Assessing the Needs of People Living with Cancer on Prince Edward Island: A Psychosocial Approach

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Dr. Kim Critchley
Dr. Philip Smith

Shannon J Classen
Charlottetown, PE
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Dedication

This thesis is dedicated to my husband, Kent Wood, and our baby, affectionately known as Bear. I love you.

Acknowledgments

The author greatly acknowledges the invaluable assistance provided by dedicated and passionate volunteers of the Canadian Cancer Society. The six volunteers, who in dedicating many evening and weekend hours to see this study through, went beyond the call of duty. Many thanks are extended to the 139 patients who shared their time and their experiences. Gratitude is also extended to the Project Advisory Committee, the Thesis Supervisory Committee, and the staff of the PEI Cancer Registry for assisting in the development and progression of this research. This project was generously funded and supported by the Atlantic Regional Training Centre, Canadian Health Services Research Foundation and the Canadian Cancer Society, PEI Division.

Abstract

The needs of 139 people living with cancer in Prince Edward Island were examined in this cross-sectional descriptive quantitative study. Primarily close-ended telephone interviews were used to identify the informational, practical and financial, as well as emotional, spiritual, and social needs of cancer patients. Level of health care service accessibility, the degree and desired mechanism in which needs are being, and can be, met were also explored. Overall, information needs ranked high among cancer patients in Prince Edward Island. Over half of patients expressed a need for several types of information. The two most common places patients look for information are health care professionals (66%) and the Internet (50%), and patients prefer to receive information via pamphlets and written materials (86%). Managing side effects such as pain, nausea, and fatigue (30%) was the most often reported practical need, as well as the most often reported unmet practical need (40%). Between 25% and 30% of patients reported several needs related to emotional, spiritual and social concerns, with roughly half of patients stating that these needs had not been met. Over half of participants (57%) indicated that they would like to receive support through individual visits with a cancer survivor, or through access to a central staff person that could guide cancer patients through their cancer experience (53%). Many patients stated that their health care services needs were accessible all of the time.

Table of Contents

Chapter One: Introduction

In Prince Edward Island, the most recent needs assessment of cancer patients was conducted in 1989 (Vachon, Conway, Math & Adair, 1989). The purposes of that study were threefold: firstly, to obtain data on specific concerns of Prince Edward Island cancer patients who went off Island for treatment, secondly, to assess the interest in and need for programs and public meetings for patients with cancer and their families, and thirdly, to examine rural/urban differences. In the 1989 needs assessment, 364 cancer patients were interviewed either by phone or in person. The sample was considered fairly representative of the Cancer Registry population at the time of the study.

Overall, Vachon et al. (1989) found seven clearly identified unmet needs of people living with cancer in Prince Edward Island. The unmet needs included a need for improved: 1.) help in dealing with the side effects of cancer; 2.) help in dealing with areas of well-being including sexuality, self-esteem, life outlook and concerns about death; 3.) help in dealing with the financial impact of cancer; 4.) help with job problems; 5.) help with the adjustment to the diagnosis, family reaction, and fear of recurrence; 6.) awareness of the resources available for support; and 7.) support services including group meetings, support sessions, public lectures, one-to-one outreach programs for patients and family members, and improved access to literature.

Since the time of this 1989 study, much has changed in cancer care in Prince Edward Island. Among the many changes that have occurred are medical advances and changes in the prevention, detection, and treatment of cancer. Together, these changes have increased survival rates, consequently making quality of life and psychological well-being more important outcomes to consider in cancer care (Weis, 2003). Marked changes in family structures, lifestyles and social support networks have also occurred over time. The most notable change, in terms of the Island context, is the addition of the Cancer Treatment Centre at the Queen Elizabeth Hospital (QEH). It is presumed that along with such changes, the needs of people living with cancer in Prince Edward Island have also changed. Thus, there is a call for a re-assessment and evaluation of the needs of people living with cancer in Prince Edward Island.

More recent research shows that people diagnosed with cancer regularly declare that they are left with little support to meet their needs after they have received a diagnosis of cancer and begun treatment (Saegrov, 2005). High levels of unmet needs for information, post-treatment care, physical activity, and help with everyday problems are frequent among cancer patients (Sanson-Fisher et al., 2000). Sanson-Fisher et al. (2000) surveyed 888 cancer patients attending one of the nine major public cancer treatment centers in New South Wales, Australia to determine the prevalence of perceived unmet needs of cancer patients undergoing treatment.

Respondents were asked to respond to several questions in five domains of need including: psychological, health system and information, physical and daily living, patient care and support, and sexuality (Sanson-Fisher et al., 2000). Overall, five of the highest rated domains of unmet needs were related to the psychological needs domain. Three of the domains of highest need were related to health system and information needs, and two of the domains were related to physical and daily living needs. More specifically, the specific items of greatest need were easy car parking at the hospital (28%), monetary allowances for travel, treatment, and equipment expenses (19%), and access to a library of books and videos about cancer and related issues (18%). On the whole, this study suggests that cancer patients experience a moderate to high level of unmet needs across many domains of need.

Furthermore, in a Canadian survey of 913 cancer patients, the results indicated that respondents were more likely to be dissatisfied with the treatment for their symptoms related to cancer than for their cancer itself (Ashbury, Findlay, Reynolds & McKerracher, 1998). It appears as if needs related to emotional, social, spiritual, practical, and financial concerns, for example, are not being readily met. There is a clear need to find out more about patients' specific concerns and priorities in all areas of cancer care (Luker et al., 1995).

If assistance provided to cancer patients is to be effective, however, it must be in the areas that patients themselves perceive as a need. The cancer community, which includes health care professionals, health care and social agencies, and government departments, cannot assume that they know the needs of cancer patients. Knowledge of the needs of cancer patients throughout the cancer journey can only come from asking patients themselves: "identification of the needs of individuals (and of the local population), whether through formal needs assessment or some surrogate, is an essential first step towards optimising the use of allocated resources" (Asadi-Lari, Tamburini & Gray, 2004, p 34). Physical and psychosocial problems associated with cancer, when left untreated, can have a substantial affect including increased health care costs, inferior survival rates, reduced productivity, and diminished quality of life (Doll et al., 2002; Girgis & Burton, 2001). Thus, assessment and awareness of such problems is crucial to aid in the prevention of problems and addressing of problems when they occur (Girgis & Burton, 2001; Wen & Gustafson, 2004).

The results of this study will expand the body of knowledge about cancer experiences in Prince Edward Island and, ultimately, establish what care people living with cancer in Prince Edward Island need. The intent is that this study will provide important baseline information that will assist in the refinement and development of supportive care interventions for cancer patients and facilitate appreciation for the vast and diverse ramifications of this disease. The specific objectives of this study are threefold:

- To identify the range of psychosocial needs of people living with cancer in Prince Edward Island;
- To establish the degree and the desired mechanism in which the psychosocial needs of people living with cancer in Prince Edward Island are being, and can be, met; and
- To prioritize the psychosocial needs of people living with cancer in Prince Edward Island.

Background

Cancer is the leading cause of premature death in Canada (Canadian Cancer Society [CCS], 2006). Cancer accounted for 989,800 potential years of life lost in 2002. This represents 32% of the potential years of life lost resulting from all causes of death. On average, 2744 Canadians will be diagnosed with cancer, and 1354 Canadians will die of cancer each week. It is estimated that 153,100 new cases of cancer, and 70,400 deaths from cancer will occur in Canada in 2006 (Canadian Cancer Society [CCS] & National Cancer Institute of Canada [NCIC], 2006). In Prince Edward Island, it is estimated that there will be 790 new cases, and 330 deaths from cancer in 2006.

In fact, the number of new cancer cases in Canada is growing twice as fast as the population is growing. Expert analysis shows that a cancer crisis will hit Canada by the year 2010 due to the aging baby boomer population, and the number of new cases of cancer each year (Canadian Cancer Society [CCS] & National Cancer Institute of Canada [NCIC], 2005). This crisis will cost approximately $176 billion in direct healthcare costs, a cost that will overwhelm the Canadian healthcare system. The impact of cancer is, however, further reaching. In addition to potential health and financial hardships, cancer also has psychosocial and emotional impact (Luker et al., 1995). In fact, health related quality of life data have been found to be strong predictors of survival (Sprangers, 2002).

People living with cancer can experience a variety of psychological, physical, emotional and social challenges (Desroches, Joza, Campbell, Gerl & Wurtak, 2005). The word ‘cancer’ can evoke frightening images of suffering, pain, and death (Saegrov, 2005). In fact, it is well established that cancer can cause uncertainty, fear, anxiety, depression, helplessness and disruption in every aspect of life for patients and their families (Greer, 1994; King, 2006; Desroches et al., 2005; Ryan et al., 2005). It is important to realize that the experience of cancer is not a single, undifferentiated event, distress can be heightened at particular times throughout the experience (Doll et al., 2002; National Breast Cancer Centre [NBCC] and National Cancer Control Initiative [NCCI], 2003). Moreover, the psychosocial impact of cancer can persist for many years after a cancer survivor is considered cured (Greer, 1994).

A psychosocial perspective is a holistic approach to cancer care that strives to improve the quality of life of people affected by cancer, from prevention through bereavement (Canadian Association of Psychosocial Oncology [CAPO], 2006). The psychosocial impact of cancer includes the understanding and treatment of the social, psychological, emotional, spiritual, quality-of-life, and functional aspects of cancer (Doll et al., 2002; Greer, 1994; King, 2006). At each stage of the cancer continuum, psychosocial needs may change (Sanson-Fisher et al., 2000; Weis, 2003). The following five stages have been identified as stages of high vulnerability for psychosocial distress: before and after receiving a diagnosis of cancer, during acute care and treatment, during rehabilitation and after-care, after recurrence, and during palliative care and progressive disease (Weis, 2003). Thus, the psychosocial perspective takes into account the continuum of needs of patients, as well as their families and friends, in recognition that the ramifications of this disease extend far beyond the medical needs of the patients (Wen & Gustafson; 2004).

The specific domains of needs within the psychosocial perspective of cancer are exemplified, but not limited to, those herein. They include physical, informational, emotional, psychological, social, spiritual, financial and practical needs. Physical needs include the ability to perform a wide range of activities of daily living, as well as physical symptoms from the disease or treatment, such as pain, fatigue, and hair loss (Sprangers, 2002). Informational needs include how to handle or manage side effects, care processes, and test results. By providing support in informational needs, knowledge, understanding and coping skills can increase and enhance a sense of control (Campbell, Phaneuf & Deane, 2004; Desroches et al., 2005). Emotional needs include abandonment, depression, and anger; support in these areas can enhance self-confidence, boost self-esteem, reduce negative feelings, and improve relationships (Campbell et al., 2004). Psychological needs are associated with the ability to cope with the illness experience and its consequences. Social needs include needs related to social relationships, interactions, and integration (Sprangers, 2002). Spiritual needs are related to the meaning and purpose in life. Finally, functional or practical needs include daily living activities, transportation, and childcare, which are essential to quality of life outcomes.

Considering the wide range and variety of psychosocial needs, it is widely accepted that there is no 'best' method of data collection for researching the psychosocial needs of cancer patients (Entwistle, Tritter & Calnan, 2002; McIllmurray et al., 2001). The type of data collection method depends on the research question, as well as the situations and preferences of the people whose needs are the focus of study. The psychosocial impact of cancer has been estimated using a number of different methods, including quality of life assessments, health care satisfaction studies, and, more recently, needs assessments (Girgis & Burton, 2001; Rainbird, Perkins & Sanson-Fisher, 2005).

Needs assessments identify specific issues with which patients have a need for assistance or support, as well as the perceived level of help required (Bonevski et al., 2000; Girgis & Burton, 2001; Rainbird et al., 2005). In this context, 'needs' can be defined as "the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being" (Girgis & Burton, 2001, p. 270). Health professionals must be aware of the met and unmet domains of need that cancer patients perceive as important, so that interventions can be accurately and appropriately planned. Improvement of patient care through the acquisition of both accurate and relevant support and interventions is a significant benefit of needs assessments (Templeton & Coates, 2001; Rainbird et al., 2005).

Needs assessments are an integral part of care planning, in part because many patients do not readily communicate their needs to clinicians (Hack, Degner & Parker, 2005; Wen & Gustafson, 2004). Lack of communication between patients and their clinicians can be partly attributed to fear and apprehension associated with being diagnosed with cancer, which often hinders patients from asking questions or seeking clarifications (Luker et al., 1995; Templeton & Coates, 2001). Communication about needs between health care professionals and patients also suffers because many patients maintain the perspective that feelings such as grief, anger, suffering, and pain are an inevitable part of cancer (Ryan et al., 2005; Wen & Gustafson, 2004). Although it could be argued that a certain amount of distress is a 'normal' response to a potentially life-threatening disease (NBCC & NCCI, 2003), when distress becomes persistent or impedes a person's ability to function, distress becomes clinically significant (Ryan et al., 2005). In addition, if initial 'normal' feelings of distress are not dealt with, clinical levels of distress are more likely to develop.

In a review of the main barriers to recognizing distress in cancer patients, Ryan et al. (2005) found that patients' beliefs that doctors do not have the time to deal with psychosocial issues, and the idea that a doctor could not help them anyway, were common barriers to communication. Patients also feel that their fears and concerns are unreasonable and impractical (Ryan et al., 2005). Other potential barriers to communicating concerns include not having the words to describe feelings, not wanting to be a burden, fear of breaking down, and/or being ashamed to admit problems (NBCC & NCCI, 2003. The result of a lack of communication is an increase in both healthcare costs and unnecessary suffering (Ryan et al., 2005; Wen & Gustafson, 2004).

Moreover, when patients do discuss their non-medical needs, they do not always receive the supportive care that they need to address their feelings and ameliorate their situation. Research has shown that although between one third and 45% of people diagnosed with cancer report significant distress, fewer than 10% of patients are referred to psychosocial care (Carlson & Bultz, 2003). One of the main reasons for a lack of referral for care is that staff and departments specializing in psychosocial oncology are continuously under-funded. In addition, primary care workers are unable to look after psychosocial needs because they are also overburdened. The result is that many patients do not receive the psychosocial care that they need. In this regard, the Canadian health care system faces very significant challenges.

Needs assessments are valuable resources that can beat this challenge. Assessment of needs provides patient input into the health care system, which leads to improved allocation and usage of scarce resources, and a consequent decrease in patient frustration with the health care system (Sanson-Fisher et al., 2000). Readily available needs-based information can also lead to more efficient time management for over-burdened health care professionals.

Chapter Two: Literature Review

This section provides a review and critique of selected literature. A collection of articles, reports, and books covering a span of over 10 years (from 1989 to 2006), and largely restricted to empirical research reports and expert opinions, was reviewed. The review was restricted to the English language and the target population is, specifically, those with cancer. Several electronic databases such as Ebscohost, PsycInfo, CINAHL and the Cochrane Collaboration were searched using combinations of 'cancer', 'patient needs', 'needs assessment', 'patient satisfaction', and 'quality of life measures' as search terms. Reference lists of relevant articles were searched for additional eligible publications. Finally, several experts and organizations in the field of cancer care were contacted to identify additional publications and grey literature.

As the brief overview of the following three studies exemplifies, the literature on cancer patients' needs clearly indicates that cancer patients' needs are vast and diverse. The Canadian Cancer Society, Saskatchewan Division, held key informant interviews, focus groups and public meetings to assess the unmet needs of a sample of 183 cancer patients (Canadian Cancer Society [CCS], 2004). The following array of unmet needs was stated by participants: better, more timely access and linkage to information and resources; improved communication with physicians; help with the burden of travel in and outside the province; more home care, palliative, and respite care; more community-based resources; better continuity in coordination of cancer care; greatly enhanced support and resources for family and caregivers; and more psychosocial resources.

Whelan et al. (1997) examined the supportive care needs of 156 newly diagnosed cancer patients attending Regional Cancer Centers in Ontario, to determine and plan supportive care strategies. Informational needs and social concerns were commonly reported perceived needs among the patients surveyed. Nearly 85% of the sample wanted a great deal of information or enough information to be well informed and 66% of patients reported a social concern of one type or another. Of the patients who identified current problems for which they needed assistance, health status was identified as the number one problem (43%). Family issues (26%), emotional concerns (11%), financial issues (8%), social concerns (6%), and practical issues (6%) were some of the other most important problems identified by patients.

Using a descriptive cross-sectional questionnaire survey, McIllmurray et al. (2001) strived to identify the prevalence of psychosocial need among adult cancer patients in northwest England. The questionnaire included 48 questions about need, relating to seven psychosocial need domains 'health professionals', 'information', 'social support networks', 'identity', 'emotional and spiritual', 'practical', and 'childcare'. With an approximate 40% return rate of the mail out questionnaire, 380 cancer patients responded. Results show that the majority of patients were women (66%) who were at the diagnosis moment (55%) of the cancer journey. Interestingly, 25 of the 48 items were rated as important for more than 50% of the patients. The areas of 'health professionals', 'information' and 'support networks' were rated as very high need categories (85%, 80%, and 75%, respectively).

These studies confirm the existence of high levels of need and unmet need in a variety of domains. Accordingly, literature on the following domains is reviewed herein: information; practical and financial; emotional, spiritual, and social; and health service needs.

Information Needs

Cancer patients frequently report unmet disease and treatment-related information and communication needs, including lack of information on the extent of the disease, prognosis, and treatment alternatives, intent, and side effects (Hack et al., 2005); cancer patients also frequently report dissatisfaction with the information which is given to them, and their ability to retain and process information (Van Der Molen, 1999). Access to information is not only an expressed need of cancer patients, but also a coping-strategy that many cancer patients use to reduce stress and anxiety throughout their cancer experience. Research has shown that people diagnosed with cancer have several information needs, which vary according to the cancer site, stage and treatment type (Templeton & Coates, 2001; Van Der Molen, 1999; Hack et al., 2005). Hack et al. (2005) state that "physicians need to move from a 'one size fits all' method of tending to patients' communication needs, to a more 'tailored' approach that considers the unique needs, skills, values, beliefs, and emotions of patients, the external factors that influence patients, and the environmental context in which the communication occurs" (p. 834). For instance, information needs cannot be addressed within a vacuum, the literature on communication goals and needs of adult cancer patients indicates that patients' communication outcomes are enhanced when physicians also attend to their emotional needs (Hack et al., 2005).

In a study of the information needs of 150 newly diagnosed women with breast cancer, Luker et al. (1995) asked women to state a preference for one item of information, in a pair of information items. Thirty-six information pairs were presented, which encompassed nine information needs involving physical, psychological, and social aspects of care and treatment. A Thurstone scaling model was used to form rank orderings of the information items, which reflected the perceived importance of each item. Information about the likelihood of cure, the spread of the disease, and treatment options were perceived as the most important items of information for newly diagnosed women with breast cancer.

No significant differences were found between the information needs based on education or social class. Age, however, displayed some minor differences. Among newly diagnosed women, younger women rated sexual attractiveness as more important than older women did.

Older women rated information regarding social life as more important than younger women did. Luker et al. (1995) also make the important point that there may be differences in information needs depending on the stage of cancer: "it is clearly important to understand when a woman's information needs may change; distance from diagnosis is probably an important variable" (p. 139).

Graydon et al. (1997) used the Toronto Informational Needs Questionnaire (TINQ – BC) to study the information needs of 70 women with breast cancer being treated by surgery, chemotherapy or radiation therapy. The TINQ-BC asks patients to rate the importance of 51 items on a five-point scale from one (not important) to five (extremely important). The items measured include five subscales: disease, investigative tests, treatments, physical and psychosocial scales.

Overall, information needs of the women were high; women with breast cancer indicate a need for information regardless of their treatment type (Graydon et al., 1997). In each of the treatment groups, patients indicated a high need for information regarding the disease, investigative tests and treatments. The authors state that: "the importance placed in these areas may be a reflection of a high degree of perceived threat, actual gaps in knowledge or lack of comprehension of the information provided" (Graydon et al., 1997, p. 63). There was no difference observed in the total number of information needs based on marital status, education, or income. Age, however, was negatively correlated with information needs, so that the younger the patient, the greater her need for information was.

In a study at the Leiden University Medical Centre in the Netherlands, women who were two to four years post-treatment for primary breast cancer were asked about their information needs and preferences regarding additional investigations and organization of follow-up care (de

Bock et al., 2004). Most important to the 84 women who responded to the survey was information on long-term effects of treatment and prognosis, discussion of prevention of breast cancer, hereditary factors, and changes in the untreated breast. Nonetheless, the authors conclude that after treatment, not all patients need all types of information. They stress that individual patient needs and preferences should be identified early in treatment and incorporated into the continuum of care. By doing so, resources are directly targeted at areas of needs and the likelihood of positive patient outcomes is maximized.

In the year 2000, the Canadian Cancer Society commissioned a study in Alberta to better understand the needs of people living with cancer (Canadian Cancer Society [CCS], 2000b). To gather this information, researchers conducted a literature and document review, a survey of cancer patients and caregivers, regional interviews and focus groups, and surveys and interviews with cancer care professionals. A previously validated survey (Bonevski et al., 2000) was slightly modified and administered to cancer patients in two tertiary cancer centres in Alberta. The results indicate that the areas of greatest need (i.e. areas where a moderate/high need was indicated) were in the domain of information needs. Of the 91 patient respondents, 62% indicated a moderate to high need to be fully informed about test results as soon as possible, 62% needed information on things they could do to help themselves get well, and 60% needed information about cancer that is under control or diminishing (remission).

Sources of Information

One of the largest studies on preferred information sources examined information using behaviour among various groups of cancer patients in Belfast, Ireland (Mills & Davidson, 2002). A sample of 341 patients rated their views of 19 sources of information on a five point Likert scale, and included any other source of information not listed on the questionnaire. Interestingly, although General Practitioners were rated as the second most common source of information, they were one of the least valued sources. Hospital consultants were the primary source of information for 95% of the sample, but rated as the third best source. Specialist nurses were not often used, but were rated as the best source of information.

Worthy of note is the role that family and friends play in information seeking (Mills & Davidson, 2002). Family and friends were identified as a source of information for nearly 75% of the sample, and rated as an excellent source of information by 61%. The authors state "this is an important finding in as much as health care professionals may view family and friends simply as a form of support for patients, when in reality patients are seeking information from them" (Mills & Davidson, 2002, p. 376).

In terms of mass media sources of information, patients did not rate these as high as they rated interpersonal sources of information (Mills & Davidson, 2002). Patients under the age of 45 made use of mass media sources more frequently than older patients. Male patients also made use of mass media sources more frequently than female patients. The authors suggest that this difference could be attributable to men preferring a passive role to information and decision-making, thus seeking a non-interactive source.

In a survey of 913 Canadian cancer patients' experiences, respondents stated that Nurses (61%), specialists (61%), and other cancer patients (60%) were very helpful sources of information on symptom management (Ashbury et al., 1998). Additionally, only 42% of respondents said that their family physician was a very helpful source of information on symptom management, yet 75% of respondents chose their doctor as a preferred source for information. Quality and accessibility of information on symptoms and symptom management appears to be as important as information about cancer and its treatment. The authors conclude that there is a need for better and more accessible information on these issues.

In a survey of 116 cancer patients from across Canada, participants were asked about their interest in three specific services for information needs (Armstrong & Lennon, 2006). Of the respondents, 66% had completed their cancer treatment, and the majority were over 55 years of age, or older. The sample was primarily composed of patients diagnosed with breast, prostate, and colorectal cancers (23%, 19%, and 14%, respectively). Among the three services asked about, which included a website devoted to cancer information and support, a toll-free phone service with volunteers who have experienced cancer, and a toll-free phone service with cancer information specialists, the service with the greatest number of respondents expressing interest was a toll-free phone service with volunteers who experienced cancer; 46% of respondents stated that they would use this service. In addition, 38% of participants said they would use a toll-free service with cancer information specialists, and 32% of respondents indicated that they would access a website devoted to cancer information and support.

Practical and Financial Needs

In a review of the challenges faced by a person with cancer, the NBCC and NCCI (2003) prepared a brief, yet comprehensive, guideline to the major issues within the practical and financial needs domain. The review explains that cancer patients experience a wide range of physical symptoms and side effects from the disease and treatment that can have a significant affect on their quality of life. Some of the more common practical symptoms experienced by cancer patients include nausea and vomiting, acute and chronic pain, fatigue, lymphoedema, disfigurement, odour, incontinence, cognitive problems, difficulty communicating, swallowing difficulties, respiratory problems, loss of appetite, nutritional deficiencies, and fertility problems.

Common financial issues faced by cancer patients include costs for screening, medical procedures, support services (including physiotherapy and counselling), prostheses, travel and accommodation, child care, and home help (NBCC & NCCI, 2003). Loss of income due to the illness and accessing the relevant financial information can impede a patient's ability to satisfy his/her financial needs. Furthermore, financial problems vary depending upon a number of factors, including eligibility for health care concession, financial assistance programs available, private health insurance coverage, and accessibility of services.

In a survey of 913 Canadian cancer patients' experiences, researchers found that fatigue and anxiety were the two most prevalent symptoms reported (78% and 77%, respectively), fatigue being the most debilitating (Ashbury et al., 1998). Overall, it was often reported that physical symptoms affected several aspects of daily living, including ability to work, social activities, family life, communication with family members, and financial situations.

Emotional, Spiritual, and Social Needs

Support has long been recognized as an important contributor to health and well-being (Campbell et al., 2004). In other words, patients who perceive that they have a lack of support are more likely to experience greater psychological distress than patients with support (NBCC & NCCI, 2003). Research has shown that improved health outcomes, such as survival and morbidity, are related to the provision of social support interventions (Desroches et al., 2004). Support can be provided through many media, including one-to-one assistance, telephone support, group support (Desroches et al., 2004; Wong, 2002) and online support (White & Dorman, 2001). Social support provides assistance and information in several areas of need, including practical assistance, emotional support, and financial advice (Campbell et al., 2004). The volunteer sector has long recognized the importance of social support.

In a review of the challenges faced by a person with cancer, the NBCC and NCCI (2003) prepared a brief, yet comprehensive, guideline to the major issues within the emotional and social needs domain. The report states that people with cancer often specify a wide range of emotional and social difficulties, which include feelings like being in a state of shock, being out of control, or being angry, fearful, or helpless. Grief, loss, distress, curtailment of activities, and fear of mortality are other key issues for cancer patients. Other specific factors that have a strong psychological impact are body image, sexuality, interpersonal difficulties, anxiety, fear of recurrence, and survival.

In the Canadian Cancer Society commissioned study in Alberta mentioned above, researchers conducted a survey of cancer patients to examine unmet cancer patient needs (CCS, 2000b). Although the results indicated that the area of greatest need (i.e. area where a moderate/high need was indicated) was in the domain of information needs, many patients also expressed a moderate to high need for emotional support. Over 50% of patients indicated that they needed help in three areas of emotional support, including: dealing with fears about cancer spreading or returning (59%), concerns about the worries and fears of those close to them (54%), and coping with uncertainty about the future (51%).

Similarly, in Ontario, the Canadian Cancer Society reported that over 70% of the 397 respondents indicated a need for emotional support (Canadian Cancer Society [CCS], 2003). Although the greatest area of need for Ontario cancer patients was service delivery, with over 80% of patients reporting specific needs in this area, emotional support is also an obvious area in need of improvement. Of the patients who expressed a need for emotional support, over half of them did not have their emotional support needs met. The main barriers to meeting this need were: not knowing what local support programs were available; not feeling comfortable discussing emotional support with doctors, family and friends; and not being able to find other cancer patients to talk to.

Supportive Programs and Services

The Canadian Cancer Society, PEI Division offers several supportive care programs and services to cancer patients including Reach to Recovery, CancerConnection, Cancer Information Service and Emergency Assistance. Reach to Recovery is a one-on-one support program for women with breast cancer. Women who have had breast cancer visit women who are currently recovering from breast cancer surgery. Visits are generally made in the hospital, but can be done in the home setting. Women are matched as closely as possible by age, and, if possible, by treatment. All women receive an attractive kit that includes information about breast cancer surgery, an exercise guide, ball, rope, pillow, and information on available cancer resources.

CancerConnection is an innovative support program where peers provide support to people diagnosed with cancer over the telephone. This peer support program is free, accessible, confidential, and responsive. The program was created in Ontario in 1995, and is growing into a nationwide program. Committed volunteers, who are cancer survivors themselves, provide hope, support, experience, and understanding to recently diagnosed cancer patients.

The Cancer Information Service is a confidential, national, bilingual, toll-free service available to cancer patients, their families, the general public, and healthcare professionals. The service is available Monday to Friday 9 a.m. to 6 p.m. For languages other than English and French, interpreter services are available. Trained information specialists are available to answer questions in clear, understandable terms, and to search for information on all types of cancer, prevention, treatment and side effects, clinical trials, complementary and alternative therapies, coping skills and techniques, emotional support services, and local community resources. The Emergency Assistance Program is a service intended to help cancer patients who do not have adequate financial resources to cover certain costs specifically associated with a cancer diagnosis. This service provides transportation, drugs, ostomy supplies, dressings, and prosthesis to cancer patients in need.

Peer support services and programs, such as some of those offered by the Canadian Cancer Society, are based on the premise that support from others who have been diagnosed with cancer can help to reduce the negative impacts of cancer (Campbell et al., 2004). In a recent study by Campbell et al., the authors conducted a systematic literature review of evaluation studies to determine: 1.) what type of cancer peer support programs have been evaluated, 2.) what is known about participants, and 3.) what benefits, risks, and barriers are associated with cancer peer support programs. A total of 21 articles reporting on 17 different peer support programs were included in the review.

The authors found that one-to-one visitor programs and support groups were the two most common programs (Campbell et al., 2004). Interestingly, the one-to-one visitor programs focused on breast cancer patients. Group supports usually had small numbers of participants, regular meetings, and included people diagnosed with the same type of cancer. Although the demographics and characteristics of participants were not regularly reported, the majority of participants were highly educated, middle-class, married, and younger than the at-risk group. Also, time since diagnosis ranged from three to eight years for 39% to 69% of participants.

The barriers of peer support that were identified included low referral rates, timing of the referral, member conflicts, upsetting discussions, and member deaths. In cases of online and phone support, lack of computer resources, skills, and time, as well as lack of control over privacy, confrontational discussions, and misleading information, are risks to support group benefits. These risks are less likely with face-to-face programs and services, as most leaders receive training and supervision from sponsoring organizations. Thus, there is a lesser probability of the occurrence of these risks occurring when a program is well facilitated (Desroches, et al., 2004).

Although response rates to program evaluations were low and there was a lack of feedback from drop-outs, many of the studies that were reviewed indicate that peer support contributed to improved coping skills, reassurance and sense of normalcy, reduction in isolation, information sharing, a better understanding of the experience and future, and, occasionally, greater confidence in talking to physicians (Campbell et al., 2004). Overall, benefits from peer support programs and services were positive, regardless of the manner in which they are delivered.

In a study of the Hope and Cope oncology volunteer peer support program in Montreal, Canada, Edgar, Remmer, Rosberger, and Rapkins (1996) surveyed 121 program users and non-users, and 50 family members, about the benefits of using the Hope and Cope program, their specific needs and how they were met by the program. Similar to many of the services offered by the Canadian Cancer Society, PEI Division, the Hope and Cope program is based on a peer support model. The program offers clinic volunteers in the oncology and radiation departments, companions, a library and office, transportation, self-help groups, hospital visits, bereavement support, education, and a newsletter.

People who used the Hope and Cope program were predominantly females who were younger than 70, and who were in the follow-up to treatment stage of cancer. Approximately half of the newly diagnosed patients surveyed waited several months before utilizing the Hope and Cope program. Interestingly, Edgar et al. (1996) found that those with greater needs utilized the program, while those with fewer needs did not. Patients primarily sought out the services of the program to provide support and information.

Health Service Needs

Although not commonly reported as an area of unmet or greatest need by cancer patients, nor commonly an area of study for researchers in the field of cancer patient needs, health services needs are an important area to examine. The following two Canadian studies illustrate specific areas of need within the health services domain.

In the year 2003, the Canadian Cancer Society, Ontario Division, examined the needs of cancer patients (CCS, 2003). Surveys asked participants about their needs and barriers faced in the areas of information and communication, health services, daily living, and emotional support. Although many areas of unmet needs were identified, the greatest area of need for Ontario cancer patients was service delivery. More specifically, 89% of the 397 cancer patients who completed the survey indicated that having all their health care providers have all their information related to their cancer care was a need. In addition, 82% expressed a need to have one person to talk to about all aspects of their cancer care, and 80% of patients expressed a need for shorter waiting times to get results from diagnostic tests.

Although patients in a survey of 913 Canadian cancer patients were satisfied with the quality of care they received for cancer treatment, respondents were less satisfied with the care that they received for their other symptoms (Ashbury et al., 1998). More specifically, 73% of respondents reported being very satisfied with the care they received for cancer treatment, compared to only 47% reporting being very satisfied with the care they received for their other symptoms. Several respondents also had four main concerns about health care services: 66% of respondents were concerned about timely diagnosis, 48% were concerned about being involved in decision-making, 42% were concerned with doctors attitudes towards them, and 35% were concerned with getting appointments.

Summary of Literature

In summary, the literature reviewed is consistent in that it clearly indicates that people with cancer have high levels of unmet need (Desroches et al., 2004; Girgis & Burton, 2001; Greer, 1994; Ryan et al., 2005; Sanson-Fisher et al., 2000). Cancer patients have several needs in the domains of information; practical and financial concerns; emotional, spiritual, and social concerns; and health services. Nevertheless, some of the most widely reported needs lie in the areas of access to information, emotional support, and health system improvement. Information appears to be the most often reported need, however the type of information needed spans across all of the domains: practical and financial; emotional, spiritual, and social; and health services.

Although much of the literature reviewed was within a Canadian context, it is duly noted that none of the studies focused specifically on cancer patient needs in Prince Edward Island. In order to assess how the needs of cancer patients in Prince Edward Island compare to needs of cancer patients elsewhere, the current study focused on the specific needs of people living with cancer in Prince Edward Island. In an attempt to assess the varied needs of cancer patients, as outlined in the literature, a holistic assessment of cancer patients' needs was conducted. Thus, the current assessment focused on all of the main areas of need identified throughout the literature, including information; financial and practical; emotional, spiritual, and social; and health services needs.

Chapter Three: Methodology

Based on the literature, the strategy of research chosen for this study was a needs assessment, which primarily utilized a quantitative survey design, with the exception of a few open-ended questions. Within this chapter, the study design, participants, instrument, procedure, ethics, and analyses are discussed.

Study Design

The purpose of the current study was to expand the body of knowledge about cancer experiences in Prince Edward Island, and, ultimately, find out what supportive care people living with cancer in Prince Edward Island need. To fully appreciate the nature of the needs of cancer patients, a cross-sectional descriptive design was utilized (Polit & Beck, 2004). This design is suited for the current study, as it is applied in studies that strive to describe the frequency of occurrence of a behaviour or condition, rather than to study relationships or causality.

A telephone survey was prepared, loosely based on a previously validated survey of the unmet supportive care needs of patients with cancer (Bonevski et al., 2000; Cossich, Schofield & McLachlan, 2004; Sanson-Fisher et al., 2000), and its adaptation by the Centre for Behavioural Research and Program Evaluation, the Canadian Cancer Society, and the National Cancer Institute of Canada, to assess the needs of cancer patients (Canadian Cancer Society [CCS], 2000a; CCS, 2000b; CCS, 2003). Permission to utilize and alter this survey to correspond with the objectives and methodology of the current study was granted by the Director of Evaluation Studies, Centre for Behavioral Research and Program Evaluation.

Based on the literature, a survey was the chosen design for this study. A telephone survey was the chosen strategy, as opposed to a mail survey, for several reasons (Carter & Beaulier, 1992; Gilmore & Campbell, 1996): firstly, although preparation time for telephone surveys can be longer than for mail surveys, data collection is much quicker. Secondly, response rates for telephone surveys are normally higher than for mail surveys, and participants are more willing to answer open-ended and complex questions over the phone. Over the telephone, the interviewer also has more control over the questions. If a participant needs more explanation about a particular question, or responds with an unclear answer, the interviewer has the ability and opportunity to explain the question further, or ask for further explanation from the respondent.

One of the main disadvantages of telephone surveys is the time it takes to conduct interviews (Carter & Beaulier, 1992; Gilmore & Campbell, 1996). Countless hours were spent on the phone, leaving messages, arranging appropriate call times, following up with participants who had concerns and questions, and conducting the interviews. A second disadvantage of phone surveys is that they yield a greater possibility of receiving socially desirable responses, as opposed to candid answers (Carter & Beaulier, 1992; Gilmore & Campbell, 1996).

Participants

In an effort to recognize and reflect that needs are not static and may change over time (Luker et al., 1995), a large sampling pool was drawn on to allow for multiple cancer sites, treatment stages, and ages of patients to be represented. The sample of eligible participants was drawn from the PEI Cancer Registry, and included all people who have been diagnosed with cancer within the past two years, but not within the last three months, before the sample was pulled from the Registry (January 2004 to November 2005). After consultation with the Registrar of the PEI Cancer Registry and staff of the Canadian Cancer Society, PEI Division, it was decided that patients who were within three months of receiving a diagnosis would not be contacted to participate in the study. This decision was made on the basis that contact about a survey during this particular timeframe could be disrespectful and overwhelming for newly diagnosed patients. The Registry was cross-referenced with the death statistics to include only patients that were still living at the time of the study. All participants were 18 years of age, or older, at the time of diagnosis, and had a clear diagnosis of cancer. There can be circumstances where patients do not fully understand their diagnosis to be cancer, and these patients were not included in the sample. Together, the Registrar and the Manager of the PEI Cancer Registry produced a list of cancers in which this could be the case. This list was composed of malignant blood disorders such as Myelodysplastic Syndrome, Refractory Anemia with Excess Blasts, Polycythemia Rubra Vera, and Essential Thrombocythemia, for example.

The resultant sample of eligible participants was 725 people diagnosed with cancer in Prince Edward Island between January 2004 and November 2005. Accordingly, these 725 people were all invited to participate in the study; however current addresses for eight people could not be found. Of the 717 eligible participants, 180 people (25% response rate) volunteered to participate. All 180 people were contacted to participate; however, 10 people could not complete the survey due to various reasons including being too ill (n = 2), out of province for several weeks (n = 2), unable to fully comprehend the survey questions (n = 4), and inability to contact the person by phone (n = 1). In addition, 32 people did not complete the survey because they were not reachable by telephone after attempting to contact them a minimum of three times each (n = 31), or receiving the consent form after data entry was completed (n = 1). Therefore, the total number of completed surveys was 139 (77.2% completion rate).

Survey Instrument

The survey instrument utilized provides a direct and comprehensive assessment of the multidimensional impact of cancer on the lives of cancer patients (see Appendix A). Accordingly, questions regarding needs are organized under four main domains: informational needs; financial and practical needs; emotional, social, and spiritual needs; as well as accessibility of health care services. The survey was designed to provide descriptive data at one fixed point in time. More specifically, respondents were asked to respond to the survey questions according to their current level of need. Thus, by including persons diagnosed with cancer within the past two years, the survey had the potential to capture information on the needs of people living with cancer at various stages within the cancer experience.

In the first section of the survey, respondents were asked about their needs for information; financial and practical assistance; and emotional, social, and spiritual support. Together, approximately 25 questions related to these domains. In the survey, items were presented with a stem question of 'at this time, do you need', with response options: 'Yes'; 'No, need satisfied', and 'No, not a need'. This format allows for identification of whether or not the patient has experienced a particular need, and whether the need that the patient experienced has been satisfied or met (Rainbird et al., 2005). In addition to these questions, there were opportunities for participants to describe ways that their various needs could be met, and opportunities to provide information on any needs that they were not directly asked about. Thus, the survey was a mix of both open and closed ended questions, to allow for rich data collection.

In the second section of the survey, respondents were asked about the accessibility of health care services. Approximately 10 questions related to this domain; items were presented with a stem question of 'at this time, are you able to', with response options: 'all of the time', 'most of the time', 'some of the time', 'not at all', and 'not applicable'. Respondents were also asked if they had any other health care service needs that they were not directly asked about. Participants were also asked about their awareness, use and satisfaction with the Canadian Cancer Society, PEI Division's, services and programs. This section of the interview was not analyzed as it is beyond the scope and purpose of this Masters thesis.

In the final section, respondents were asked a series of demographic and cancer-related questions. Questions regarding the patient's age, gender, marital status and family size, family income, insurance coverage, level of education, employment situation, and region of residence were also asked. Patients identified the primary source of their cancer, date of current diagnosis, and stage of treatment that they were in at the time of interview.

Survey Validity and Reliability

In order to ensure that the reformatted survey thoroughly and appropriately assessed the needs of cancer patients, a six member Advisory Committee provided guidance and expert advice with aspects of the content validity of the survey (Fink, 1995). The Committee was consulted on aspects of the survey content, formatting, wording, question ordering, and survey delivery. The Advisory Committee represented members from the University of Prince Edward Island, Centre for Behavioural Research and Program Evaluation (CBRPE), Canadian Cancer Society, PEI Division, and cancer survivors.

The face validity of the survey (Fink, 1995) and the degree of respondent burden (Wen & Gustafson, 2004) was examined by pilot testing. Before beginning the study, pilot tests with cancer survivors and caregivers were completed in order to assess the clarity, comprehensiveness, and acceptability of the survey. Nine pilot tests were performed. According to the recommendations made from the pilot tests, redundant items were removed and complex language was simplified. During the piloting, the surveys took approximately 20 minutes to complete.

The inter- and intra-rater reliability was enhanced by training and monitoring of interviewers (Fink, 1995). The volunteer interviewers were persons who had intimate experience with cancer and excellent interpersonal skills. All interviewers attended a full day training session on interviewing techniques and the study purpose, design, and instrument; interviewers were also given a training manual in order to assist them with the surveys (see Appendix B). The first part of the session involved a detailed description of the research project, including the background, study design, and respondent selection and confidentiality. The second section involved training on the programs and services provided by the Canadian Cancer Society, PEI Division. The third section of the session involved training on how to conduct telephone surveys. Interviewers were given instruction on how to conduct surveys including probing, prompting, and recording responses. The session ended with piloting of the surveys and feedback on the survey instrument. Interviewers were encouraged to continue to practice delivering the survey instrument in order to acquire a high level of comfort with, and understanding of, the instrument.

In order to ensure inter and intra-rater reliability throughout the collection period of the study, the Principal Investigator monitored all interviewers and provided assistance where necessary. Debriefing also took place after each session of interviewing was completed. In addition, surveys were entered into the database as soon as possible after they were completed, in order to monitor and assess the level of completeness and accuracy of the recording of responses for each interviewer.

Procedure

In order to maintain the confidentiality of the patients in the PEI Cancer Registry, active consent from patients was sought before their names were released to the Principal Investigator. More specifically, the initial contact regarding participation in the survey was done by mail under the auspices of the Manager of the Cancer Registry. All eligible participants were sent an information letter explaining the purpose of the study, and a consent form which, when signed, allowed the release of their name and phone number for participation in this study (see Appendix C). Patients who wished to participate returned the consent form to the Cancer Registry in a reply-paid envelop. Only when patients gave written consent to participate was patient contact information released to the Principal Investigator. This information was kept secure in a locked cabinet at the Canadian Cancer Society, PEI Division, office.

Within two weeks of receiving participant contact information, six trained volunteer interviewers and the Principal Investigator began contacting participants. As mentioned above, the volunteer interviewers were persons who had intimate experience with cancer and excellent interpersonal skills. All interviewers also attended a multi-part training session and were given a training manual in order to assist them with the surveys.

Each interview began with an introduction and description of the study, as well as obtaining confirmation that the participant wanted to participate. Participants were also assured that the survey was confidential and voluntary. If there were no questions from respondents, the survey commenced. If an answering machine was reached rather than the participant, a message was left for the participant to contact the Canadian Cancer Society in regards to a survey. In addition, if a primary caregiver volunteered to do the survey on behalf of the person diagnosed with cancer, the survey was conducted with the caregiver. This occurred in six cases for various reasons, but mostly due to the patient being hard of hearing. In all cases, the spouse of the patient completed the survey. Additionally, in two cases, a husband and wife completed the survey together. One survey was also done as a face-to-face interview due to difficulty hearing over the telephone. Before declaring a potential respondent as unreachable, three attempts to contact each participant were made. In order to avoid disturbing participants, and administrative burden, three attempts to call was considered appropriate and sufficient.

All calls to respondents took place at the Canadian Cancer Society, PEI Division, office and ended before 9:00 pm, each evening. No information from the surveys, personal or otherwise, was permitted to leave the Canadian Cancer Society office. All interviewers signed a Declaration of Confidentiality form, ensuring that the confidentiality and anonymity of respondents was maintained (see Appendix D). This form advised interviewers of the confidential nature of the information, and instructed them to exercise all reasonable care and caution in protecting confidential information.

The surveys occurred in two waves, in order to allow for time in between to evaluate the procedure, and to ensure the survey was acceptable and comprehensible to respondents. Due to human and financial resources, the original plan was to invite 200 cancer patients to participate. Accordingly, in the first wave, 175 invitations were sent out to a random sample of people who were diagnosed with cancer in PEI within the last two years. Three of these letters were sent back with wrong addresses (n = 172). The response rate from the first wave was 26% (44 respondents). Due to the 26% response rate and the remaining human and financial resources, it was determined that adequate resources were available to increase the sample to include all persons diagnosed with cancer between January 2004 and November 2005. No other changes were made to the protocol or the survey for the second wave. Accordingly, the remaining 550 people diagnosed with cancer in Prince Edward Island between January 2004 and November 2005 were invited to participate. Five of these letters were sent back with wrong addresses (n = 545). The response rate for the second wave was 25% (136 respondents).

At the end of each interview, participants were offered information on issues related to living with cancer, such as information about cancer, financial and practical assistance, or support programs and services. Respondents were offered this information through various mediums, such as the Canadian Cancer Society's toll free phone service, website, or local office. Respondents were also asked if they would like to receive a copy of the results of the study through one of two mediums: the Canadian Cancer Society website (www.cancer.ca), or to be included in a mail-out of the results. In closing, respondents were thanked for their time and contribution.

Ethics

Eligible participants were selected from the PEI Cancer Registry. The PEI Cancer Registry collects data on all cancers diagnosed on residents of Prince Edward Island, and is enabled to do so by law under the Provincial Health Act. Information from the Cancer Registry is normally only released to Statistics Canada and is strictly confidential, and thus was not released without proper consent. Permission to utilize the PEI Cancer Registry was granted by both the Manager and the Registrar of the PEI Cancer Registry and the Provincial Health Services Authority Research Ethics Board (PHSA REB). In addition, participants were asked for their consent before the PEI Cancer Registry released their contact information to the Principal Investigator. The University of Prince Edward Island's Research Ethics Board also granted ethics approval.

Analysis

Descriptive statistics were generated for quantitative demographic characteristics, treatment and needs variables. To identify differences between key sub-samples of participants, Chi-Square analyses were conducted. The independent variables used in these comparisons were: type of cancer, sex of patients, and stage of cancer treatment.

An approach guided by a phenomenological perspective was used to analyze the qualitative data (Morse, 1994). More specifically, the intent of the analysis "was to understand the ongoing, experienced reality of people's lives rather than to seek an objective truth that explains observed events" (Stringer & Genat, 2004, p. 91). Interviews were first analyzed separately to reveal points of commonality and difference in perspectives. The process resulted in a large stack of discrete pieces of information that were sorted, selected, and organized into a system of categories (Stringer & Genat, 2004). After formulating categories, the researcher placed the categories "in an organized system that clarifies the relationship between features and elements of experience" (Stringer & Genat, 2004, p. 107). The issues that are related between data sets are identified as themes. Where applicable, quotes were used to exemplify the themes.

Chapter Four: Results

In this chapter, needs are reported by each domain: information; financial and practical; emotional, spiritual, and social; and health services. Following are the most often reported and greatest needs. Finally, the specific needs of breast cancer patients are compared to the needs of all other cancer diagnoses, the needs of women cancer patients are compared to men cancer patients, and the needs of patients undergoing treatment are compared to patients in the post-treatment stage. The demographic and treatment characteristics of respondents are also discussed in detail. Where applicable, quotes have been used to illustrate the findings.

Demographic and Treatment Characteristics of Respondents

The total number of completed surveys was 139 (77.2% completion rate). There were six instances where a spouse of the cancer patient completed the survey, one instance where a survey was completed by a married couple, and one instance where a survey was completed in a face-to-face interview due to hearing impairment. It can be stated with confidence that the results would occur within +/-8.5 percentage points 95 out of 100 times.

The length of the phone surveys ranged from a minimum of 12 minutes to a maximum of 60 minutes. The mean phone call length was 25 minutes with a standard deviation of 8.7 minutes (n = 137[1]). Nearly 40% of participants (37.4%, n = 52) wanted further information or support from the Canadian Cancer Society. Among them, 19.4% (n = 27) requested information on support programs and services, 18.7% (n = 26) requested information about cancer, and 13.7% (n = 19) requested information about financial or practical assistance. Furthermore, 83.5% (n = 116) of respondents expressed an interest in receiving a copy of the final report.

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[1] Two cases missing data.

Table 1 shows the demographics of the sample of cancer patients interviewed in comparison to population and cancer patient data for Prince Edward Island. The sample was between the ages of 60 and 69 (36%); in comparison to the Prince Edward Island population for the year 2004 (Provincial Treasury, 2006), this age group is significantly overrepresented in the study sample. The grounds to this overrepresentation likely lie in the fact that cancer primarily affects elderly individuals (CCS & NCIC, 2006). A more accurate comparison to evaluate the representativeness of the study sample would be to contrast it with data on the incidence of cancer diagnoses by age group for Prince Edward Island, unfortunately data this specific are not currently available.

Of patients interviewed, 47% of the sample were men and 53% of the sample were women. According to data on the population of cancer patients in Prince Edward Island for the year 2003[2] (CCS & NCIC, 2006), the sample very slightly overrepresented women cancer patients in Prince Edward Island. Breast cancer was the most common diagnosis (22%), followed by prostate cancer (18%), and colon/rectum cancer (14%). When compared to the population of cancer patients in Prince Edward Island for the year 2003 (CCS & NCIC, 2006), the study sample is a good representation of the main cancer diagnoses in Prince Edward Island (14% breast, 18% prostate, and 14% colorectal). The only cancer site that was not well represented in the sample was lung cancer. Only 2% of the sample had received a diagnosis of lung cancer compared to 13% of the population. This is not unexpected, as lung cancer has a poor prognosis and a high mortality rate. Overall, the study sample is fairly representative of the Prince Edward Island cancer population; important characteristics of age, gender and cancer diagnosis are distributed similarly in the two groups.

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[2] Data for the year 2003 was the most recent province-specific data available at the current time.

Table 1. Sample Demographics Compared with the Prince Edward Island Population

	Survey Sample		PEI (data)	
	(N = 139)		(N = 137 861 [1])	
Characteristics	**No.**	**%**	**No.**	**%**
Age (yrs) [a]				
20 –29	-	-	17889	13%
30-39	6	4%	17830	13%
40-49	13	9%	21627	16%
50-59	25	18%	19225	14%
60-69	50	36%	12220	9%
70-79	32	23%	8306	6%
80+	13	9%	5340	4%
Gender [b]				
Male	66	47%	420	54%
Female	73	53%	360	46%
Primary Cancer Site [b]				
Breast	31	22%	110	14%
Colon and rectum	20	14%	105	14%
Prostate	25	18%	140	18%
Skin	10	7%	20	3%
Bowel	8	6%	-	-
Lymphoma	8	6%	30	4%
Kidney	4	3%	20	3%
Leukemia	4	3%	25	3%
Thyroid	4	3%	5	-
Esophagus	3	2%	5	-
Liver	3	2%	-	-
Lung	3	2%	100	13%
Bladder	2	1%	30	4%
Brain	2	1%	15	2%
Pancreatic	2	1%	20	3%
Stomach	2	1%	15	2%
Cervix	1	-	10	1%
Head	1	-	-	-
Larynx	1	-	5	-
Multiple Myeloma	1	-	10	1%
Ovarian	1	-	5	-
Gall Bladder	1	-	-	-
Uterine	1	-	15	2%
Unknown Primary	1	-	-	-
Total	**139**	**100%**	**780**	**100%**

[a] Source: Provincial Treasury (2006). Province of Prince Edward Island Thirty Second Annual Statistical Review 2005. Retrieved January 14, 2007 from http://www.gov.pe.ca/photos/original/32annualreview.pdf. Actual data for the year 2004.

[b] Source: Canadian Cancer Society/National Cancer Institute of Canada (2006). *Canadian Cancer*

Statistics 2006. Retrieved May 21, 2006 from http://www.cancer.ca/vgn/images/portal/cit_86751114/31/21/935505792cw_2006stats_en.pdf.pdf. Actual data for new cases of cancer for most common cancer sites for the year 2003.

[1] PEI population in the year 2004.

Just over half of the sample had completed post-secondary education (54%), resided in Queens region (56%), lived with one other person (58%) and were semi or fully retired (50%) at the time of the survey (see Table 2). The majority of the sample (70%) had private health insurance, while only 40% of the sample had provincial health insurance. The level of annual household income of respondents ranged relatively evenly, from $16,000 to $51,000, or greater, with a median income of between $31,000 to $50,000; however, 23% of respondents did not answer this particular question. The majority of the sample, were married (76%), were in the post treatment stage of their cancer treatment (75%) during their first diagnosis of cancer (85%). Most participants were diagnosed in the year 2005 (55%) and 39% of the sample were diagnosed in the year 2004.

Table 2. Cancer Patient Demographic and Treatment Characteristics

Patient Characteristics*		**Percent (frequency)**
Marital Status	Married	76% (n = 105)
	Divorced/Separated	4% (n = 6)
	Widowed	13% (n = 18)
	Never Married/Single	7% (n = 10)
Highest Education Level Completed [a]	Elementary	7% (n = 9)
	Junior High	13% (n = 18)
	High School	26% (n = 36)
	Post - Secondary	54% (n = 75)
Region of Residence in PEI [b]	Queens	56% (n = 78)
	Prince	32% (n = 44)
	Kings	11% (n = 15)
Number of people living in household [a]	Live alone	13% (n = 18)
	Two	58% (n = 81)
	Three	17% (n = 23)
	Four and Above	12% (n = 16)
Work Status [d]	Working full or part time	32% (n = 44)
	Retired or semi retired	50% (n = 70)
	Unemployed	7% (n = 10)
	Medical/disability leave	7% (n = 9)

Retain Private Health Insurance	Yes	70% (n = 96)
Retain Provincial Health Insurance	Yes	40% (n = 55)
Level of Household Income	Less than $15,000	9% (n = 12)
	$16,000 t0 $30,000	20% (n = 28)
	$31,000 to $50,000	25% (n = 34)
	$51,000 and greater	24% (n = 33)
	Would rather not answer	23% (n = 32)
Treatment Characteristics		**Percent (frequency)**
First diagnosis of cancer	First Diagnosis	85% (n = 118)
	Recurrence	15% (n = 21)
Date of diagnosis	**Pre-2003	5% (n = 7)
	2004	39% (n = 54)
	2005	55% (n = 76)
	**2006	1% (n = 2)
Treatment status	Pre Treatment	11% (n = 15)
	Active Treatment	14% (n = 20)
	Post Treatment	75% (n = 104)

*Due to rounding, totals may be greater than 100%

** Although the study sample was taken from the PEI Cancer Registry for the period of January 2004 to November 2005, the date of diagnosis used in the study was obtained from cancer patients' own recollection and report. Thus, there are a few discrepancies between dates of diagnosis. This is not considered significant as this variable only occurred outside of the possible time frame for 9 patients (6% of the sample).

a One case missing data (N = 138)

b Two case missing data (N = 137)

d Six case missing data (N = 133)

As previously mentioned, in the first section of the survey, respondents were asked about their needs for information; financial and practical assistance; and emotional, social, and spiritual support. Together, approximately 25 questions related to these domains. The results for each of these domains are reported below.

Current Information Needs

Each of the seven individual questions of need within the information domain were examined to assess the frequency of respondents who reported each of the response categories (no need – not applicable, need – already satisfied, and need - unmet). As can be seen in Table 3, the two greatest areas of current information needs are information on the type of cancer diagnosis (69.1%) and who to contact with a problem, concern, or question (68.3%). The greatest unmet information need was information about financial assistance from provincial or community programs (64.9%).

Table 3. Proportion of Cancer Patients with Current Information Needs (N = 139)

Type of Information Need	Expressed Need*	Need Unmet (% of 'expressed need')
Your type of cancer	69.1% (n = 96)	34.4% (n = 33)
Who to contact when you have a problem, concern, or question	68.3% (n = 95)	25.3% (n = 24)
Managing your cancer	57.6% (n = 80)	42.5% (n = 34)
More information about your medical test results	53.2% (n = 74)	28.4% (n = 21)
Services, programs, or supports for cancer patients	50.4% (n = 70)	41.4% (n = 29)
Treatment options	43.2% (n = 60)	33.3% (n = 20)
Information about financial assistance from provincial or community programs	41.0% (n = 57)	64.9% (n = 37)

*The number of respondents in the 'expressed need' column is the sum of respondents who expressed a satisfied need or an unmet need.

Other Information Needs

Respondents were asked to identify other information needs that they currently had that were not directly asked through the survey questions. Fourteen respondents stated other areas of need related to information. Interestingly, the majority of patients did not mention other specific areas of information that they needed, rather they made statements that related to their concerns about the information that they did receive. For instance, one of the overarching comments made was that the quantity of information could be overwhelming: "You get to the point of not wanting to know any more" (54 year old female breast cancer survivor). In addition, participants also need information to relieve anxiety and fear associated with cancer recurrence. They expressed a need for reassurance: "People say not to worry, you make up your own mind about treatment, but don't know if it's right" (59 year old male prostate cancer survivor).

Sources of cancer-related information

Respondents were asked where they usually look for cancer related information that they need. Patients provided various responses to this question without any aid from the interviewer. The two most common places patients look for information are health care professionals (66%) and the Internet (50%). The most common Internet sites mentioned were search engines, such as Google, and Canadian cancer cites. A few participants expressed that it is necessary to exercise caution when utilizing the Internet to seek cancer related information. More specifically, one participant said, "The Internet makes you paranoid" (55 year old unknown primary male patient in pre treatment stage) and another participant stated, "[I] don't believe everything I read" (68 year old female breast cancer survivor). As a follow up to this question, interviewers then listed several ways in which patients could receive the information that they need. Patients were asked to identify which of these methods they preferred. Pamphlets and written materials were the most often chosen method (86%). A high percentage of patients (70%) also preferred to receive cancer related information through one-on-one consults.

Current Practical and Financial Needs

Each of the seven individual questions of need within the practical and financial domain were examined to assess the frequency of respondents who reported each of the response categories (no need – not applicable, need – already satisfied, and need - unmet). The three most often reported needs within this domain were: managing side effects like pain, nausea, and fatigue, getting to and from cancer appointments, and covering costs for medications and drugs associated with having cancer (see Table 4). Between 25% and 30% of participants identified these three practical and financial areas as needs.

In terms of unmet practical and financial needs, the cost of special foods or health supplies (50%) and work related issues, such as getting time off (47%), were the most commonly mentioned unmet needs. Assistance with personal care such as bathing, eating, or dressing (8%), and with cooking, childcare, cleaning or shopping (8%) were less frequently unmet than any of the other financial and practical needs.

Table 4. Proportion of Cancer Patients with Current Financial or Practical Needs (N = 139)*

Type of Financial/Practical Need	Expressed Need	Unmet Need (% of 'expressed need')
Managing side effects like pain, nausea, and fatigue, for example [a]	29.7% (n = 41)	39.0% (n = 16)
Getting to and from cancer appointments	26.6% (n = 37)	8.1% (n = 3)
Covering costs for medications and drugs associated with having cancer	25.2% (n = 35)	25.7% (n = 9)
At home with cooking, childcare, cleaning, or shopping	18.7% (n = 26)	7.7% (n = 2)
Covering costs of special foods or health supplies	12.9% (n = 18)	50.0% (n = 9)
Work related issues, such as getting time off	10.8% (n = 15)	46.7% (n = 7)
Personal care such as bathing, eating, or dressing, for example	8.6% (n = 12)	8.3% (n = 1)

*The number of respondents in the 'expressed need' column is the sum of respondents who expressed a satisfied need or an unmet need.

[a] One case missing data (N = 138)

Current Emotional, Spiritual, and Social Needs

Each of the eight individual questions of need within the emotional, spiritual, and social need domain were examined to assess the frequency of respondents who reported each of the response categories (no need – not applicable, need – already satisfied, and need - unmet). Accepting the presence and the uncertainty of cancer was the greatest expressed need; 34% of participants expressed this need, and nearly half of them (49%) did not have this need met. In fact, for nearly all of the specific areas of need, with the exception of feeling in control of the situation, approximately half of the participants with expressed needs did not have their needs met.

Table 5. Proportion of Cancer Patients with Current Emotional, Spiritual, and Social Needs (N = 139)*

Type of Emotional, Spiritual and Social Needs	Expressed Need	Unmet Need (% of 'expressed need')
Accepting the presence and the uncertainty of cancer [a]	34.1% (n = 47)	48.9% (n = 23)
Dealing with feelings such as fear, anxiety, depression, or loneliness [a]	30.4% (n = 42)	52.4% (n = 22)
Supporting the concerns of those close to you [a]	30.4% (n = 42)	40.5% (n = 17)
Working through feelings about death and dying [a]	23.9% (n = 33)	51.5% (n = 17)
Getting support to help you feel more in control of your situation [a]	23.9% (n = 33)	36.4% (n = 12)
Trying to maintain a positive outlook	20.9% (n = 29)	48.3% (n = 14)
Concerns about changes in sexual relationships or intimacy	17.2% (n = 24)	50.0% (n = 12)
Coping with awkwardness in talking to others about cancer	11.5% (n = 16)	43.8% (n = 7)

*The number of respondents in the 'expressed need' column is the sum of respondents who expressed a satisfied need or an unmet need.
[a] One case missing data (N = 138)

Other Emotional, Spiritual, and Social Needs

Respondents were able to express other emotional, spiritual, and social needs that they currently had that were not directly asked through the survey questions. Although not many comments were made in this section, ten comments in total, the overarching response was a desire to get on with life. The majority of participants made comments such as: "[I] don't want to talk to others just about cancer" (80 year old female breast cancer survivor) and "[I] miss doing what I always did" (72 year old male oesophagus cancer survivor).

Sources of Support

Respondents were also asked how they would prefer to receive the support that they need (see Table 6). Over half of participants (57%) responded that they would like to receive support through individual visits with a cancer survivor. It was frequently mentioned that the individual visits must be with a survivor of similar diagnosis as the cancer patient's: "The individual support must be with the same type of cancer to mean anything" (53 year old female colorectal cancer survivor).

Just over half of respondents (53%) also preferred to receive support through access to a central staff person that could guide them through their cancer experience. Some of the participants were very supportive of the idea of a central staff person, stating that this role was "desperately" (40 year old female breast cancer survivor) needed. One respondent had this to say in respect to the necessity of having access to a central staff person to guide them through their experience: "Definitely, you have to make huge decisions, and no one to ask, so you don't know if you're making the right decision" (37 year old female breast cancer survivor). In addition, some participants also mentioned that the Cancer Treatment Centre, Oncology department at the Queen Elizabeth Hospital, friends, cancer survivors, and doctors already fulfilled the role of a central staff person. Participants were also asked to identify any other means of support that they were not directly asked about; 13% of respondents mentioned that the support of friends, family and other survivors was a preferred source. The least preferred method of support was online chats with other cancer survivors (12%).

Table 6. Sources to Receive Support (N = 139)*

Method of Support	Percent (frequency)
Individual visits with a cancer survivor	56.8% (n = 79)
Having access to a central staff person to guide you through your cancer experience	52.5% (n = 73)
Contact by phone with a cancer survivor	43.2% (n = 60)
Talking to a counsellor who works with cancer patients like a psychologist, social worker, or nurse	42.4% (n = 59)
Group supports with other survivors	37.4% (n = 52)
Other	17.3% (n = 24)
Having online chats with cancer survivors	11.5% (n = 16)

*The total number of respondents does not equal the total sample size (N = 139) because respondents could choose more than one method to look for cancer-related information.

Current Accessibility of Health Services Needs

Respondents were asked an additional seven questions, which served to identify to what extent their health services needs were accessible. The health services needs domain was assessed using a five-point scale in which participants responded that their need had been met 'all of the time', 'most of the time', 'some of the time', 'not at all', or was 'not applicable' to their current situation. Overall, health care services were accessible either all or most of the time (see Table 7). In fact, between 68% and 84% of cancer patients responded that their health services needs were accessible all of the time. Accessing cancer services that are close to home was the least accessible service; 9% of respondents stated that cancer services that are close to home were not at all accessible.

Table 7. Frequency of Accessible Health Services Needs (N = 139)*

Health Service Need	Accessible all of the time	Accessible most of the time	Accessible some of the time	Not at all accessible
Friend/family member with you during appointments and/or treatments (N = 126)	84.3% (n = 101)	12.7% (n = 16)	1.5% (n = 4)	1.5% (n = 5)
All health care providers know your medical information (N = 134)	83.1% (n = 113)	12.5% (n = 17)	1.5% (n = 2)	1.5% (n = 2)
Enough time with your cancer doctors (N = 137)	80.2% (n = 92)	12.7% (n = 27)	3.2% (n = 12)	4.0% (n = 6)
Appointment times that suit your schedule (N = 136)	73.5% (n = 100)	21.3% (n = 29)	2.9% (n = 4)	2.2% (n = 3)
Medical appointments in a timely manner (N = 135)	71.1% (n = 96)	17.0% (n = 23)	8.9% (n = 12)	3.0% (n = 4)
Cancer services close to home (N = 124)	70.2% (n = 87)	15.3% (n = 19)	5.6% (n = 7)	8.9% (n = 11)
Information about your test results in a timely manner (N = 136)	68.4% (n = 93)	14.7% (n = 20)	11.0% (n = 15)	5.9% (n = 8)

*The sample size varies for each question because certain questions were not applicable to participants due to their particular stage of cancer (pre treatment, treatment, or post treatment) at the time of the survey.

Most Often Reported Current Needs

In order to determine the most often reported needs of respondents, each reported need within the information; practical and financial; and emotional, spiritual, and social domains, were examined. Table 8 displays the ten most often reported needs of all respondents. Of the ten most often reported needs, seven were within the information needs domain. Information about specific cancer types was the most often reported need (69%); 68% of participants had a need for information on who to contact with a problem, concern, or question, and 58% of participants had a need for information on managing cancer.

Table 8. Ten Most Often Reported Current Needs of all Participants (N = 139)*

Rank	**Domain**	**Need**	**Need (% of all participants)**
1	Information	Your type of cancer	69.1% (n = 96)
2	Information	Who to contact when you have a problem, concern, or question	68.3% (n = 95)
3	Information	Managing your cancer	57.6% (n = 80)
4	Information	More information about your medical test results	53.2% (n = 74)
5	Information	Services, programs or support for cancer patients	50.4% (n = 70)
6	Information	Treatment options	43.2% (n = 60)
7	Information	Information about financial assistance from provincial or community programs	41.0% (n = 57)
8	Emotional, Spiritual and Social	Accepting the presence and the uncertainty of cancer**	34.0% (n = 47)
9	Emotional, Spiritual and Social	Dealing with feelings such as fear, anxiety, depression, or loneliness**	30.4% (n = 42)
	Emotional, Spiritual and Social	Supporting the concerns of those close to you**	30.4% (n = 96)
10	Financial and Practical	Managing side effects like pain, nausea, and fatigue**	29.7% (n = 41)

*This table shows the 10 most often reported needs (whether satisfied or unmet) within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.
** One case missing data (N = 138)

In order to determine the most often reported unmet needs of all participants, each reported unmet need within the information; practical and financial; as well as emotional, spiritual, and social domains, were examined. Table 9 displays the ten most often reported unmet needs of all respondents. Of the ten most often reported unmet needs, seven unmet needs were within the information needs domain. Information about financial assistance from provincial or community programs was the most often reported unmet need (27%); 25% of participants stated that their need for information on managing cancer was currently unmet, and 24% of participants stated that their need for information on their type of cancer was currently unmet. The three other most often reported unmet current needs were within the emotional, social, spiritual domain.

Table 9. Ten Most Often Reported Unmet Current Needs of all Participants (N = 139)*

Rank	Domain	Need	Unmet Need (% of all participants)
1	Information	Financial assistance from provincial or community programs	26.6% (n = 37)
2	Information	Managing your cancer	24.5% (n = 34)
3	Information	Your type of cancer	23.7% (n = 33)
4	Information	Services, programs or supports for cancer patients	20.9% (n = 29)
5	Information	Who to contact when you have a problem, concern or question	17.3% (n = 24)
6	Emotional, Spiritual and Social	Accepting the presence and uncertainty of cancer**	16.7% (n = 23)
7	Emotional, Spiritual and Social	Dealing with feelings such as fear, anxiety, depression, or loneliness**	15.9% (n = 22)
8	Information	More information about your medical test results	15.1% (n = 21)

9	Information	Treatment options	14.4% (n = 20)
10	Emotional, Spiritual and Social	Working through feelings about death and dying**	12.3% (n = 17)
		Supporting the concerns of those close to you**	12.3% (n = 17)

***This table shows the 10 most often reported unmet needs within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.**
****One case missing data.**

Greatest Current Needs

As a final question about current needs, participants were asked to identify their greatest current need. The majority of participants stated one or more area of greatest need. In all, 104 comments were received for this question. A thematic analysis of the results shows that each of the domains was often identified as an area of greatest need. However, practical needs, in particularly dealing with side effects and financial burdens, were most often mentioned.

Approximately 25% of all of the comments made reflected a greatest need within the domain of practical and financial needs. The majority of these comments related to dealing with side effects, such as incontinence and a lack of energy. Also commonly mentioned was the need for financial assistance in all aspects of cancer. Just over 9% of respondents stated that this was their greatest need. A few comments referred to transportation issues, such as "getting around more" (84 year old female bowel cancer survivor).

Accessibility of health services was mentioned nearly as often as practical and financial needs (24% and 25% of comments, respectively). Accessibility of local services was the most often mentioned comment. Participants mentioned that aspects of local health services, such as access to new therapies and clinical trials; healing mechanisms for the mind, body and spirit; and more doctors, were significant needs: "[You] have to heal the body, mind, and spirit. Doctors are responsible for 50%, PEI has no access to these things" (40 year old female breast cancer survivor).

Also commonly mentioned were issues around the scheduling of appointment times and long wait times: “To have appointment times scheduled so that you don’t have to worry so much, and call when you have questions, you will know you will be able to see someone” (54 year old female breast cancer survivor). Overall, participants expressed that scheduled appointment times would help to alleviate anxiety and allow them to carry on with daily life activities. For instance, one patient made the following important comment and suggestion: “Radiation is scheduled on a daily basis – at 5x per week for 32 weeks, a set schedule would be better” (60 year old female rectal cancer survivor). Comments about wait times included the time between diagnosis and treatment, the time it takes to receive medical test result, and the time spent in the waiting room before an appointment. “When at hospital, appointment is for 10:00 and then you sit and wait for an hour” (53 year old female colorectal cancer survivor).

The emotional, spiritual, and social domain was the next most apparent theme. More specifically, 20% of comments reflected an aspect of emotional, spiritual, or social support as an area of greatest need. Support from survivors, family and friends were often identified as a need: “Survivor visits – I thrive on those stories, I love survivor stories” (67 year old female breast cancer survivor). Emotional support in terms of mental health counselling, dealing with depression, and the ‘fear factor’ of having cancer were also often mentioned.

The next most often mentioned domain of greatest need was information needs. Thirteen percent of responses referred to availability, clarity, and timeliness of information about the disease, treatment, results, and prognosis as areas of great need. For example, one participant stated that “time with doctors to review clearly with patient about options, etc.” (69 year old female breast cancer survivor) was a significant need. Another participant mentioned that “Having accurate, concise information, promptly” (60 year old female cervical cancer survivor) was a great need. Also apparent within the expressed need for available, clear, and timely information about the disease, treatment, results and prognosis, was a need for assurance about disease prognosis: "[To] have some kind of certainty with where you're at (dependent on test results, etc.), have a predictable outcome" (47 year old female thyroid patient undergoing treatment), and, "To know how long I will be here for" (84 year old female bowel cancer survivor)

Outside of the four domains: information needs; practical and financial needs; emotional, social, and spiritual needs; and health services accessibility, one other theme emerged as an area of greatest need. Unique, yet common enough to warrant attention, was the response of no particular needs and being thankful for life as it stands: "[I] have my wife, food, and a roof – have all my needs" (60 year old male prostate cancer survivor), and, "[I] don't have any, [I] think I'm very lucky" (82 year old male prostate cancer survivor). Overall, the majority of participants were optimistic and seemed to take one day at a time: "[I] feel very lucky, feel healthy now and to get along with what I have" (66 year old female skin cancer survivor), and, "[I] don't have any really, take one day at a time. One of those things you have no control over. Go with the flow" (68 year old male prostate cancer survivor). Patients exhibited a sense of hopefulness. The 'spirit of survivorship' emerged from the conversations with patients from across Prince Edward Island.

Prevalence of Needs by Type of Cancer

Breast cancer was the most often reported cancer (22%). Table 10 shows the demographics of the breast cancer patients who participated in the study. The majority of breast cancer patients were between the ages of 60 and 69 (32.3%), married (58.1%), with post-secondary education (51.6%), and living in either Queens (48.3%) or Prince (44.8%) Counties. Furthermore, breast cancer patients often lived with one other person (45.2%), worked full or part time (38.7%), or were fully or semi-retired (38.7%), with a median household income of between $31,000 and $50,000 per year. Most breast cancer patients had private health insurance (64.5%), but no provincial health insurance (29%).

Table 10. Breast Cancer Patient Demographics (N = 31)

Patient Characteristics		**Percent (frequency)**
Age	30-39	3% (n = 1)
	40-49	16.1% (n = 5)
	50-59	25.8% (n = 8)
	60-69	32.2% (n = 10)
	70-79	12.9% (n = 4)
	80+	9.7% (n = 3)
Marital Status	Married	58.1% (n = 18)
	Divorced/Separated	16.1% (n = 5)
	Widowed	19.4% (n = 6)
	Never married/single	6.5% (n = 2)
Highest Education Level Completed	Elementary	6.5% (n = 2)
	Junior	6.5% (n = 2)
	High	35.5% (n = 11)
	Post Secondary	51.6% (n = 16)
Region of Residence in PEI [a]	Queens	48.3% (n = 14)
	Prince	44.8% (n = 13)
	Kings	6.9% (n = 2)
Number of people living in household	Live alone	25.8% (n = 8)
	Two	45.2% (n = 14)
	Three	16.1% (n = 5)
	Four and Above	13.0% (n = 4)
Work Status	Working full or part time	38.7% (n = 12)
	Retired or semi retired	38.7% (n = 12)
	Unemployed	6.5% (n = 2)
	Medical/disability leave	16.1% (n = 5)
Retain Private Health Insurance	Yes	64.5% (n = 20)
Retain Provincial Health Insurance	Yes	29% (n = 9)
Level of Household Income	Less than $15,000	9.7% (n = 3)
	$16,000 t0 $30,000	19.4% (n = 6)
	$31,000 to $50,000	29% (n = 9)
	$51,000 and greater	9.7% (n = 3)
	Would rather not answer	32.3% (n = 10)
Treatment Characteristics		**Percent (frequency)**
First diagnosis of cancer	First Diagnosis	90.3% (n = 28)
	Recurrance	9.7% (n = 3)
Date of diagnosis	*Pre-2003	3.2% (n = 1)

	2004	45.2% (n = 14)
	2005	51.6% (n = 16)
Treatment status	Pre Treatment	6.5% (n = 2)
	Active Treatment	16.1% (n = 5)
	Post Treatment	77.4% (n = 24)

[a] Two cases missing data (N = 137)

* Although the study sample was taken from the PEI Cancer Registry for the period of January 2004 to November 2005, the date of diagnosis used in the study was obtained from cancer patients' own recollection and report. Thus, there are a few discrepancies between dates of diagnosis. This is not considered significant as this variable only occurred outside of the possible time frame for 1 patient (1% of the sample).

To get a general sense of the needs of breast cancer patients, the number of unmet needs was examined. Within each domain (information; practical and financial; and emotional, spiritual, and social), the number of unmet needs for each patient was tallied and placed into one of three categories: no unmet needs, one to three unmet needs, or four or more unmet needs. Approximately 94% of practical and financial needs were met, and 71% of emotional, spiritual, and social needs were met (see Table 11). However, 36% of participants had one to three unmet information needs, and 16% of participants had four or more unmet information needs. The accessibility of health care services for breast cancer patients was also examined. The number of needs met all of the time, most of the time, some of the time, and not at all was tallied for each patient. Table 11 shows that four or more health service needs were accessible all of the time for 81% of participants.

Table 11. Frequency of Needs Unmet and Accessibility of Health Services for Breast Cancer Patients (N = 31)

	Percent (Frequency)		
	0 Needs Unmet	**1 to 3 Needs Unmet**	**4 or more Needs Unmet**
Need Domain			
Information	48.4% (n = 15)	35.5% (n = 11)	16.1% (n = 5)
Practical and Financial	93.5% (n = 29)	6.5% (n = 2)	0.0% (n = 0)
Emotional, Spiritual and Social	71.0% (n = 22)	16.1% (n = 5)	12.9% (n = 4)

Accessibility of Health Services	0 Needs Accessible	1 to 3 Needs Accessible	4 or more Needs Accessible
All of the Time	0.0% (n = 0)	19.4% (n = 6)	80.6% (n = 25)
Most of the Time	58.1% (n = 18)	32.3% (n = 10)	9.7% (n = 3)
Some of the Time	80.6% (n = 25)	19.4% (n = 6)	0.0% (n = 0)
Not at All	87.1% (n = 27)	12.9% (n = 4)	0.0% (n = 0)

To get a more specific picture of the unmet needs of breast cancer patients, the three most often reported unmet needs for breast cancer patients were also examined within the three domains: information; practical and financial; and emotional, spiritual, and social needs (see Table 12). The need for information on managing cancer was the most often reported unmet need (29%). One of the most often reported unmet needs was within the emotional, spiritual, and social domain. More specifically, 23% of breast cancer patients reported that feelings about death and dying were the most often unmet need.

The three most often reported needs for breast cancer patients were also examined within the three domains: information; practical and financial; and emotional, spiritual, and social needs. The information domain was the most often reported area of need. More specifically, 58% of participants needed information on their type of cancer; 55% of respondents wanted information on who to contact with a problem, concern or question; and 48% of respondents wanted more information about medical test results.

Table 12. Three Most Often Reported Unmet and Current Needs for Breast Cancer Patients (N = 31)

Rank	Domain	Unmet Need Item	Percent (frequency)
1	Information	Managing your cancer	29.0% (n = 9)

2	Information	Financial assistance from provincial or community programs	25.8% (n = 8)
3	Information	Services, programs or supports for cancer patients	22.6% (n = 7)
3	Information	Your type of cancer	22.6% (n = 7)
3	Emotional, Spiritual, and Social	Feelings about death and dying	22.6% (n = 7)

Rank	**Domain**	**Current Need Item**	**Percent (frequency)**
1	Information	Your type of cancer	58.1% (n = 18)
2	Information	Who to contact with a problem, concern, or question	54.8% (n = 17)
3	Information	Medical test results	48.4% (n = 15)

***This table shows the three most often reported unmet needs within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.**

Breast cancer patients (N = 31) were compared to patients diagnosed with all other types of cancer (N = 108), to examine the differences in need that may be related to the differential support each group is formally offered. Arguably, breast cancer patients have access to more formal support services and programs than any other cancer diagnosis. For example, when a person is diagnosed with breast cancer, the health care professional offers the newly diagnosed patient the Seeds of Hope kit. This kit contains information about breast cancer surgery, an exercise guide, ball and rope, a soft pink pillow, and information available on cancer resources. In addition, after treatment, a volunteer and breast cancer survivor from the Canadian Cancer Society invites the recovering breast cancer patient to participate in the Reach to Recovery program. The Reach to Recovery program is a one-to-one support program for women with breast cancer, wherein women who have recovered from breast cancer visit women recovering from breast cancer. No other cancer diagnosis in Prince Edward Island has the same degree of proactive formalized support.

In order to assess the difference in the level of need, breast cancer patients were compared to all other cancer patients on the number of unmet needs in each domain: information; practical and financial; as well as emotional, social, and spiritual needs. Within each domain, the number of unmet needs for each patient was tallied and placed into one of three categories: no unmet needs, one to three unmet needs, or four or more unmet needs. Chi-square tests were used to test for statistically significant differences.

Approximately 50% of people with cancer, regardless of the type, have no unmet information needs (48.4% breast cancer and 46.3% other cancer types, see Table 13). Furthermore, approximately one third of all cancer patients have no unmet emotional, social or spiritual needs (71% of breast cancer patients and 64.8% of people diagnosed with other types of cancer). The relationships between cancer type and unmet information needs as well as emotional, social or spiritual needs were not significant.

Alternatively, 93.5% of people with breast cancer have no unmet practical or financial needs compared to only 71.3% of people with other types of cancer. The relationship between cancer type and unmet practical and financial needs is statistically significant, x^2 (1, 139) = 6.59, $p< .05$. Persons with breast cancer have significantly fewer unmet practical and financial needs than people diagnosed with other types of cancer.

Table 13. Frequency of Unmet Current Needs by Cancer Type (N = 139)

		Frequency of Unmet needs		
Need Domain	**Type of Cancer**	**0**	**1 to 3**	**4 or more**
Information x^2 (2, 139) = 0.10, p>.05	Breast (N = 31)	48.4% (n = 15)	35.5% (n = 11)	16.1% (n = 5)
	Other (N = 108)	46.3% (n = 50)	35.2% (n = 38)	18.5% (n = 20)

Practical & Financial* x^2 (1, 139) = 6.59, $p<$ .05	Breast (N = 31)	93.5% (n = 29)	6.5% (n = 2)	-
	Other (N = 108)	71.3% (n = 77)	28.7% (n = 31)	-
Emotional, Spiritual & Social x^2 (2, 139) = 2.86, $p>$.05	Breast (N = 31)	71.0% (n = 22)	16.1% (n = 5)	12.9% (n = 4)
	Other (N = 108)	64.8% (n = 70)	28.7% (n = 31)	6.5% (n = 7)

* Significant at the p < .05 level

Breast cancer patients were also compared to all other cancer patients on the accessibility of health services needs. The number of needs met all of the time, most of the time, some of the time, and not at all, was tallied for each patient. Chi-square tests were used to test for statistically significant differences between cancer type and the degree of health services accessibility. As Table 14 shows, the relationship between cancer type and accessibility of health services needs was not significant at any degree of health care service accessibility. In fact, 81% of breast cancer patients had four or more health services needs accessible all of the time, and 72% of all other cancer patients had four or more health services needs accessible all of the time.

Table 14. Frequency of Accessible Health Services Needs by Cancer Type (N = 139)

		Number of Needs Met		
Degree of Accessibility	**Type of Cancer**	**0**	**1 to 3**	**4 or More**
All of the Time x^2 (2, 139) = 2.28, $p>$.05	Breast (N = 31)	-	19.4% (n = 6)	80.6% (n = 25)
	Other (N = 108)	6.5% (n = 7)	21.3% (n = 23)	72.2% (n = 78)
Most of the Time x^2 (2, 139) = 0.73, $p>$.05	Breast (N = 31)	58.1% (n = 18)	32.3% (n = 10)	9.7% (n = 3)
	Other (N = 108)	50.9% (n = 55)	40.7% (n = 44)	8.3% (n = 9)
Some of the Time x^2 (2,139) = 1.58, $p>$.05	Breast (N = 31)	80.6% (n = 25)	19.4% (n = 6)	-
	Other (N = 108)	70.4% (n = 76)	27.8% (n = 30)	1.9% (n = 2)
Not at All x^2 (2, 139) = 1.22, $p>$.05	Breast (N = 31)	87.1% (n = 27)	12.9% (n = 4)	-
	Other (N = 108)	78.7% (n = 85)	20.4% (n = 22)	0.9% (n = 1)

Prevalence of Needs by Sex

There were 66 men and 73 women who participated in the study. Table 15 displays the characteristics of the men and women with cancer who participated in the study. Both men and women were most often between the ages of 60 and 69 (39% and 33%, respectively), married (89% and 63%, respectively), with post-secondary education (47% and 60%, respectively), and living with one other person (70% and 48%, respectively) in Queens County (56% and 56%, respectively). Men and women were also commonly semi or fully retired (29% and 34%, respectively). Both men and women had a median annual household income of between $31,000 and $50,000, had private health insurance (76% and 63%, respectively), and no provincial health insurance (50% and 69%, respectively). The current diagnosis of cancer was a first diagnosis for over 80% of both men and women (83% and 86%, respectively). The majority of men and women were diagnosed in the year 2005 (56% and 53%, respectively) and were in the post-treatment stage of diagnosis (79% and 71%, respectively).

Table 15. Characteristics of Men and Women with Cancer (N = 139)[a]

Patient Characteristics		Men (N = 66) Percent (frequency)	Women (N = 73) Percent (frequency)
Age	30-39	1.5% (n = 1)	6.8% (n = 5)
	40-49	6.1% (n = 4)	12.3% (n = 9)
	50-59	15.2% (n = 10)	20.5% (n = 15)
	60-69	39.4% (n = 26)	32.9% (n = 24)
	70-79	33.3% (n = 22)	13.7% (n = 10)
	80+	4.5% (n = 3)	13.7% (n = 10)
Marital Status	Married	89.4% (n = 59)	63% (n = 46)
	Divorced/Separated	1.5% (n = 1)	6.8% (n = 5)
	Widowed	3% (n = 2)	21.9% (n = 16)
	Never married/single	6.1% (n = 4)	8.2% (n = 6)
Highest Education Level Completed	Elementary	9.1% (n = 6)	4.1% (n = 3)
	Junior	18.2% (n = 12)	8.2% (n = 6)
	High	25.8% (n = 17)	26% (n = 19)
	Post Secondary	47% (n = 31)	60.3% (n = 44)
Region of Residence in PEI	Queens	56.1% (n = 37)	56.2% (n = 41)
	Prince	31.8% (n = 21)	31.5% (n = 23)
	Kings	12.1% (n = 8)	9.6% (n = 7)

Number of people living in household	Live alone	6.1% (n = 4)	19.2% (n = 14)
	Two	69.7% (n = 46)	47.9% (n = 35)
	Three	15.2% (n = 10)	17.8% (n = 13)
	Four and Above	7.6% (n = 5)	15.1% (n = 11)
Work Status	Working full or part time	28.8% (n = 19)	34.2% (n = 25)
	Retired or semi retired	56.1% (n = 37)	45.2% (n = 33)
	Unemployed	6.1% (n = 4)	8.2% (n = 6)
	Medical/disability leave	1.5% (n = 1)	11% (n = 8)
Retain Private Health Insurance	Yes	75.8% (n = 50)	63% (n = 46)
	No	24.2% (n = 16)	37% (n = 27)
Retain Provincial Health Insurance	Yes	48.5% (n = 32)	31.5% (n = 23)
	No	50% (n = 33)	68.5% (n = 50)
Level of Household Income*	Less than $15,000	7.3% (n = 4)	15.4% (n = 8)
	$16,000 to $30,000	20.0% (n = 11)	32.7% (n = 17)
	$31,000 to $50,000	34.5% (n = 19)	28.8% (n = 15)
	$51,000 and greater	38.2% (n = 21)	23.1% (n = 12)
Treatment Characteristics		**Percent (frequency)**	**Percent (frequency)**
First diagnosis of cancer	First Diagnosis	83.3% (n = 55)	86.3% (n = 63)
	Recurrence	16.7% (n = 11)	13.7% (n = 10)
Date of diagnosis	*Pre-2003	6.1% (n = 4)	4.1% (n = 3)
	2004	37.9% (n = 25)	39.7% (n = 29)
	2005	56.1% (n = 37)	53.4% (n = 39)
	**2006	-	2.7% (n = 2)
Treatment status	Pre Treatment	12.1% (n = 8)	9.6% (n = 7)
	Active Treatment	9.1% (n = 6)	19.2% (n = 14)
	Post Treatment	78.8% (n = 52)	71.2% (n = 52)

[a] Totals do not always equal 100% due to missing information

* For this question, n = 55 for men and n = 52 for women participants.

** Although the study sample was taken from the PEI Cancer Registry for the period of January 2004 to November 2005, the date of diagnosis used in the study was obtained from cancer patients' own recollection and report. Thus, there are a few discrepancies between dates of diagnosis. This is not considered significant as this variable only occurred outside of the possible time frame for 9 patients (6% of the sample).

The three most commonly reported cancers for women were breast (43%), colorectal (46%), and bowel (10%) (see Table 16). For men, the most commonly reported cancers were prostate (38%), colorectal (12%), and lymphoma (7%). The fourth most common cancer for both men and women was skin cancer, at a frequency of 7% for women and 8% for men.

Table 16. Most Frequent Cancers Reported by Sex (N = 139)

Women (N = 73)		Men (N = 66)	
Type of Cancer	**Percent (frequency)**	**Type of Cancer**	**Percent (frequency)**
Breast	42.5% (n = 31)	Prostate	37.9% (n = 25)
Colorectal	16.4% (n = 12)	Colorectal	12.1% (n = 8)
Bowel	9.6% (n = 7)	Lymphoma	7.6% (n = 5)
Skin	6.8% (n = 5)	Skin	7.6% (n = 5)
Thyroid	4.1% (n = 3)	Leukemia	6.1% (n = 4)
Lymphoma	4.1% (n = 3)	Liver	4.5% (n = 3)
Kidney	2.7% (n = 2)	Esophagus	4.5% (n = 3)
Other	13.7% (n = 10)	Other	19.7% (n = 13)
Total	**100% (n = 73)**	**Total**	**100% (n = 66)**

The three most often reported needs within the information; practical and financial; and emotional, social, and spiritual domains for men and women are displayed in Table 17. Of interest is the fact that all three of the most often reported needs for both men and women were within the information domain. More specifically, information on the specific type of cancer diagnosed was the most often reported need for women (70%) and the second most often reported need for men (68%). The most often reported need for men was information on who to contact with a question, problem or concern (71%). This same need was the second most often reported for women (66%).

Table 17. Three Most Often Reported Needs Men and Women* (N = 139)

	Men (n = 66)		Women (n = 73)	
Rank	**Item (Domain)**	**Percent (frequency)**	**Item (Domain)**	**Percent (frequency)**
1	Who to contact when you have a question, problem or concern (Information)	71.2% (n = 47)	Your type of cancer (Information)	69.9% (n = 51)
2	Your type of cancer (Information)	68.2% (n = 45)	Who to contact when you have a question, problem or concern (Information)	65.8% (n = 48)

3	Managing your cancer (Information)	63.6% (n = 42)	More information about your medical test results (Information)	53.4% (n = 39)

*This table shows the three most often reported needs (whether satisfied or unmet) within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.

The most often reported unmet needs for men and women were also examined within the three domains. Table 18 shows that information needs were the most frequent unmet domain for both men and women. For men, the most frequent unmet need was information on financial assistance form provincial or community programs (27%). Amongst women respondents, 29% stated that information on managing cancer and the specific cancer diagnosis were the number one unmet need. It is of interest to note that the third most often reported unmet need for women was within the emotional, social, and spiritual domain, whereas the third most often reported unmet need for men was within the information domain. More specifically, 21% of women reported that dealing with feelings such as fear, anxiety, depression or loneliness was one of their greatest unmet needs.

Table 18. Three Most Often Reported Unmet Needs Men and Women* (N = 139)

	Men (n = 66)		Women (n = 73)	
Rank	**Item (Domain)**	**Percent (frequency)**	**Item (Domain)**	**Percent (frequency)**
1	Financial assistance from provincial or community programs (Information)	27.3% (n = 18)	Managing your cancer (Information) Your type of cancer (Information)	28.8% (n = 21) 28.8% (n = 21)
2	Treatment options (Information)	22.7% (n = 15)	Services, program or supports for cancer patients (Information) Financial assistance from provincial or community programs (Information)	26.0% (n = 19) 26.0% (n = 19)

3	Managing your cancer (Information)	19.7% (n = 13)	Dealing with feelings such as fear, anxiety, depression or loneliness (Emotional, Social, Spiritual)	20.5% (n = 15)

***This table shows the three most often reported unmet needs within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.**

In order to assess the difference in the level of need between the sexes, women patients were compared to men patients with respect to the number of unmet information; practical and financial; as well as emotional, social, and spiritual needs. Within each domain, the number of unmet needs for each patient was tallied and placed into one of three categories: no unmet needs, one to three unmet needs, or four or more unmet needs. Chi-square tests were used to test for statistically significant differences.

Table 19 shows that men and women do not significantly differ in the number of information, practical and financial, or emotional, social, and spiritual needs. Half of men and 44% of women have no unmet information needs. Similarly, men and women have very few unmet practical and financial needs (72.7% and 79.5%, respectively). Finally, 65.2% of men and 67.1% of women have no unmet emotional, spiritual and social needs.

Table 19. Frequency of Unmet Needs by Sex (N = 139)

		Percent (Frequency)		
Domain	**Sex**	**0 Needs Unmet**	**1 to 3 Needs Unmet**	**4 or more Needs Unmet**
Information x^2 (2, 139) = 0.53, p>.05	Men (n = 66)	50.0% (n = 33)	33.3% (n = 22)	16.7% (n = 11)
	Women (n = 73)	43.8% (n = 32)	37.0% (n = 27)	19.2% (n = 14)
Practical & Financial x^2 (2, 139) = 0.87, p>.05	Men (n = 66)	72.7% (n = 48)	27.3% (n = 18)	-
	Women (n = 73)	79.5% (n = 58)	20.5% (n = 15)	-
Emotional, Spiritual & Social	Men (n = 66)	65.2% (n = 43)	30.3% (n = 20)	4.5% (n = 3)

x^2 (2, 139) = 2.76, p>.05	Women (n = 73)	67.1% (n = 49)	21.9% (n = 16)	11.0% (n = 8)

Women and men were also compared on the number of health services needs that were accessible all of the time, most of the time, some of the time, and not at all (see Table 20). Chi-square tests were used to test for statistically significant differences. Similar to each of the three need domains, men and women did not significantly differ in the accessibility of health services needs. Both men and women had most of their health services needs met all of the time. More specifically, 68% of men had 4 or more of their health services needs met all of the time and 80% of women had 4 or more of their health services needs met all of the time.

Table 20. Frequency of Accessible Health Services Needs by Sex (N = 139)

		Percent (Frequency)		
Degree of Accessibility	**Sex**	**0 Needs Met**	**1 to 3 Needs Met**	**4 or more Needs Met**
All of the Time x^2 (2, 139) = 2.89, p>.05	Men (n = 66)	7.6% (n = 5)	24.2% (n = 16)	68.2% (n = 45)
	Women (n = 73)	2.7% (n = 2)	17.8% (n = 13)	79.5% (n = 58)
Most of the Time x^2 (2, 139) = 1.61, p>.05	Men (n = 66)	47.0% (n = 31)	43.9% (n = 29)	9.1% (n = 6)
	Women (n = 73)	57.5% (n = 42)	34.2% (n = 25)	8.2% (n = 6)
Some of the Time x^2 (2,139) = 2.35, p>.05	Men (n = 66)	72.7% (n = 48)	24.2% (n = 16)	3.0% (n = 2)
	Women (n = 73)	72.6% (n = 53)	27.4% (n = 20)	-
Not at All x^2 (2, 139) = 2.16, p>.05	Men (n = 66)	77.3% (n = 51)	22.7% (n = 15)	-
	Women (n = 73)	83.6% (n = 61)	15.1% (n = 11)	1.4% (n = 1)

The relationship between preferences for types of support and gender was also examined. Accordingly, cross-tabulations and Chi-square analyses were performed. Men and women were compared on the seven different types of support asked in the questionnaire, including individual visits with a cancer survivor; contact by phone with a cancer survivor; talking to a counselor who works with cancer patients, like a psychologist, social worker, or nurse; having online chats with cancer survivors; group supports with other cancer survivors; having access to a central staff person to guide you through your experience; and other ways. Two significant differences were found between men and women in regards to preferred means of support.

There were statistically significant differences found between men and women and their preference for support through contact by phone with a cancer survivor, x^2 (1, 139) = 6.60, $p<.05$. The results show that women prefer support through contact by phone with a cancer survivor, when compared to men. Approximately half (53%) of women prefer support through contact by phone with a cancer survivor, compared to only 32% of men.

There were also statistically significant differences found between men and women in their preference for support through online chats with a cancer survivor, x^2 (1, 139) = 5.99, $p<.05$. The results show that women prefer support through online chats with a cancer survivor when compared to men; 18% of women prefer support through online chats with a cancer survivor, compared to only 5% of men. However, it should be noted that only a small percentage of all participants (11.5%, n = 16) preferred support through online chats.

Prevalence of Needs by Treatment Stage

Due to the possibility of unique needs for patients at different stages of the cancer journey, and to assess the validity of examining needs for all cancer patient as a whole, patients currently undergoing treatment (n = 20) and patients who have not yet undergone treatment (n = 15) were combined into a 'treatment' group (n = 35), and compared to patients in post treatment status (n = 104). The three most often reported needs within the information; practical and financial; and emotional, social, and spiritual domains for the treatment and post treatment groups are displayed in Table 21. Of interest is the fact that for both treatment and post treatment groups, all three most often reported needs are within the information domain. Moreover, the three most often reported specific needs are the same for both groups, only in a varying rank. Information on who to contact with a question, problem or concern was the most often reported need for the post treatment group (68%) and the second most often reported need for the treatment group (69%). The most often reported need for the treatment group was information on type of cancer diagnosis (77%). This same need was the second most often reported for the post treatment group (66%).

Table 21. Three Most Often Reported Needs by Treatment Stage* (N = 139)

	Post Treatment Group (n = 104)		**Treatment Group (n = 35)**	
Rank	**Item (Domain)**	**Percent (frequency)**	**Item (Domain)**	**Percent (frequency)**
1	Who to contact when you have a question, problem or concern (Information)	68.3% (n = 71)	Your type of cancer (Information)	77.1% (n = 27)
2	Your type of cancer (Information)	66.3% (n = 69)	Who to contact when you have a question, problem or concern (Information)	68.6% (n = 24)
3	Managing your cancer (Information)	56.7% (n = 59)	Managing your cancer (Information)	60.0% (n = 21)

***This table shows the three most often reported needs (whether satisfied or unmet) within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.**

The most often reported unmet needs for the post treatment and treatment groups were also examined within the three domains: information; practical and financial; and emotional, spiritual, and social. Table 22 shows that information needs were the most frequently unmet need domain for both post treatment and treatment groups. The three specific unmet information needs were information on financial assistance from provincial or community programs, managing cancer, type of cancer diagnosis, and services, program or supports for cancer patients.

Table 22. Three Most Often Reported Unmet Current Needs by Treatment Stage* (N = 139)

	Post Treatment Group (n = 104)		Treatment Group (n = 35)	
Rank	**Item (Domain)**	**Percent (frequency)**	**Item (Domain)**	**Percent (frequency)**
1	Financial assistance from provincial or community programs (Information)	22.1% (n = 23)	Financial assistance from provincial or community programs (Information)	40.0% (n = 14)
	Managing your cancer (Information)	22.1% (n = 23)		
2	Your type of cancer (Information)	21.2% (n = 22)	Managing your cancer (Information)	31.4% (n = 11)
			Managing your cancer (Information)	31.4% (n = 11)
3	Services, program or supports for cancer patients (Information)	19.2% (n = 20)	Services, program or supports for cancer patients (Information)	25.7% (n = 9)

*This table shows the three most often reported unmet needs within the domains: information, practical/financial and emotional/spiritual/social. It does not include health services accessibility.

The difference in the level of unmet need between post treatment and treatment groups was examined. Within each domain (information; practical and financial; and emotional, spiritual, and social), the number of unmet needs for each patient was tallied and placed into one of three categories: no unmet needs, one to three unmet needs, or four or more unmet needs. Chi-square tests were used to test for statistically significant differences.

Table 23 shows that post treatment and treatment groups do not significantly differ in the number of information; practical and financial; or emotional, social, and spiritual needs. Half of the post treatment group and 37% of the treatment group have no unmet information needs. Similarly, post treatment and treatment groups have very few unmet practical and financial needs

(76% and 77%, respectively). Finally, 64% of the post treatment group and 71% of the treatment group have no unmet emotional, spiritual and social needs.

Table 23. Frequency of Unmet Current Needs by Treatment Stage (N = 139)

Domain	Treatment Stage	Percent (Frequency) 0 Needs Unmet	 1 to 3 Needs Unmet	 4 or more Needs Unmet
Information x^2 (2, 139) = 2.53, $p>.05$	Post (n = 104)	50.0% (n = 52)	34.6% (n = 36)	15.4% (n = 16)
	Treatment (n = 35)	37.1% (n = 13)	37.1% (n = 13)	25.7% (n = 9)
Practical & Financial x^2 (1, 139) = 0.20, $p>.05$	Post (n = 104)	76.0% (n = 79)	24.0% (n = 25)	-
	Treatment (n = 35)	77.1% (n = 27)	22.9% (n = 8)	-
Emotional, Spiritual & Social x^2 (2, 139) = 4.03, $p>.05$	Post (n = 104)	64.4% (n = 67)	25.0% (n = 26)	10.6% (n = 11)
	Treatment (n = 35)	71.4% (n = 25)	28.6% (n = 10)	0.0% (n = 0)

Post treatment and treatment groups were also compared on the number of health services needs that were accessible all of the time, most of the time, some of the time, and not at all (see Table 24). Chi-square tests were used to test for statistically significant differences. Similar to each of the three need domains, overall, post treatment and treatment groups did not significantly differ in the accessibility of health services needs. Both post treatment and treatment groups had most of their health services needs met all of the time. More specifically, 75% of the post treatment group had four or more of their health services needs met all of the time and 71% of the treatment group had four or more of their health services needs met all of the time.

Nevertheless, post treatment and treatment groups did significantly differ on the accessibility of health service needs met most of the time, x^2 (2, 139) = 7.87, $p< .05$. A higher percentage of the treatment group had four or more of their needs met most of the time when compared to the post treatment group. More specifically, 20% of the treatment group had four or more of their needs met most of the time, compared to only 5% of the post treatment group.

Table 24. Frequency of Accessible Health Services Needs by Treatment Stage (N = 139)

		Percent (Frequency)		
Degree of Accessibility	**Treatment Stage**	**0 Needs Met**	**1 to 3 Needs Met**	**4 or more Needs Met**
All of the Time x^2 (2, 139) = 1.77, $p > .05$	Post (n = 104)	4.8% (n = 5)	20.2% (n = 21)	75.0% (n = 78)
	Treatment (n = 35)	5.7% (n = 2)	22.9% (n = 8)	71.4% (n = 25)
Most of the Time* x^2 (2, 139) = 7.87, $p < .05$	Post (n = 104)	55.8% (n = 58)	39.4% (n = 41)	4.8% (n = 5)
	Treatment (n = 35)	42.9% (n = 15)	37.1% (n = 13)	20.0% (n = 7)
Some of the Time x^2 (2, 139) = 2.25, $p > .05$	Post (n = 104)	75.0% (n = 78)	23.1% (n = 24)	1.9% (n = 2)
	Treatment (n = 35)	65.7% (n = 23)	34.3% (n = 12)	-
Not at All x^2 (2, 139) = 0.43, $p > .05$	Post (n = 104)	79.8% (n = 83)	19.2% (n = 20)	1.1% (n = 1)
	Treatment (n = 35)	82.9% (n = 29)	17.1% (n = 6)	-

* Significant at the p < .05 level

Chapter Five: Discussion

The purpose of this study was to expand the body of knowledge about cancer experiences in Prince Edward Island and, ultimately, establish what care is needed by people living with cancer in Prince Edward Island. The intent is that this study will provide important baseline information that will assist in the refinement and development of supportive care interventions for cancer patients and facilitate appreciation for the vast and diverse ramifications of this disease. The specific objectives of this study are threefold:

- ☐ To identify the range of psychosocial needs of people living with cancer in Prince Edward Island;
- ☐ To establish the degree and the desired mechanism in which the psychosocial needs of people living with cancer in Prince Edward Island are being, and can be, met; and
- ☐ To prioritize the psychosocial needs of people living with cancer in Prince Edward Island.

Telephone surveys were used as the data source. One hundred and thirty nine people diagnosed with cancer between January 2004 to November 2005 were interviewed. Questions asked pertained to four domains of need: information; practical and financial; emotional, social, and spiritual; and health services. In this chapter, the results will be discussed. Links to other studies and recommendations for further research will be made.

Sample Demographics and Representativeness

As reported in the results, breast cancer was the most common diagnosis represented in the sample (22%), followed by prostate cancer (18%), and colon/rectum cancer (14%). When compared to the population of cancer patients in Prince Edward Island for the year 2003 (CCS & NCIC, 2006), the study sample is a good representation of the main cancer diagnoses in Prince

Edward Island (14% breast, 18% prostate, and 14% colorectal). The only cancer site that was not well represented in the sample was lung cancer. Only 2% of the sample had been diagnosed with lung cancer compared to 13% of the population. The low response rate from lung cancer patients is not unexpected as lung cancer has a poor prognosis, and a high mortality rate; lung cancer is the leading cause of cancer death worldwide (Hill, Amir, Muers, Connolly, & Round, 2003).

By sex, 47% of the sample were men and 53% of the sample were women. According to data on the population of cancer patients in Prince Edward Island for the year 2003[3] (CCS & NCIC, 2006), the sample very slightly overrepresented women cancer patients in Prince Edward Island. The majority of the sample was between the ages of 60 and 69 (36%); in comparison to the Prince Edward Island population for the year 2004 (Provincial Treasury, 2006), this age group is significantly overrepresented in the study sample. The grounds of this overrepresentation likely lie in the fact that cancer primarily affects elderly individuals (CCS & NCIC, 2006). A more accurate comparison to evaluate the representativeness of the study sample would be to contrast it with data on the incidence of cancer diagnoses by age group for Prince Edward Island; unfortunately, data this specific is not currently available. Overall, the study sample is fairly representative of the Prince Edward Island cancer population; important characteristics of age, gender and cancer diagnosis are distributed similarly in the two groups.

Current Information Needs

Similar to many studies in the field of cancer patient needs (CCS, 2000b; Hack et al., 2005; McIllmurray et al., 2001; Templeton & Coates, 2001; Van Der Molen, 1999; Whelan et al., 1997), information was a very commonly reported area of current need. For instance, in a study by Whelan et al. (1997), nearly 85% of the sample wanted a great deal of information or enough information to feel well informed. In the current study, the types of information patients

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[3] Data for the year 2003 was the most recent province-specific data available at the current time.

need varied from information on cancer and how to manage cancer to information about the types of services, programs, and supports available for cancer patients. Over half of patients expressed a need for information on their type of cancer (69%); who to contact with a problem, concern, or question (68%); how to manage cancer (58%); medical test results (53%); and services, programs, and supports for cancer patients (50%).

These results are similar to those reported in a study by the Canadian Cancer Society which sought to better understand the needs of people living with cancer in Alberta (CCS, 2000b). The surveys showed that over half of patients had a moderate to high need to be fully informed about test results as soon as possible (62%), and needed information on things they could do to help themselves get well (62%).

Further research points to the need for information on treatment as important (de Bock et al., 2004; Graydon et al, 1997; Luker et al., 1995). Although 43% of the current sample reported that information on treatment options was important for them, it was not one of the top information needs in the current study. The difference in importance placed upon information on treatment between the current study and the literature on information needs could be due to the different stage of treatment that the study samples were in at the time of the survey. The majority of the current sample was in the post treatment stage, whereas much of the literature focuses on patients who were newly diagnosed (Luker et al., 1995) or currently being treated (Graydon et al, 1997) at the time of the survey. Furthermore, a study that did include patients in the post-treatment stage of cancer did find an expressed need for information on treatment; however, the information they needed specifically related to the long-term effects of treatment and prognosis (deBock et al., 2004).

Additionally, 41% of patients in the current study expressed a need for information about financial assistance from provincial or community programs. Regrettably, 65% of patients who expressed the need for information about financial assistance, and 41% of patients who had a need for information about services, programs, and supports, did not receive assistance with these needs. It is not known whether these areas are unmet because there are few services, programs, and supports for cancer patients, or because there is a lack of knowledge about the services, programs, and supports that are available.

Sources of Information

The most common source for Prince Edward Island patients to look for information was health care professionals (66%). This is consistent with the literature on sources of information for cancer patients (Ashbury et al., 1998; Mills & Davidson, 2002). Health care professionals, such as nurses, specialists, and general practitioners are some of the most common sources of information. Additionally, other cancer patients, as well as family and friends, are commonly reported sources of information in the literature (Ashbury et al., 1998; Mills & Davidson, 2002). Unfortunately, patients were not directly asked about these sources of information in the current study. Nonetheless, when given the opportunity to mention other sources of information, 17% of patients mentioned cancer patients, as well as family and friends.

In terms of mass media sources of information, Mills and Davidson (2002) found that patients did not rate these as high as they rated interpersonal sources of information. A high percentage of patients in the current study (70%) preferred to receive cancer related information through one-on-one consults. Ironically, 50% of the current sample also used the Internet as a source of information. Additionally, 86% of the sample preferred to receive information through pamphlets and written materials.

Current Practical and Financial Needs

Managing side effects such as pain, nausea, and fatigue was the most often reported need as well as one of the most often reported unmet need, within the practical and financial needs domain. Approximately 30% of patients said that this was a need and 40% of them were not able to satisfy this need. Interestingly, in the 1989 study of cancer patients' needs in Prince Edward Island (Vachon et al., 1989), managing side effects was also reported as a high area of need. Furthermore, side effects, such as fatigue and anxiety, were the most prevalent symptoms reported in a more recent Canadian survey (Ashbury et al., 1998). The next most common need for the current sample was getting to and from cancer appointments, with close to 30% of patients expressing this need. Other research points to travel, such as traveling outside of their home province (CCS, 2004) and easy car parking at the hospital (Sanson-Fisher et al., 2000) as areas of concern.

Although not largely reported as a need, covering the costs of special foods, health supplies, medications and drugs associated with having cancer represented two of the three most often unmet practical and financial needs in the current study; 13% of participants expressed that covering the costs of special foods and health supplies was a need, and 50% of those patients did not have this need met. In addition, 25% of patients expressed that covering the costs of medications and drugs associated with having cancer was a need, and 26% of them could not meet this need. It is of critical importance to address these two areas of financial need, not because they are widely unmet, but because of the severe impact of not having the finances to cover such significant aspects of cancer care as medications, drugs, health supplies, and special foods.

Dealing with the financial impact of cancer is not a new problem for patients. In 1989, Vachon et al. also reported that this was a common problem for cancer patients in Prince Edward

Island. In 2000, one of the most commonly referenced cancer patients needs assessment also reported finances as a noteworthy and great area of need (Sanson-Fisher et al., 2000).

Current Emotional, Spiritual, and Social Needs

Findings show that between 25% and 30% of patients reported accepting the presence and the uncertainty of cancer; dealing with feelings such as fear, anxiety, depression and loneliness; supporting the concerns of those close to them; working through feelings about death and dying; and getting support to help them feel more in control of their situation, as current needs. These results are very similar to the emotional concerns reported in the literature. Adjustment to the diagnosis, family reaction, and fear of recurrence (Vachon et al., 1989); support for family and caregivers (CCS, 2004), dealing with fears about cancer spreading or returning, concerns about those close to them, and coping with uncertainty (CCS, 2000b) have been cited as needs in previous Prince Edward Island and Canadian cancer patients needs assessments.

Patients in the current study also did not have their needs in this domain readily met. With the exception of getting support to help them feel more in control of their situation, roughly half of patients who expressed emotional, spiritual or social concerns did not have their needs met. This is not uncommon, as recent research shows that people diagnosed with cancer regularly declare that they are left with little support to meet their needs (Saegrov, 2005).

The lack of met needs in this area could be related to a lack communication about these areas of need between the patient and health care professionals. Research shows that patients do not readily communicate their needs to clinicians (Hack et al., 2005; Wen and Gustafson, 2004). Lack of communication may be a result of many barriers, including the perception that doctors do not have the time to deal with psychosocial needs (Ryan et al., 2005), fear of breaking down or being ashamed to admit problems (NBCC & NCCI, 2003), or the perception that these feelings of grief, anger, suffering, and pain are inevitable (Ryan et al., 2005; Wen and Gustafson, 2004). Even when patients do communicate their needs, fewer than 10% are referred to psychosocial care (Carlson & Bultz, 2003).

Sources of Support

Over half of the participants (57%) in the current study stated that they would like to receive support through individual visits with a cancer survivor. In a systematic review of the literature on peer support programs, Campbell et al. (2004) found similar results. One of the most common programs for support was one-to-one visitor programs. In the current study, it was who had a similar diagnosis. According to the principles of optimal matching theory, as outlined by Campbell et al. (2004), when patients who are comparable in terms of variables such as sex, age, and type of cancer, support one another, support is more effective. That is, "optimal matching theory suggests that illness creates the need for social support in many different areas (e.g. physical needs, relationships, financial), and that "need specific support" offers maximum adjustment" (Campbell et al., 2004, p. 3).

The second most commonly preferred type of support was through access to a central staff person that could guide cancer patients through their cancer experience (53%). A little better than 40% of patients said they would like to receive support through contact by phone with a cancer survivor, representing the third most common choice of support methods. It is not surprising that the three most commonly preferred types of support are interpersonal formats. Although there is a lack of research in the area of preferred sources of social support, research on sources of informational support shows that patients rate interpersonal sources higher than print and media sources (Mills & Davidson, 2002).

Current Accessibility of Health Care Services Needs

The majority of participants in the current study stated that their health care services needs were accessible all of the time. Some of the key areas in which health care service needs were not always accessible were accessing cancer services close to home, getting medical appointments in a timely manner, and receiving information about test results in a timely manner. Between 12% and 17% of respondents claimed that their needs were not always met in these areas. This finding is similar to what other Island research on general population health services needs has found.

For people living in Prince Edward Island, there has been an increase in unmet health needs over time (Van Til, 2003). In 1995, only 2% of Prince Edward Islanders aged 12 and over expressed unmet health needs, compared to 4% of Canadians. In 2001, 12% of Prince Edward Islanders aged 12 and over expressed unmet health needs, compared to 13% of Canadians. In this regard, an unmet health need is defined as a situation in which a person requires health care or advice, but does not receive it. It is a measure of perceived access to care. The major reason for unmet needs in Prince Edward Island was cited to be wait times.

Greatest Current Needs

Participants were asked to consider all of their current needs and identify their greatest current need. Interestingly, the most often mentioned domains of need were: practical and financial needs (25%); health services accessibility (25%); and emotional, social, and spiritual needs (20%). This finding is contrary to the results of the individual domain questions that were asked in the survey. For instance, examination of the most often reported needs of cancer patients across all three domains shows that needs within the information domain was most often reported (see Table 8).

Although it is unclear as to why the priority of needs varied between the two areas of questioning, there are a few points to consider. Firstly, the entire sample did not respond to the question about greatest current needs, only 75% of the sample reported a greatest need. The most common reason patients gave for not identifying an area of greatest current need was that they did not have one, or that they already mentioned it in the domain questions.

Secondly, it is plausible that patients did not identify information needs as their greatest area of need because they clearly reported them as needs in the earlier sections of the survey. There is support for this theory, as the information needs that patients did mention in the greatest current needs section were not directly asked in the structured survey questions. More specifically, the greatest information need that patients mentioned was a need for readily available, clear, and timely information. The structured survey questions focused on specific types of information rather than aspects of readability and comprehension; thus, patients did not have the opportunity to express this greatest need earlier in the survey. The other greatest information need that patients specifically mentioned was a need for information on assurance about their prognosis and outcome. This question was not asked in the structured survey questions either.

Taken together, the results from the structured domain questions and greatest need question point to the well-supported concept that cancer patients have high levels of unmet need in a variety of areas (Desroches et al., 2004; Girgis & Burton, 2001; Greer, 1994; Ryan et al., 2005; Sanson-Fisher et al., 2000). Cancer patients have several needs in the domains of information; practical and financial concerns; emotional, spiritual, and social concerns; and health services.

Prevalence of Needs by Type of Cancer

Results show that breast cancer patients have significantly fewer unmet practical and financial needs than people with other types of cancer. More specifically, 94% of people with breast cancer have no unmet practical and financial needs, compared to only 71% of people with all other types of cancer. It is not surprising that there is a difference between needs of breast cancer and other cancer patients. As was previously mentioned, breast cancer is the only type of cancer in Prince Edward Island where, upon diagnosis, patients are proactively offered both information and support. For instance, the kit that breast cancer patients receive upon diagnosis contains information and resources about programs and services available to them. This information may aid them in fulfilling their practical and financial needs.

Prevalence of Needs by Sex

Statistically significant differences were found between men and women in their type of preferred support. Women more often wanted to receive support through contact by phone with a cancer survivor, when compared to men. Approximately 50% of women preferred support through phone contact with a cancer survivor, compared to only 32% of men. Women also preferred online chats with a cancer survivor more often than men; 18% of women preferred support through online chats, compared to only 5% of men. It should be duly noted, however, that only a very small proportion of the overall sample (12%) preferred to receive support through online chats with a survivor. Although research on support preferences for cancer patients is lacking, even more so in terms of comparing support preferences for men and women cancer patients, it is not surprising to find that women prefer 'personalized' support mediums, when compared to men. The research on sources of information support for cancer patients suggests that men prefer to receive information through non-interactive and passive sources (Mills & Davidson, 2002).

Prevalence of Needs by Stage of Cancer

Information was the most important need, no matter which stage of cancer patients were in. This is consistent with the literature, which clearly indicates that information is the most often reported need. Nonetheless, the literature also clearly states that although cancer patients have several information needs, they do vary according to the cancer site, stage and treatment type (Hack et al., 2005; Templeton & Coates, 2001; Van Der Molen, 1999). In the current study, very subtle differences in primary information needs were observed. Cancer patients in the post treatment group were primarily in need of information on who to contact with a problem, question or concern. Cancer patients in the treatment group were primarily in need of information on their type of cancer. Important to note is the small sample size of patients in the treatment group: the treatment group represented a combination of patients currently undergoing treatment (n = 20) and patients waiting to begin treatment (n = 15).

Interestingly, significant differences in accessibility of health care services were observed in between the treatment and post treatment groups. Twenty percent of the treatment group had four or more of their needs met most of the time, compared to only 5% of the post treatment group. This finding may be due to the lack of formalized continuation of care for patients in the survivorship stage of cancer (Doll et al., 2002). Nonetheless, it should be duly noted that although this finding is statistically significant, clinical significance is unlikely. That is, the majority of patients in both groups had their needs met all of the time; specifically, 75% of patients in the post treatment group and 71% of patients in the treatment group. In addition, the actual number of patients who did not have four or more of their health services needs met most of the time is very small (n = 12).

Study Design Challenges

When assessing needs, there are many methodological issues and problems of measurement and assessment. As Lindblad, Ring, Glimelius and Hansson (2002) state, these challenges include the a variety of tools used, timing of assessments, response shift in patients' perception, and difficulty in interpreting findings (King, 2006). In addition, an often cited problem with assessing needs is that patients have a tendency to say that they want as much information as possible about all aspects of their care and treatment (Luker et al., 1995; Vachon, 1992). For instance, a problem with asking about needs is that simply asking about a specific need may increase the importance patients place on that need (Graydon et al., 1997).

From a research point of view, examining needs does present challenges, both in the design and the analysis of the findings. There is a possibility that when people are asked to simply indicate what they want or need, a 'wish list' of wants and desires emerges (Vachon, 1992). This wish list would incorporate both specific cancer needs and more general needs, wants, and desires not necessarily related to cancer. To counteract this possibility, questions can be framed to ask participants about their specific needs resulting from a cancer diagnosis. To combat this challenge in the current study, a technique of referring the patient back to the issue at hand throughout the interview was utilized. Patients were often prompted to think about their current situation as it related to their cancer experience when answering questions. Specifically, the phrase 'at this time in your cancer experience' was used in every fifth question.

Another methodological issue with assessing needs is to distinguish between 'met' and 'unmet' needs (Vachon, 1992). If a participant does not report a need in a certain area, it is misleading to interpret this to mean that there is no need in that area. It could be the case that there is a need but it has already been met in such a way that it is not perceived as a need, and thus not reported. The danger in this misinterpretation comes from the possibility of redirecting resources and services away from existing areas of need where they are, in fact, successfully meeting the needs of people living with cancer. In order to neutralize the risk of misinterpreting met needs, interviewers were instructed, and questioning was constructed, to distinguish between met and unmet needs in all areas of study.

Socially desirable responding is an additional consideration for most studies within the humanities and social sciences fields, and needs assessments are no exception to this potential bias. Socially desirable responses must be considered because they may shape the report people give about their experiences. For instance, cancer patients may feel that they are likely to be praised if they 'think and talk positively' (Wilkinson & Kitzinger, 2000 as cited in Entwistle et al., 2002). Furthermore, patients may be reluctant to talk about symptoms, concerns and problems because of the fear that they may be seen as ungrateful. Patients may also assume that responding in a socially desirable way is best because if they were to explain their experiences as they truly are, nothing could be done to help them anyway (Turner et al., 2005). Therefore, responses must be interpreted accordingly.

The relationship between the researcher and those researched can also influence the data collected. What is reported can highly depend on the roles and relationships between participants and researchers. For instance, an anthropologist who 'goes in as a stranger', a clinical researcher who 'goes in as a health professional', and a person with cancer who 'goes in as a peer' will encounter different issues and be enlightened with different aspects (Richards & Emslie, 2000 as cited in Entwistle et al., 2002). For this reason, the Principal Investigator and the volunteers chosen to act as interviewers in the current study were all people with intimate knowledge and experience of the varied affects of a cancer diagnosis. After discussion with the Advisory

Committee, it was determined that cancer patients would appreciate and feel more comfortable talking to a 'peer' interviewer rather than a 'stranger' or 'health professional'.

Some minor areas for improvement of the survey instrument are apparent and required before future research should utilize this instrument. For instance, the question in which patients were asked to indicate their preferred source for cancer related information should not have included the word 'or' in the choice of 'pamphlets or written material'. The use of the word 'or' caused some confusion among respondents, whom often felt that they had to make a choice between pamphlets or written material. In future research, the choice should be changed to read 'written material', since written material would include pamphlets.

Research has shown that friends and family play a significant role as sources of information for cancer patients (Ashbury et al., 1998; Mills & Davidson, 2002). Unfortunately, patients were not directly asked about this source of information in the current study, yet when given the opportunity to mention other sources of information, 17% of patients mentioned cancer patients, family and friends as preferred sources. Thus, the choice of 'cancer patients' and 'family and friends' should be added to the list of information sources. In addition, 13% of respondents preferred support through friends and family as an option in the sources of support question. Thus, the choice of 'family and friends' should be added to the list of support sources as well.

Another area for improvement was in the health services accessibility area. There were ten question asked in this section; however, because they were often misunderstood by participants, three of the questions were not included in the analysis: 'Are you able to have one health professional guide you through your cancer experience?', 'Are you able to receive medical support in your home when needed?', and 'Are you able to access new therapies or clinical trials?'. In response to the first question, patients felt that their doctor was the one person who did guide them through their experience; however, the question was meant to assess whether or not a patient navigator would be of use to patients in Prince Edward Island. Patients often answered the second question, about medical support in their home, with a reply of 'What kind of support?', 'I don't know', and 'I guess so, if I needed it'. From these types of responses, it does not appear that this health service was often sought or even considered by patients. The third question, about clinical trials and new therapies, was often misunderstood as well, because patients could not remember if they were offered this type of treatment or if they did in fact have this kind of treatment.

In addition, all of the health services accessibility questions in the current study related to the treatment of the disease itself, and not to the treatment of psychosocial needs or symptom care. Perhaps a different picture of health services needs would have been painted in the current study if some of the focus of the health services questions were on psychosocial needs. In the literature, a large Canadian survey showed that cancer patients were satisfied with the quality of care they received for cancer treatment; however, they were much less satisfied with the care that they received for their other symptoms (Ashbury et al., 1998). More specifically, 73% of respondents reported being very satisfied with the care they received for cancer treatment, compared to only 47% who reported being very satisfied with the care they received for their other symptoms.

Future Areas of Research

This study effectively provided insight into the three main objectives set forth. As research does, the findings have led to identified areas for appropriate future research. As information appears to be the greatest need for patients in Prince Edward Island, more research is needed on how the cancer community can supply patients with the type, format, and source of information that they need. It is still unclear whether patients prefer interpersonal or media sources of information. In addition, further research should more closely examine the differences in information needs for women and men, as well as for patients across various stages of the cancer continuum.

Many patients in the current study identified unmet emotional, spiritual and social needs. Future research should address the best ways to supply support to patients. Specific questions requiring further study include how to relieve the known barriers to communicating concerns and needs, to what extent patients prefer interpersonal versus mass media sources of support, and what sources of support are preferred by men and women.

A consistent finding between the current study and the literature was that patients often report a need for assistance with side effects, including fatigue and anxiety. Future research should focus attention on ways to help patients alleviate these needs and support them in doing so. Financial troubles with the costs of medications, drugs, health supplies, and special foods is of concern for a minority of patients. Nonetheless, this is a major problem that can affect all areas of quality of life for patients and their families. Future research should focus on ways to get existing financial programs and services information to patients, as well as focus on what types of programs and services could be proposed to assist patients with their financial needs, and what organizations are capable of assisting patients with this need.

As previously mentioned, the level of accessibility of health services as they relate to psychosocial needs in addition to the treatment of the disease requires further examination. The current study did not assess the accessibility of health service, as they relate to psychosocial needs, yet additional Canadian research found that these needs are poorly met by health care services (Ashbury et al., 1998).

An examination of the needs of cancer patients over the continuum of the cancer experience is also warranted. Although the current study attempted to provide a cross sectional view of cancer patients' needs throughout the continuum, the majority of participants were in the post-treatment stage of their cancer journey. Thus, the current study findings relate primarily to the needs of patients in the post-treatment stage. It is well recognized that there are five stages of high vulnerability for psychosocial distress in cancer patients: before and after receiving a diagnosis of cancer, during acute care and treatment, during rehabilitation and after-care, after recurrence, and during palliative and progressive disease (Weis, 2003). A longitudinal study that assessed patients' needs from the time of diagnosis to five-year survival, for example, would yield data on the needs of cancer patients as they move through the stages. This type of far-reaching study would be a rich source of information that would enable the cancer community to better understand and support the specific needs of patients.

Although the current study reflected the cancer population in Prince Edward Island in terms of type of cancer, gender, and age, there is also a need to study other populations whom are likewise deeply affected by cancer, and not well represented in the current findings. These populations include young persons, minority populations, specific types of cancer patients (i.e. lung cancer), and patients in the pre-treatment and treatment stages of cancer. Future research could partner with the staff of the Cancer Registry to facilitate the purposeful selection of people diagnosed with cancer, who fall into one of these populations.

Although the current study effectively provided insight into the three main objectives set forth, the results cannot be generalized to all persons living with cancer in Prince Edward Island.

The applicability of the findings should take into account that the sample size obtained was relatively small for survey research (Fowler, 1990; Gilmore & Campbell, 1995); a 25% response rate was achieved. Nonetheless, a small sample size was anticipated considering that the population being studied was primarily older and suffering from a potentially life-threatening illness. The sample size is also comparable to recent needs assessment research conducted by the Canadian Cancer Society, which obtained response rates of between 10% and 23% in Alberta (Canadian Cancer Society, 2000b) and Ontario (Canadian Cancer Society, 2003).

Additionally, although the current study reflected the cancer population in Prince Edward Island in terms of type of cancer, gender, and age, the demographics of cancer patients who did not participate in the study were not random. The greatest area of sample bias was with the stage of cancer represented in the study sample. The overwhelming majority of participants were in the post-treatment stage of cancer. A further bias in the sample was the type of cancer that participants were diagnosed with. Although the study sample was representative of the most common types of cancer diagnosed in Prince Edward Island (CCS & NCIC, 2006), lung cancer was not well represented in the sample. Only 2% of the sample had received a diagnosis of lung cancer compared to 13% of the population. As previously discussed, this is not unexpected, as lung cancer has a poor prognosis and a high mortality rate. The small sample size, as well as the non-randomness of cancer patients who participated in the survey, make the results primarily applicable to older (ages 60 to 69) cancer patients in Prince Edward Island who are in the post treatment stage of their cancer journey.

In conclusion, the current study has established insight into three main areas of need for Island cancer patients ages 60 to 69 in the post treatment stage of cancer. The main findings were in the domains of information; emotional, spiritual, and social concerns; as well as financial and practical needs. The most frequent area of reported need was for information. Over half of participants expressed a need for several types of information, ranging from information on cancer and how to manage cancer, to information about the types of services, programs, and supports available for cancer patients. The most frequently reported area of unmet needs was for assistance with emotional, spiritual, and social concerns. Between 25% and 30% of patients reported several needs related to emotional, spiritual, and social concerns, with roughly half of patients stating that these needs had not been met. Although not commonly reported, there is also a profound need for assistance in the area of practical and financial issues. Covering the costs of special foods, health supplies, medications and drugs associated with having cancer represented two of the three most often unmet practical and financial needs in the current study. It is of critical importance to address these two areas of financial need, not because they are widely unmet, but because of the severe impact of not having the finances to cover such significant aspects of cancer care as medications, drugs, health supplies, and special foods.

References

Armstrong, J., & Lennon, M.J. (2006). *Improving communications of Canadian Cancer Society Information and Support Services*. Environics Research Group: Toronto, Ontario.

Asadi-Lari, M., Tamburini, M., & Gray, D. (2004). Patients' needs, satisfaction, and health related quality of life: Towards a comprehensive model. *Health and Quality of Life Outcomes, 2*, 32-46.

Ashbury, F., Findlay, H., Reynolds, B., & McKerracher, K. (1998). A Canadian survey of cancer patients' experiences: Are their needs being met? *Journal of Pain and Symptom Management, 16 (5)*, 298 – 306.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., Boyes, A., & the supportive care review group (2000). Evaluation of an instrument to assess the needs of patients with cancer. *Cancer, 1*, 217-225.

Campbell, H.S., Phaneuf, M.R., & Deane, K. (2004). Cancer peer support programs – do they work? *Patient Education and Counseling, 55*, 3 – 15.

Canadian Association of Psychosocial Oncology (2006). What is psychosocial oncology? Retrieved July 18, 2006 from www.capo.ca/eng/about_psychosocial _oncology.asp

Canadian Cancer Society (2000a). An emotional support needs assessment of cancer patients in Regina, Saskatchewan. *Centre for Behavioural Research and Program Evaluation.*

Canadian Cancer Society (2000b). Assessing the needs of persons living with cancer in Alberta: A report for the Canadian Cancer Society, Alberta/N.W.T. *Downie and Associates, Inc: Calgary, Alberta.*

Canadian Cancer Society (2003). *Breaking down the barriers: Study of cancer patient and* *caregiver needs in Ontario*. Canadian Cancer Society, Ontario Division.

Canadian Cancer Society (2004). *Talking about cancer: Improving the quality of life of people living with cancer across Saskatchewan*. Canadian Cancer Society, Saskatchewan Division.

Canadian Cancer Society (2006). General cancer stats for 2006. Retrieved October 8, 2006 from http://www.cancer.ca/ccs/internet/standard/0,2283,3172_14423__langId-en,00.html

Canadian Cancer Society & National Cancer Institute of Canada (2005). Canadian Cancer Statistics 2005. Retrieved August 27, 2006 from http://www.cancer.ca.

Canadian Cancer Society & National Cancer Institute of Canada (2006). Canadian Cancer Statistics 2006. Retrieved August 27, 2006 from http://www.cancer.ca.

Carlson, L.E., & Bultz, B.D. (2003). Cancer distress screening: Needs, models, and methods. *Journal of Psychosomatic Research, 55*, 403-409.

Carter, K., & Beaulieu, L. (1992). Conducting a community needs assessment: Primary data collection techniques. Retrieved October 8, 2006 from http://edis.ifas.ufl.edu/pdffiles/HE/HEO6000.pdf

Cossich, T., Schofield, P., & McLachlan, S.A. (2004). Validation of the cancer needs questionnaire (CNQ) short-form version in an ambulatory setting. *Quality of Life Research, 13*, 1225 – 1233.

de Bock, G.; Bonnema, J.; Zwaan, R. van de Velde, C.; Kievit, J., & Stiggelbout, A. (2004). Patient's needs and preferences in routine follow-up after treatment for breast cancer. *British Journal of Cancer, 90*, 1144 – 1150.

Desroches, N., Joza, J., Campbell, H.S., Gerl, L., & Wurtak, G. (2004). *Evaluation of the Taking*

Charge Information and Support Group, Canadian Cancer Society, Manitoba Division. Centre for Behavioural Research and Program Evaluation. University of Waterloo. Waterloo, Ontario, 2005.

Doll, R. et al. (2002). Canadian strategy for cancer control supportive care/cancer rehabilitation \ workgroup: Final report. Retrieved 13, 2005 from http://www.cancercontrol.org/cscc/pdf/ finalsupportiveJan2002.PDF

Edgar, L., Remmer, J., Rosberger, Z., & Rapkins, B. (1996). An oncology volunteer support organization: The benefits and fit within the health care system. *Psycho-Oncology, 5*, 331 – 341.

Entwistle, V., Tritter, J.Q., & Calnan, M. (2002). Researching experiences of cancer: the importance of methodology. *European Journal of Cancer Care, 11*, 232-237.

Fink, A. (1995). *The survey handbook.* Sage Publications, Inc.: Thousand Oaks, California.

Fowler, F.J. (Jr.) (1990). *Survey research methods (Revised Edition)*. Sage publications, Inc.: Thousand Oaks, California.

Girgis, A., & Burton, L. (2001). Cancer patients' supportive care needs: Strategies for assessment and intervention. *NSW Public Health Bulletin, 12(10)*, 269-271.

Gilmore, G., & Campbell, M. (1995). *Needs assessment strategies for health education and health promotion (2nd Ed.)*. McGraw Hill. Massachusetts: Boston.

Graydon, J. et al. (1997). Information needs of women during early treatment for breast cancer. *Journal of Advanced Nursing, 26*, 59-64.

Greer, S. (1994). Psycho-oncology: Its aims, achievements and future tasks. *Psycho-Oncology, 3*, 87 – 101.

Hack, T., Degner, L., & Parker, P. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology, 14*, 831 – 845.

Hill, K., Amir, Z., Muers, M., Connolly, K., & Round, C. (2003). Do newly diagnosed lung cancer patients feel their concerns are being met? *European Journal of Cancer Care, 12*, 35 – 45.

King, C.R. (2006). Advances in how clinical nurses can evaluate and improve quality of life for individuals with cancer. *Oncology Nursing Forum, 33 (1)*, 5 – 12.

Luker, K.A., Beaver, K., Lemster, S.J.; Owens, R.G., Degner, L.F., & Sloan, J.A. (1995). The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing, 22*, 134-141.

McIllmurray, M.B., Thomas, C., Francis, B., Morris, S., Soothill, K., & Al-Hamad, A. (2001). The psychosocial needs of cancer patients: Findings from an observational study. *European Journal of Cancer Care, 10*, 261-269.

Mills, M., & Davidson, R. (2002). Cancer patients' sources of information: Use and quality issues. *Psycho-Oncology, 11*, 371 – 378.

Morse, J.M. (1994). Designing funded qualitative research. In N.K. Denzin and Y.S. Lincoln (Eds.) *Handbook of qualitative research* (pp. 220 –235). Thousand Oaks: California: Sage Publications.

National Breast Cancer Centre and National Cancer Control Initiative (2003). Clinical practice guidelines for the psychosocial care of adults with cancer. *National Breast Cancer Centre: Camperdown, NSW.*

Polit, D.F., & Beck, C.T. (2004). *Nursing research: Principles and methods (7th Ed.)*. Lippincott Williams & Wilkins. Philadelphia: PA.

Provincial Treasury (2006). Province of Prince Edward Island: Thirty-Second Annual Statistical

Review 2005. Retrieved January 14, 2007 from http://www.gov.pe.ca/photos/original/32annualreview.pdf

Rainbird, K.J., Perkins, J.J., & Sanson-Fisher, R.W. (2005). The needs assessment for advanced cancer patients (NA-ACP): A measure of the perceived needs of patients with advanced, incurable cancer. A study of validity, reliability, and acceptability. *Psycho-Oncology, 14,* 297- 306.

Ryan, H., et al. (2005). How to recognize and manage psychological distress in cancer patients. *European Journal of Cancer Care, 14,* 7 – 15.

Saegrov, S. (2005). Health, quality of life and cancer. *International Nursing Review, 52,* 233-240.

Sanson-Fisher, R. et al., (2000). The unmet supportive care needs of patients with cancer. *Cancer, 88,* 226-237.

Sprangers, M. (2002). Quality of life assessment in oncology: Achievements and challenges. Acta Oncologica, 14 (3), 229 – 237.

Stringer, E., & Genat, W. (2004). *Action research in health.* Upper Saddle River, New Jersey: Pearson Education Inc.

Templeton, H., & Coates, V.E. (2001). Adaptation of an instrument to measure the informational needs of men with prostate cancer. *Journal of Advanced Nursing, 35(3),* 357 – 364.

Turner, J., Zapart, S., Pedersen, K., Rankin, N., Luxford, K., & Fletcher, J. (2005). Clinical practice guidelines for the psychosocial care of adults with cancer. *Psycho-Oncology, 14,* 159 – 173.

Vachon (1992). *Final report on the needs of people living with cancer across Canada.* Toronto, Ontario: Canadian Cancer Society.

Vachon, M.; Conway, B., Lancee, W.J., & Adair, W.K. (1989). *Report on the needs of persons living with cancer in Prince Edward Island.* Canadian Cancer Society, PEI Division.

Van Der Molen, B. (1999). Relating information needs to the cancer experience: 1. Information as a key coping strategy. *European Journal of Cancer Care, 8,* 238 – 244.

Van Til, L. (2003). Prince Edward Island health indicators: Provincial and regional. Retrieved January 14, 2007 from http://www.gov.pe.ca/photos/original/hss_healthind02.pdf.

Weis, J. (2003). Support groups for cancer patients. *Support Care Cancer, 11,* 763-768.

Wen, K., & Gustafson, D.H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes, 2,* 1 –22.

Whelan, T. et al. (1997). The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer, 80,* 1518 – 1524.

White, M., & Dorman, S.M. (2001). Receiving social support online: implications for health education. Health Education Research, 16 (6), 693 – 707.

Wong, A.Y.M. (2003). *Matching Criteria in Peer Support Programs: A Literature Review.* Centre for Behavioural Research and Program Evaluation, University of Waterloo, Ontario, 2002.

Appendix A: Telephone Interview

Call Record

Respondent Name: ______________________ ID #: ____________________

Phone #: __________________

Date:	Time:	Interviewer Name:	Result:	When to Call Back:

Please note:
If you need to call back, please include when to call back.
If the respondent refused to participate or stopped the survey partway through, please include why the person refused and at what point in the interview. If you need to finish the interview later, please record when.

INTRODUCTION

Hello. Could I please speak to (name of interviewee).

(IF WRONG NUMBER, TERMINATE INTERVIEW : "sorry to have bothered you")
(IF NOT AVAILABLE, ASK "when might be a good time to call back?" RECORD INFORMATION ON CALL SHEET)

Hello. This is (YOUR NAME) and I am a trained (VOLUNTEER) with the Canadian Cancer Society, PEI Division. We are doing an Island-wide project in order to find out the needs of people living with cancer and what can be done to support their needs. Recently, you replied to a letter from the Cancer Registry indicating that you would like to participate in this study. Is now a good time for you?

(IF YES, CONTINUE)
(IF NO, ASK: Is there a better time for me to call back? RECORD REPLY ON CALL SHEET)

I'll tell you more about the study before we begin.
The Canadian Cancer Society, PEI Division is interviewing people who have been diagnosed with cancer to learn more about the needs of cancer patients. This information will be used by the Canadian Cancer Society to refine our programs and services, including our work with other cancer organizations and government programs in the province.

If you should choose to participate, your answers will be kept confidential, and your name will not appear on any materials produced from the information you give, however your words may be used. It is a completely voluntary study and you may choose not to answer any questions you do not wish to without penalty. You may also end the interview at any time without penalty. Participating will not affect your health care. The interview will take about 20 minutes to complete. Do you have any questions before we begin?
(IF YOU ARE NOT ABLE TO ANSWER, ASK THE RESPONDENT TO HOLD AND ASK SHANNON)

PART ONE: NEEDS

Before we begin, can you tell me what type of cancer you have been diagnosed with; this will ensure that I only ask you the applicable questions?

TYPE OF CANCER: ___________________________

I am going to ask you questions about your need for information, support, and assistance, such as getting to and from treatments or getting help at home. We are interested in the needs of people at all stages of the cancer experience, so when you answer please tell me about your needs AT THIS TIME. If you do not need anything at this time, please tell me.

Do you have any questions?
(IF YOU ARE NOT ABLE TO ANSWER, ASK THE RESPONDENT TO HOLD AND ASK SHANNON)

If you would like me to repeat what I have just explained at any time, please ask and I will gladly do so.

I will start by asking you what types of information you need to help you with your cancer experience. **At this time, do you need information about**

1.) services, programs or supports for cancer patients?
Yes.........**1** No, need satisfied.........**2**
No, not a need **3**

2.) your type of cancer?
Yes.........**1** No, need satisfied.........**2**
No, not a need **3**

3.) managing your cancer?
Yes.........**1** No, need satisfied.........**2**
No, not a need **3**

4.) **At this time, do you need information about** treatment options?
Yes.........**1** No, need satisfied.........**2**
No, not a need **3**

5.) who to contact when you have a problem, concern or question?
Yes.........**1** No, need satisfied.........**2**
No, not a need **3**

6.) **At this time, do you need more information about** your medical test results?
Yes.........**1** No, need satisfied.........**2**
No, not a need **3**

7.) financial assistance from provincial or community programs?
Yes.........**1** No, need satisfied....**2**
No, not a need......**3**

8.) At this time in your cancer experience, do you have any other information needs that I have not asked you about?

____

____

9.) Can you tell me where you usually look for cancer-related information? (DO **NOT** READ. CHECK ALL THAT APPLY)

- ☐ Internet (please specify which sites): ______________________
- ☐ Friends or Family
- ☐ Doctor or Health Care Professional
- ☐ Library
- ☐ Canadian Cancer Society Staff or volunteer
- ☐ Cancer Information telephone service
- ☐ Are there other people or places you look? (please specify): __________
____
____

10.) I am going to list ways to receive information, can you tell me how you would prefer to receive the information that you need?
(NAME EACH. CHECK ALL THAT APPLY)

- ☐ Pamphlets or written material
- ☐ On television
- ☐ Over the phone
- ☐ In one-on-one consults
- ☐ At public meetings or forums
- ☐ At education sessions or workshops
- ☐ On the internet
- ☐ Are there other ways? (please specify): ___________ ______________________________ ______________________________

Next I would like to ask you some questions about practical and financial assistance.
At this time, do you need assistance

11.) at home, for example with cooking, childcare, cleaning, or shopping?

Yes.........1	No, need satisfied....2
	No, not a need......3

12.) with personal care such as bathing, eating, or dressing, for example?

Yes.........1	No, need satisfied....2
	No, not a need......3

13.) managing side effects like pain, nausea, and fatigue, for example?

Yes.........1	No, need satisfied....2
	No, not a need......3

14.) **At this time, do you need assistance** in covering costs for medications and drugs associated with having cancer?

Yes.........1	No, need satisfied....2
	No, not a need......3

15.) to cover costs of special foods or health supplies?

Yes.........1	No, need satisfied....2
	No, not a need......3

16.) with any work related issues, such as getting time off?

Yes.........1	No, need satisfied....2
	No, not a need......3

17.) getting to and from cancer appointments?

Yes.........1	No, need satisfied....2
	No, not a need......3

18.) At this time in your cancer experience, do you have any other practical or financial needs that I have not asked you about?

____

____

____

Now I would like to ask you about emotions and feelings that can develop when you have cancer. **Do you currently need help in**

19.) dealing with feelings such as fear, anxiety, depression, or loneliness?
Yes .... 1 No, need satisfied........ 2
No, not a need 3

20.) getting support to help you feel more in control of your situation?
Yes .... 1 No, need satisfied 2
No, not a need 3

21.) accepting the presence and the uncertainty of cancer?
Yes .... 1 No, need satisfied 2
No, not a need 3

22.) working through feelings about death and dying?
Yes .... 1 No need satisfied 2
No, not a need 3

23.) **Do you currently need help in** trying to maintain a positive outlook?
Yes .... 1 No need satisfied 2
No, not a need 3

24.) supporting the concerns of those close to you?
Yes .... 1 No need satisfied 2
No, not a need 3

25.) coping with awkwardness in talking to others about cancer?
Yes .... 1 No need satisfied 2
No, not a need 3

26.) concerns about changes in sexual relationships or intimacy?
Yes .... 1 No need satisfied 2
No, not a need 3

27.) At this point in your cancer experience, do you have any other emotional, spiritual, or social needs that I have not asked you about?

____

____

____

28.) I'm going to name ways to receive support during your cancer experience. Please let me know what types of support would interest you the most. (**NAME EACH.** CHECK ALL THAT APPLY)

- ☐ Individual visits with a cancer survivor
- ☐ Contact by phone with a cancer survivor
- ☐ Talking to a counselor who works with cancer patients like a psychologist, social worker or nurse
- ☐ Having online chats with cancer survivors
- ☐ Group supports with other survivors
- ☐ Having access to a central staff person to guide you through your cancer experience
- ☐ Are there any other ways? (please specify):

____

____

Now I would like to learn more about your needs for health services such as having enough time with your doctor. We are interested in knowing how often your health services needs have been met. For each question, please indicate whether the need has been met **all of the time, most of the time, some of the time, not at all** or is **not applicable** to your current situation. **At this time in your cancer experience, are you able to**

29.) get appointment times that suit your schedule?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

30.) access cancer services close to your home?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

31.) get medical appointments in a timely manner?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

32.) access information about your test results in a timely manner?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

33.) **At this time in your cancer experience, are you able to** have enough time with your cancer doctors?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

34.) have one health professional guide you through your cancer experience?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

35.) receive medical support in your home when needed?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

36.) access new therapies or clinical trials?
- All of the time...........**1**
- Most of the time....**2**
- Some of the time........**3**
- Not at all.........**4**
- Not applicable........**5**

37.) have a friend or family member with you during your appointments and/or treatments?

All of the time..........**1**
Most of the time....**2**
Some of the time........**3**
Not at all.........**4**
Not applicable........**5**

38.) have all your health care providers know your medical information?

All of the time..........**1**
Most of the time....**2**
Some of the time........**3**
Not at all.........**4**
Not applicable........**5**

39.) At this time in your cancer experience, do you have any other health services needs that I have not asked you about?

40.) After considering ALL of your current needs, what is your greatest need?

41.) What ONE thing could the PEI Division of the Canadian Cancer Society be doing to meet the needs of cancer patients in PEI?

SECTION TWO: About Yourself

Now I would like to ask a few questions about you. This will help us understand who participated in the survey.

What year were you born? ____________.
(yyyy)

What is the highest level of education you completed?

- ☐ Elementary school
- ☐ High School
- ☐ Trade School
- ☐ College
- ☐ University

What region do you live in (IF NECESSARY, ASK: What community do you live in?):

- ☐ Queens
- ☐ East Prince
- ☐ West Prince
- ☐ Eastern Kings
- ☐ Southern Kings
- ☐ Community: ________________

How many people live in your household including yourself?_______ people

What is your current work situation?

- ☐ Full-time employment
- ☐ Part-time employment
- ☐ Household duties
- ☐ Student
- ☐ Retired
- ☐ Semi-retired
- ☐ Unemployed
- ☐ Looking for work
- ☐ Medical leave/disability
- ☐ Other (please specify): ___________________

Is this your first diagnosis or a recurrence?

- ☐ First diagnosis
- ☐ Reoccurrence

When were you diagnosed (with your recurrence, IF APPLICABLE)?

-- --   -- -- -- --
m m   y y y y

At this time, are you receiving active treatment such as radiation, chemotherapy or surgery?

- ☐ Not yet (diagnosis and treatment planning)
- ☐ Yes (radiation, chemotherapy, surgery, injections, or treatment drugs)
- ☐ No (after active treatment)
- ☐ Other (please specify): ______________________

What is your present marital status?

- ☐ Married
- ☐ Common-law/living together as a couple
- ☐ Separated or divorced
- ☐ Widowed
- ☐ Single, never married
- ☐ Other (please specify): ____________________

Do you have coverage under private health insurance?

- ☐ Yes
- ☐ No

Do you have coverage under a provincial health care plan such as the financial/social assistance program or the seniors drug cost assistance program?

- ☐ Yes
- ☐ No

What was your total household income before taxes for 2005? Was it (NAME EACH CATEGORY)

- ☐ Less than $15,000
- ☐ $16,000 to $30,000
- ☐ $31,000 to $50,000
- ☐ $51,000 and over
- ☐ Would rather not answer

Would you like information on anything we've talked about?
- ☐ No (SKIP TO END OF INTERVIEW SECTION)
- ☐ Yes

What would you like information on?
- ☐ Support Services
- ☐ Financial/Practical Assistance
- ☐ Information about cancer
- ☐ Other (please specify): ____________________

You can get the information you want from many sources, we have a toll free phone service, a website, a local office, and a Manager of Support Services who I could ask to contact you. Would you like to receive the information you want from any of these sources? (DO **NOT** READ. CHECK ALL THAT APPLY AND GIVE ALL INFORMATION NECESSARY)

☐ Toll Free Number
The number is 1 888 939-3333.

☐ Website
The website address is www.cancer.ca

☐ Local office phone call or drop in
Our phone number is (902) 566-4007 and we are located at 1 Rochford Street in Charlottetown.

☐ Contact from Lowleen (Manager of Support Services)
I will not tell her that you are a participant in the survey. I will only give her your name and number and tell her you are looking for information (FILL OUT PHONE MESSAGE SLIP).

☐ Other (please specify):

____

____

END OF INTERVIEW SECTION
This completes our interview. Do you have any comments you would like to add?

____

____

____

When the study is finished, would you like a copy of the results?
☐ Yes
We plan to post the results on our website at www.cancer.ca. However, if you prefer, you can contact us in June and we can send you the results or you can leave me your

mailing address and I will add it to a separate mailing list that is not attached to this survey?

GIVE OUR PHONE NUMBER: (902) 566-4007
OR
RECORD NAME AND ADDRESS ON THE SHEET PROVIDED.

- ☐ No

Thank-you for taking the time to answer these questions. Your time has been truly invaluable. We could not achieve our goals without your help.

------------------------------------END OF INTERVIEW ------------------------------------

APPROXIMATE PHONE CALL LENGTH:______MINUTES

PLEASE RECORD THE SEX OF THE RESPONDENT
- ☐ Male
- ☐ Female

INTERVIEWERS COMMENTS:
____
____
____
____
____
____
____

Appendix B: Manual for Interviewers

Canadian Cancer Society
Société canadienne du cancer
PRINCE EDWARD ISLAND DIVISION

ASSESSING THE NEEDS OF PEOPLE LIVING WITH CANCER IN PRINCE EDWARD ISLAND: MANUAL FOR INTERVIEWERS

This manual is intended to provide you with the information you need to conduct telephone surveys for the project entitled "Assessing the Needs of People Living with Cancer in Prince Edward Island". This manual is yours to keep, so please feel free to add your own notes, as you feel necessary. If you need clarification on any of the following information or have any questions, please do not hesitate to contact Shannon Classen by phone (902) 566-4007 or by email sclassen@pei.cancer.ca.

Table of Contents

Section I: Description of the Project: Assessing the Needs of Persons Living with Cancer in Prince Edward Island

The Canadian Cancer Society, PEI Division, operates in accordance with the goals set by the volunteer Board of Directors. One of the goals is that "People living with cancer have access to the support services they need to improve their quality of life". In order to work towards this goal, information on the current needs of people living with cancer is required. Therefore, the objectives of this study are threefold:

- To identify the needs of Islanders living with cancer;
- Establish the degree and the mechanism in which the needs of Islanders living with cancer could be met; and
- Prioritize the needs of Islanders living with cancer.

Once this information is obtained, recommendations will be made to the Canadian Cancer Society, PEI Division. The information and recommendations will be used to guide the work of the Canadian Cancer Society, PEI Division. For instance, new programs may be created and existing services may be refined. If the Canadian Cancer Society, PEI Division can not directly meet a need that is expressed, the Canadian Cancer Society, PEI Division will use its advocacy role to promote the recommendation.

Background

In 1989, the Canadian Cancer Society, PEI Division conducted a needs assessment of people living with cancer. Since that time, much has changed in cancer care. The most notable change is the addition of the Cancer Treatment Centre at the Queen Elizabeth Hospital (QEH). It is presumed that along with such changes, the needs of people living with cancer in PEI have also changed. Thus, it is in due course that the Canadian Cancer Society, PEI Division examines what its clientele currently need. Furthermore, other Divisions across Canada such as Alberta, Ontario, and Saskatchewan have conducted recent needs assessments. In order to keep up with standards of care across the nation, PEI must obtain current information on patient needs.

Study Design

The survey is a cross sectional design. Participants will be asked to provide descriptive data at one fixed point in time. More specifically, participants will be asked to respond to the survey questions according to their current level of need. The survey has been designed to produce information to describe the needs of people living with cancer and to understand how those needs change through the cancer experience.

The method used to gain this information will be telephone surveying. The telephone surveys will use a combination of open and close-ended questions (see the survey). Ethical approval to conduct this study has been granted from the Provincial Health Services Authority (PHSA) Research Ethics Board (REB).

In order to recruit respondents, we are working with the staff of the PEI Cancer Registry. Kim Vriends, Manager of the Cancer Registry, is sending information letters and consent forms to a random sample of cancer patients. Patients are asked to return the signed consent form back to the staff of the PEI Cancer Registry if they are interested in participating. Pre-addressed and postage-paid envelopes have been provided. The contact information for the participants who consent to participate will then be given to the Principal Investigator, Shannon Classen, Coordinator of Research and Evaluation, Canadian Cancer Society, PEI Division. Participants will be contacted in two waves. The first wave will include surveying 100 to 150 participants. The second wave will include surveying another 100 to 150 participants. The exact number of participants is dependent on the response rate and the availability and commitment of interviewers.

In early January, 2006 letters will be sent out to the first wave of potential participants from the staff of the PEI Cancer Registry. During this time, the interviewers will be trained. It is expected that the first wave of telephone surveys will take place from February 6, 2006 to February 11, 2006. Between 100 and 150 surveys will be conducted during this time frame. Participants will be contacted by the interviewers from Monday to Thursday between 6pm and 9pm and on Saturday between 10am and 6pm.

In late February, 2006, the second wave of letters will be sent out to another random sample of 100 to 150 patients. It is expected that the second wave of telephone surveys will take place from March 20, 2006 to March 25, 2006. Between 100 and 150 surveys will be conducted during this time frame. Participants will be contacted by the interviewers from Monday to Thursday between 6pm and 9pm and on Saturday between 10am and 6pm.

The Principal Investigator is Shannon Classen, Coordinator of Research and Evaluation, Canadian Cancer Society, PEI Division. The Principle Investigator is responsible for the study design, data analysis, and report writing. Trained Canadian Cancer Society, PEI Division, volunteers and staff will be responsible for conducting the telephone surveys.

An Advisory Committee has also been formed in order to provide input, guidance, and expertise to the project. The Committee will provide guidance through each stage of the study. The Advisory Committee members include:

Dr. Philip Smith, Professor, University of Prince Edward Island

Patsy Beattie-Huggan, President, The Quaich Inc. and Cancer Survivor

Dr. Sharon Campbell, Director Evaluation Studies, Centre for Behavioural Research and Program Evaluation (CBRPE)

Thelma Fraser, Programs Committee Chair and Member of Board of Directors, Canadian Cancer Society, PEI Division and Cancer Caregiver

Dawn Binns, Executive Director, Canadian Cancer Society, PEI Division

Holly Smith, Director of Programs, Canadian Cancer Society, PEI Division

Lowleen Coles, Manager of Support Services, Canadian Cancer Society, PEI Division

Respondents

Participants have been randomly selected from the PEI Cancer Registry in order to generate a sample of 200 to 300 respondents. The sample size is dependent on the response rate and the availability and commitment of interviewers. This sample will include a random selection of people who have been diagnosed with cancer within the past two years, but not within the past three months, and are 18 years of age or older. Patients who may not be aware that they have cancer will not be included in the sample. Dr. Dryer, Registrar of the PEI Cancer Registry and Kim Vriends, Manager of the PEI Cancer Registry, are working on a list of cancers in which this could be the case.

Respondent safety, confidentiality and alert system

Patient confidentiality will be fully maintained. The contact information and the responses of participants will be secured in a locked cabinet at the Canadian Cancer Society, PEI Division office. No information will be released or printed that would identify any person who participates. Furthermore, all of the interviewers conducting the telephone surveys will be asked to sign a Declaration of Confidentiality form. After the telephone interviews are complete, the contact information for participants will be destroyed. There will be no way to link the completed interviews with contact information.

Funding

This project is funded by the Canadian Cancer Society, PEI Division and the Center for Behavioral Research and Program Evaluation (CBRPE). CBRPE is located at the University of Waterloo and is funded by the National Cancer Institute of Canada (NCIC). NCIC is the research partner of the Canadian Cancer Society. This research project has received Full Provincial Health Services Authority Research Ethics Board approval.

Section II: Programs and Services of the Canadian Cancer Society, PEI Division

Currently, the Canadian Cancer Society, PEI Division offers several services and programs to support people living with cancer. The Canadian Cancer Society, PEI Division provides support programs such as Reach to Recovery and CancerConnection. The Canadian Cancer Society, PEI Division also provides funding for Camp GoodTime, offers practical and financial support and supplies reliable cancer information through print materials, by telephone, and on the Internet.

Reach to Recovery

This program is a one-on-one support program for women with breast cancer. Women who have had breast cancer visit women who are currently recovering from breast cancer surgery. Visits are generally made in the hospital, but can be done in the home setting. Women are matched as closely as possible by age, surgery type, and if possible, by treatment, if known at the time. All women receive an attractive kit that includes information about breast cancer surgery, an exercise guide, ball and rope, a soft pink pillow, and information on available cancer resources. This program was initiated in 1977 by Louise Samson and has been operational in PEI for approximately 30 years. In 2003/2004, the program had 25 breast cancer survivor volunteers and two coordinators.

CancerConnection

The Canadian Cancer Society's CancerConnection is an innovative support program where peers provide support to people diagnosed with cancer. This telephone peer support program is free, accessible, confidential, and responsive. Created in Ontario in 1995, CancerConnection is growing into a nationwide program. Committed volunteers provide the hope that only comes from speaking with "someone who's been there". All of our CancerConnection volunteers have experienced cancer themselves, either as a survivor or as a caregiver, and can truly "understand". In this way, they are able to provide the hope, support, and the understanding necessary to help someone.

Cancer Information Service

The Canadian Cancer Society's *Cancer Information Service* is a national, bilingual, toll-free service available to cancer patients, their families, the general public, and healthcare professionals. Trained information specialists take the time to answer your questions in clear understandable terms and search for the information you need about:

- ☐ all types of cancer
- ☐ prevention
- ☐ cancer treatment and side effects
- ☐ clinical trials
- ☐ coping with cancer
- ☐ emotional support services
- ☐ help in the community
- ☐ complementary and alternative therapies

The service is available Monday to Friday 9 a.m. to 6 p.m in English and French. For other languages, interpreter services are accessible. All inquiries are confidential.

Emergency Assistance

The Canadian Cancer Society's Emergency Assistance Program is a service intended to help cancer patients who do not have adequate financial resources with certain costs specifically associated with a cancer diagnosis. This service provides transportation on and off the Island, drugs, ostomy supplies, dressings and prosthesis to cancer patients. To ensure that great care is taken in spending the money donated by Islanders:

- ☐ assistance will not duplicate government programs;
- ☐ financial need must be properly assessed, including proof of income;
- ☐ assistance will be applied to expenses directly due to the cancer diagnosis;
- ☐ the policy is subject to change to ensure it remains affordable and continues to meet the real needs of Islanders.

Camp GoodTime

Camp GoodTime is a one-week summer camp in Nova Scotia where island children aged 7–15, living with cancer, can enjoy the freedom and fun of camp life. A brother, sister or friend may accompany the camper for a week of swimming, canoeing, arts and crafts, outdoor education, camp fires, special programs, meeting new friends, and growing - a week they will never forget.

Section III: Telephone Surveying

This section is intended to provide you with the information and instructions necessary to complete telephone surveys. Please review the sample survey in detail before reviewing this section.

Before the Interview

Before beginning interviews, please review this checklist to make sure that you are prepared:

- ☐ I have reviewed and understand all of the survey questions
- ☐ I have the call record information
- ☐ I have ensured that the ID # of the respondent is at the top of every page of the survey
- ☐ I have:
    - ○ A pen;
    - ○ My interviewer manual;
    - ○ A phone message pad; and
    - ○ My form to record the names and addresses of respondents who want the report mailed to them.

Beginning the Interview

As was mentioned, all respondents have consented to your call. Each of them have received an information letter and signed a consent form that permitted the PEI Cancer Registry to provide us with their contact information. Below is a sample of the information letter and consent form that all respondents received. In case a respondent refers to this letter, it may be helpful to know that the information letter was printed on Canadian Cancer Society letterhead and the consent form was printed on bright yellow paper.

Information Letter (printed on Canadian Cancer Society letterhead):

[DATE]

Dear [NAME] :

The Prince Edward Island Cancer Registry is assisting the Canadian Cancer Society, PEI Division, with a study on the needs of people living with cancer. The goal of the study is to learn more about the information, emotional, practical, and financial needs of people living with cancer. The Prince Edward Island Cancer Registry collects data on all cancers diagnosed on residents of Prince Edward Island and is enabled to do so by law under the Provincial Health Act. This information is normally only released to Statistics Canada and is strictly confidential; it will not be released to the Canadian Cancer Society, PEI Division without your consent.

Your name has been randomly chosen by the Registry to receive this invitation to voluntarily participate in the study. If you give your consent to participate in this study, the cancer registry will release your name and phone number to the Canadian Cancer Society, PEI Division and they will contact you in the next few weeks. If you do not want to participate, do not complete or return the attached consent form to the Cancer Registry and you will not be contacted.

The Canadian Cancer Society, PEI Division, with the help of staff and volunteers, will be contacting Islanders who have agreed to participate. These volunteers are fully trained and have experience with cancer themselves. They understand what people living with cancer experience. If you agree to participate, one of these volunteers or a staff member will be contacting you by phone within the next few weeks. You will be asked questions about your specific needs and the phone call will last approximately 20 minutes.

If you have any questions, comments or concerns please do not hesitate to contact me, Kim Vriends, PEI Cancer Registry, at (902) 894-2167. For specific questions about the study you can contact Shannon Classen at (902) 566-4007, Coordinator of Research and Evaluation, Canadian Cancer Society PEI Division.

Please sign the release on the enclosed form and return it in the stamped addressed envelope if you would like to have your name and phone number released to the Canadian Cancer Society, PEI Division for participation in this study.

Sincerely,

Kim Vriends
Manager
P.E.I. Cancer Registry

Consent Form (printed on a bright yellow sheet of paper):

IF YOU WISH TO PARTICIPATE IN THE STUDY, PLEASE FILL OUT THIS FORM AND MAIL IT IN THE ENVELOPPE PROVIDED

I, ____________________________ (print name), agree to have my name and phone number released to the Canadian Cancer Society, PEI Division for participation in the study "Assessing the Needs of Persons Living with Cancer in Prince Edward Island."

Signature ______________________________ Date ___________________

Phone # _________________

When beginning each interview, please stick to the introductory statement that is provided on the first page of the survey. It is very important that all respondents receive the same introduction to the project and the same instructions. In order to feel comfortable with delivering the introductory statement, you may wish to practice it several times.

During the Interview

It is very important to maintain a neutral attitude when conducting interviews. A neutral attitude is one that does not imply criticism, surprise, approval or disapproval of anything the respondent says, or of anything contained in the survey. The point is to refrain from any behaviors that could influence how the respondent answers the questions. The interviewer is intended to be a neutral medium through which questions and answers are transmitted. Here are some guidelines to help you maintain a neutral attitude:

- Avoid interjecting your own opinions;
- Avoid any unnecessary or overly enthusiastic reinforcement;
- Be an "active" listener but only give the minimum of reinforcement, such as "OK," "I see,"...[and] "uh-huh."
- Never suggest an answer.

It is necessary to ask all questions in the order they are presented and exactly as worded. The purpose of this is standardization; the less variation there is in the way interview questions are delivered from one interview to another and from one interviewer to another, the better the chances that answers will be comparable. Each respondent needs to hear the same question to ensure comparability of answers. Even a difference of one word could drastically change the meaning and thus the response.

Survey Instructions to Interviewers

For some questions in the survey, you will notice that there are instructions to you, the interviewer. All instructions are to be read and not said to the respondent. Please note that instructions are printed in ALL CAPS (see the sample survey).

Survey Probes

For some questions in the survey, you may need to probe for clarity and completeness of the response. Probing is used to obtain more information if a respondent's answer is unclear, irrelevant, or incomplete. Please remember to keep probes neutral. Probes are to be used at your own discretion, they are not provided on the survey. Here are some examples of acceptable interview probes.

Show Interest	An expression of interest and understanding, such as "uh-huh", "I see", and "yes", conveys the message that the response has been heard and more is expected.
Pause	Silence can tell a respondent that you are awaiting to hear more.
Repeat the Question	This can help a respondent who has not understood, misinterpreted, or strayed from the question to get back on track.
Repeat the Reply	This can stimulate the respondent to say more, or recognize an inaccuracy.
Ask a Neutral Question:	
For Clarification	"What do you mean exactly?" or "Could you please explain that?"
For Specificity	"Could you be more specific about that?" or "Tell me about that"
For Relevance	"I see. Well, let me ask you again" (REPEAT QUESTION AS WRITTEN) or "Would you tell me how you mean that?"
For Completeness	"What else?" or "Can you think of an example?"

Also remember that if you feel that it is necessary, you may repeat the preamble and response options at any time.

The **preamble** is dependent on the type of need you are asking about:

- ☐ At this time, do you need information about [read question] – *information needs*
- ☐ At this time, do you need assistance with [read question] - *practical/financial needs*
- ☐ At this time, do you need help in [read question] – *emotions/feelings*
- ☐ At this time, are you able to [read question] – *health services needs*

The **responses** are also dependent on the type of need you are asking about:

- ☐ The responses to *information, practical/financial, and emotions/feelings* needs are:
  - **Yes** (i.e. this is a need)
  - **No, need satisfied** (i.e. this was a need, but the need has been met)

  - **No, not a need** (i.e. this is not a need, it is not a problem)
- **Please note that it is very important to fully understand the difference between the responses: 'need satisfied' and 'not a need'. If you are unclear, please ask.**
- The responses for *health services needs* are:
  - All of the time, most of the time, some of the time, not at all, and not applicable.

Recording Responses

When recording responses, please write clearly, neatly, and legibly. Here are some other guidelines to make recording responses easier:

- Write "NA" (no answer) when the respondent does not want to answer a question.
- If you used a probe, please write "probed" by the question.
- To record respondents' answers, circle the number associated with the response given.
- Answers to open-ended question should be written verbatim, if possible. Please try your best, it is recognized that this will be difficult.

Ending the Interview

When ending the interview it is also important to stick to the script provided. However, please feel free to answer any questions that the respondents may have and discuss any concerns that may come up regarding the content of the survey. If you need assistance, please do not hesitate to contact Shannon Classen.

Other Procedures

- If you need assistance at any time, please do not hesitate to ask Shannon Classen.
- Please alert Dawn Binns, Executive Director, Canadian Cancer Society, PEI Division if you should expect that respondent safety is a concern.
- Do NOT put a respondents name or phone number on the completed survey. This information is recorded on the call sheet and will be separated from the completed survey by Shannon Classen. Only the ID # of the respondent should be placed on the survey.

- ☐ Calls may only be made from the Canadian Cancer Society, PEI Division office.
- ☐ Calls may only be made during the scheduled dates and times or as otherwise authorized by Shannon Classen.
- ☐ All completed interviews must be given to Shannon Classen at the end of each session so they may be kept secure in a locked cabinet.
- ☐ Please make calls to each telephone number until you either reach a respondent or determine that the respondent cannot be reached at this number (three attempts):
    - o If busy, call back at least 30 min later
    - o If no answer, call back during the next session
    - o If you get an answering machine please state your name and that you are calling in regards to the "assessing the needs of people living with cancer in PEI" project and will call back at a later time. Call back during the next session.
    - o If a respondent is unavailable, politely ask when you might call back. If someone agrees to an interview at a particular time, call back at that time.
    - o If you get a wrong number, verify that you dialed correctly.
- ☐ Please record every call you make, even if the number was not working, no answer was received, or the interview was not completed (there is a spaced provided on the call record sheet).
- ☐ Time your last call so that it will end by 9pm, unless a respondent has asked you to call back later.
- ☐ Please proofread every survey to find and correct errors, clarify handwriting, and add clarifying notes (if necessary).

Ethics and Confidentiality

All persons involved in the research project have an ethical responsibility to maintain the confidentiality of the respondents. This means not only following protocol regarding not putting names on surveys, but also not sharing a person's responses with anyone. A Declaration of Confidentiality Form has been prepared for all interviewers to sign. You will be asked to read and sign this form and give it to Shannon Classen before beginning to conduct interviews.

Forms and Administrative Procedures

Please make sure to keep track of your hours and your mileage (if necessary). A schedule and mileage sheet has been provided. If you are scheduled to do interviews and cannot make it, please let Shannon Classen know as soon as possible so that a replacement may be found.

Appendix C: Information Letter and Consent Form (printed on Canadian Cancer Society letterhead)

[DATE]

Dear [NAME] :

The Prince Edward Island Cancer Registry is assisting the Canadian Cancer Society, PEI Division, with a study on the needs of people living with cancer. The goal of the study is to learn more about the information, emotional, practical, and financial needs of people living with cancer. The Prince Edward Island Cancer Registry collects data on all cancers diagnosed on residents of Prince Edward Island and is enabled to do so by law under the Provincial Health Act. This information is normally only released to Statistics Canada and is strictly confidential; it will not be released to the Canadian Cancer Society, PEI Division without your consent.

Your name has been randomly chosen by the Registry to receive this invitation to voluntarily participate in the study. If you give your consent to participate in this study, the cancer registry will release your name and phone number to the Canadian Cancer Society, PEI Division and they will contact you in the next few weeks. If you do not want to participate, do not complete or return the attached consent form to the Cancer Registry and you will not be contacted.

The Canadian Cancer Society, PEI Division, with the help of staff and volunteers, will be contacting Islanders who have agreed to participate. These volunteers are fully trained and have experience with cancer themselves. They understand what people living with cancer experience. If you agree to participate, one of these volunteers or a staff member will be contacting you by phone within the next few weeks. You will be asked questions about your specific needs and the phone call will last approximately 20 minutes.

If you have any questions, comments or concerns please do not hesitate to contact me, Kim Vriends, PEI Cancer Registry, at (902) 894-2167. For specific questions about the study you can contact Shannon Classen at (902) 566-4007, Coordinator of Research and Evaluation, Canadian Cancer Society PEI Division.

Please sign the release on the enclosed form and return it in the stamped addressed envelope if you would like to have your name and phone number released to the Canadian Cancer Society, PEI Division for participation in this study.

Sincerely,

Kim Vriends
Manager
P.E.I. Cancer Registry

IF YOU WISH TO PARTICIPATE IN THE STUDY, PLEASE FILL OUT THIS FORM AND MAIL IT IN THE ENVELOPPE PROVIDED

I, ____________________________ (print name), agree to have my name and phone number released to the Canadian Cancer Society, PEI Division for participation in the study "Assessing the Needs of Persons Living with Cancer in Prince Edward Island."

Signature ____________________________ Date ____________________

Phone # ________________

Appendix D: Interviewer Declaration of Confidentiality

Canadian Cancer Society
Société canadienne du cancer
PRINCE EDWARD ISLAND DIVISION

Interviewer Declaration of Confidentiality Form

I, ____,
have been made aware of the confidential nature of information concerning patients. Whether or not such confidential information may be available to me through my telephone interview or inadvertently, the person's rights to privacy shall be respected. I will not reveal their identity to anyone outside the Patient Needs Assessment Project, including my family and friends.

I will exercise all reasonable care and caution in protecting printed or written confidential information from causal observation, unauthorized personnel, or other abuse.

I understand that if a problem arises, I will relay this to the Executive Director of the Canadian Cancer Society, PEI Division, Dawn Binns, either in person, by telephone, but not in writing.

Signature: ________________________________

Date: _____________________________

UNIVERSITY *of*
PRINCE EDWARD ISLAND

550 University Avenue
Charlottetown
Prince Edward Island
Canada C1A 4P3

July 4, 2006

To: Ms. Shannon Classen
School of Nursing

Dear Ms. Shannon Classen ,

Re: "**__**Assessing the needs of patients living with cancer: A holistic approach.**__**"

The above mentioned research proposal has now been reviewed under the expedited review track by the UPEI Research Ethics Board. I am pleased to inform you that the proposal has received ethics approval.

The approval for the study as presented is valid for one year. It may be extended following completion of the Annual Renewal and Amendment Form. Any proposed changes to the study must also be submitted on the same form to the UPEI Research Ethics Board for approval.

Sincerely,

[redacted]

Malcolm Murray, BA, MA, Ph.D.
Associate Professor of Philosophy
Chair, UPEI Research Ethics Board

cc: Dr. Katherine Schultz, Vice President, Research & Development, UPEI

Dr. Kimberley Critchley, School of Nursing

UNIVERSITY of
PRINCE EDWARD ISLAND

550 University Avenue
Charlottetown
Prince Edward Island
Canada C1A 4P3

University of Prince Edward Island
Research Ethics Board
Certificate Of Approval

Title of Proposal : **Assessing the needs of patients living with cancer: A holistic approach.**

Protocol Number : **1001271**

Name of Investigator: **Ms. Shannon Classen**

Date Submitted : **3 March 2006**

Effective Date : **4 July 2006**

End Date : **4 July 2008**

Signature : [redacted] Date : July 4/06
Chair, Research Ethics Board

cc: Dr. Katherine Schultz, Vice President, Research & Development, UPEI

Dr. Kimberley Critchley, School of Nursing