personal/family preferences.

The supportive care interventions offered to each patient must be based on careful assessment of an individual's perception of the illness situation, personal needs, desired goals, and ways of coping (Fitch, 2008). Patients with cancer require specific types of supportive care interventions depending on their needs, which are conceptualized in Appendix A (Supportive Care Framework). All patients entering the cancer care system require basic supportive care services to satisfy their SCNs. Some may require specialized interventions to meet their SCNs and a few may require intensive interventions (e.g., for severe and/or complex symptoms or psychological distress). It is essential for regional cancer centres, such as the JCC to design their own structure and procedures for coordinating supportive cancer care services that are suitable for a particular community, its geography, culture, and existing resources. Changes that are implemented should be made on the basis of explicit evidence, including empiric information, and the voice of consumers.

Chapter Summary

This quantitative study is a first step in a comprehensive needs assessment to identify the specific met and unmet SCNs of patients with newly diagnosed ACC (stages III and IV). It provides insight into the severity, prevalence, and importance of SCNs and the existing gaps between unmet needs and use of available supportive care services. The results of this needs assessment will be used to inform the future planning and evaluation of new supportive care services, specific to this vulnerable patient population.

This chapter provided an overview of the disease, treatment, and prognosis as well as the theoretical framework of the study. It also provided a brief introduction to the potential burden of illness associated with ACC and the rationale for developing a better understanding of the SCNs of this patient population. Chapter 2 provides a review, critique, and synthesis of research-based literature relevant to the SCNs of patients with CRC. Chapter 3 outlines the purpose, research questions, and design of this study. The research methods for data collection and analysis also are discussed. Chapter 4 reports the study findings of a self-report questionnaire that examined the SCNs of patients with

ACC during the diagnostic phase (i.e. prior to starting adjuvant treatment) of the cancer continuum. Chapter 5 provides an in-depth discussion of the study findings. The thesis concludes with recommendations for designing needs-based supportive care services for patients with ACC, followed by the implications for nursing practice and future research.

CHAPTER 2

Literature Review

This chapter begins by defining needs, unmet needs, and needs assessment. Following this, the rationale for conducting a needs assessment and the appropriate use of study designs to measure factors related to this study such as, prevalence and severity, is presented. An overview of background literature related to SCNs among patients with different types and stages of cancer is described. Finally, a literature review and critique of relevant supportive care studies are provided to establish the need for this study and rationale for some of its design features.

Needs and Needs Assessment

Foot (1996) defined needs as the requirement for some action or resource that is necessary, desirable, or useful to attain optimal well-being. Carr and Wolfe (1976) stated that “unmet needs are defined as differences between services judged necessary to deal appropriately with health problems and services actually received” (p. 418).

According to Rossi and Freeman (1993), a needs assessment is the “systematic appraisal of the type, depth, and scope of a problem” (p. 56). A needs assessment is a research activity designed to determine a community’s service needs and utilization patterns (Warheit, Bell, & Schwab, 1977), to identify gaps in service provision (Windsor, Baranowski, Clark, & Cutter, 1984), and to prioritize the creation of service programs (Fishman & Neigher, 1979; Siegel, Attkisson, & Carson, 1978). It is important to note that a systematic needs assessment is the first step in planning a relevant ambulatory or community-based program (Hackbarth, 2001; Myers, 1988). Quantitative assessment is essential to identify and describe the extent and importance of unmet SCNs among patients recently diagnosed with ACC.

An important question to ask at this point is: What are appropriate study designs to investigate a range of needs, their frequency, and specific issues about the needs, for example, severity of SCNs or unmet needs?

Prior to addressing this question, it is essential that the difference between qualitative and quantitative studies in the field of advanced CRC be articulated, as there are studies of needs in the literature that employ either a qualitative or quantitative design. While it is possible to conduct a needs assessment using a mixed methods (Macnee, 2004), none were found in the literature on the topic under investigation.

Qualitative studies "focus on understanding the complexity of humans within the context of their lives and on building a whole or complete picture of a phenomenon of interest" (Macnee, 2004, p.24). According to Marshall and Rossman (2006), the main purpose of the qualitative research method is to describe, explore, and explain the phenomenon being studied. Common examples of this paradigm are the phenomenological method (describing the lived experience), the grounded theory method (seeking to develop theory about key social processes), and the ethnographic method (examining groups of individuals to ascertain life ways or patterns) (Streubert & Carpenter, 2006).

Quantitative research "focus on understanding and breaking down the different parts of a phenomenon or picture to see how they do or do not connect" (Macnee, 2004, p. 24). Research questions related to the cause, prognosis, diagnosis, prevention, treatment, or economics of health problems are best answered using quantitative research designs (Cullum, Ciliska, Haynes, & Marks, 2008).

Appropriate designs for needs assessment are observational in nature, with the cross-sectional survey being the major study design used for this type of research. With the cross-sectional design, observations are made at a point of time or within a period of time. Variables such as prevalence or severity can be described and associations can be examined (Hulley, Cummings, Browner, Grady, & Newman, 2007). Another possibility for the design of a needs assessment is the prospective cohort design, whereby the subjects are observed at the present and then followed into the future to determine outcomes or changes over time, using measures including incidence (Hulley et al., 2007). Incidence is calculated using a numerator which is the number of subjects presenting with a new outcome of interest emerge among those who were initially free of it at the outset of the study, over the denominator, the number of subjects who were susceptible to the outcome when the study began. The latter study design can permit examination of needs, for example, frequency, and severity, at the outset of the study, provided that the time period examined (usually at the beginning of the study) does not exclude subjects with needs at the outset (Time 1).

In the case of cross-sectional studies, the proportion of a group of individuals possessing a clinical condition or outcome in a given time point is measured. This is called prevalence. The numerator is the number of subjects with the outcome(s) of interest and the denominator is the total number of subjects examined (Fletcher, Fletcher, & Wagner, 1996). As indicated above, prevalence can be examined at the beginning of a prospective cohort study if the presence of needs is not an exclusionary criterion of entry into the study (Fletcher et al., 1996). The severity of the SCNs can usually be identified from the magnitude/degree of the need measured using a reliable and valid scaled questionnaire.

Common Supportive Care Needs among Patients with Cancer

A general overview of supportive care needs assessments.

This section provides a general overview of the SCNs, as identified by Fitch (2000) (refer to the Fitch's definition of SCNs in Chapter 1) among patients with cancer. In keeping with Fitch's Supportive Care Framework for Cancer Care (2008), studies that addressed one or more domains of SCNs (i.e., physical, social, emotional, informational, psychological, spiritual, practical) were selected for review.

Supportive care needs may vary depending on several factors such as the type of cancer, stage or extent of disease, and the phase of the cancer care trajectory. Before examining studies of patients with CRC, a brief overview of four quantitative studies examining the SCNs of adults with various types of cancer are presented.

To retrieve the relevant research literature about the SCNs of patients with cancer, the existing published evidence was identified through computer searches. The electronic databases included in the search were: OVID Medline, PubMed, CINAHL, TRIP, Embase, Cochrane Database of Systematic Reviews, and PsycINFO. The search strategy was created to identify articles that had "carcinoma/neoplasm" and "needs assessment/supportive care needs/health services needs and demands" in the key words or text of the article. Hand searches were done of articles highlighted from the reference lists of electronic publications.

Weisman and Worden (1976) conducted semi-structured interview to investigate the needs of 120 patients with newly diagnosed cancers of various types in Massachusetts, US. They found that patients with poorer prognoses experienced a greater number of concerns that were reported in the first few weeks following diagnosis and that the concerns decreased through the next 100 days during the post-diagnosis assessment period. A cross-sectional survey of Ontarians (n=134) revealed that newly diagnosed patients had greater physical and emotional needs compared to those receiving post-treatment follow-up care (Whelan et al., 1997). More recently, in a cross-sectional study, the CCS (2003) surveyed Ontarians with different types of cancer (n=397) and found that over 80% of patients identified unmet needs related to supportive care, access to and delivery of cancer services, communication, and information. Similarly, a Canadian study of patients (n=46) with breast, thoracic, GI, and genitourinary cancer identified six categories of unmet SCNs related to daily living, information, emotional support, interaction with the healthcare team, physical health, and social relationships (Hohenadel et al., 2007).

Another recent cross-sectional survey was conducted in 2009 by the Cancer Quality Council of Ontario (CQCO) to assess patients' satisfaction with ambulatory cancer services (n=4,773). Approximately half (58%) of the patients were satisfied with services related to emotional support. When "emotional support" was examined in detail, according to its sub-components, only 34% and 42% of patients, respectively, reported that they received information about relationship changes and emotional changes from cancer (CCO, 2010a).

Studies examining the SCNs of adults with different types of cancer report high levels of unmet needs related to information (Foot & Sanson-Fisher, 1995), physical functioning, activities of daily living, psychological support (Mor, Masterson-Allen, Houts, & Siegel, 1992; Newell, Sanson-Fisher, Girgis, & Ackland, 1999; Sanson-Fisher et al., 2000), and emotional well-being (Mizuno, Arita, & Kakuta, 2005). Soothill et al. (2001) reported unmet social, emotional, and daily living needs among adults receiving treatment for different types of cancer. Houts et al. (1988) found that patients experience unmet emotional and spiritual needs at diagnosis and unmet practical needs in the palliative phase of disease.

Studies of supportive care needs related to advanced cancer.

Using a similar search strategy as above, the literature on the SCNs of patients with advanced stage cancer was retrieved by using key search terms such as, “advanced stage” and “carcinoma/cancer” and “needs assessment/supportive care needs/health services needs and demands”. Published cross-sectional studies have identified that adult with advanced cancer experience significantly higher levels of needs compared to those with localized disease (Foot & Sanson-Fisher, 1995; Sanson-Fisher et al., 2000; Mor, Allen, Siegel, & Houts, 1992). In addition, Weitzner, McMillan, and Jacobsen (1999) reported that unmet needs of patients with cancer who are receiving palliative care were greater than those receiving curative treatment.

An overview of colorectal cancer studies on specific supportive care needs.

Since the 1980s, several studies have identified that patients with CRC report physical problems such as pain, fatigue, altered bowel patterns, changes in appetite, and weight loss (Maguire, Walsh, Jeacock, & Kingston, 1999; Whynes & Neilson, 1997), and psychological issues such as depression, anxiety, coping difficulties, body image changes, impaired sexual functioning, social isolation, uncertainty, and loneliness (Fernsler, Klemm, & Miller, 1999; Galloway & Graydon, 1996; Klemm, Miller, & Fernsler, 2000; Knowles, Tierney, Jordell, & Cull, 1999; Kurtz, Kurtz, Stommel, Given, & Given., 2002; Lynch, Cerin, Newman, & Owen, 2007; Sprangers, Taal, Aaronson, & te Velde, 1995; Ulander, Jeppson, & Grahn, 1997; Whynes & Neilson, 1997). Key results of a number of these studies follow.

Using a prospective cohort design, Lynch et al. (2007) examined the differences in the physical activity of patients with CRC before and after diagnosis (within six months). One of the key findings was that CRC-specific factors such as adjuvant therapy and having a stoma negatively impacted physical activity post-diagnosis. In a review of 17 studies, Sprangers et al. (1995) found that following surgical procedures for CRC, patients without stomas generally did better in terms of psychological, social, and sexual functioning than patients with stomas. However, both patient groups (with or without stoma) suffered from physical impairment induced by frequent or irregular bowel movements and diarrhea.

In another prospective cohort study, Ulander et al. (1997) explored QOL and independence in activities of daily living (ADL) among patients with CRC preoperatively and at follow-up, five to eight months later. At intake, 70% of patients reported ADL independence. This figure decreased to 57% at post-operative follow-up. Patients with colon cancer had significantly less pain and constipation at follow-up than did patients with rectal cancer.

A prospective cohort study of symptoms before and three months after surgery for patients with CRC suggested an association between certain symptoms, such as rectal bleeding and heartburn, and the presence of late-stage cancer (Whynes & Neilson, 1997). Patients with CRC receiving adjuvant chemotherapy post-resection were examined in a prospective cohort study to determine changes in information and knowledge needs over four points in time throughout their six months of treatment (Knowles et al., 1999). Patients' perceived information needs and anxiety levels deceased over the six-month period with significant improvement in QOL. However, Knowles et al. (1999) identified two points on the cancer care continuum when information was lacking. The first was prior to starting treatment and the second was after the completion of chemotherapy.

The only study examining the concerns of patients and their spouses after a diagnosis of colon cancer was conducted by Northouse, Schafer, Tipton, and Metivier (1999) in the US. This descriptive cross-sectional study interviewed 30 patients and their spouses using a structured interview format and performed a qualitative analysis of the interview data. Nearly 50% of the patients had stage III or IV colon cancer. The authors found that 47% of patients expressed negative feelings (fear, anger, disgust, surprise, loss of control) about the initial diagnosis. Fifty-seven percent of patients reported lifestyle changes and unmet information needs and 53% of patients cited fear of cancer recurrence.

The major limitations of this study were overrepresentation of male patients (80%) and recruitment over a variable time interval (two to 36 months after diagnosis).

The diagnosis of cancer can evoke a variety of psychological responses. One such response is a feeling of uncertainty which has been identified as a common experience among patients diagnosed with CRC (Galloway & Graydon, 1996; Northouse et al., 1999; Shaha et al., 2008). In a cross-sectional study, the influence of life stage on psychosocial adjustment in 100 post-operative patients with CRC in Japan was examined (Nishigaki et al., 2007). The authors found that younger patients (age 35 to 65 years) with advanced CRC exhibited poor adjustment due to their domestic role of child-rearing and fear of recurrence and death. For patients over 65 years of age, the psychosocial adjustment was poorer for patients with colon cancer compared to those with rectal cancer.

Klemm et al. (2000) described the demands of illness experienced by patients treated for CRC using a descriptive cross-sectional study design. Demands of illness were found to be greater among men and those with metastatic disease. On the other hand, increased psychological distress was reported for patients less than 45 years of age (Fernsler et al., 1999; Klemm et al.) and for women with CRC (Kurtz et al., 2002). Social adjustment issues, such as impaired relationships with family and friends, marital problems, and restricted social activities, have been identified as major problems following the diagnosis of CRC (DeCosse & Cennerazzo, 1997; Druss, O'Conner, & Stren, 1969; Sprangers et al., 1995; Thomas, Madden, & Jehu, 1987).

A number of studies compared patients with CRC and those with other types of cancer. Patients with CRC had higher levels of unmet SCNs compared to patients with breast cancer (Sanson-Fisher et al., 2000), greater information needs than men with prostate cancer (Boudioni et al., 2001), more body image issues than those with lung or prostate cancer (Schag, Ganz, Wing, Sim, & Lee, 1994), and the greatest decline in physical functioning due to extensive treatment such as surgery and adjuvant therapy in comparison to elderly patients with lung, breast, or prostate cancer (Given, Given, Azzouz, & Stommel, 2001).

To summarize at this point, the studies examined in this section of the chapter were cross-sectional surveys, prospective observational studies, and prospective cohort studies using several cohorts involving varied populations of patients with different types of cancer, advanced cancer and CRC. The existing quantitative literature identifies that significant physical, functional, social, psychological, and informational needs exist among patients with CRC, irrespective of the stage of disease. These needs are influenced by patient age, gender, stage of cancer, treatment, and the phase of care along the cancer continuum. In addition, studies indicate that patients with CRC may have more frequent and severe needs compared to those with other types and stages of cancer. Therefore, further exploration of the SCNs of patients with CRC is warranted.

The next section examines and critically appraises the research literature related to the prevalence and the severity of met/unmet needs among patients with CRC. This exercise is important as the methods and findings were used to inform this study's design (see Chapter 3).

Studies of supportive care needs of adults with colorectal cancer.

The literature focused on the prevalence and severity of SCNs in patients with CRC were identified through computer searches of the electronic databases, such as OVID Medline, PubMed, CINAHL, TRIP, Embase, Cochrane Database of Systematic Reviews, and PsycINFO. The search strategy was created to identify articles that had “CRC” or “colorectal carcinoma/neoplasm” and “needs assessment/supportive care needs/health services needs and demands” and/or “advanced stage” and/or “early diagnosis/diagnosis” in the key words or text of the article. Relevant articles highlighted from the reference lists of electronic publications were hand searched. Articles written in English and published from 1969 to 2010 were considered, as the history of SCNs assessment for patients with CRC dates back to the late 1960s.

The titles and abstracts were reviewed for relevance. Initially, articles were considered relevant if they explored SCNs of patients with CRC regardless of disease stage, treatment strategy, or phase in the cancer continuum. Only quantitative studies were considered that examined unmet/met SCNs of patients with CRC and employed appropriate designs to determine the prevalence of needs, and possibly the severity of needs. Three studies were assessed as suitable for this literature review (Macvean et al., 2007; Bailey & Corner, 2004; and Maguire et al., 1999). A summary of these three studies are outlined in Appendix B.

Macvean et al. (2007) evaluated the feasibility of a volunteer-delivered intervention, called the Pathfinder Program, to reduce the unmet SCNs of Australians with CRC. They conducted a prospective cohort study of 52 patients who were identified from a population-based registry within four months of CRC diagnosis. First, the pre-intervention needs were assessed using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), the 59-item Supportive Care Needs Survey (SCNS) (Sanson-Fisher et al., 2000), and a CRC-specific checklist. The Pathfinder interventions were then offered, and patients were interviewed to determine its impact on health and wellbeing.

For the purpose of this prevalence literature review, only the pre-intervention phase of the study was considered. In the pre-intervention period, the most common needs reported by participants were fear of cancer spreading and returning, concerns about family members, uncertainty of future, anxiety, and fatigue. In relation to CRC-specific concerns, the most common were "gas or wind", changes in weight, and bowel problems (diarrhea, constipation, pain). The anxiety and depression scores in the pre-intervention phase also were reported as high.

The pre-intervention phase was a cross-sectional study which is a suitable research design for estimating the prevalence and severity of needs. The study used an effective requirement strategy for sample selection with a high response rate (93%). Data were collected using reliable and valid tools. However, inclusion of patients with all stages of CRC restricts the applicability of the study findings to patients with ACC (stage III or IV).

To examine the older patients' experiences before and after treatment for CRC, Bailey and Corner (2004) conducted a six-site, prospective, longitudinal cohort study over three-year period in Southampton, United Kingdom. For the purpose of this prevalence literature review, only the pre-treatment phase of the study was considered. In total, 337 patients, aged 58-95 years, with any stage of CRC were interviewed before commencing treatment. Data were collected using the OARS Multidimensional Functional Assessment Questionnaire (OMFAQ) (Fillenbaum, 1988), the Rotterdam Symptom Checklist (RSCL) (de Haes, van Knippenberg, & Niejt, 1990), and a morbidity score derived from a subscale of the OMFAQ.

In the pre-treatment phase, patients reported high psychological distress, severity of morbidity, and poorer QOL and physical health. A strong association was reported between self-care capacity impairment and death occurrence within six to eight months of entering the study, indicating the importance of early functional assessment and tailored interventions. The pre-treatment phase was essentially a cross-sectional design which is appropriate for an examination of prevalence and severity; and reliable and valid tools were used to assess patients for functional status, physical problems, and emotional distress. Unfortunately, the inclusion of patients with any CRC stage and the restricted age range lowers the generizability of the results to the proposed study patient population.

Maguire et al. (1999) conducted a descriptive study to determine the prevalence of patients’ key physical complaints, their main concerns, the prevalence of affective disorders, and the congruence of the carers’ and general practitioners’ (GPs) assessment of these. Sixty-one patients with advanced or recurrence of CRC were identified from a database and approached for participation. Forty-eight carers and 58 GPs of the agreed patients were also interviewed to identify their perceptions of the illness and to determine the congruence of physical and psychological concerns. Data were collected using a semi-structured interview, a concerns checklist (Harrison, Maguire, Ibbotson, MacLeod, & Hopwood, 1994), and the Psychiatric Assessment Schedule (Dean, Surtees, & Sashideran, 1983).

The most common physical complaints were related to pain, appetite, pyrexia, breathlessness, and nausea/vomiting. The congruence between patients' and carers' reports of physical complaints was high for appetite loss (77%), nausea/vomiting (75%), and pain (72%). Low congruence was observed between the estimates of patients' physical complaints and GPs' perceptions (highest being for pain-33%). Patients reported their major concerns in relation to physical evaluation, illness, and inability to do things. About 22% of patients suffered from an affective disorder, which was recognized by the GPs in only five patients. The study used a rigorous sample selection strategy by identifying patients from a population-based database. However, lack of details about the specific research methodology and failure to calculate required sample size, limit the credibility and trustworthiness of the study findings.

Research to date provides evidence that CRC may have a substantial impact on the physical, psychological, social, and sexual functioning of patients across all stages and time points of the cancer continuum. However, in the few quantitative studies reported in the literature, the inclusion of patients with all stages of CRC, failure to report the adequacy of the sample size, and possible differences in healthcare systems limit the applicability of the study findings to patients with ACC in Canada. In addition, current research data does not identify patients who may be at greatest risk or may require more intensive and tailored supportive care interventions.

Most of these studies focus on patients with both colon and rectal cancer as well as across all stages. However, patients with colon and rectal cancer may experience different subsets of needs because of the difference in tumor location, prognosis, and the impact of different treatment regimens. Moreover, CCO (2008a) reports that in the Central West Ontario region, about 60% of patients diagnosed with CRC had colon cancer, among which 59% were classified with stage III and IV. No studies have specifically identified the SCNs of Canadians with newly diagnosed ACC (stage III or IV) at the time of referral to the cancer care system. The paucity of data on SCNs in the colon cancer patient population identifies the importance of documenting the types of unmet needs, the prevalence and severity, using the most rigorous quantitative research design and sampling criteria that are both possible and feasible.

Chapter Summary

In summary, a number of studies have identified the impact and experiences of patients diagnosed with CRC. Previous research has demonstrated that patients with advanced cancer have different and more severe unmet needs. However, no studies have examined the severity, prevalence, and importance of unmet SCNs specific to ACC among Canadians. It seems likely that this group would be quite vulnerable in terms of the number and severity of presenting needs. Future needs assessment studies in this population may inform the development and delivery of appropriate healthcare services at the time of diagnosis for this high risk group of patients.

CHAPTER 3

Methods

This chapter describes in detail the methodology employed to conduct a needs assessment. The chapter starts with an outline of the study purpose, the associated research questions, and the rationale for the study. Specific study methods related to the research design, setting, participants, sample size, recruitment, data collection, and data analysis are then outlined. The chapter also provides information about the various questionnaires used for data collection and the different data analysis tests performed.

Study Purpose

The purpose of this research study was to conduct the first phase of a needs assessment to identify the met and unmet SCNs of patients with newly diagnosed advanced stage III or IV colon cancer at the JCC. This quantitative study is the first step of a comprehensive needs assessment to identify unmet SCNs in terms of severity, prevalence, and patient priorities. The study results provide baseline data to inform the future planning and evaluation of new supportive care services designed to address the specific priorities and unmet needs of this vulnerable patient population.

Research Questions

The specific questions addressed in this study are:

- What are the types, prevalence, severity, and importance of unmet SCNs experienced by adults newly diagnosed with advanced stage (stage III or IV) colon cancer?

- Are specific patient (age, gender, place of residence) and disease (stage of colon cancer, type of recommended therapy) related characteristics associated with the identified priority needs?
- Are there gaps between patient reports of priority unmet needs and patient use of existing supportive care services?

Rationale for Proposed Study

According to Fitch (2008), different patient forums (CCS, 1997; Health Canada, 1993) and stakeholder meetings (Canadian Strategy for Cancer Control, 2002; Canadian Strategy for Cancer Control, 2005) have reported several shortcomings in the provision of integrated supportive care services for patients and families with cancer. One of the barriers to integrated services has been the absence of relevant data about the patterns of SCNs over time and the degree of service use (Fitch, 2000). Other than physical needs, healthcare professionals frequently fail to fully assess the broad range of SCNs at scheduled patient clinic visits. Fitch (2005) states that nurses must not only care for physical symptoms, but also provide support for the psychosocial, practical, and spiritual consequences of advanced stage disease among patients with cancer. Many patients in Ontario are also unaware of, or underutilize the existing supportive care services (Whelan et al., 2003), particularly before and following care provided within a cancer program (DeGrasse & Hugo, 1996).

The CCS's (2003) cross-sectional survey of patients' and caregivers' needs in Ontario identified that long wait times also contributed to unmet needs and gaps in supportive care services. About 80% and 73% of patients and caregiver participants respectively, indicated a need for shorter waiting times to obtain appointments with cancer specialists (i.e. oncologists in a cancer centre) and to begin cancer treatments. They also reported that the "initial waits created anxiety and were a great source of dissatisfaction" (p. 22). Patients with newly diagnosed cancer in Ontario have an average median wait time of 4.8 weeks (CCO, 2009) before commencing therapy in a cancer-specific treatment centre such as the JCC. More specifically, less than half (49%) of patients with GI cancer are seen, from the referral to the specialist consult, within the target of 14 days (CCO, 2011a).

Another study conducted at the JCC identified that at the time of referral, patients with newly diagnosed cancer frequently reported physical, emotional, social, and informational needs (Whelan et al., 1997). This study formed the basis for developing a general supportive care program aimed at meeting a broad range of needs for patients with cancer and their families at the JCC. However, the literature indicates that patient needs and demands for healthcare services are often specific to the type of cancer, stage of disease, treatment modality, prognosis, and pre-existing co morbidity.

There is a steady increase in the incidence and survival rates of patients with ACC among Ontarians (CCO, 2004; CCS & NCIC, 2011; Shah, 2008), as indicated in Chapter 1. This patient group has significant problems and needs due to complications resulting from liver or lung metastasis, the lack of clarity about chemotherapy choices, and the stigma attached to this cancer diagnosis (Galloway & Graydon, 1996; Northouse et al., 1999; Shah; Shaha et al., 2008). The care of patients with ACC requires the assessment and management of needs related to specialized treatment (surgery, chemotherapy, and/or radiation therapy), symptom control, and psychosocial support (Young & Rhea, 2000).

The current cancer care system is challenged to allocate limited financial and human resources to address the growing needs for cancer services. Furthermore, many individuals are “lost in transition” between initial diagnosis and commencing cancer treatment due to the fragmented healthcare system and long waiting times (CCO, 2009; CCS, 2003). Consequently, there is an urgent need to develop more effective models of supportive care to meet the rising demands of care for patients and families affected by colon cancer starting at the diagnostic phase (Appendix C-Model of Rising Demand for Needs-driven Care). It is therefore essential to identify the priority SCNs of patients who have been recently diagnosed with ACC (stage III or IV) at a local level. While the purpose of this study is to examine needs specific to patients at the JCC, some of the results may be generalizable (Macnee, 2004) to similar patient populations with colon cancer at other regional cancer centres in Ontario.

As a first step in planning supportive care strategies, this quantitative study is one component of a comprehensive assessment to identify the SCNs of patients newly diagnosed with ACC. The results of this study can be used by healthcare planners to design effective models of supportive care services specific for this patient population prior to and at the point of entry into the cancer care system in centres like the JCC. The study builds on the evidence that patients with colon cancer may have unmet SCNs and that the distress associated with their unmet needs may be heightened at the time of diagnosis, especially for those with advanced disease.

Study Design

This descriptive study is a needs assessment, using a cross-sectional survey design to identify and describe the SCNs of patients with ACC. A needs assessment is a systematic process for discovering who has needs, why they exist, and which solutions might meet the identified needs (Edmonton Social Planning Council, 2009).

Determination of the gaps between needs and healthcare services through a needs assessment can inform subsequent program modifications and evaluation within regional cancer centres such as the JCC. A needs assessment can also help healthcare planners to prioritize the introduction of new health services and maximize the use of existing services in times of scarce resources.

The survey approach provides a “snapshot of how things are at a specific time” (Denscombe, 1998). Surveys are well suited to descriptive studies that aim to gather information on certain phenomena such as beliefs, activities, preferences, or attitudes through self-report by study participants (Dicenso, Guyatt, & Ciliska, 2005; Kelley, Clark, Brown, & Sitzia, 2003). According to Kelley et al. (2003), descriptive studies can be used to estimate specific parameters in a population (e.g. the prevalence of SCNs among adults recently diagnosed with ACC) and to examine associations (e.g. between identified needs and patient characteristics such as age or gender).

Setting

The JCC is a tertiary comprehensive cancer care facility in Hamilton, Ontario providing radiation, chemotherapy, and supportive care services. It is one of the nine regional cancer centres in Ontario, Canada and serves a population of 2.3 million in the

Central West region of the province. Within this region, there are nearly 246 new cases of colon cancer each year, of which 59% have advanced disease, both stage III and IV combined (CCO, 2008a). Each year, approximately 146 patients with ACC are referred to the JCC by surgeons or GI specialists for radiation and /or chemotherapy.

Study Participants

Between February and November 2010, all patients recently diagnosed with colon cancer who were referred to the JCC for cancer treatment, were screened for eligibility to participate in the study. Patients were eligible for the study if they met the following criteria: age 18 years or older; newly diagnosed with pathology or biopsy confirmed ACC (AJCC stage III or IV); referred to the JCC for chemotherapy or radiation; had no obvious mental or intellectual impairment; could speak, read, and understand English; and had the physical and cognitive ability to complete the self-report questionnaire. Patients were specifically excluded if they had a recurrence of colon cancer or if they were receiving or had received prior chemotherapy or radiation treatment.

Sample Size

The Supportive Care Framework of Fitch (2008) identifies that approximately 20% of patients entering the cancer system have unmet SCNs and require basic supportive care services (Appendix A-Supportive Care Framework). Moreover, the prevalence of significant psychological distress has been reported to be between 20% and 30% for mixed groups of outpatients with cancer (Derogatis et al., 1983; D’Arcy, 1982; Farber, Weinerman, & Kuypers, 1984; Fitch, Vachon, Greenberg, & Franssen, 1996; Whelan et al., 1997). The CCS’s (2003) survey of needs reported that 20% of Ontarians identified barriers to meet their health service needs. In order to capture patients with moderate to severe unmet needs, a 20% prevalence of unmet needs was identified as being clinically significant and may warrant new interventions or approaches to care delivery. To estimate the 20% prevalence of severe or distressing unmet needs with a 95% confidence interval and a 10% margin of error, a required sample size of 62 patients was determined as per the statistical equation $n = \frac{z^2\sigma^2}{d^2}$ (Daniel, 2005; Loney, Chambers, Bennett, Roberts, & Stratford, 2001). According to CCO (2008a), each year nearly 146 patients with ACC (stage III and IV combined) are referred to the JCC for adjuvant treatment.

Recruitment

Previous qualitative studies explored the experiences of being diagnosed with cancer by interviewing patients in the first few weeks following their diagnosis (Gotay, 1984; Weisman & Worden, 1976). Houldin and Lewis (2006) recruited patients in the first three months following diagnosis to describe the experiences of living with newly diagnosed stage III or IV CRC. Taylor (2001) suggests that patients with CRC should be interviewed within a few weeks of being given their diagnosis in order to collect more accurate data regarding their SCNs during this time period. The majority of patients receive their definitive diagnosis and treatment recommendations from the oncologist during their first appointment at the JCC. Therefore, eligible patients were approached during the first or care plan appointment (before they began treatment) for participation in the study.

Eligible patients were identified by the primary care team (i.e., GI disease site nurses and oncologists) at the time of the patient's first visit to the JCC using a screening tool (Appendix D- Screening Tool). The primary care team informed eligible patients of the study and sought patients' permission to be contacted by the student researcher. The student researcher approached all interested patients in-person during their clinic visit, described the study and invited them (Appendix E-Telephone Script/Invitation Letter) to participate and provided them with an information sheet (Appendix F-Participant Information Sheet). The patients were asked for their willingness to complete the self-report survey and their informed consent (Appendix G-Consent Form for Participants) was obtained.

Data Collection

Patients were asked to complete a questionnaire to identify and describe SCNs they had experienced since first learning they may have colon cancer. The method of a self-administered written questionnaire was selected as studies have shown that patients prefer identifying unmet needs in a questionnaire rather than through a face-to-face or telephone interview (Bonevski et al., 2000; Sanson-Fisher et al., 2000; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Self-administered questionnaires have several other advantages. They are inexpensive to produce, are less labour intensive compared to interviews and/or focus group, and yield quantifiable responses (Mansell, Bennett, Northway, Mead, & Moseley, 2004; Esposito, 2001). Patients were asked to complete and return the questionnaire package prior to starting chemotherapy or radiation, to avoid confusion with pre and post treatment needs.

Procedure and instruments.

Demographic and clinical data collected from eligible and consenting patients included: age, gender, the first three letters of their postal code, marital status, education level, perceived stage of disease at diagnosis, and other health problems (Appendix H – Section A: Demographic data sheet). These demographic and clinical data were collected to analyze the relationship between patient or disease characteristics and the reported priority needs.

General supportive care needs questionnaire.

General and colon cancer-specific measures were used to identify the SCNs of adults with ACC (stage III or IV). The Supportive Care Needs Survey-Short Form (SCNS-SF) (Appendix H – Section B: SCNS-SF34), a revised version of Supportive Care Needs Survey (SCNS) Long Form 59, is a 34-item self-report written questionnaire developed by researchers in Australia (Bonevski et al., 2000; Sanson-Fisher et al., 2000). This scale identifies five domains of need patients may have as a result of their cancer: physical and daily living, psychological, patient care and support, health system and information, and sexuality. For each item, participants responded on a five-point scale: "1 = no need, not applicable," "2 = no need, satisfied," "3 = low need," "4 = moderate need" or "5 = high need". According to Bonevski et al., the purpose of the SCNS is "to provide a direct and comprehensive assessment of the multidimensional impact of cancer (including assessment of health services and treatment delivery) on the lives of … cancer patients" (p. 218). The SCNS is identified as one of the most comprehensive instruments for assessing the full range of needs related to health status (Richardson, Medina, Brown, & Sitzia, 2007).

Recent research has identified the SCNS as an excellent index of the global needs of oncology patients (Bonevski et al., 2000) and is an instrument with excellent psychometric properties (Bonevski et al.2000; Richardson et al., 2007; Sanson-Fisher et al., 2000). The internal reliability of all five subscales of the SCNS yields Cronbach alpha coefficients ranging from 0.87-0.97 (Bonevski et al., 2000; Richardson et al., 2007). Construct validity was demonstrated by factor analysis and revealed five factors with eigenvalues greater than one, which together accounted for 64% of the total variance (Bonevski et al., 2000; Richardson et al., 2007; Sanson-Fisher et al., 2000).
Flesch-Kincaid tests of reading ease indicate that the self-administered SCNS-SF, which takes approximately 20 minutes to complete, is easily understood by people with reading ability at the fourth to fifth grade level (Bonevski et al., 2000; Richardson et al., 2007; Sanson-Fisher et al., 2000). The SCNS-SF questionnaire asks participants to indicate the magnitude of their need (low, moderate, or high), which allows one to identify the extent of one need item relative to others.

Snyder et al. (2007) investigated different types of needs assessments and found that patients with cancer indicated a greater preference for the SCNS versus the other questionnaires. The SCNS has been utilized to identify unmet SCNs in a wide range of cancer populations including patients with breast cancer (Aranda et al., 2005; Minstrell, Winzenberg, Rankin, Hughes, & Walker, 2008), prostate cancer (Steginga et al., 2001), brain cancer (Janda et al., 2008), CRC (Macvean et al., 2007), and mixed types of cancer (Sanson-Fisher et al., 2000; Snyder et al.).

Colorectal cancer-specific tool.

As the SCNS-SF questionnaire does not include specific CRC related needs, a nine-item CRC subscale taken from the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) was incorporated into the survey (Cella et al., 1993). The FACT-C (36-items) is comprised of the Functional Assessment of Cancer Therapy-General's (FACT-G) four subscales and the CRC subscale. The CRC subscale assesses the QOL in patients with colon cancer related to swelling or cramps in the stomach, weight, bowel pattern, digestion, diarrhea, appetite, appearance of the body, and stoma problems (Appendix H – Section C: CRC-specific concerns [FACT-C]). The CRC subscale of the FACT-C was found to have adequate convergent and divergent validity (Ward et al., 1999). Research suggests that the FACT-C is a reliable and valid measure with good internal consistency (alpha coefficients above 0.85) and concurrent validity. A study specific priority needs checklist incorporating need items from both the SCNS-SF questionnaire and FACT-C subscale was used to identify the top priority needs or problems for patients with stage III or IV colon cancer (Appendix H –Section D: Priority Needs). A similar checklist has been used effectively to examine the SCNs of men with advanced prostate cancer (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2010).

Health service utilization tool.

The Health Service Utilization (HSU) Questionnaire is a standard questionnaire designed to assess the type and quantity of health services used by patients (Browne, Gafni, Roberts, Goldsmith, & Jamieson, 1995) (Appendix H-Section E: HSU Questionnaire). Through this self-report questionnaire, the respondents reported their use of different types of direct and indirect healthcare services such as social services, community services, emergency services, hospitalization, outpatient medical procedures, diagnostic tests, blood tests, and pharmacy services. Previous studies using this questionnaire have reported high levels of agreement (0.72-0.99) between the patients' response and medical records (Browne, Arpin, Corey, Fitch, & Gafni, 1990; Browne et al., 1995). This questionnaire also included an up-to-date inventory of cancer related health services available for patients with CRC in the Central West Ontario region.

Prior to conducting the survey, the study questionnaire was piloted with six patients undergoing treatment or on follow-up care for colon cancer at the JCC. For the pilot testing, patients completed the questionnaires and then provided comments on a reviewer form (Appendix I- Reviewer Form) about the acceptability, clarity, readability, and completeness of the questionnaires and time required to complete it. Based on reviewer comments, modifications were made to improve the readability of the questionnaire by increasing the font size and bolding the text in shaded sections.

All eligible consenting patients were given the questionnaire package (Appendix G), and if indicated, a stamped self-addressed reply envelope to take home. Patients were given options to either complete the questionnaire on the same day in the clinic or to complete the questionnaire at home and return it. All the consented patients took the questionnaires home and returned it at their next appointment or by mail within 7-14 days. Patients who did not return the questionnaires within 15 days received one or two reminder telephone calls by the student researcher.

Data Analysis

The collected data were entered into a database and were double-checked by a research assistant who randomly selected and counter checked ten participants' data entry to ensure there were no errors in entering data. All analyses were carried out using Statistical Package for the Social Sciences (SPSS) (SPSS Inc., version 17, Chicago, III) software. Descriptive statistics in the form of frequency counts, percentages, and mean or median scores were utilized to describe the patient population. The prevalence, severity, and importance of the unmet SCNs were identified by calculating the percentage and mean scores of the reported unmet needs. Pearson correlation was performed to examine the relationship between patient's age and reported priority unmet needs. Chi-square tests were utilized to test for associations between the priority unmet needs and categorical data related to patient or disease characteristics such as gender, marital status, education level, family support, place of residence, and patient's perception of the stage of colon cancer at diagnosis.

Prior to data analysis, the scores for negatively worded questions on the FACT-C subscales were reversed so that high scores always represented better QOL. The severity of colorectal-specific concerns was determined by calculating the mean scores for each item on the FACT-C subscale. Secondary outcomes of interest involved an assessment of health service use determined by frequency counts for each item on the HSU questionnaire. Potential gaps in meeting patient priority SCNs were determined by descriptive comparison of the frequency, severity, and importance of reported unmet needs and patient reported use of existing healthcare services relevant to specific health needs.

Chapter Summary

This chapter outlined the purpose, rationale, and research questions that were addressed in this study. The study methods were described in detail in relation to the research design, setting, sample, recruitment strategies, and the various tools used for data collection. A summary of statistical tests and methods used for data analysis also were provided.

CHAPTER 4

Results

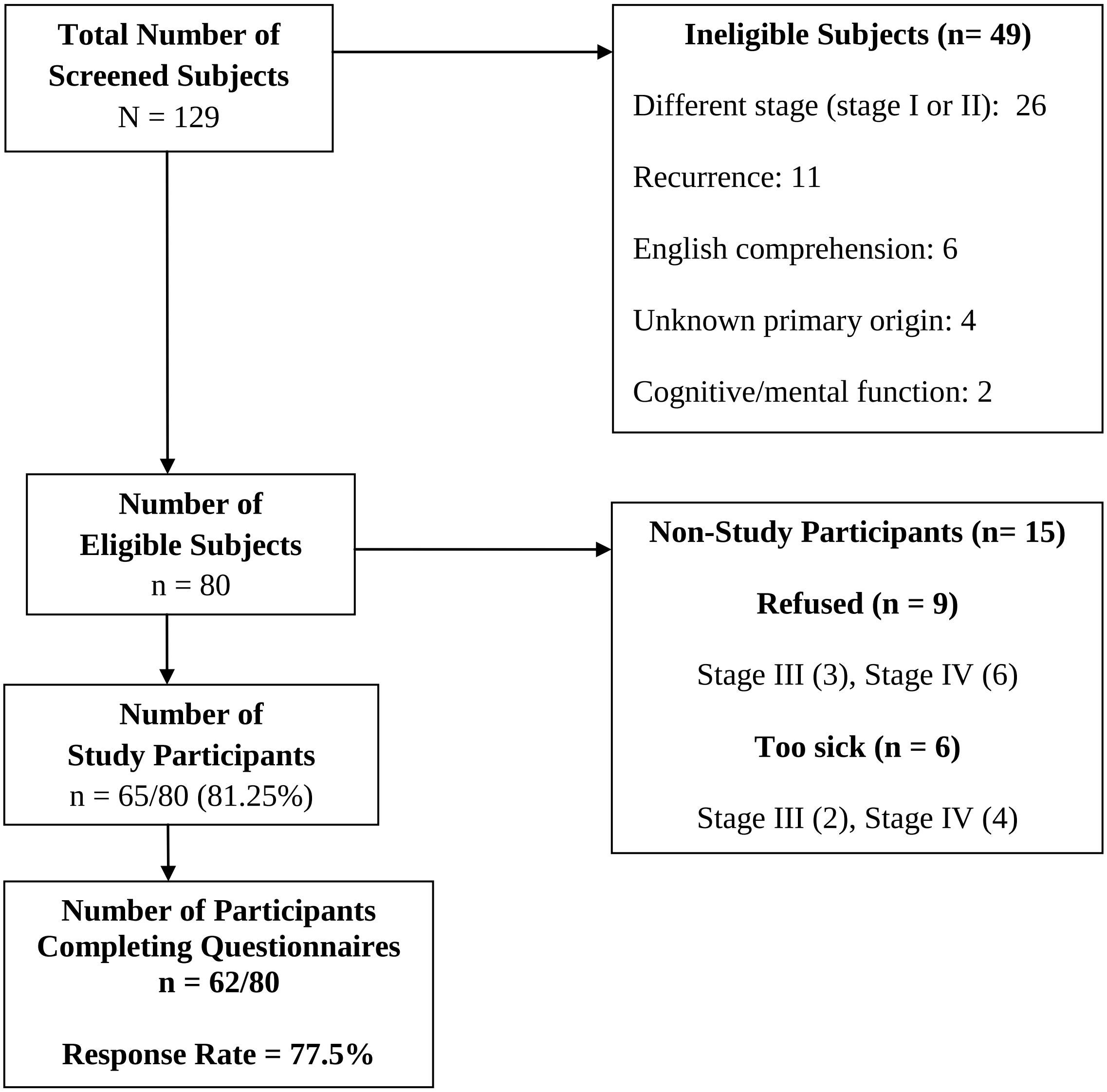
This chapter summarizes the results of the needs assessment. The chapter begins with an overview of the demographic characteristics of the study sample. Specific study findings in relation to the prevalence, severity of unmet SCNs and of CRC concerns, and priority unmet needs are described. The relationship between priority unmet needs and patient or disease characteristics also are reported. Participants' use of healthcare services and resources related to supportive care, laboratory testing, medications, and the use of supplies/devices are also described.

Sample

Between February and November 2010, 129 potential study patients were identified and screened from clinic appointment schedules (Figure 1) at the time of their initial clinic visit to the JCC. Forty-nine patients were ineligible because they had stage I or II disease (n=26), had recurrent CRC (n=11), could not understand or speak English (n=6), had cancer of unknown primary origin (n=4), or had impaired mental health or cognitive function (n=2). Of 80 eligible patients, 65 or 81.3% patients consented and agreed to participate in the study. Reasons for non-participation included refusal (n=9) or that patients were too sick (n=6). Four of the six patients who were too sick were admitted to the hospital for palliative care at the time of their first clinic visit and assessment for study participation. Non-study participants were mostly male (10/15) and had stage IV (10/15) disease. Non-study and study participants were similar in gender (predominantly men) and median age (66 and 65 years respectively). Of the 65 participating patients, 62 (95.4%) completed and returned the questionnaires. One patient died prior to completing the questionnaire and two patients failed to return the questionnaire in spite of two reminder phone calls by the student researcher. Overall, 62 out of the 80 eligible patients completed and returned the questionnaire, with a response rate of 77.5%.

Figure 1

Flow Diagram of Study Population and Sample



Of the returned questionnaires, there were minimal missing data with only 7.1% of items without a response. Table 1 provides a summary of study participants and their demographic characteristics. The median age of participants was 65 years. The majority of participants were married men who had completed high school education or less. Less than half (42%) of the participants lived in Hamilton; others lived in surrounding communities within the health region. Based on patient perceptions of their stage of colon cancer at diagnosis, there were equal proportions of patients who believed they had stage III (39%) and stage IV (39%) disease; however, 22% reported to be unaware of their disease stage.

Prevalence of Unmet Supportive Care Needs

The prevalence of unmet SCNs was assessed by calculating the frequency and the percentage of patients with a score of three or more indicating low, moderate, high need for each of 34-items in the SCNS-SF questionnaire. Table 2 outlines the proportion of patients reporting each of the unmet SCNs categorized by five domains (psychologic, health system and information, physical and daily living, patient care and support, and sexuality) according to the Supportive Care Needs Framework (Fitch, 2008). The most prevalent or frequently reported unmet SCN identified by 83.9% of the participants was ‘fears about the cancer spreading’. The least prevalent unmet SCN identified by 17.8% of the participants was ‘to be given information about sexual relationships’.

Table 1

Demographic Characteristics of Study Sample

Characteristics	Total (N=62)	Percentage (%)
Age (years)		
Age range	36 - 91	
Median age	65	
Gender		
Male	39	63
Female	23	37
Place of residence		
Hamilton	26	42
Other than Hamilton	34	55
Missing	2	3
Marital status		
Married	44	71
Living together/common-law	6	10
Separated	1	2
Divorced/annulled	4	6
Widowed	5	8
Never married/single	2	3
Education status		
High school or less	37	60
College	12	19
University	10	16
Postgraduate	2	3
Missing	1	2
Patient's perception of the stage of colon cancer		
Stage III	24	39
Stage IV	24	39
Do not know	14	22

Table 2

Prevalence of Unmet Supportive Care Needs With a Score ≥ 3 from the SCNS-SF Questionnaire (n=62)

Supportive care needs	Count (n=62)	Percentage (%)
Domain 1: Psychologic		
Fears about the cancer spreading	52	83.9
Worry that the results of treatment are beyond your control	50	80.7
Concerns about the worries of close ones	47	75.8
Uncertainty about the future	46	74.2
Anxiety	42	67.8
Learning to feel in control of the situation	42	67.7
Feeling down or depressed	38	61.3
Feelings of sadness	37	59.6
Feelings about death and dying	35	56.5
Keeping a positive outlook	35	56.4
Domain 2: Health system and information		
Having one member of hospital staff to talk to about everything	37	59.6
Informed about things to help get well	35	56.5
Informed about test results as soon as feasible	32	51.7
Adequately informed about the benefits and side-effects of treatment	31	50.1
Explanations of the tests	30	48.4
Having access to professional counselling as needed	30	48.4
Treated in a hospital or clinic that is physically pleasant	29	46.8
Written information about the important aspects of your care	29	46.7
Treated like a person not just another case	28	45.2
Information about aspects of managing illness and side-effects	27	43.5
Informed about cancer which is under control or diminishing	25	40.4

Supportive care needs	Count (n=62)	Percentage (%)
Domain 3: Physical and daily living		
Lack of energy/tiredness	38	61.3
Not being able to do the things used to do	37	59.7
Feeling unwell a lot of the time	34	54.9
Work around the home	33	53.2
Pain	26	41.9
Domain 4: Patient care and support		
Reassurance by medical staff that the feeling is normal	30	48.4
More choice about which cancer specialists to see	26	41.9
Hospital staff attending promptly to physical needs	26	41.9
Hospital staff acknowledging, and showing sensitivity to, feelings and emotional needs	25	40.3
More choice about which hospital to attend	21	33.9
Domain 5: Sexuality		
Changes in sexual feelings	20	32.2
Changes in sexual relationships	18	29.0
To be given information about sexual relationships	11	17.8

The top ten most frequently reported unmet needs according to the SCNS-SF questionnaire are shown in Table 3. In addition to ‘fears about the cancer spreading’, other highly prevalent unmet SCNs experienced by 60% or more of participants also related to psychological issues (uncertainty of treatment outcomes and the future, concerns about their family, anxiety, depression, feeling in control), physical function, and ADL (lack of energy and not being able to do the usual activities).

Table 3

Top Ten Frequently Reported Unmet Supportive Care Needs (N=62)

Supportive care needs	Number (%)	Domain
Fears about the cancer spreading	52 (83.9)	Psychologic
Worry that the results of treatment are beyond your control	50 (80.7)	Psychologic
Concerns about the worries of close ones	47 (75.8)	Psychologic
Uncertainty about the future	46 (74.2)	Psychologic
Anxiety	42 (67.8)	Psychologic
Learning to feel in control of the situation	42 (67.7)	Psychologic
Feeling down or depressed	38 (61.3)	Psychologic
Lack of energy/tiredness	38 (61.3)	Physical and daily living
Not being able to do the things used to do	37 (59.7)	Physical and daily living
Feelings of sadness	37 (59.6)	Psychologic

Severity of Unmet Needs and Colorectal Cancer-Specific Concerns

The severity of unmet SCNs was measured by calculating the mean scores for each of the 34-items in the SCNS-SF questionnaire. The top ten most severe unmet SCNs are listed in Table 4. Similar to prevalence, the most severe unmet SCNs were fears about the cancer spreading (3.79 ±1.269), worry that the results of treatment are beyond control (3.67 ±1.313), and concerns about the worries of close ones (3.61 ±1.310). On the SCNS scale, these mean scores greater than three reflect a low to moderate level of need.

Table 4

Mean Scores of the Top Ten Severe Supportive Care Needs

Supportive care needs	Number	Mean (SD)
Fears about the cancer spreading	62	3.79 (± 1.269)
Worry that the results of treatment are beyond your control	61	3.67 (±1.313)
Concerns about the worries of close ones	62	3.61 (±1.310)
Uncertainty about the future	62	3.48 (±1.364)
Having one member of hospital staff to talk to about everything	62	3.26 (±1.413)
Anxiety	62	3.21 (±1.345)
Informed about things to help get well	61	3.16 (±1.356)
Informed about test results as soon as feasible	59	3.15 (±1.311)
Lack of energy/tiredness	62	3.08 (±1.406)
Adequately informed about the benefits and side-effects of treatments	61	3.07 (±1.289)

Note: SCNS scale where 1= not applicable, 2= satisfied, 3= low need, 4= moderate need, 5= high need. SD = standard deviation.

In addition, the severity of the CRC-specific needs and their impact on health related quality of life (HRQOL) was captured by calculating the mean scores for each item in the FACT-C subscale (Table 5). On the FACT-C scale, lower scores reflect poorer HRQOL. The two most severe CRC-specific concerns that negatively impacted on HRQOL were related to the body appearance (Mean=1.77, SD=1.37) and bowel control (Mean = 2.28, SD=1.63). Based on the FACT-C subscale, a mean score of less than three reflects poor HRQOL in relation to body appearance and bowel control.

Table 5

Mean Scores of the FACT-C subscale

Colorectal cancer-specific concerns	**Number**	**Mean**	**Standard Deviation (SD)**
I like the appearance of my body	62	1.77	1.372
I have control of my bowels	61	2.28	1.634
I have a good appetite	62	2.48	1.501
I can digest my food well	61	2.66	1.482
I am losing weight	61	2.69	1.361
I have swelling or cramps in my stomach area	61	3.00	1.438
I have diarrhea	60	3.20	1.205

Note: FACT-C subscale where 0= Not at all, 1= A little bit, 2= Some what, 3= Quite a bit, 4= Very much. Negatively stated items (i.e. I am losing weight, I have swelling/cramps in my stomach area and I have diarrhea) were reversed before calculating the mean scores, so that higher score reflect a better HRQOL.

Priority Unmet Needs

A priority needs checklist, incorporating both the SCNS-SF questionnaire and the FACT-C subscale, was used to identify the top three priority unmet needs for study participants. Frequency counts were tabulated for each of the unmet need items to determine the most frequently reported priority unmet needs (Table 6). Of the 62 participants, 60 reported at least three priority unmet needs. The top three most frequently reported priority unmet needs were uncertainty about the future (43.5%), fatigue (24.2%), and information about disease or treatment (22.6%). None of the participants identified needs related to indigestion, vomiting, headaches, physical appearance, family communication, and sexual desire as a priority.

Table 6
Priority Unmet Needs

Priority unmet needs	Frequency (n=62)	Percentage (%)
Uncertainty about the future	27	43.5
Fatigue	15	24.2
Information about disease or treatment	14	22.6
Overall well being	10	16.1
Control of bowel movements	9	14.5
Appetite	9	14.5
Sleeping	9	14.5
Stomach pain or cramps or discomfort	8	12.9
Physical activity	8	12.9
Treatment side effects	8	12.9
Pain	6	9.7
Loss of weight	6	9.7
Family coping	6	9.7
Enjoying time with family and friends	5	8.1
Nausea	4	6.5
Finances	4	6.5
Constipation	3	4.8
Urinary problems	3	4.8
Mood	3	4.8

Priority unmet needs	Frequency (n=62)	Percentage (%)
Thinking or concentration	3	4.8
Emotional coping	3	4.8
Emotional support	3	4.8
Work responsibilities	3	4.8
Abdominal swelling	2	3.2
Diarrhea	2	3.2
Sexual function	2	3.2
Household responsibilities	2	3.2
Family responsibilities	2	3.2
Rectal discomfort or bleeding	1	1.6
Dizziness	1	1.6
Practical needs	1	1.6
Embarrassed due to ostomy (if applicable)	1	1.6
Difficult to care for ostomy (if applicable)	1	1.6
Indigestion	0	0
Vomiting	0	0
Headaches	0	0
Physical appearance	0	0
Family communication	0	0
Sexual desire	0	0

Priority Unmet Needs and Patient or Disease Characteristics

Pearson correlation was conducted to examine the relationship between age and reported priority unmet needs. One positive, but weak association was identified between patient's age and control of bowel movement (r= +0.274, p=0.031), indicating that older patients were more likely to report priority unmet needs related to bowel function.

To explore whether specific patient and disease related variables were associated with priority unmet needs, Pearson Chi-Square tests were performed. Table 7 outlines only the selected patient characteristics with significant association. Men were more likely to report priority unmet needs related to uncertainty about the future (p= 0.039) compared to women. Participants with 'high school or less' education reported priority unmet needs related to fatigue (p=0.005) and appetite (p=0.010) compared to those with 'college or more' education. Participants with higher levels of education (college or more) were more likely to report priority unmet needs related to family coping (p=0.027) compared to those with 'high school or less'. Unmet needs related to appetite (p= 0.011) were less likely to be reported by participants with support at home (married/living together/common-law) compared to those without support at home (separated/divorced/ widowed/never married). No significant association was observed between priority unmet needs and the participant's place of residence (Hamilton versus surrounding communities) or their perceived stage of colon cancer.

Table 7

Selected Patient Characteristics Associated with Priority Unmet Needs

Patient characteristics	Number	Significant priority unmet needs	Fisher's Exact 1-sided tests (p-value)
Gender			
Male	21	Uncertainty about the future	**0.039**
Female	6		
Marital Status			
Married/living together/ common-law	45	Appetite*	**0.011**
Separated/divorced/widowed/ never married	7		
Education			
High school or less	14	Fatigue	**0.005**
College or more	1		
High school or less	9	Appetite	**0.010**
College or more	0		
High school or less	1	Family coping	**0.027**
College or more	5		

Note: Only the priority unmet needs with significant p-value are shown. * Refer to greater number of patients (n=45) 'with support at home' reporting appetite as not a priority unmet need compared to those 'without support at home' (n=7).

Use of Supportive Care Services

The frequency counts for patients' reported use of available services documented on the HSU questionnaire were calculated and the top ten most frequently used services are shown in Table 8. The most frequently used healthcare services identified by 91.9% participants were the 'family-physician or walk-in clinic' and 'physician specialist'. More than 50% of the study participants had accessed the Emergency Department (ED) in the past six months. Nearly half of them (46.8%) have used Community Care Access Care (CCAC) services or a home nurse. Less than 20% of the participants reported using nutrition or social worker services. Although 27.4% of participants had accessed on-line cancer information, less than half (11.3%) used cancer information services offered by the CCS.

With respect to utilization of other community supportive services, only 4.8% of participants had used CCS volunteer drivers and only 3.2% had used support group services (e.g., Cancer Assistance Program [CAP] Circle of Friends). Use of other services (e.g., physiotherapist, psychiatrist, occupational therapist, public health nurse, visiting home maker, Meals on Wheels, CRC Association services, Wellwood peer support, Wellspring information resources, CAP drivers or Wellspring child care) were infrequent.

Table 8

Top Ten Frequently Used Healthcare and Supportive Care Services (N=62)

Services	**Frequency (n=62)**	**Percentage (%)**
Family physician or walk-in clinic	57	91.9
Physician specialist	57	91.9
Emergency Department	34	54.8
In-home nurse/CCAC nurse	29	46.8
On-line cancer information access	17	27.4
Unpaid providers/helpers (i.e. priest, neighbour)	13	21.0
Nutritionist	12	19.4
Social Worker	9	14.5
Financial assistance - Ontario Drug Benefits	8	12.9
911 service	7	11.3
Ambulance service	7	11.3
Cancer Information Services (Canadian Cancer Society)	7	11.3

Use of Hospital Services, Diagnostic Tests, Medications and Devices

About 92% of study participants were hospitalized in the previous six months, and nearly 35% were admitted to hospital more than once. The majority of participants (95.2%) had undergone out-patient diagnostic tests in the previous six months. The most commonly performed tests were blood tests (100%), scans (95.2%), scopes (90.3%), and x-rays (90.3%). About 82.3% of study participants reported taking medications in the previous two days. Of the participants taking medication recently, 59.7% were taking more than five medications per day. Approximately one-third of the participants also used supplies, aides or devices (such as a wheelchair, walker, dressings, syringes, support pillows) in the past six months.

Chapter Summary

'Fears about the cancer spreading' was the most prevalent unmet SCNs. Unmet SCNs experienced by 65% or more of participants related to lack of control about treatment outcomes, the uncertain future, and concerns about family member's well-being. Patients also rated these needs as being most severe. The two most severe CRC-specific concerns were related to body appearance and bowel control. Significant association was noted between priority unmet needs (uncertain future, fatigue, appetite, and family coping) and patient gender, education level, and home support. Patient priorities for improving their health and patient use of available healthcare services were identified.

Chapter 5 further examines major study findings and discusses the contributions of this research to better understand the SCNs of patients with recently diagnosed ACC.

CHAPTER 5

Discussion

An exploration of the study results is the focus of this chapter. Based on participants' reported priority unmet needs and use of existing services the potential gaps in healthcare services are identified. Study findings about the SCNs among patients newly diagnosed with ACC are examined in relation to the existing research literature. Study strengths and limitations are also identified. Different types of nursing roles in cancer control are described with an emphasis on how various models of specialized nursing roles could be used to address the needs of patients with ACC during the diagnostic period. The chapter concludes with the implications of study results for supportive care and nursing practice. Implications for future research are also identified.

Potential Gaps between Priority Unmet Needs and Health Services

Regional cancer centres such as the JCC are responsible for developing high quality, needs-driven supportive care services that improve the health of the cancer population they serve. The purpose of the study was to identify the prevalence, severity, and importance of unmet SCNs experienced by patients recently diagnosed with stage III or IV colon cancer at the JCC. Patients' use of healthcare services over the previous six-month period was identified.

An unmet health need is recognized as the difference between services deemed necessary to deal with a particular health problem and the services actually received (San Martin, Gendron, Berthelot, & Murphy, 2004). Unmet health needs may be due to variability in the availability, accessibility, affordability, and the effectiveness of healthcare services and/or patient awareness of, or satisfaction with, these services. The examination of health service use in this study provides an opportunity to identify potential gaps and/or opportunities for enhancing existing or developing new healthcare services, particularly in relation to patients' identified priority needs for improving their health.

From the patients' perspective, the top three reported priority unmet needs were related to an uncertain future (43.5%), fatigue (24.2%), and information (22.6%). These priority unmet needs were also reported as the most common and severe needs by the participants (Table 3 and Table 4, pg. 43-44). The prevalence of these priority needs exceeds the study's apriori threshold of 20%, indicating a clinically significant unmet need warranting specific interventions such as the redesign or enhancement of existing or the implementation of new healthcare services (Fitch, 2008).

Similar to the findings of the current study, prior research also identifies feelings of uncertainty as a common experience among patients diagnosed with CRC (Galloway & Graydon, 1996; Northouse et al., 1999; Shaha et al., 2008; Whelan et al., 1997). A phenomenological study on patients' perceptions of life after advanced GI cancer diagnosis reported mental changes such as uncertainty and despair, in addition to other physical, practical, and positive changes (Winterling, Wasteson, Glimelius, Sjoden, & Nordin, 2004). Although psychological concerns, such as an uncertain future, were identified in this thesis study as the most common priority unmet need, participants reported limited use of relevant existing supportive care services. For example, just 14% had visited a social-worker and only 3% had consulted a psychiatrist in the previous six months. Only 3% reported using support group services such as those provided by the CAP Circle of Friends or the Wellwood Resource Centre. Addressing psychosocial concerns early in the cancer continuum may be important for preventing the development of more severe psychosocial issues over the course of cancer treatment and follow-up care. High levels of anxiety at the time of diagnosis may be predictive of future symptoms of psychological distress (Nordin, Berglund, Gliemelius, & Sjoden, 2001). Newly diagnosed patients with significant psychological concerns may experience poorer long-term adjustment, higher levels of functional impairment, poorer QOL, and higher expenditures for the use of healthcare services (Bryant-Lukosius, Browne, Gafni, Dicenso, & Neville, 2003).

The current study did not collect information about the underlying reasons for the limited use of the existing supportive care services. Some potential reasons for this limited use might be that patients were unaware of existing services and/or that these services were not easily accessible, as reported by Ontarians in other Canadian studies (Fitch 2000; Whelan et al., 1997; Whelan et al., 2003).

Cancer-related fatigue has been defined as “a persistent subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning” (Mock et al., 2000, p. 151). Fatigue was reported as the second priority unmet need by 24% of participants. A previous study of patients with newly diagnosed cancer, at the time of initial referral to the JCC, also identified fatigue as one of the most commonly reported symptoms (66%) (Whelan et al., 1997). Other studies suggest that fatigue is one of the most common symptoms experienced by patients with advanced cancer (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003; Kozachik & Bandeen-Roche, 2008). A prospective cohort study of elderly patients with cancer, reported that late-stage CRC was associated with a significant increased risk of fatigue (Kozachik & Bandeen-Roche, 2008).

A growing body of research suggests that fatigue can occur concurrently with other symptoms including anxiety, psychological distress, and depression (Ahlberg, Ekman, Wallgren, & Gaston-Johansson, 2004; Koschera, Hickie, Hadzi-Pavlovic, Wilson, & Lloyd, 1999; Pawlikowska et al., 1994). A systematic review of literature on cancer-related fatigue and psychological distress symptoms identified an association between fatigue and anxiety and depression (Brown & Kroenke, 2009). It is possible that such a relationship might have been experienced by participants in the current study, resulting in the most common priority needs related to psychological concerns and fatigue.

A systematic review of non-pharmacological interventions for the management of cancer-related fatigue (Jacobsen, Donovan, Vadaparampil, & Small, 2007) found that few studies have been conducted on patients with CRC or those with metastatic disease. Some of the non-pharmacological interventions evaluated in this review included supportive group therapy, educational programs, relaxation therapy, psychotherapy, and exercise program. Jacobsen et al (2007) summarized that psychological interventions were more effective than activity-based interventions in preventing or relieving cancer-related fatigue. However, their results must be interpreted with caution, as the majority of studies focused on patients with breast cancer or non-metastatic disease or those undergoing active treatment. In the current JCC study, participants' use of non-pharmacological interventions relevant to fatigue management such as support groups, recreational activities (e.g. yoga), and information resources were infrequent.

In the current study, participants with ACC reported wanting more information about their disease and treatment, treatment benefits and outcomes. These findings are consistent with numerous studies demonstrating that unmet needs related to information are prevalent and poorly satisfied among patients with newly diagnosed cancer (CCO, 2010a; Northouse et al., 1999; Whelan et al., 1997). Unmet information needs were also reported by 57% of patients in a cross-sectional study that examined their concerns after colon cancer diagnosis (Northouse et al., 1999). In another cross-sectional study of newly diagnosed Ontarians with cancer, 85% of patients had specific informational needs related to treatment, disease, procedures, and health promotion (Whelan et al., 1997). The percentage of participants reporting information needs as a priority unmet need in the current survey was lower (23%) than that reported by Whelan et al. These differing results in unmet informational needs may be due to the lower representation of participants with CRC (7%) in the Whelan et al. study. Patient satisfaction related to informational needs also scored the lowest in relation to cancer care in Ontario (CCO, 2010a).

Despite the high need for information reported by current study participants, only 27% had accessed on-line cancer information while less than 12% had used cancer information services offered by the CCS. This gap in the use of existing cancer care information resources may be due to lack of patient access to electronic computer-based information and/or lack of awareness of high quality information services, factors which were not explored in the study.

The CCS's (2003) report on SCNs identified that patients and caregivers expressed unmet needs because they are unaware of local support services for financial assistance, transportation, home care, or emotional support. Patients and families are often unaware of where to turn for help, what help is available or how to access it, particularly before and following care provided within a cancer care program (DeGrasse & Hugo, 1996; Fitch, 2000). Similarly, participants with ACC in the current study have minimally accessed relevant, community based supportive care services appropriate to priority unmet needs, during the diagnostic phase. In contrast, a greater proportion (54.8%) of participants have used more acute care medical services such as the ED that are less likely to be effective in addressing identified priority needs related to psychosocial concerns, fatigue, or information.

Comparison of Results with Previous Studies

Supportive care needs and priority needs.

Overall, the results suggest that patients with newly diagnosed ACC experience high levels of unmet SCNs across a range of domains, at the time of first presentation to the JCC. The highest levels of unmet SCNs were related to psychological well-being and accounted for half of the top ten unmet needs identified in this study. The remaining unmet SCNs were related to physical function and ADL.

Unmet SCNs associated with psychological well-being experienced by 65% or more of participants were related to fear of cancer spreading, lack of control about treatment outcomes, an uncertain future, and the well-being of family members. Other studies have also found a high prevalence of psychosocial needs among patients diagnosed with CRC (Galloway & Graydon, 1996; Northouse et al., 1999; Shaha et al., 2008).

A study conducted by Macvean et al. (2007) used a longer version of the SCNS but also reported that ‘the fear of cancer spreading’ was the most prevalent SCN among Australian patients with CRC. However, the percentage of patients reporting this need was substantially lower in the Macvean et al. study (38%) compared to the current JCC study (84%). Patients in both studies had a similar mean age (64 years) but the difference in the time since diagnosis of CRC (i.e. one to ten days in the JCC study versus four months post diagnosis in the Macvean et al. study), may account for this difference. Other studies have reported a decline in psychological distress in the months following a new diagnosis of advanced cancer (Mizuno, Kakuta, Ono, Kato, & Inoue, 2007; Knowles et al., 1999; Weisman & Worden, 1976). Macvean et al. also identified concerns about family well-being and uncertain future in the top five most frequently reported SCNs.

Previous studies have reported that younger patients and women with CRC have increased psychological concerns (Fernsler et al., 1999; Klemm et al., 2000; Kurtz et al., 2002; Simon, Thompson, Flashman, & Wardle, 2009). This finding contrast with the current study, which found that a greater proportion of men reported priority unmet needs related to ‘uncertainty about the future’ compared to women. These differences in study findings may reflect the larger proportion of male participants (63%) in the JCC study.

Unmet SCNs related to physical function and ADL (such as tiredness and inability to do things one used to do) also were reported among participants with ACC, a finding that has been commonly found among patients with CRC (Northouse et al., 1999; Ulander et al., 1997). Northouse et al. (1999) examined the concerns of patients and spouses after the diagnosis of colon cancer and reported that 57% of patients had lifestyle changes associated to functional ability in relation to managing disease symptoms (i.e. diarrhea and colostomy). Among patients with CRC, independent ADL were found to decline from 70% preoperatively to 57% at five to eight months follow-up (Ulander et al., 1997).

A comparative study of elderly Americans with colon, breast, lung, and prostate cancer found that those with colon cancer experienced the greatest decline (61%) in physical functioning due to extensive treatment (surgery plus adjuvant therapy) (Given et al., 2001). They also observed that fatigue had a consistent and significant impact on physical functioning. This suggests that better management of fatigue during the diagnostic period for newly diagnosed patients with CRC may be helpful for improving or maintaining patient functional ability and usual ADL. Nearly half of participants (47%) had used CCAC services or home care nurse in six months prior to their first JCC appointment, which could be related to fatigue and ability to perform ADL.

Colorectal cancer-specific needs.

With respect to CRC-specific needs, the most severe concerns were related to body appearance and bowel control. This finding is consistent with other studies reporting higher body image issues among CRC population (Northouse et al., 1999;

Pieper & Mickols, 1996; Schag et al., 1994; Taylor, 2001). Patients with CRC reported more body image concerns compared to those with lung or prostate cancer (Schag et al., 1994). Bowel problems such as, diarrhea, constipation, gas pain also were identified as common CRC-specific symptoms (about 40-58%) among Australians diagnosed with CRC (Macvean et al., 2007).

Body appearance and bowel control concerns among patients with CRC may be due to disease consequences or the physical impact of surgical colon resection resulting in a colostomy, fecal incontinence, loss of anal sphincter control, or nerve damage. In the current study, a significant association was observed between the participant’s age and control of bowel movement, indicating that older participants may have more severe unmet needs related to bowel control. This greater level of need may be related to declining bowel function associated with normal physiological changes with advancing age (Barrett, 1996; Taylor, Lillies, & LeMone, 1989).

The level of achieved education had an impact on the perceived importance of unmet needs. Participants who had completed lower levels of education reported priority unmet needs related to fatigue and appetite. In contrast, participants with higher levels of education reported family coping as priority compared to those with lower levels of education. Norwood (1999) suggests that Maslow's hierarchy of human needs can help to explain patient needs and the kinds of information that individuals seek at different levels of need. For example, at the top of the hierarchy, enlightening information is sought by individuals seeking to meet their belongingness needs. While at the lower level, individuals seek coping information in order to meet their basic needs. In the current study, highly educated participants may have greater access to resources to meet their basic physical needs, compared to those with less education. This may explain their primary concern related to family coping and reflect information seeking to meet their social needs related to love, belongingness, and acceptance (Maslow, 1943).

The current study found no significant association between priority unmet needs and participants' perceived stage of colon cancer. The large proportion of participants (23%) who were unaware of the stage of their colon cancer may account for these findings. However, on further analysis, the actual staging information derived from screening tool completed by a member of the patient's healthcare team, was compared with the priority unmet needs and no significant association was observed.

Study Strengths and Limitations

To the best of our knowledge, the current study is the first cross-sectional survey conducted to assess the prevalence, severity, and importance of SCNs and healthcare service use among Canadians newly diagnosed with ACC (stage III or IV). The study findings document the actual needs, which are derived from the patients' self-reported survey, rather than the assumed needs of the patients with ACC.

Several methodological components of the study contribute to the internal validity of and confidence in the findings, namely:

- a high response rate with over 77.5% of eligible, participating patients completing the self-report questionnaires;
- the completeness of data collection with only 7.1% of questionnaire items missing a response; and

- the use of valid and reliable measures (such as SCNS-SF questionnaire, FACT-C subscale, and HSU questionnaire) encompassing a comprehensive spectrum of need domains and healthcare services relevant to patients with colon cancer.

This is the first study among the colon cancer population to examine patient use of health services during the diagnostic phase. This quantitative needs assessment did not provide information about the appropriateness of service use or whether the use of alternative services would have been more cost-effective in meeting patients' unmet SCNs. However, the lack of service use in some areas of priority unmet need suggests that strategies may be required to promote patient awareness and use of existing high quality healthcare services such as the CCS's Cancer Information Service.

From a geographic perspective, study findings represent the views of patients with colon cancer in one regional cancer centre. This may limit the generalizability of the results beyond the study population. A limitation often associated with surveys is the reliance on participant reporting. Self-report data may not be accurate or complete due to its reliance on participants' memories and the possibility of social desirability bias (Newell et al., 1999). The likelihood of recall bias in the study is limited because participants were recruited for participation shortly after their diagnosis of colon cancer and during their first cancer clinic appointment at the JCC. The use of valid and reliable measures such as SCNS-SF questionnaire, FACT-C subscale, and HSU questionnaire helps mitigate bias associated with self-reporting. An underestimation in the prevalence of unmet needs may be due to potential self-selection of participants who could have fewer health concerns and/or unmet SCNs. A small proportion of patients (7.5%) were too ill to participate in the study; thus the healthcare needs of this more vulnerable population may not be fully understood. Finally, a needs assessment based purely on quantitative data fails to identify factors that influence how or why SCNs are met or not met. Thus, specific strategies to address barriers and therefore to improve the supportive services cannot be made.

Implications for Improving Supportive Care in Colorectal Cancer

The current survey provides a “snapshot” of the prevalence of SCNs at the starting point of a long cancer journey for adults with ACC (stage III or IV). The paucity of relevant data about the patterns of SCNs and levels of service use has been identified as an important barrier to the co-ordination and integration of supportive care services (Fitch, 2000). Fitch (2008) reiterates that “to be effective, supportive care must be based upon, and matched with, an individual’s needs within the context of his or her unique situation” (pg. 11). It is essential for regional cancer programs such as the JCC to develop needs-driven supportive services that are suitable for their particular community, geography, culture, and based on the available resources. As a first step, this study has identified unmet needs related to psychological support and information as the most common and important issues among patients newly diagnosed with ACC. The results of this study inform potential ways healthcare services may be improved to better meet the priority and unmet SCNs of this specific patient population. The following section outlines potential areas for improving cancer care delivery.

Several provincial and national reports acknowledge that current cancer care services are fragmented due to the failure to integrate and coordinate a range of health and supportive care services. Patients and families require access to these services in order to cope with and live well following a cancer diagnosis (CCO, 2009; CCS, 2003). During the diagnostic phase, patients often feel “lost in transition” as they hang in the balance while awaiting their first cancer clinic appointment (CCS, 2003). Lack of care coordination can impede access to the appropriate assessment and management of unmet health and information needs and can further heighten levels of anxiety and psychosocial distress; not unlike the unmet physical, psychosocial, and information needs experienced by newly diagnosed patients with ACC in this study. Previous studies report that patients and families are unaware of existing supportive cancer care services and how and where to access them, particularly before entering a cancer care program (CCS, 2003; DeGrasse & Hugo, 1996; Fitch, 2000).

The development of innovative models of cancer care delivery during the diagnostic phase, as patients’ transition from primary care to cancer-specific treatment settings, may aid in alleviating and/or preventing distress related to unmet health needs. One such innovative model should comprise these key features: 1) improved comprehensive assessment and management of patients’ priority unmet needs in a timely manner; 2) use of existing supportive care services; and 3) increased patient awareness of community resources. Improved coordination of supportive care services, especially those in the community, will be essential for increasing patients’ access to services relevant for meeting their priority psychological, physical function, and information needs. One possible strategy to improve care coordination is the introduction of a patient navigator role. Following the success of the patient navigation program first initiated by Freeman (2004), the findings of several other studies suggest that the patient navigator should be an integral part of cancer care system (Association of Community Cancer Centers, 2010; Davis, Darby, Likes, & Bell, 2009; Fillion et al., 2009; Freeman & Reuben, 2001; Freund et al., 2008; Hede, 2006; Koh, Nelson, & Cook, 2011; Robinson & Watters, 2010; Walsh et al., 2011).

In their literature review, Wells et al. (2008) define patient navigation as a "barrier-focused intervention" with common functions, such as the ability to identify individual patient-level barriers, provide a defined episode of cancer-related care and have a definite endpoint, such as between diagnosis and commencing treatment. Wells et al. state that "patient navigation aims to reduce delays in accessing the continuum of cancer care services" (p. 2001). Similarly, the use of a patient navigator role during diagnostic phase as a defined episode of care may assist in promoting the continuity of cancer care for patients newly diagnosed with ACC. Wells et al. acknowledge that the patient navigator may be a lay person and not necessarily a certified health or social service professional. This individual can be prepared for the role with special training and can be supervised by a healthcare professional.

Hede (2006) reports that a patient navigator has the potential to transform complex and fragmented healthcare services to provide a patient-centered care approach. A navigator can guide patients through the complex cancer care system by helping them overcome barriers and effectively use the existing community resources, such as support groups, information services, transportation facilities, spiritual support, and financial counseling services.

Paskett, Harrop, and Wells (2011) conducted a literature review of existing research on patient navigation and categorized the tasks of patient navigation into instrumental interventions (i.e. task-oriented like providing information) and relationship interventions (like strengthening interpersonal relationships and addressing family needs). Prior studies suggest that patient navigators are also effective for improving timely access to cancer care services (Freund et al., 2008; Wells et al., 2008), bridging communication gaps among healthcare providers and services (Robinson & Watters, 2010), and enhancing overall patient satisfaction (Fillion et al., 2009). Newly diagnosed patients with breast and CRC reported satisfaction with navigators who provided emotional support, information, and problem-solving assistance (Carroll et al., 2010). The introduction of a patient navigator role for the colon cancer population at the JCC may assist in promoting care coordination and addressing priority unmet needs related to psychological support and information.

Other innovative strategies can be incorporated into the current model of supportive cancer care for patients with ACC to meet their physical, psychosocial, and informational needs. For example, Hohenadel et al. (2007) reports that the Personal Coach Program (PCP) was used to identify SCNs for Canadians with significant financial and social barriers and to improve their access to services in Toronto, Ontario. The study found high patient satisfaction with the PCP, improved accessibility of services, and positive impact on both physical and emotional health of underserved patients with cancer. Macvean et al. (2007) evaluated a telephone-based volunteer delivered intervention called the Pathfinder Program designed to address the unmet SCNs of Australians with CRC. This program was found to be feasible, acceptable for patients, and had the potential to reduce the prevalence of SCNs. These approaches (PCP and Pathfinder Program) emphasize the importance of providing extensive and targeted interventions for satisfying common and severe unmet SCNs among patients with ACC.

Implications for Nursing Practice

The study results highlight the prevalence, severity, and importance of unmet psychological, functional, and information needs related to a new diagnosis of ACC. Many patients expressed fears about the cancer spreading, in addition to other psychological issues including lack of control about treatment outcomes, an uncertain future, anxiety, and concern about the well-being of family members. Furthermore, body appearance and bowel control were identified as the severe CRC-specific concerns.

The study findings suggest the need for better assessment and management of SCNs for patients with newly diagnosed ACC. Knowledge gained from this descriptive study may help nurses and other healthcare providers at the JCC provide more responsive, emotionally sensitive, and client-oriented care for this vulnerable patient population at the time of diagnosis. Recommendations for improving nursing practice related to nursing assessment and management of SCNs, innovative nursing roles, and management of CRC-specific concerns are described in the upcoming sections.

Nursing Assessment and Management of Supportive Care Needs

During the diagnostic phase, nurses in primary healthcare and cancer care settings are often the first point of contact in triaging and responding to patient concerns or needs. This provides nurses with a unique opportunity to assess and address SCNs in a timely manner (Fitch, 2000). In addition to physical symptom assessment of patients, nurses play a vital role in the initial evaluation of psychosocial, practical, and spiritual consequences of cancer diagnosis (Fitch, 2000; Fitch, 2005). Initiating a dialogue with patients about the impact and meaning of being diagnosed with ACC may provide nurses with a better understanding of the patient's health needs (Fitch, 2000 & 2005). Based on the patients' needs, nurses can then: (1) provide targeted interventions; (2) offer referral to other healthcare professional who can provide more intensive care for patients with complex issues; and (3) encourage patient use of existing supportive services.

Patients with advanced disease often experience a cluster of symptoms rather than one single health problem. As a result, the interventions aimed at these symptom clusters need to use a combined approach where individual symptoms are not addressed in isolation of each other (Dodd, Miaskowski, & Lee, 2004; Fitch, 2005). For example, the need for information is often fueled by patient desire to reduce feelings of confusion, fear, and anxiety and to promote self-care management and coping strategies. Sawyer (2000) states that offering essential and relevant information can assist patients with cancer in addressing their physical and psychological needs by providing them with a sense of control over their lives and enhancing compliance to treatment. In addition, a literature review on the importance of information giving for newly diagnosed patients with cancer reports that the provision of information may reduce symptoms of anxiety, promote self-care, and enhance recovery (Mills & Sullivan, 1999). Mills and Sullivan (1999) also identified that nurses play a vital role in providing information to help patients understand their illness, prognosis, or treatment options, which in turn could affect their psychosocial well-being.

Types of Nursing Roles in Cancer Control

The Canadian Association of Nurses in Oncology (CANO, 2001) identifies three types of nursing roles involved in the care of people living with cancer and their families; the generalist, specialized, and advanced nursing roles. The generalist nurse is one who has graduated from a diploma or baccalaureate level program and is prepared to work in a variety of healthcare settings (i.e. acute, community or primary health, or long-term care). A specialized oncology nurse is one who has a combination of expanded education and experience focused on cancer care and who works in a cancer-specific care setting. According to CANO, an advanced oncology nurse is Master’s prepared with the theoretical knowledge in nursing and other sciences and provides advanced care to individuals, families, and communities.

The generalist nurse may work in settings where patients with CRC receive care along with other patient populations, such as an ED, family practice settings in primary care, surgical units, endoscopy suites, or community. For patients undergoing diagnostic tests, such as a colonoscopy, a generalist nurse in these settings assesses the impact of the cancer on the patient and family, offers baseline information and support, and provides appropriate referral to specialized and advanced oncology nurses for consultation related to cancer-specific issues (CANO, 1995).

Specialized nurses work in cancer-specific community, outpatient, and hospital settings. Specialized oncology nurses possess broad knowledge, skill, and experience in caring for the cancer population. A specialized nurse conducts holistic and cancer-specific patient assessments, implements interventions that promote self-care practices, and supports patient and family in making decisions about their cancer care (CANO, 2001). Moreover, they can help patients navigate between illness and health roles and can reduce system barriers to care by aiding patient navigation between various health sectors (i.e., acute care, primary healthcare, and cancer care sectors) in order to access appropriate healthcare and community resources and other nursing experts such as advanced oncology nurses (CANO, 1995).

The Canadian Nurses Association (CNA) (2002) defines advanced nursing practice as an umbrella term “that maximizes the use of in-depth nursing knowledge and skill in meeting the health needs of clients…advanced nursing practice extends the boundaries of nursing’s scope of practice and contributes to nursing knowledge and the development and advancement of the profession” (p. 1). The CANO (1995) identifies five domains of the advanced oncology nurse role, including advanced clinical practice, education, research, scholarly/professional leadership, and organizational leadership. Advanced practice nurses play an important role in supporting generalized and specialized nurses by consistently interpreting and sharing relevant research findings;

coaching and mentoring them in the use of clinical evidence; and using critical thinking and synthesis for making decision in complicated and dynamic situations.

The CCO’s consensus report on ‘Cancer System Planning – Advanced Practice Nursing (APN)’ states that “APN roles provide potential for developing innovative and sustainable models of cancer care delivery through maximal use of their multi-dimensional expertise and flexible, expanded scope of practice” (CCO, 2008b, p. 3). The consensus report recommends the use of APN roles for complex patients at high risk for severe complications and poor health outcomes. The CRC population was identified as one of the top three priority areas for the deployment of additional advanced practice nurses (CCO, 2008b).

Advance practice nurses make up a small proportion of the general and cancer nursing workforce in Canada (Canadian Institute for Health Information, 2010). One effective use of advanced practice nurses, as a limited resource, is to target their roles during the diagnostic period, for patients with ACC experiencing severe and complex healthcare needs, such as men, patients with less education and those with fewer social supports.

Compared to advanced practice nurses, there are greater numbers of specialized oncology nurses available to improve patient access to care across the cancer continuum including the diagnostic phase and CCO's Cancer Care Plan 2011-2015 emphasizes the need to strengthen the contribution of specialized nursing roles in cancer care (CCO, 2011b). The literature identifies a number of different models of specialized practice (e.g., nurse-led supportive care) and types of specialized nursing roles (e.g., case manager, nurse navigator). Further discussion in the next section will examine how these specialized oncology nursing models and roles can be used to improve care for patients with ACC during the diagnostic phase.

Specialized nursing models and roles.

A systematic review of specialized oncology nurse-led supportive care models demonstrated positive outcomes in relation to improved satisfaction, reduced uncertainty, lower anxiety, and improved access to support services (Sussman, Howell, O'Brien, & Whelan, 2004). An exploratory study of the follow-up care needs for patients with CRC recommended nurse-led clinics and/or telephone follow-up by specialized nurses for providing information that is tailored to individual patient needs and for enhancing responsiveness to urgent patient health concerns (Beaver et al., 2010). These nurses are skilled at prioritizing the relevant information and presenting this information in an appropriate and sensitive manner.

An abundance of oncology specialized roles have evolved over the past few years, such as the nurse-led clinical case manager, oncology nurse navigator, and nurse advocate. Nurse-led clinical case manager and nurse navigator roles are receiving increased recognition as a standard in the Canadian cancer system for facilitating increased access to care (Canadian Strategy for Cancer Control, 2001). The roles of clinical case manager and nurse navigator are described below with their implications for care of patients with ACC.

Case manager role.

According to the Commission of Case Manager Certification, “case managers work to assist the clients in achieving optimal wellness, self-management and functional capability by linking clients with service providers and resources throughout the continuum of health and human services and care settings” (p. 136). The American Nurses Credentialing Centre (2009) reports that nurse case managers can decrease fragmentation of care, thereby enhancing care quality and patient outcomes. Howell and Jackson (1998) introduced the Interlink Community Cancer Nursing (ICCN) model as a specialized oncology nurse who provides case management and direct supportive care services for Ontarians through home-visits, telephone follow-up, and teaching and coaching to improve self-management of healthcare needs. Interlink nurses also assisted patients by navigating the healthcare system, referring them to appropriate services, and advocating for the health services and resources that patients and their families required.

Howell et al. (2008) evaluated the effectiveness of the ICCN in coordinating care and meeting SCNs of patients and families. The results of this evaluation study suggest that nurse-led models of supportive care have the potential to reduce unmet SCNs, improve care continuity, and impede physical and emotional distress. As case managers are constant in the cancer journey of patients, they can develop a therapeutic relationship with patients of CRC which encourages the discussion of sensitive issues around sexuality, body image, and incontinence (Campbell & Borwell, 1999).

An accumulating body of evidence suggests that the nurse-led supportive care models that provide case management, such as the ICCN, may also improve the patient’s understanding of illness, reduce the fear, and uncertainty of living with cancer (Clayton, Mishel, & Belyea, 2006); decrease psychological distress (Howell, Fitch, & Caldwell, 2002; Howell & Jackson, 1998); and lower anxiety (Sussman et al., 2004). Therefore, one possible approach to meet the extensive psychological concerns of newly diagnosed patients with ACC at the JCC is the introduction of a similar nurse-led case management role that interfaces between the cancer centre and community before and after the patient's first cancer clinic appointment.

Oncology nurse navigator role.

Similar to a case management model, a recent innovation that may improve symptom management for patients with ACC during diagnostic period is the introduction of the Oncology Nurse Navigator (ONN) role. Wells et al. (2008) differentiates the case manager from the patient navigator as "patient navigation focuses on one health condition instead of the broader objective of case management to improve health in general" (p. 2005). The ONN offers interventions designed to reduce health disparities by overcoming individual and logistic barriers for improved cancer care coordination. Prior studies have shown that coordination of services by an ONN streamlined cancer care for patients with GI, breast, lung, and lymphoma disease (Anonymous, 2007); improved the experience of patients with newly diagnosed breast cancer (Houlahan, 2006); improved patient satisfaction in a lung cancer program (Fischel & Dillman, 2009); facilitated effective patient transition across the cancer continuum (Case, 2011); and reduced wait times (Richard, Parmar, Calestagne, & McVey, 2010). The results of an exploratory study by Hebert and Fillion (2011) described the important role the ONN plays in screening and assessing patient needs along the cancer continuum and providing support through targeted interventions to decrease unmet needs among patients with cancer.

For newly diagnosed patients with ACC in the community, the ONN can identify the full range of needs, offer tailored nursing interventions, and refer patients to appropriate supportive care resources. The current study found that over 50% of participants used costly acute care services (i.e., hospital, ED) in the six-month period leading up to their first cancer clinic appointment. It is possible that the use of an ONN could help to avoid the use of these more expensive and not necessarily effective healthcare services through more timely and comprehensive patient assessment and referral to more appropriate community-based supportive care services.

A Canadian cohort study of patients with head and neck cancer found that those receiving nurse navigation services reported higher satisfaction with care and required fewer hospital admissions compared to patients who did not have access to a nurse navigator (Fillion et al., 2009). The ONN can integrate across multiple service agencies to ensure smooth passage of patients through a care model that is coordinated and continuous during the diagnostic phase. Newly diagnosed patients with ACC, who may be at greater risk for severe unmet needs, such as men, those with less education and/or fewer social supports, may benefit from more intensive care provided by the ONN through comprehensive assessments, care coordination, and patient education.

Management of Colorectal Cancer-Specific Concerns

The two greatest CRC-specific concerns identified by study participants were related to body appearance and bowel control. Among the participants, 13 of them (21%)

reported having an ostomy. Factors that might contribute to a loss of bowel control or fecal incontinence are nerve damage due to colon resection, loss of anal sphincter control, and psychological responses from stress, anxiety, or depression. Oncology nurses play an important role in assessing and managing disease related concerns. Baseline assessment should include the patient's normal bowel pattern, dietary intake, and any other medical conditions or procedures that could increase the risk for altered bowel pattern. Oncology specialized nurses possess the knowledge and skills necessary to advise non-drug measures for bowel control (Campbell & Borwell, 1999). These measures may include dietary modifications, life style changes, muscle strengthening exercise, and identifying and restricting contributing medications, and avoiding other predisposing factors such as stress and anxiety (Meissner, 1996; Viale & Sommers, 2007). A descriptive study of patient perspectives on CRC, reinforced that oncology nurses need to assist patients in the management of CRC-specific symptoms and offer referral to an ostomy specialist nurse (Sahay, Gray, & Fitch, 2000).

The aim of nursing care for patients undergoing CRC surgery is to promote rehabilitation, self-care, independence, and the resumption of an acceptable lifestyle (Campbell & Borwell, 1999). According to Dest and Cerrato (2000), surgery for CRC can seriously affect a person's body image. A 'change in body appearance' was reported as one of the important concerns by patients with a colostomy before and after discharge from the hospital (Pieper & Mickols, 1996). Changes in appearance and function can lead to an alteration in body image. A study by Northouse et al. (1999) found that up to 17% of patients undergoing colon resection wanted greater preparation for having a colostomy and for managing their care at home. Extensive pre and post-operative nursing care of patients undergoing a stoma surgery is recommended for enabling them to anticipate and understand the physical and psychological outcomes of the surgery (Salter, 1995). By preparing the patient for expected outcomes, he or she is better able to accept a change in body image.

Direction for Future Research

This descriptive study is a first step in a comprehensive needs assessment and identifies the prevalence, severity, and importance of unmet needs for patients with newly diagnosed ACC. Quantitative needs assessments do not help us to understand the reasons behind why or how needs are met or unmet and why existing services meet or do not meet patient's priority needs. Future qualitative studies are required to identify and understand factors that contribute to unmet SCNs and gaps in service use among patients with colon cancer in the diagnostic phase. This will assist in developing specific strategies to address these needs and fill gaps in the current cancer care system.

A similar study of patients with newly diagnosed ACC is currently being conducted at a satellite cancer centre in a small community hospital. The future comparison of the patients' SCNs, priority unmet needs, and their use of healthcare services between the JCC and this satellite cancer centre will aid in identifying regional and systemic issues that may impact patients' unmet needs during the diagnostic phase. This comparative needs assessment may also facilitate the applicability of study findings to other similar cancer populations in Ontario.

Future research is also required to develop and evaluate the impact of innovative models of supportive cancer care and nurse-led interventions for patients with colon cancer during the diagnostic phase.

Plan for Dissemination of Results

The results of this study will be shared with the community and study participants at an open public forum, such as the Wellwood Cancer Support Group and Wellspring discussion series. In addition, the results will be open for feedback and discussion through a presentation to the GI Disease Site Team at the JCC. The findings will also be presented to other stakeholder groups, such as the Supportive Cancer Care Research Unit at McMaster University.

A manuscript will be prepared for publication in a peer-reviewed journal including the Canadian Oncology Nursing Journal, Oncology Nursing Forum or Supportive Care in Cancer, whose readership includes healthcare planners, administrators, oncology nurses, and other supportive care service providers. Abstracts for oral and/or poster presentations will be submitted for annual conferences such as the 2012 CANO conference. To reach the interested cancer population, the inventory of the various supportive care services in the Central West Ontario region will also be shared with the public via cancer information services, such as the CCS, JCC Patient Education Library, Wellwood, and Wellspring information lines.

Conclusion

This study has identified the prevalence, severity, and importance of SCNs of patients recently diagnosed with ACC (stage III or IV) at the JCC. Patients with newly diagnosed ACC have substantive unmet SCNs. The most common and priority unmet needs were related to psychological support and information. Men and patients with less education and/or fewer social supports have reported more severe needs related to psychological wellbeing, fatigue, and appetite. The most severe CRC-specific concerns were related to body appearance and bowel control. The study also offers information about the existing gaps between unmet needs and use of available healthcare services. Few patients with colon cancer utilize existing community and cancer care resources that are relevant to their unmet SCNs in the diagnostic phase.

For supportive care services to be effective, relevant needs must be assessed. As a first step, this study has identified the SCNs of new patients with ACC. The JCC, being one of the regional cancer centres, is responsible for the coordination and provision of supportive services related to physical, psychological, and social wellbeing and symptom management. The study results can inform the planning of innovative and effective models of supportive cancer care for patients with ACC at the JCC.

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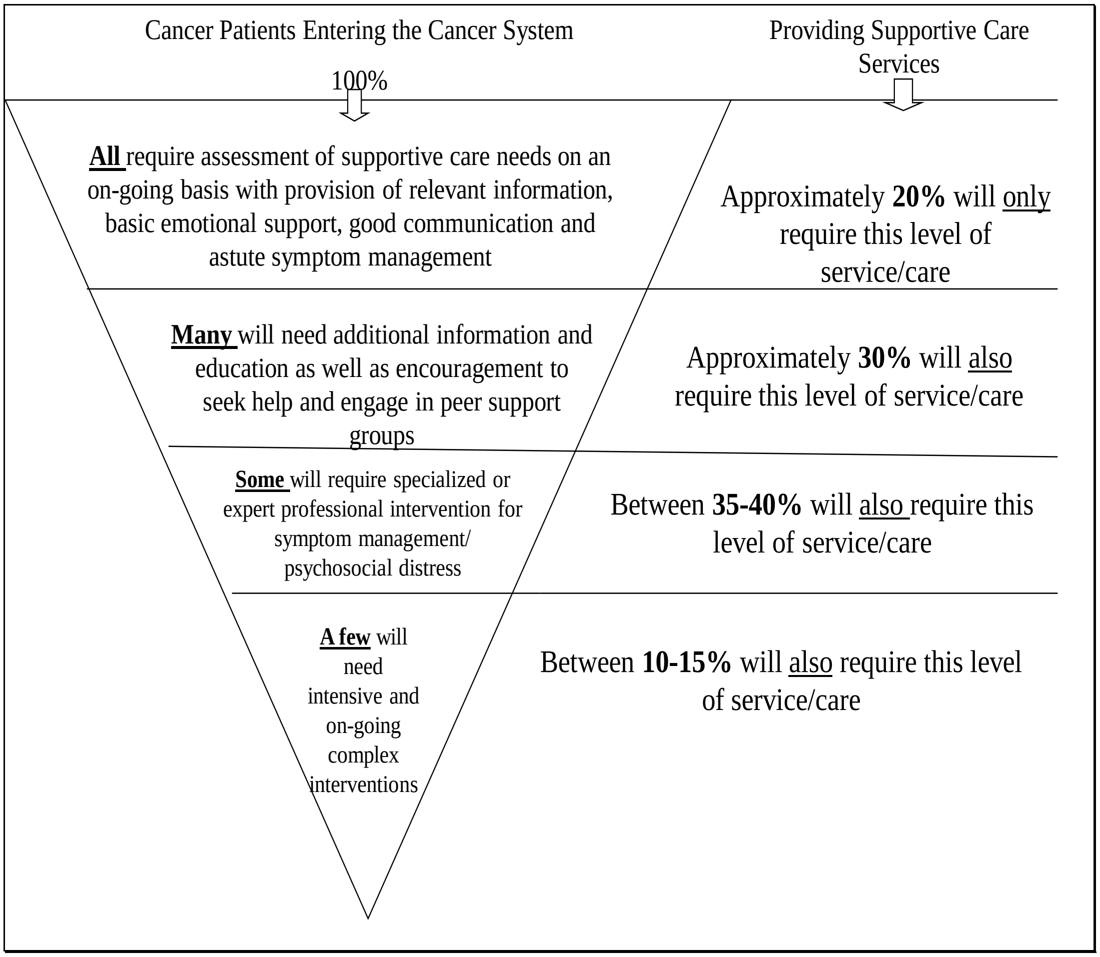
Appendix A

Figure One: Supportive Care Framework

Service provision based on proportion of patients requiring assistance



All require assessment of supportive care needs on an on-going basis with provision of relevant information, basic emotional support, good communication and astute symptom management

Approximately **20%** will only require this level of service/care

Many will need additional information and education as well as encouragement to seek help and engage in peer support groups

Approximately **30%** will also require this level of service/care

Some will require specialized or expert professional intervention for symptom management/ psychosocial distress

Between **35-40%** will also require this level of service/care

A few will need intensive and on-going complex interventions

Between **10-15%** will also require this level of service/care

Source: Fitch (2008). Supportive Care Framework. *Canadian Oncology Nursing Journal,* 18(1), p. 12.

Appendix B

Literature Review Grid

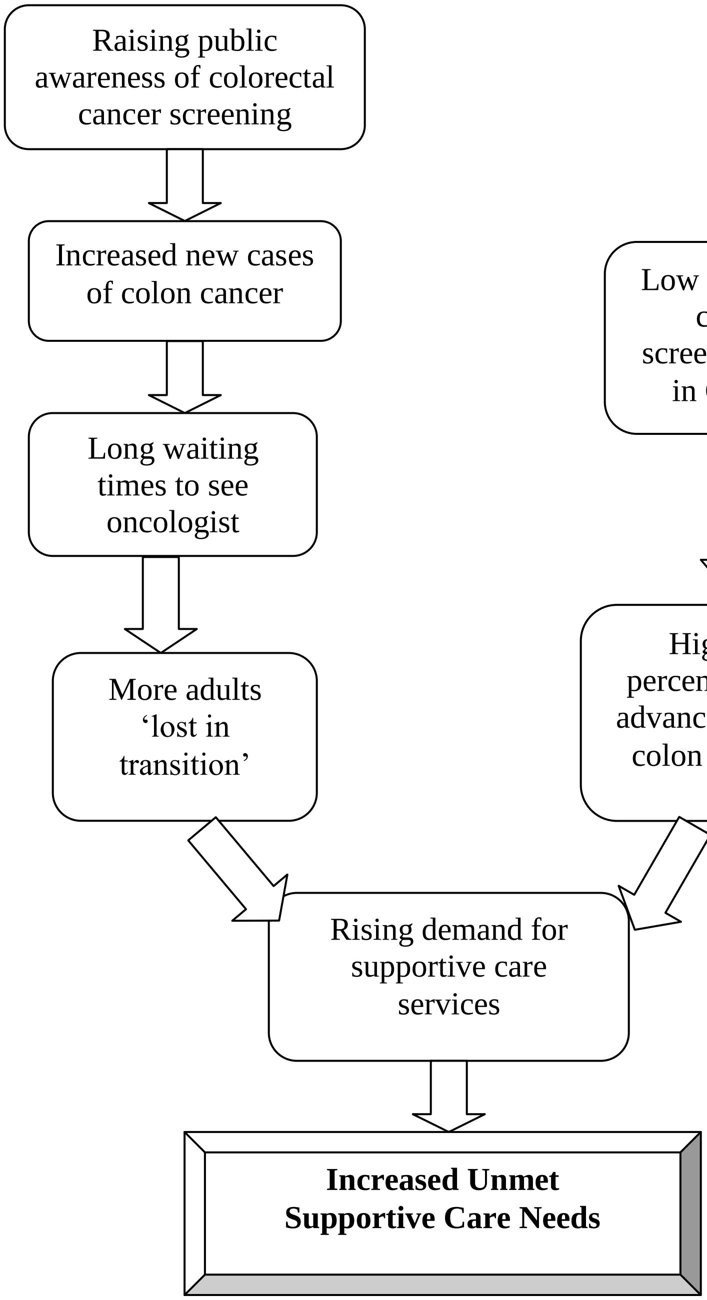
Summary of quantitative studies of supportive care needs among patients with colorectal cancer

STUDY	OBJECTIVE OF STUDY	STUDY DESIGN AND SETTING	SAMPLING AND RESPONSE RATE	DATA COLLECTION AND METHODS	KEY FINDINGS	STRENGTHS AND LIMITATIONS
Macvean et al. (2007)	To describe a volunteer-delivered intervention (Pathfinder program) to reduce the unmet needs of patients with colorectal cancer.	Prospective cohort study Sample identified from a population-based Victorian Cancer Registry, Australia.	52 patients with colorectal cancer of all stages diagnosed within four months. Response rate is 93% to time 1 (at entry).	Needs assessment questionnaires (HADS), SCNS-LF and CRC- specific checklist.	Common needs were fear, weight change, bowel problems. .	**Strengths** - Effective recruitment strategy as patients were recruited from a population-based registry who were diagnosed within the past four months - Used valid and reliable tools such as (HADS, SCNS-LF) - High response rate **Limitations** - Small sample size did not allow analyses of differences based on cancer treatment or staging.
Bailey & Corner (2004)	To examine older patients' experiences before and after treatment for colorectal cancer; to analyze changes in functional status, severity of morbidity and service use in the pre- and post-treatment period.	Prospective cohort study Patients recruited from six study centres in Southampton, UK.	337 patients aged 58-95 years with colorectal adenocarcinoma across all stages were interviewed pre-treatment.	Interviews done at the study entry using OARS Multidimensional Functional Assessment Questionnaire (OMFAQ), Rotterdam Symptom Checklist (RSCL) and a morbidity score subscale.	High psychological distress, severity of morbidity, poorer QOL and physical health.	**Strengths** - A large multi-centre study conducted over 3 years. - Generizability possible as the sample representativeness was examined. **Limitations** - Findings applicable only for patients over 58 years. - Validity and reliability of the instruments not mentioned. - Quantitative data fails to elucidate patients' experiences in detail.

STUDY	OBJECTIVE OF STUDY	STUDY DESIGN AND SETTING	SAMPLING AND RESPONSE RATE	DATA COLLECTION AND METHODS	KEY FINDINGS	STRENGTHS AND LIMITATIONS
Maguire et al. (1999)	To determine patients' key physical complaints, their main concerns and the carers' perception of these. To identify the prevalence of affective disorders in patients and their GP's ability to diagnose these.	Descriptive study Patients were identified from the Trafford colorectal database, UK.	Patients with advanced CRC or recurrence of CRC or whose death was certain would be expected with 12 months. 61 patients with terminal CRC; their 48 carers and 58 general practitioners (GPs).	Semi-structured interviews (to determine physical symptoms); a concerns checklist (to assess severity of patients' concerns); and the Psychiatric Assessment Schedule (to identify affective disorders).	* Major physical concerns were pain, appetite loss, and pyrexia. * The congruence between patients' and carers' reports was high for appetite loss, nausea/ vomiting, pain. * Less congruence was noted for breathlessness and pyrexia. * 22% of patients suffered from an affective disorder, which was recognized by the GPs in only 5 cases.	**Strengths** - Included terminally ill patients with advanced stage and recurrent colorectal cancer. - Sample selection from a population-based database. **Limitations** - Study design not clear - The reliability and validity of the tool (i.e. concerns checklist) were not reported.

Appendix C

Figure Two: Model of Rising Demand for Needs-driven Care



Source: A model adapted from Fitch (2008) illustrates the rising demand for need-driven supportive care services for patients newly diagnosed with colon cancer.
Fitch (2008). Supportive Care Framework. *Canadian Oncology Nursing Journal,* 18(1), p. 12.

Appendix D

Screening Tool

Adults Newly Diagnosed with Colon Cancer (Stage III or IV): Supportive Care Needs Study

This study will identify the supportive care needs and use of cancer care services by patients recently diagnosed with stage III or IV colon cancer.

Definitions:

Patients eligible for this study have colon cancer with stage III or IV according to the TNM (tumor, node involvement, and metastasis) staging system of the American Joint Committee on Cancer (AJCC).

Stage III colon cancer: (T1-T4, N1-N2, M0): The cancer has grown through the colon wall and spread to the nearby lymphnodes. It is also referred as locally ACC

Stage IV colon cancer: (any T, any N, M1): The cancer has grown through the colon wall and into nearby or distant organs. This is called as metastasis colon cancer.

Eligible patients have these criteria (please provide a √ in the box provided for each item :

- 18 years or older ☐
- have pathology or biopsy confirmed staging of colon cancer (check one only)
    - Stage III ☐
      Or
    - Stage IV ☐
- Recommended type of treatment (check one only)
    - adjuvant treatment ☐
      Or
    - palliative treatment ☐
- have no obvious mental or intellectual impairment ☐
- Patient can speak, read and understand English ☐

Patient meets all of the above criteria (circle the best response): **YES** **NO**

Eligible patient agreed to be contacted (circle the best response): **YES** **NO**

If Yes, Patient's Name: ____________________________

How can we contact (circle one)

By phone number: (____) _____________

Or

During clinic visit

If No, provide reason for non participation:

Appendix E

Telephone Script/Invitation Letter

A STUDY IDENTIFYING THE SUPPORTIVE CARE NEEDS OF ADULTS NEWLY DIAGNOSED WITH STAGE III or IV COLON CANCER REFERRED TO JURAVINSKI CANCER CENTRE

My name is Suganya Vadivelu. I am a Registered Nurse and a Master's student in the School of Nursing at McMaster University. I am conducting a research study at the Juravinski Cancer Centre to identify the types of supportive care needs and services that patients feel are most important for those with stage III or IV colon cancer around the time of diagnosis.

I would like to invite you to participate in this research study. The main purpose of the study is to learn more about the met and unmet supportive care needs of patients with newly diagnosed colon cancer. The results of this study will identify patient priorities for improving the current model of supportive care services specific to patients with colon cancer during their initial diagnosis. Study information will be used to help improve care and services provided at Juravinski Cancer Centre.

If you agree to be a part of this study, you will be asked to complete a questionnaire about your needs and use of cancer care services. The questionnaire will take about 20 minutes to complete. There are no costs to you for participating in this study.

As a token of appreciation you will receive a Shoppers Drug Mart gift voucher regardless of whether you complete the questionnaire or not. Participation in the study is completely voluntary. You are under no obligation to complete this survey and your non participation will in no way affect your care at Juravinski Cancer Centre. 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 healthcare providers. You 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) 387-9711 ext. 64124 or you could also speak to the Local Principal Investigator of this study, Dr. Denise Bryant-Lukosius at (905) 387 9711 ext. 67701.

If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-387-9711 ext. 67701.

Appendix F

PARTICIPANT INFORMATION SHEET

A STUDY IDENTIFYING THE SUPPORTIVE CARE NEEDS OF ADULTS WITH NEWLY DIAGNOSED STAGE III or IV COLON CANCER REFERRED TO JURAVINSKI CANCER CENTRE

Principal Investigator: Ms. Suganya Vadivelu, Nurse Educator, Juravinski Cancer Centre, Hamilton.

Local Principal Investigator: Dr. Denise Bryant-Lukosius, Assistant Professor, McMaster University, Hamilton.

Co-Investigators: Dr. Carolyn Ingram, Prof. Ann Mohide

Sponsor: de Souza Institute fellowship

You are being invited to participate in a research study about supportive care needs because you have been identified as a patient recently diagnosed with stage III or IV colon cancer and referred to Juravinski Cancer Centre (JCC) for treatment. 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 information sheet 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. Feel free to discuss it with your family and/or your oncologist.

Why is this research being done?

Stage III or IV colon cancer is a cancer that has grown through the lining of the lower bowel or has spread to other parts of the body. Research suggests that patients with other types of cancer may have increased need for physical, practical and psychological support especially at the time of diagnosis. Unfortunately, there is limited research to identify the types of needs and services that are most important to patients with newly diagnosed stage III or IV colon cancer. Regional cancer programs such as the JCC are responsible for developing appropriate supportive cancer care services. This study will help the JCC to determine if new and more specialized support services are required to best meet the needs of patients with colon cancer.

What is the purpose of this study?

The purpose of the proposed study is to identify the met and unmet supportive care needs of patients with recently diagnosed colon cancer (stage III or IV) who is referred to JCC. Information gained from this study will inform the design of appropriate supportive care services for patients with colon cancer at JCC.

What is involved in the study?

If you are interested in participating in this study you will be asked to complete a questionnaire which will assess your needs for support and the types of healthcare services you have used since it was first identified that you may have colon cancer. Completing the questionnaire will take about 15 to 20 minutes of your time.

What are the possible side effects?

Some people might feel anxious when they are asked to respond to the questions related to needs. This is a natural reaction. If you experience this, you should discuss any concerns you have with your primary care nurse, oncologist or family physician.

What are the potential benefits?

You may not receive a direct personal benefit by completing the survey. However, the information you provide may help us learn more about the best way to provide support and healthcare services for future patients with colon cancer.

What will happen if I decide not to participate?

It is important for you to know that you can choose not to take part in this study. Your participation is entirely voluntary and you can withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not negatively affect your medical treatment or your relationship with medical staff.

What information will be kept private?

All information obtained during the course of this study is strictly confidential. All the questionnaires will be coded with a confidential ID number, which will be used to monitor returns so that those who have completed the questionnaire do not receive a follow up phone call. Upon return of the questionnaire, the research assistant will document this return on the participant list, and the coded label will be removed from the questionnaire and destroyed. All data collected during this study will be securely stored in a locked filing cabinet in the research office of the Local Principal Investigator. Other members of the research team and the statistician will not be able to link you with your answers to the questionnaire.

The results of the research will be presented in a summary format so that individual participants cannot be identified. You will not be identifiable in the presentation, publication, or reporting of study findings or recommendations, as the study results will be presented in an aggregate format. The data for this research study will be retained for 10 years following completion and will only be available to the Local Principal Investigator.

Will I be paid to participate in the study?

As a token of appreciation for your participation, a Shoppers Drug Mart gift voucher will be enclosed in the questionnaire package.

Will there be any costs?

You will not incur any expenses as a result of participating in this study.

If I have any questions or problems, whom can I call?

If you have any questions about this project or wish to discuss any concerns about the questionnaire now or later, please contact:

The Principal Investigator of the study:
Ms. Suganya Vadivelu,
Graduate student at McMaster University
Nurse Educator, Juravinski Cancer Centre
905-387-9711 ext. 64124
Or
The Local Principal Investigator of the study:
Dr. Denise Bryant-Lukosius,
Assistant Professor in the School of Nursing at McMaster University
Director, OAPN, Juravinski Cancer Program
905-387-9711 ext. 67701
Or
If you have any questions regarding your rights as a research participant, you may contact:
Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-521-2100 ext. 42013.

By completing and mailing the survey back to the study research assistant, you do not waive your legal rights or release the investigator (s) and sponsors from their legal and professional responsibilities.

This information sheet is for you to keep

Appendix G

CONSENT FORM FOR PARTICIPANTS

A STUDY EXAMINING THE SUPPORTIVE CARE NEEDS AND CANCER CARE SERVICES FOR PATIENTS RECENTLY DIAGNOSED WITH STAGE III OR IV COLON CANCER REFERRED TO JURAVINSKI CANCER CENTRE

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

Signature of participant	Printed name of participant	Date
Signature of person obtaining consent	Printed name of person obtaining consent	Date
Signature of Local Principal Investigator	Printed name of Local Principal Investigator	Date

Appendix H

SURVEY OF SUPPORTIVE CARE NEEDS OF PATIENTS RECENTLY DIAGNOSED WITH COLON CANCER (STAGE III OR IV)

Information and Instructions

Thank you for consenting to participate in this study. Each question is important and we appreciate your time, patience and commitment to completing the survey.

Please read the instructions for each question carefully and answer each question as honestly and completely as possible.

Where indicated, circle the appropriate number or place an (x) or (√) inside the answer box provided.

Watch for changes in scoring on different questions. Some questions ask you to score between 1 and 4 while others ask for 0 to 4 or 1 to 5.

Also, take time to check both sides of each sheet so that you do not miss any questions.

Feel free to speak to the research assistant if you have any questions about any item or require assistance in completing the questionnaire.

Please return the completed questionnaire to the research assistant today in the clinic or return it at your next appointment or mail it in the self-addressed envelope within 7 days.

THANK YOU FOR COMPLETING THIS SURVEY!!!

SECTION A: DEMOGRAPHIC DATA SHEET

1. Are you:

- ☐ Male
- ☐ Female

2. Your age: __________years

3. Your postal code (first three digits): __ __ __

4. Your present marital status (check the appropriate answer):

- ☐ Married
- ☐ Living together/common-law
- ☐ Separated
- ☐ Divorced/Annulled
- ☐ Widowed
- ☐ Never married/single

5. Your highest level of education completed (check the appropriate answer):

- ☐ High School or less
- ☐ College
- ☐ University
- ☐ Postgraduate

6. Do you know what stage of colon cancer you are diagnosed with (check the appropriate answer):

- ☐ Yes
  - If yes, Stage III ☐
  - Stage IV ☐
- ☐ Do not know

7. In addition to colon cancer, what other health problems do you have that require regular medical follow-up and/or treatment? (check all that apply to you):

☐ Heart diseases (heart attack, angina)

☐ Circulation (e.g. stroke, blood clot)

☐ High blood pressure/Hypertension

☐ Lung (Asthma, bronchitis)

☐ Diabetes/high blood sugar

☐ Mental health problems (depression, anxiety)

☐ Another cancer (please specify) _______________

☐ Others (please specify) ________________________

☐ None

☐ Arthritis

☐ Liver disease

☐ Kidney disease

☐ Hearing problems

☐ Vision issues

SECTION B: SUPPORTIVE CARE NEEDS SURVEY (SCNS-SF34)

To help us plan better services for people with colon cancer, we are interested in whether or not needs you may have faced as a result of having cancer have been met. For every item on the next two pages, please indicate whether you needed help with this issue since you first learned that you may have colon cancer. Put a circle around the number which best describes whether you have needed help with this since diagnosis.

There are 5 possible answers to choose from:

NO NEED	1	**Not applicable** – This was not a problem for me as a result of having cancer.
	2	**Satisfied** – I did need help with this, but my need for help was satisfied at the time.
SOME NEED	3	**Low need** - This item caused me little concern or discomfort. I had little need for additional help.
	4	**Moderate need** – This item caused me some concern or discomfort. I had some need for additional help.
	5	**High need** - This item caused me a lot of concern or discomfort. I had a strong need for additional help.

For example:

Since you first learned that you may have colon cancer, what was your level of need for help with:	**NO NEED**		**SOME NEED**		
	Not Applicable	Satisfied	Low Need	Moderate need	High need
1. Being informed about things you can do to help yourself to get well	1	2	3	[✓ 4]	5

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

Now, please complete the <u>following questions 1 to 34</u> by circling around the number as shown above.

Since you first learned that you may have colon cancer, what was your <u>level of need</u> for help with:	**NO NEED**		**SOME NEED**		
	Not applicable	**Satisfied**	**Low Need**	**Moderate need**	**High need**
1. Pain	1	2	3	4	5
2. Lack of energy/tiredness	1	2	3	4	5
3. Feeling unwell a lot of the time	1	2	3	4	5
4. Work around the home	1	2	3	4	5
5. Not being able to do the things you used to do	1	2	3	4	5
6. Anxiety	1	2	3	4	5
7. Feeling down or depressed	1	2	3	4	5
8. Feelings of sadness	1	2	3	4	5
9. Fears about the cancer spreading	1	2	3	4	5
10. Worry that the results of treatment are beyond your control	1	2	3	4	5

Since you first learned that you may have colon cancer, what was your <u>level of need</u> for help with:	**NO NEED**		**SOME NEED**		
	Not applicable	**Satisfied**	**Low Need**	**Moderate need**	**High need**
11. Uncertainty about the future	1	2	3	4	5
12. Learning to feel in control of your situation	1	2	3	4	5
13. Keeping a positive outlook	1	2	3	4	5
14. Feelings about death and dying	1	2	3	4	5
15. Changes in sexual feelings	1	2	3	4	5
16. Changes in your sexual relationships	1	2	3	4	5
17. Concerns about the worries of those close to you	1	2	3	4	5
18. More choice about which cancer Specialists you see	1	2	3	4	5
19. More choice about which hospital you attend	1	2	3	4	5
20. Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
21. Hospital staff attending promptly to your physical needs	1	2	3	4	5
22. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5
23. Being given written information about the important aspects of your care	1	2	3	4	5
24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25. Being given explanations of those tests for which you would like explanations	1	2	3	4	5

Since you first learned that you may have colon cancer, what was your <u>level of need</u> for help with:	**NO NEED**		**SOME NEED**		
	Not applicable	**Satisfied**	**Low Need**	**Moderate need**	**High need**
26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
27. Being informed about your test results as soon as feasible	1	2	3	4	5
28. Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29. Being informed about things you can do to help yourself to get well	1	2	3	4	5
30. Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31. To be given information about sexual relationships	1	2	3	4	5
32. Being treated like a person not just another case	1	2	3	4	5
33. Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

SECTION C: COLORECTAL CANCER-SPECIFIC CONCERNS (FACT-C)

Below is a list of statements that other people with your illness have said are important. By **circling one number per line**, please indicate how true each statement has been for you during the past 7 days.

COLORECTAL CANCER-SPECIFIC CONCERNS	**Not at all**	**A little bit**	**Some what**	**Quite a bit**	**Very much**
During the past 7 days:					
1. I have swelling or cramps in my stomach area	0	1	2	3	4
2. I am losing weight	0	1	2	3	4
3. I have control of my bowels	0	1	2	3	4
4. I can digest my food well	0	1	2	3	4
5. I have diarrhea	0	1	2	3	4
6. I have a good appetite	0	1	2	3	4
7. I like the appearance of my body	0	1	2	3	4
8. Do you have an ostomy appliance? No__ Yes__ If yes; answer #8a & # 8b. If no, go to # 9					
8a. I am embarrassed by my ostomy appliance	0	1	2	3	4
8b. Caring for my ostomy appliance is difficult	0	1	2	3	4

9. Looking at the above 9 questions, how much would you say these COLORECTAL CANCER CONCERNS affect your quality of life? **(Circle one number)**

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very much so

SECTION D: PRIORITY NEEDS

Think back now for a moment about the needs or problems you have identified in earlier questions. If **only three** of these needs could be made better, which would be a priority or the most important for you?

Circle **only three** of your priority needs below:

- Pain
- Fatigue
- Stomach pain or cramps or discomfort
- Abdominal swelling
- Constipation
- Diarrhea
- Rectal discomfort or bleeding
- Control of bowel movements
- Loss of weight
- Indigestion
- Appetite
- Nausea
- Vomiting
- Headaches
- Dizziness
- Urinary problems
- Sleeping
- Physical activity
- Overall well being
- Physical appearance
- Mood
- Uncertainty about the future
- Enjoying time with family and friends
- Thinking or concentration
- Information about disease or treatment
- Treatment side effects
- Family communication
- Family coping
- Sexual desire
- Sexual function
- Emotional coping
- Emotional support
- Work responsibilities
- Household responsibilities
- Family responsibilities
- Finances
- Practical needs
- Embarrassed due to ostomy (if applicable)
- Difficult to care for ostomy (if applicable)
- Other (describe):

SECTION E: THE HEALTH SERVICE UTILIZATION QUESTIONNAIRE

In this section we want to learn more about the types of health services you have used within the **last 6 months**. Answer all that apply to you.

I. In the **last 6 months**, how many visits have you had with a:

1. Family Physician or walk-in clinic …. . ...______
2. Physician specialist ....______
3. Emergency room ....______
4. Physiotherapist/ Chiropractor ....______
5. Psychiatrist...______
6. Psychologist ....______
7. Social Worker ....______
8. Family Counselor...______
9. Occupational Therapist ....______
10. Probationary Services ....______
11. Nutritionist ....______
12. Naturopath/Homeopath...______
13. Public Health Nurse ....______
14. In-home nurse/CCAC nurse..______
15. Homemaker ....______
16. Meals on Wheels *(past 6 months)*..______
17. Employment Retraining Services ....______
18. Recreational Services (*e.g.* yoga, gym). ....______
19. Other healthcare providers/services...______
    Please specify providers:____

20. Other unpaid providers/helpers *(i.e. priest, neighbour)*..........................______

21. 911..______

22. Ambulance ....______

23. Since you first learned that you may have colon cancer, how many times have you used any of the following services?

a. Cancer Information Services *(Canadian Cancer Society)* ....______

b. Colorectal Cancer Association of Canada ....______

c. Wellwood information centre of Hamilton ....______

d. Wellspring information resources...______

e. Cancer centre library *(on the main floor, next to front entrance)* ....______

f. Self-help or support groups such as:
- Wellwood peer support program ....______
- Cancer Assistance Program (CAP) circle of friends.........................______
- Wellspring discussion series ....______
- Look Good, Feel Better *(for women)*...______
- Miles to go healing circles cancer support group ....______

g. Spiritual support *(Religious leaders e.g. Minister, Priest, Rabbi, Imam)* ....______

h. Transportation services such as:
- Canadian Cancer Society volunteer drivers......................................______
- Darts...______
- Cancer Assistance Program (CAP) drivers.......................................______
- Wellspring drivers...______

i. Financial counselling or assistance programs:
- Social assistance...______
- Ontario Drug Benefits..______
- Trillium plan ....______
- Wellspring child care ....______

j. On-line cancer information access *(i.e. Cancer Care Ontario, CancerNet, American Cancer Society, Colorectal Cancer Research)*..______

k. Legal counselling..______

II. Have you had a hospital admission in the past **6 months**? ☐Y ☐ N

If yes, number of hospital admissions in the last 6 months ....______

Total number of days in the hospital *(6 months)* ....______

III. Have you had any out-patient tests done in the past **6 months**? ☐Y ☐ N

If yes, how many times for each of the following tests:

- Blood...______
- Specimens *(i.e. urine, stool sample, throat swab)* ....______
- Scopes *(i.e. endoscopy, colonoscopy, sigmoidoscopy)* ....______
- X-rays..______
- Scans *(i.e. ultrasound, CT scan)* ....______
- Breathing tests *(i.e. spirometry)*. ....______
- ECG *(heart monitoring)*..______
- EEG *(brain waves)* ....______
- EMG *(muscles)*..______
- Other tests ....______

Please specify test: ________________________________

IV. Have you taken any medications over the **past 2 days**? ☐Y ☐ N

If yes, please list any medications that you have taken in the last 2 days (including prescription medications, over-the-counter drugs, homeopathic, etc.):

Drug name, dose and frequency____________________________________

Drug name, dose and frequency____________________________________

Drug name, dose and frequency____________________________________

Drug name, dose and frequency____________________________________

V. Have you used any supplies, aids or devices in the past **6 months** ☐ Y ☐ N
(i.e. wheelchairs, syringes, walker, crutches, dressings, pillows, tissues, etc.)

Item description ______________________________

Cost to nearest $ ☐☐☐

Item description ______________________________

Cost to nearest $ ☐☐☐

Item description ______________________________

Cost to nearest $ ☐☐☐

Please return the completed questionnaire to the research assistant today in the clinic or return it at your next appointment or mail it in the self-addressed envelope within 7 days.

THANK YOU FOR COMPLETING THIS SURVEY!!!

Appendix I

REVIEWER FORM

COLON CANCER NEEDS ASSESSMENT QUESTIONNAIRE

Reviewer #: _____

Date of Completion:

Reviewer Instructions

Your assistance in piloting this new questionnaire is greatly appreciated.

Please review the **participant information sheet and consent form** prior to completing the questionnaire, so that you understand the overall purpose of the study. You need not sign the consent form, it is just for your review.

Please **complete the questionnaire** as if you were a participant in the study.

If there are questions in which the wording of instructions, purpose of the question, or item responses is unclear, ambiguous, incomplete, intrusive, or inappropriate please indicate this directly on the questionnaire. If possible provide suggestions for improvement.

Please circle any typographical, grammar, or spelling errors directly on the questionnaire.

Please complete the attached **reviewer feedback form**.

Return the entire package including reviewer instructions & feedback form, consent form, and questionnaire today in the clinic after completion.

Colon Cancer Needs Assessment Questionnaire: Reviewer Feedback Form

1. From start to finish, how many uninterrupted minutes did it take you to complete the questionnaire?

   ________ minutes

2. The time it took to complete the questionnaire was (check one):

   ☐ Appropriate for the study purpose
   ☐ Too long
   ☐ Too short

3. As a study participant, the length of the questionnaire would (check one):

   ☐ Be feasible for me to complete

   ☐ Be a possible but unlikely barrier for me in completing the questionnaire

   ☐ Be a likely and major barrier for me in completing the questionnaire

4. In terms of overall content, are there any questions NOT included in this questionnaire that you feel would be important for identifying the supportive care needs of patients recently diagnosed with stage III or IV colon cancer?

   ☐ No
   ☐ Yes If yes, describe:

   ____
   ____
   ____

5. In terms of overall content, are there any questions NOT included in this questionnaire that you feel would be important for assessing the patient's awareness of the existing supportive care services and the degree to which they are used by patients with colon cancer?

   ☐ No
   ☐ Yes If yes, describe:

   ____
   ____

6. Are there questions you feel are unimportant, irrelevant, or redundant and could be eliminated from the questionnaire without jeopardizing the accuracy and completeness of the study results?

☐ No
☐ Yes If yes, please list the questions by their number:

____
____
____
____

7. Questionnaire Format:
   a) The overall format of the questionnaire was:

☐ Very Easy to Read ☐ Easy to Read ☐ Somewhat Easy to Read ☐ Difficult to Read

   b) Overall, the questionnaire instructions were:

☐ Very Clear ☐ Clear ☐ Not Very Clear ☐ Confusing

   c) Overall, the font size made the questionnaire:

☐ Very Easy to Read ☐ Easy to Read ☐ Somewhat Easy to Read ☐ Difficult to Read

   d) Overall, the white space between questions was sufficient and made the questionnaire easy to read.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

   e) Overall, the questions were ordered in a logical and organized manner that was easy to follow:

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

8. The 3 most important suggestions I have for improving this questionnaire are:

____
____
____

Glossary

Advanced Colon Cancer (ACC): Refers to ACC is that which extends beyond the colon to nearby lymph nodes and to distant organs such as the liver or lungs. It usually cannot be cured or controlled with treatment.

Adjuvant therapy: A treatment method used in addition to the primary therapy; used to increase the effectiveness of treatment (CCO, 2004).

Cancer continuum: Refers to all phases of cancer illness from diagnosis to the end of life.

Chemotherapy: Treatment of cancer using medications which target and destroy any rapidly dividing or cancer cells (CCO, 2004).

Colon: The large bowel, which is a tube-like organ connected to the small intestine at one end and the anus at the other; forms the final 5 to 6 feet of the large intestine, in which stool is formed through the absorption of residual fluid from digested food.

Colonoscopy: An examination of the colon in which a lighted flexible instrument called colonoscope is inserted through the rectum into the colon.

Colorectal cancer: Cancer of the colon or of the rectum.

Colorectal cancer screening: The process for finding polyps or tumor cells in the colon and rectum.

Co-morbidity: The presence of coexisting or additional diseases with reference to an initial diagnosis or with reference to the index condition that is the subject of study. Co morbidity may affect the ability of affected individuals to function and also their survival; it may be used as a prognostic indicator for length of hospital stay, cost factors, and outcome or survival.

Confidentiality: The means through which the identity of information, data, persons, research findings or any other knowledge or intellectual property is protected.

Correlation coefficient: A measure of association that indicates the degree to which two variables have a linear relationship; this coefficient, represented by the letter r, can vary between +1 and -1; when r = +1, there is a perfect positive linear relationship in which one variable relates directly with the other; when r = -1, there is a perfect negative linear relationship between the variables.

Cross-sectional study: A study in which the presence or absence of disease or other health-related variables are determined in each member of the study population or in a representative sample at one particular time. This contrasts with longitudinal studies which are followed over a period of time (Hulley et al., 2007).

Diagnosis: The process of identifying a disease, such as cancer, from its signs and symptoms.

Flesch-Kincaid Test: A method of determining the difficulty of a written passage by a formulation that provides an estimate of how many people in the U.S. Would be able to read and understand the passage; used in determining patient comprehension of hospital forms.

Incidence: A rate showing how many new cases of a disease occurred in a population during a specified interval of time (usually expressed as a number of new cases per unit time per fixed number of people: e.g., number of new cases of cancer per 100,000 persons in one year).

Internal consistency: A method of establishing the reliability of a questionnaire with a single administration by examining how strongly its questions are related to one another.

Metastatic/metastasis: The spread of cancer from the original tissue through the blood or lymph system to another part of the body (CCO, 2004).

Oncologist: Doctor who specializes in cancer treatment.

Palliative care: Care given to ease pain or other symptoms without curing the underlying disease.

Prevalence of unmet needs: The proportion of unmet needs reported by a group of population.

Prognosis: a forecast or prediction of the likely course of a disease, outcome of treatment and risk of relapse.

Psychometrics: Is the field of study concerned with the theory and technique of psychological measurement, which includes the measurement of knowledge, abilities, attitudes, personality traits, and educational measurement. The field is primarily concerned with the construction and validation of measurement instruments such as questionnaires, tests, and personality assessments.

Qualitative research studies: Research studies that focus on gathering nonnumeric information using focus groups, interviews, document analysis and product analysis.

Quantitative data: information gathered in numeric form.

Quantitative research method: Research methods that focus on gathering numeric information or nonnumeric information that is easily coded into a numeric form, such as survey.

Questionnaires: A list of questions submitted orally or in writing to obtain personal information or statistically useful data.
Predetermined sets of questions used to collect data - clinical data, social status, occupational group, etc. The term is often applied to a self-completed survey instrument.

Radiation therapy or radiotherapy: The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy) (CCO, 2004).

Recurrence: The return (relapse) of detectable cancer after first treatment resulted in no detectable signs of cancer (remission).

Regression analysis: Procedures for finding the mathematical function which best describes the relationship between a dependent variable and one or more independent variables.
In linear regression the relationship is constrained to be a straight line and least-squares analysis is used to determine the best fit.
In logistic regression the dependent variable is qualitative rather than continuously variable and likelihood functions are used to find the best relationship.
In multiple regression the dependent variable is considered to depend on more than a single independent variable.

Reliability: This is an indication of the consistency of a test measuring the same particular factor over time. It can be used to determine the consistency of a measure, instrument, or observer. The relationship between test items intended to measure the same skill or knowledge is termed as internal reliability. An assessment tool has a high reliability if it yields similar results when given to the same sample of subjects at two different times, and be different assessors.

Resection: Removal of part of the body in an operation.

Service/program gaps: Gaps in service use may occur due to unawareness of the existing services, ineffective services or lack of accessible, affordable services.

Severity of unmet needs: The degree or level of unmet needs among a group of population.

Staging system: A system to describe the extent of a cancer inside the body. If the cancer has spread, the stage describes how far it has spread from the original site to other parts of the body (CCO, 2004).

Stoma: artificial opening into the bowel created by surgery to act as an exit for feces or body waste; this opening in the wall of the abdomen allows the feces to be diverted and collected in a bag.

Supportive care: Services offered to prevent, control or relieve complications and side effects and to improve the patient's comfort and quality of life (Fitch, 2000).

Supportive care services: Refers to services required to meet the physical, social, emotional, informational, psychological, spiritual and practical needs of patients during cancer journey (Fitch, 2000).

Survey: An ordered series of questions about attitudes, behaviors or personal characteristics administered to individuals in a systematic manner.

TNM staging system: a system for describing the extent of cancer in a patient's body; T describes the size of the tumor and whether it has invaded nearby tissue; N describes any lymphnodes that are involved; and M describes metastasis (spread of cancer from one body part to another) (Greene et al., 2002).

Validity: The extent to which an assessment measures what it is meant to measure and the extent to which inferences and actions made on the basis of test scores are appropriate and accurate. It is also a measure of the usefulness, meaningfulness and appropriateness. It is an indication of the consistency with which the tool or assessment measures what it is designed to measure, excluding extraneous features from such measurement.