THE ROLE OF INFORMATIONAL SUPPORT IN RELATION TO HEALTH CARE SERVICE USE AMONG INDIVIDUALS NEWLY DIAGNOSED WITH CANCER

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Abstract

Background: The relationship between informational support and use of health care services among individuals newly diagnosed with cancer remains little documented despite its importance for optimal care delivery. **Aim:** To document the role of informational support in light of patterns of health services used by women and men newly diagnosed with cancer. **Method:** A sequential mixed methods approach (i.e., quantitative-qualitative) was conducted among women and men newly diagnosed with either breast or prostate cancer. First, an existing quantitative database was used to determine whether an intervention relying on multimedia tool as a complement to the provision of usual cancer informational support to patients (N = 250) would modify subsequent health care service use. A follow-up qualitative inquiry with distinct individuals also newly diagnosed (N = 20) was conducted to explore this relationship further. Next, the resulting quantitative and qualitative findings were merged and reanalyzed using a quantitative-hierarchical approach to enhance our understanding of the phenomenon. **Findings:** Several personal and contextual factors were found to qualify the relationship between cancer informational support and health service use. Although quantitative analyses showed no significant differences in terms of overall reliance on health care services among participants who received more intense cancer informational support as opposed to those who received care as usual, several sex differences were noted in terms of number of visits to health care professionals, time spent with nurses and satisfaction with cancer information received. Qualitative findings revealed that participants reported a variety of experiences pertaining to cancer information received (e.g., positive, unsupportive or mixed) as well as several processes at play (e.g., cancer information seen as enabling, confirming, or conflicting). These differences in informational support, in turn, influenced their subsequent service utilization (e.g., more phone calls made to health professionals, reduction in face-to-face visits, reluctance to use cancer-related services). The mixed data analysis clarified further the findings allowing a broader perspective to emerge. **Conclusion**: Findings underscore that the relationship between cancer information and use of services is not as straightforward as initially anticipated. These findings provide initial insights that may inform future research on the topic and assist health care providers in optimizing their cancer informational interventions to guide patients in their reliance on health care services.

Résumé

Introduction: La relation entre le soutien informationnel et l'utilisation des services de santé chez les individus nouvellement diagnostiqués d'un cancer demeure peu documentée malgré son importance dans la prestation de soins optimaux. **But de l'étude:** Documenter le rôle de l'information en lien avec les modes d'utilisation des services de santé par les femmes et les hommes nouvellement diagnostiqués d'un cancer. **Méthodologie:** Une approche séquentielle de méthode mixte de recherche (i.e., quantitative - qualitative) a été réalisée avec des femmes et des hommes nouvellement diagnostiqués d'un cancer du sein ou d'un cancer de prostate. Tout d'abord, une base existante de données quantitatives a été utilisée pour déterminer si une intervention utilisant des outils multimédias comme complément au soutien informationnel usuel dispensé aux patients (N= 250) pourrait modifier l'utilisation subséquente des services de santé. Par la suite, un suivi qualitatif auprès de participants distincts également nouvellement diagnostiqués d'un cancer (N = 20) a été réalisé pour explorer davantage cette relation. Finalement, les résultats quantitatifs et qualitatifs ont été fusionnés et analysés de nouveau en utilisant une stratégie hiérarchique quantitative pour accroître notre compréhension du phénomène. **Résultats:** Plusieurs facteurs contextuels et personnels ont été identifiés pour qualifier la relation entre le soutien informationnel sur le cancer et l'utilisation des services de santé. Même si les analyses des données quantitatives n'ont démontré aucune différence significative dans l'utilisation des services de santé pour les individus ayant reçu un soutien informationnel plus intense contrairement à ceux qui ont expérimenté une approche traditionnelle, plusieurs différences en regard du sexe ont été identifiées en termes de nombre de visites aux professionnels de la santé, le temps passé avec les infirmières et la satisfaction pour l'information reçue. Les résultats qualitatifs ont révélé des expériences variées rapportées par les participants concernant l'information reçue sur le cancer (par exemple, positive, inadéquate ou mixte) ainsi que plusieurs mécanismes sous-jacents à l'utilisation des services (par exemple, l'information sur le cancer perçue comme un mécanisme facilitant, confirmatif, ou apportant de la confusion). Ces différences, en termes de soutien informationnel, ont influencé à leur tour l'utilisation des services (par exemple, plus d'appels téléphoniques effectués aux professionnels de la santé, réduction des visites face-à-face, réticence à utiliser les services). L'analyse mixte a expliqué les résultats plus en profondeur permettant l'émergence d'une perspective plus large.

Conclusion: Les résultats soulignent que la relation entre le soutien informationnel et l'utilisation des services n'est pas aussi simple comme initialement anticipée. Ces résultats fournissent de nouvelles perspectives pouvant informer les travaux futurs de recherche sur le sujet et assister les professionnels dans l'optimisation des interventions informationnelles pour guider les patients dans l'utilisation des services de santé.

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CHAPTER 1

INTRODUCTION

The relationships between patient informational support and the use of health care services among newly diagnosed patients with cancer remain poorly understood despite their crucial roles in optimal psychosocial adjustment to cancer. It has been estimated that one third of people diagnosed with cancer will experience long-term psychological difficulties, and their needs for supportive care will be unmet (Boberg et al., 2003; National Audit Office [NAO], 2005; Vivar & McQueen, 2005; Zabora, Loscalzo et al., 1998). Cancer informational needs of patients with or at risk for cancer are predicted to increase in complexity, and the demand for cancer-related services is estimated to intensify at a yearly rate of 7 to 10% (Cancer Care Ontario [CCO], 2002), particularly with respect to ambulatory oncology services (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007). It is well known that psychosocial needs of oncology patients are complex and change over time (Echlin & Rees, 2002; Gray, Fitch, Davis, & Phillips, 1997a; Heyman & Rosner, 1996; Rees & Bath, 2000). This need for support throughout the cancer illness trajectory is well documented (Rosenbaum & Rosenbaum, 2005). Psychosocial and educational support is increasingly recognized and used as an important component of comprehensive oncology care (Fitch, 2000; National Cancer Institute of Canada [NCIC], 2005; Visser & van Andel, 2003). Interestingly, this support is not only helpful but also cost-effective (Carlson & Bultz, 2004).

The World Health Organization (WHO; 2003) reported that by 2020, the number of individuals newly diagnosed with cancer and needing cancer-related information will have increased radically (by 50%). Therefore, evaluation of new approaches is urgently required (Gysels & Higginson, 2007). The need for timely informational support for cancer care to assist individuals with such cancer-related distress is an identified priority areas for the Government of Canada (Canadian Institutes of Health Research [CIHR], 2006).

Primary sources of cancer information for patients are health care professionals; they are in a key position to offer useful information and tips. With hands-on information (e.g., pamphlets), which contributes to optimal adjustment to cancer, health professionals can help patients, for example, to restore control and increase their quality of life (Helgeson & Cohen, 1996; Helgeson, Cohen, Schulz, & Yasko, 1999; 2001; Lambert & Loiselle, 2007). In addition, patients who are better informed tend to report more satisfaction with their medical care and their interactions with health care providers (Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2005; Chelf et al., 2001).

Since the 1950s, research has been concerned with issues related to access to and utilization of health care services (Wolinsky, 1976). Studies have focused mostly on factors that best predict the use of health care services such as treatment modalities, comorbidity, physical function, pain, and an array of sociodemographic variables (e.g., age, income, education), often with one main goal of reducing costs (Andersen, 1995; Muller, 1986). To date, for oncology patients, several studies have been conducted on the role of information in improving patients' knowledge and health outcomes, and in reducing cancer mortality (Broeders et al., 2002; Gornick, Eggers, & Riley, 2004). However, few studies have examined the relationships between informational support and use of health care services in oncology (Gray, Goel et al., 2000; Steginga et al., 2008). To date, oncology patients are more likely to use community health services and to visit emergency facilities when their needs are not fulfilled (Carlson & Bultz, 2004).

Clarifying the role of informational support related to the use of health care services is important for several reasons: (1) Patients with cancer demand more information than they receive; they show an increased desire to understand and participate in their own care (Chelf et al., 2001; Farrell, Towle & Godolphin, 2006; Loiselle & Dubois, 2003; NCIC, 2005; Rosenbaum & Rosenbaum, 2005); (2) The information age exposes patients to all kinds of information of varying quality (Berland et al., 2001; Loiselle & Dubois, 2003; Rozmovits & Ziebland, 2004); and (3) We are not in a strong position to assess how trends in access to cancer information affect health care costs such as use of services by patients (Andersen & Newman, 1973; Blaum, Liang & Liu, 1994; de Boer, Wijker & de Haes, 1997; Wolinsky, Culler, Callahan, & Johnson, 1994). Past research has raised questions such as: Does the variability in health care service use by patients best explain their use of services or cancer-related information? If the latter, what is the specific role of information in regulating use of health care services? Do better informed oncology patients use health care services differently? The present dissertation provides insights into these questions with a sequential mixed methods design.

Study Purpose and Questions

The main purpose of the present dissertation was to examine the role of informational support in relation to health care service use among individuals newly diagnosed with cancer. The specific goals were to:

(1) Use an existing quantitative database to determine further how differential provision of cancer information may have an impact on health care service used by this group; and

(2) Document, using an in-depth exploration, how patients' experience with cancer information may alter (or not) subsequent use of health care services.

(3) Combine quantitative and qualitative results to further understand quantitative data by refining them with qualitative data collected.

Research questions were answered in three steps using a mixed methods design (Figure 1). The first inquiry performed a secondary quantitative analysis by using data collected in the CIHR-funded study of my supervisor and her colleagues (Loiselle, Edgar, & Batist, 2002-2005) to answer the following research questions:

(1) Does reliance on health care services vary between a group that is exposed to cancer information through a multimedia intervention and a separate group that receive usual care? Are there potential sex differences in the findings?

(2) Are participants more satisfied with informational support provided by the intervention as opposed to support received in the usual care condition?

(3) Do the aforementioned factors vary across time (e.g., between T1 [i.e., 1 to 6 weeks postdiagnosis] and T3 [i.e., 3 months postintervention])?

The second qualitative inquiry sought to answer the following questions:

(1) What is it like, for individuals newly diagnosed with cancer, to be provided with or to have to seek cancer-related information?

(2) What is it like to negotiate health care services just after learning that one has cancer?

(3) To what extent is cancer-related informational support (both formal and informal) helpful or unhelpful in guiding reliance on cancer-related services?

Organization of Dissertation

This doctoral dissertation is divided into five parts and includes three manuscripts. The first chapter introduces the topic, the purpose of the dissertation, the research questions for the quantitative and qualitative studies, the contribution of the coauthor to the manuscripts and the statement of originality of this work. The second chapter summarizes the literature review in five sections mainly about breast cancer and prostate cancer, conceptual framework used to guide this study, the concept of informational support (i.e., background, preferences, informational source, and potential barriers), the findings pertaining to health care service use, and last relationships between informational support and health care service use. The third chapter presents the methods used for this dissertation work, and the fourth chapter presents findings in three manuscripts entitled: (1) "The Impact of a Multimedia Cancer Informational Intervention as Opposed to Usual Care on Health Care Service Use Among Individuals Newly Diagnosed with Breast or Prostate Cancer," (2) "Understanding the Role of Informational Support in Relation to Health Care Service Use Among Newly Diagnosed Individuals" for qualitative findings, and (3) "Cancer Informational Support and Health Care Service Use Among Individuals Newly Diagnosed: A Mixed Methods Approach." The last chapter provides an overall discussion of findings; strengths and limitations of the research design are also examined. References, tables, and figures are presented at the end of the dissertation for all chapters, including the manuscripts.

Contribution of Authors

The manuscripts included in this thesis are the original work of the candidate and her supervisor Dr. Carmen Loiselle who was actively involved through the complete process of the dissertation providing her own feedback and improvements. All authors have made substantial contributions to the intellectual content of the papers. See Appendix A for a copy of the agreement of co-authorship.

Manuscript One: Secondary Quantitative analysis

The candidate and Dr. Carmen Loiselle decided on the specific method for the conduct of the secondary analysis. Dr. Carmen G. Loiselle supplied, as principle investigator of the large CIHR study (Loiselle, Edgar, & Batist, 2002-2005), the complete original data related to the variables needed for the secondary analysis. The candidate worked as a research trainee and part-time coordinator for the large study; she also participated in the development of the interviewer training guide, the study Web site content, code books, and study questionnaires. She worked on the data entry process and data cleaning. The candidate was responsible for secondary data analysis. Drs. Carmen Loiselle, Brenda MacGibbon, Hassan Younes, Marie-Claude Gauvin, and Zhenfeng Ma, doctoral student, provided critical guidance during data analysis and interpretation. The candidate was responsible for providing an initial draft of the manuscript. The candidate and Dr. Carmen Loiselle then made several revisions to the manuscript.

Manuscript Two: Qualitative Study

The candidate and Dr. Carmen Loiselle conceptualized and designed the follow-up study. The candidate collected and analyzed the data. Drs. Carmen Loiselle and

Mélanie Lavoie-Tremblay provided critical guidance during data analysis and interpretation. The candidate was responsible for providing an initial draft of the manuscript. The candidate and Dr. Carmen Loiselle made significant revisions to the manuscript.

Manuscript Three: Mixed method and mixed design analysis

The candidate and Dr. Carmen Loiselle conceptualized and designed the mixed methods study. The candidate was responsible for the mixed design analysis and presenting a first draft of the manuscript to Dr. Carmen Loiselle. The candidate and Dr. Carmen Loiselle then made several revisions to the manuscript. The candidate and Drs. Carmen Loiselle and Pierre Pluye then made critical revisions to the manuscript.

Statement of Original Contribution to Knowledge

The main contribution of this doctoral research is to document quantitatively and qualitatively the role of informational support in relation to health care service use among individuals newly diagnosed with cancer. The first manuscript provides statistical data on relationships among informational support and a new cancer diagnosis relative to health care service use with regard to sources of support and patterns of service use among women diagnosed with breast cancer and men diagnosed with prostate cancer. To our knowledge, this is the first study on this topic among women and men with either breast cancer or prostate cancer. The manuscript contributes to the development of knowledge on health care services by providing a broad understanding of the research problem and documenting the systematic assessment of informational support in their subsequent use of health care services, taking into account potential sex differences in such health-related outcomes. Findings were then further explored in the qualitative study and guided the next step of the mixed methods design.

The second manuscript explores in greater depth the participants' experiences with cancer information and health care services using a descriptive study. The manuscript contributes to the development of nursing knowledge on health care services by highlighting three main experiences with informational support and several underlying processes found to guide service use among individuals newly diagnosed with cancer. To our knowledge, these processes have not been reported elsewhere. This study provides guidance for health care professionals in the development of tailored strategies to support individuals depending on the level of support needed and available.

By using a mixed method analysis, the third manuscript reports on the integration of quantitative and qualitative findings to increase understanding of the role of cancer informational support and use of health care services. The manuscript contributes to the development of knowledge in oncology care by using a comprehensive approach to confirm some findings and to elaborate on others. To our knowledge, it is the first published inquiry to rely on a mixed methods approach to examine the role of informational support in relation to the reliance on health care services among individuals newly diagnosed with cancer.

CHAPTER 2

REVIEW OF THE LITERATURE

The review of the literature is divided into five main sections. The first section reviews statistical trends in terms of prevalence of cancer for women with breast cancer and men with prostate cancer. The second section outlines a framework, Andersen and Newman's Behavior Model of Health Service Use (Andersen, 1995; Andersen & Newman, 1973) used as guide in this study. The third section presents the state of knowledge of patients' informational support. The fourth section reviews the state of knowledge relevant to health care service used by patients newly diagnosed with cancer. The fifth section deals with the literature pertaining to informational support in relation to health care service use including the exploration of a sex difference with regard to informational support and the use of health care services.

Breast Cancer and Prostate Cancer Prevalence Rates

Statistics on women with breast cancer and men with prostate cancer confirm that these two diseases remain a serious public health concern (Jemal et al., 2008; NCIC, 2008) and the most frequently diagnosed cancers in both Canada and the United States (American Cancer Society [ACS], 2008). In Canada, incidence rates for lung, colorectal, breast, and prostate cancer are among the highest in the world (Globocan, 2002; NCIC, 2005). Of Canadian women, 1 in 9 is expected to be diagnosed during her lifetime with breast cancer and 1 in 27 women is expected to die from it (NCIC, 2008); an estimated 22,400 Canadian women and approximatively 6000 in Quebec will be diagnosed with breast cancer. Particularly in Quebec, the number of cases of breast cancer has doubled in the past 20 years and remains the second leading cause of death for women (Ministère de la santé et des services sociaux [MSSS], 2005). In the United States, 182,460 women will be diagnosed with this disease and 40,480 will die of it (ACS, 2008; Jemal et al., 2008); in Canada, 5,300 will die of it (NCIC, 2008). Although incidence is increasing, some have noted that mortality is decreasing (NCIC, 2005; Rutgers, 2004) with the result that breast cancer represents one of the most significant challenges in terms of survivorship (Helgeson, Snyder, & Seltman, 2004; Tomich & Helgeson, 2002) because women are diagnosed earlier and survive longer (Glanz & Lerman, 1992).

In Canada, 1 in 7 men men is expected to be diagnosed during his lifetime with prostate cancer, mostly after age 60, and 1 in 27 men is expected to die from it (NCIC, 2008); an estimated 24,700 Canadian men and approximatively 4,400 in Quebec will be diagnosed with prostate cancer. In the United States, more than 186,320 will be diagnosed with this disease and 28,660 will die of it (ACS, 2008; Jemal et al., 2008); in Canada, 4,300 will die of it (NCIC, 2008). In 2008, prostate cancer will continue to be the leading form of cancer diagnosed in men (Jemal et al., 2008). Nevertheless, despite the fact that prostate cancer has become one of the most diagnosed cancers in North America after skin cancer (Davison & Goldenberg, 2003; Gray, Goel, Fitch, Franssen, & Labrecque, 2002), prostate cancer deaths are dropping (Jemal et al., 2008; NCIC, 2008). Diagnosed early, it is highly treatable and survival rates are high (ACS, 2007; Jemal et al., 2005).

Thus, to date, women with breast cancer and men with prostate cancer are diagnosed earlier and survive longer, and these remain the most frequently and most commonly diagnosed cancers in both Canada and the United States (ACS, 2008; Ashbury, Findlay, Reynolds, & McKerracher, 1998; NCIC, 2008). Statistics on new cases and survivorship justify the continuation of research that may address important psychosocial issues with this population. Prevalence rates are a useful indicator of the burden posed by cancer both at the personal and social levels and in terms of health care system costs. Whereas breast cancer has the largest survivor population (more than two million) and has been the most extensively studied group from the standpoint of psychosocial effects (American Institute of Medicine [IOM], 2004), prostate cancer has received relatively less attention (Bennett & Badger, 2005; Echlin & Rees, 2002; Visser & van Andel, 2000, 2003). Research that addresses new questions and explores potential sex differences in behaviors relative to psychosocial issues pertaining to common forms of cancer is much needed.

Conceptual Framework

The conceptual model used to guide this dissertation work was Andersen and Newman's Behavioral Model of Health Service Use (Andersen, 1995; Andersen & Newman, 1973). Developed more than 30 years ago with the aim of delineating factors or conditions that facilitate or impede the use of health services, this model allows us to identify potential relationships among the studied variables with the goal of understanding how and why people use health care services (Davidson, Andersen, Wyn, & Brown, 2004). Not yet applied directly in health care oncology service use, this model offers a useful approach by which to enhance our understanding of the contribution of factors related to health care service used. One of the most frequently used models for analyzing patient utilization of health care services (Phillips, Morrison, Andersen, & Aday, 1998), the Behavioral Model of Health Service Use, has been extensively studied in the United States (Andersen, Bozzette et al, 2000; Heslin et al., 2001; Kadushin, 2004; Shah, Rathouz, & Chin, 2001; Thind & Andersen, 2003) and internationally including Canada (Fernandez-Mayoralas, Rodriguez, & Rojo, 2000; Lima & Kopec, 2005; Vasiliadis, Lesage, Adair, Wang, & Kessler, 2007). This model has been used in various areas such as preventive screening services (Phillips, Haas et al., 2004; Tye, Phillips, Liang, & Haas, 2004), dental care (Heslin et al., 2001), emergency care (Shah et al., 2001), home care (Kadushin, 2004), long-term care (Bradley et al., 2002), and alternative therapies (Kelner & Wellman, 1997); for several populations such as the elderly (Shah et al., 2001), and children (Thind et al., 2003); and with several chronic health problems such as human immunodeficiency virus (HIV; Heslin et al., 2001), addiction (Saitz, Lharson, Horton, Winter, & Samet, 2004), and mental disorders (Badger, McNiece, & Gagan, 2000; Goodwin & Andersen, 2002; Vasiliadis et al., 2007), or to evaluate post-traumatic stress disorder symptoms in cancer survivors (Andrykowski & Cordova, 1998). In a systematic review of health care utilization, Phillips et al. (1998) found that about half of the studies reviewed (N = 139) used one component of the Andersen model and 14% used the complete model. Andersen (1995) indicated that selective use of the model's variables is adequate because its purpose is to document how certain factors facilitate or impede health care service use.

For instance, whereas variations in health care utilization have been documented as a function of (1) the predisposition to use services (predisposing factors as sex and age); (2) the ability to obtain services (enabling resources as support from professionals and family members); and (3) medical needs (Andersen, 1995; Andersen & Newman, 1973), to date, informational support as an enabling resource has not been systematically examined. Broadly, the model suggests that health care service use is determined by societal factors (e.g., demographics, family and individual, technology, and political changes), health care service system factors (e.g., resources available, organization of services), and individual factors (e.g., predisposing characteristics, enabling resources, and needs; Figure 2) and posits that utilization of health services depends upon: individual predisposition to use such services, the ability or means to use these services, and the need for health care. In this study only individual factors (i.e., sex, informational support) as shown in Figure 3 are used to guide the exploration of the outcome (i.e., health care service use).

The first component, individual characteristics, includes three factors: predisposing characteristics, enabling resources, and needs. Use of health services was found to depend on these three factors, which are well-established predictors of health care use (Davidson et al., 2004). The model suggests that people use health care services as functions of their tendency to use or not to use any services, even though these predisposing characteristics are not directly responsible for use; enabling or impeding conditions that facilitate or delay the use of services; and needs of services that are recognized by people or health care professionals. More than three decades of research on these factors gives empirical support to these factors that have been found to be generalizable across settings and various populations (Davidson et al., 2004).

Predisposing characteristics refer to the characteristics of a person and include sociodemographic variables such as age, sex, race, ethnicity, income, and marital status.

The literature shows, for instance, a lesser use of health services among people with lower education, the unemployed, and ethnic minority groups (Bradley et al., 2002; Forrest & Whelan, 2000; Hulka & Wheat, 1985; Mechanic, 1979; Vasiliadis et al., 2007). Characteristics of the family were also suggested to be important determinants for care demand (Sindelar, 1982).

Enabling resources are the resources, such as social support and regular sources of care, that are available to individuals. Empirical findings show that enabling resources associated with less use of care services are related mainly to patients having no regular source of support for health care (Andersen & Newman, 1973; Kouzis & Eaton, 1998; Manning et al., 1987; Vasiliadis et al., 2007). In the present study, enabling resources refers specifically to informational support from health care professionals (e.g., oncologist, nurse) and family, friends, as well as access to technology such as the Internet and the Web.

Needs refers to individuals' perceived limitations related to illness as estimated by the individuals themselves and their family and friends. The need factor has been found to be the most significant in explaining utilization variance (Andersen & Newman, 1973; Blaum et al., 1994; de Boer et al., 1997; Kubrin, 1995; Hulka & Wheat, 1985; Jewett, Hibbard, & Weeks, 1992; Mechanic, 1976; Vasiliadis et al., 2007; Wolinsky et al., 1994). As noted by Andersen (1995) in a review of his model, this could be explained, in part, by recall bias due to self-reported utilization; limitations of survey data on the type of services sought and/or received; and insufficient attention given to the purpose of the visit, site of delivery, and to provider-related variables.

The main outcome of the Andersen model is the *use of health care services.* Health care services include: visits to the hospital primary care providers, visits to hospital specialists, hospitalizations, visits to the emergency room, visits to outpatient clinics, visits to pharmacists, home care visits, visits to alternative care providers, visits to other specialty clinics, and telephone consultations. Measures of health care system utilization should include the type of visit (physician, dentist, or hospital), location of visit (home, office), the purpose of the visit (preventive, illness-related), and time intervals during which services are used (Thind & Andersen, 2003).

To elucidate further the relative contribution of individuals' characteristics to health service use, the present dissertation work used the Behavioral Model of Health Service to explore key potential factors such as enabling resources (e.g., informational support by health care professionals) and control factors as predisposing characteristics (e.g., sex) in determining use of health care services by patients newly diagnosed with cancer.

This framework was a useful guide for the organization and interpretation of relevant findings and for the understanding of the role of informational support in subsequent use of health care services among women and men newly diagnosed with cancer.

Informational Support

Background

The term *informational support* can be vague without adequate theoretical underpinnings. A review of the current literature reveals that, even if a large number of articles on informational support is retrieved, most of the time, it is not clear what was measured. Mills and Sullivan (1999) clearly identified this problem in a comprehensive review of the literature with patients newly diagnosed with cancer.

The concept of informational support has often been studied as part of the larger concept of social support (Campbell, Phaneuf, & Deane, 2004, 2006). House's classification scheme of types of social support includes: emotional, instrumental (material aid or finance), and informational support. Inspired by House (1981) and House and Kahn (1985), *informational support* refers to access to or receipt of advice, suggestions, and additional knowledge about a situation (Campbell et al., 2004, 2006; Dunkel-Schetter, 1984; Heh & Fu, 2003; Helgeson & Cohen, 1996). Informational support can be provided by individuals (e.g., family, friends, health care providers), interactive technology (e.g., computer, CD-ROM, the Internet, chatrooms, telephone helplines), and other sources such as mass media (e.g., magazines, newspapers, television; Finney Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Gysels & Higginson, 2007; Shaw et al., 2007). Information may include knowledge about the medical condition, prognosis, and treatment plan and could also include what patients may expect to experience emotionally, cognitively, spiritually, and physically. Information could be provided at different times along the illness trajectory at the time of initial biopsy, in diagnosis, treatment, adjustment post-treatment, metastatic disease or recurrence, and in palliative care. Informational support may not only increase knowledge, informed decision-making, self-care skills, and adherence to treatment but also may be instrumental in decreasing anxiety, fear, and distress and increasing hope and empowerment (Lambert & Loiselle, 2007). In addition, patients who are better informed tend to report greater satisfaction with their medical care and their interactions with health care providers (Andreassen et al, 2005; Chelf et al., 2001).

Initially, emotional support was the most frequently studied component in research on social support (Hamilton & Sandelowski, 2004). Of those components, informational support is getting more attention (Hamilton & Sandelowski, 2004; Mills & Sullivan, 1999). In the early 1990s, the change in terminology from patient education to patient informational support epitomized the growing impact of patient-centered care and the move away from an earlier, more prescriptive approach. The importance of information as support, mainly during periods of high stress, is particularly well documented in studies of people with cancer (Cawley, Kostic, & Capello, 1990; Cowley, Heyman, Stanton & Milner, 2000; Davison, Degner & Morgan, 1995; Degner et al., 1997; Echlin & Rees, 2002; Harrison, Galloway, Graydon, Palmer-Wickham & Rich-van der, 1999; Leydon et al., 2000; Luker et al, 1995).

Individuals' preferences for health information

Evidence suggests that illness-related information should be tailored to the preferences of individuals (Chelf et al., 2001; Davidson & Mills, 2005; Helgeson et al., 2001; Rees, Bath, & Lloyd-Williams, 1998; Rees, Sheard, & Echlin, 2003; Turner, et al., 2005). However, patients' preferences are often poorly understood with the result that they do not get the information needed to engage in optimal health behavior (Fallowfield, 2001; Say & Thomson, 2003).

Overall, preferences in terms of amount of information revealed that, although some patients (women and men) have found it beneficial to receive a lot of information, others felt confused or overwhelmed by the abundance (Echlin & Rees, 2002; Mills &

Sullivan, 1999). The degree of unsolved concerns of patients with cancer in the first 4-8 weeks following diagnosis was associated with both concomitant and succeeding affective disorders (Parle, Jones, & Maguire, 1996). In addition, the amount and the type of information given to patients at the time of diagnosis varies from one professional to another. In general, lack of illness information has been cited as the greatest cause of anxiety (Evans, 1995; McCaul et al., 1999; Saares & Suominen, 2005) leading to dissatisfaction with health care services and less involvement in treatment decision-making (Hack, Degner, & Dyck, 1994; Wilson, Andersen, & Meischke, 2000); too much information has led to increased stress and dissatisfaction with health care services (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998; Rees et al., 2003), thus generating anxiety and confusion (Butow, Devine, et al., 2004; Caley, Kostic, & Capello, 1990; Echlin & Rees, 2002; Hack, 1999; Williams & Schreier, 2004). In addition, inaccurate, misleading, and/or inappropriate information was found to contribute to delays in seeking treatment and dissatisfaction, which might undermine confidence in professionals (Robinson, Patrick, Eng, & Gustafson, 1998).

More precisely and following the amount of information, several studies showed some distinct preferences between women and men. For example, preferences for the format of information revealed that women with breast cancer preferred verbal forms of information from health care professionals around the time of diagnosis (Rees & Bath, 2000), whereas men treated for early stage prostate cancer identified written information, the Internet, and videos as preferred forms of information before and after treatment (Davison, Keyes, Elliott, Bewrkowitz, & Goldenberg, 2004). Preferences for the role of individuals in their care were also investigated. Mainly, for women diagnosed with breast cancer, younger, more highly educated women want more information and desire a more collaborative role in their care (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Fogel, Albert, Schnabel, Ditkoff & Neugut, 2002; Galloway et al., 1997; Jenkins, Fallowfield, & Saul, 2001; Mills & Sullivan, 1999; Satterlund, McCaul, & Sandgren, 2003). For men diagnosed with prostate cancer, being younger (under 70), married, more educated, and having a low stage of the disease was found to influence the kind and amount of information desired (Davison et al., 1995; Wong et al., 2000). Older men with less education wanted less information and preferred a more passive role in their care (Cassileth et al., 1980; Degner & Sloan, 1992). However, a trend indicates that men are becoming more active in their care at time of diagnosis (Davison, Gleave, et al. 2002; Davison, Goldenberg, Wiens, & Gleave, 2007). Thus, informational preferences that are patient-centered have to be promoted to be adequately respected (Chelf et al., 2001; Davison et al., 2002; Helgeson et al., 2001; Rees et al., 1998).

The literature revealed two additional distinctions between preferences of women and men diagnosed with cancer in relation to informational support. The first distinction is that men preferred and considered informational support more important than emotional or psychological support compared to women (Davison, Parker, & Goldenberg, 2004; Shapiro et al., 2004), who tended to use a much wider circle for psychological support and were more likely to give encouragement and support each other than to seek or provide information (Helgeson, 2005; Moody, 2003). These differences were also suggested by Klemm et al. (1999) with an Internet cancer support group with individuals diagnosed with breast or prostate cancer. In addition, needs for care delivery (i.e., having access to their medical record, getting the diagnosis as quickly as possible, minimizing delay between decision for treatment and having the treatment, etc.) seemed to be more important for men than informational support needs (Boberg et al., 2003).

The second distinction is that most of the studies for men diagnosed with cancer involved partners (Echlin & Rees, 2002; Riechers, 2004). Partners are identified usually as the preferred primary caregivers and are responsible for most of the support to patients diagnosed with prostate cancer (Carlson, Bultz, Speca, & St. Pierre, 2000; Sormanti & Kayser, 2000); their role during the cancer trajectory has been well documented in a number of studies (Arrington, 2005; Boehmer & Babayan, 2005; Heyman & Rosner, 1996; Lavery & Clarke, 1999; Ptacek, Pierce, Ptacek, & Nogel, 1999). In a survey conducted with 80 couples to assess information and decision-making strategies of men with prostate cancer (Davison et al., 2002), the authors found that all of the men (100%) wanted their partners included in the decision about treatment. In contrast, the preference for spouse involvement is not universal as illustrated in few studies (Boehmer & Clark, 2001; Docherty, Brothwell & Symons, 2007). When partners are involved, information given to patients and their spouse are not necessarily identical in content and quantity throughout the medical process (Bar-Tal, Barnoy, & Zisser, 2005; Echlin & Rees, 2002; Lavery & Clarke, 1999; Longman, Atwood, Blank-Sherman, & Benedict, 1992; Mason, 2005).

Informational Sources

Health care professionals are an important source of informational support for patients with cancer (Bakker, Fitch, Gray, Reed, & Bennett, 2001; Crawford et al., 1997; Davison et al., 2003; Dunn, Steginga, Occhipinti, McCaffrey, & Collins, 1999; Helgeson & Cohen, 1996; Rees & Bath, 2000; Silliman, Dukes, Sullivan, & Kaplan, 1998). Informational support, mainly from physicians and nurses, is reported by women and men diagnosed with breast or prostate cancer to be helpful in understanding and managing their disease (Ashbury et al., 1998; Roberts et al., 2002). These findings were also documented elsewhere (Davison, Keyes et al., 2004; Davison, Parker et al., 2004; Maly, Leake, & Silliman, 2003; Roberts et al., 2002; Saares & Suominen, 2005). However, informational support is also reported to be unhelpful (Braslis, Santa-Cruz, Brickman, & Soloway, 1995; Heathcote et al., 1998; Helgason et al., 1996; Heathcote et al., 1998; Roberts et al., 2002), as it contributes to superfluous and unreasonable worries (Dunkel-Schetter, 1984; Kerr, Engel, Schlesinger-Raab, Sauer, & Holzel, 2003; Lacey, 2002; Maly et al., 2003; Montazeri et al., 2001; Saares & Suominen, 2005). Nevertheless, the majority of men were still satisfied even if the information was not satisfactory (Davison, Goldenberg, Gleave, & Degner, 2003; Dunn et al., 1999). An extensive literature review (Echlin & Rees, 2002) suggested that this group might overestimate its knowledge.

Family and friends are an additional source of informational support for patients with cancer (Brady & Helgeson, 1999; Chaitchik, Kreitler, Rapoport, & Algor, 1992; Davison & Degner, 1997; Davison et al., 2002; Gray, 1996; Schapira, Meade, McAuliffe, Laurence, & Nattinger, 1999). Riechers (2004), in her extensive review of the literature on the importance of including partners in the diagnosis of prostate cancer, revealed that partners are helpful because they provide better informational support than other sources. However, mixed findings were noted in several studies. Two studies

(Neuling & Winefield, 1988; Smith, Redman, Burns, & Sagert, 1985) reported that family members and friends were perceived as unhelpful for adjustment to cancer when they provided too much information.

Recent changes in the health care environment have challenged traditional approaches to giving information such as pamphlets, videotapes, and books, and have forced the adoption of new strategies (Balmer, 2005; Gysels & Higginson, 2007; Helft, 2004; Mills & Sullivan, 1999; Wofford, Smith, & Miller, 2005). Interactive health communication (IHC), or the use of information technology (IT), is an additional source of multimedia informational support for patients diagnosed with cancer. IHC is defined as the interaction of an individual such as consumer, patient, caregiver, or professional with or using an electronic device or communication technology to access or transmit health information and support (Loiselle, Edgar et al. 2008; Murray, Burns, See, Lai, & Nazareth, 2005; Robinson et al., 1998).

Recently, a meta-analysis (Murray et al., 2005) and two systematic reviews (Gysels & Higginson ; 2007; Wofford et al., 2005) were completed on the topic. The Cochrane meta-analysis (Murray et al., 2005) suggested that interactive informational support contributes to improved knowledge of patients about their disease and develops the user's ability to re-examine the information frequently over time. Giving information to patients with computer-assisted learning is often more effective than conventional methods. IHC can complement health care services by empowering patients and relatives by using informational support. These findings, which include women with breast cancer and men with prostate cancer as well as their partners, are reported elsewhere (Davison et al., 2002; Gustafson, Hawkins, Pingree, et al., 2001; Molenaar et al., 1996; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000).

The systematic review by Wofford et al. (2005) explored the potential role of multimedia, defined as the use of graphics (animation, video and/or audio), with or without the use of supporting text in office-based patient information. Results showed that knowledge improved for patients, who were more comfortable in care participation. However, no significant change was noted in decision-making, anxiety, or depressive symptoms; nor was there improvement in health care service use by patients. The authors concluded that clinical researchers have not yet convincingly shown that computer-based patient information leads to better health-related outcomes.

The systematic review by Gysels and Higginson (2007) explored whether interactive technologies for patient education in cancer care improve knowledge, satisfaction, and decision-making processes and were slightly superior to traditional methods. Results showed that there is a trend toward improved patient knowledge and satisfaction but the ways in which the interventions are delivered and the extent of communication with health care professionals affect patient responses. However, interactive technology is able to tailor the information to the individual, can be matched to patient's preferences, and facilitates involvement and learning in an active way (Davison et al., 2007; Shaw et al., 2007).

Recently, Davison, Goldenberg, Wiens, and Gleave (2007) conducted a randomized study with men diagnosed with prostate cancer (N = 324) to compare generic (i.e., video) and individualized (i.e., computer) informational support. This study found that generic and individualized information interventions were similar in providing decisional support.

Potential Barriers

Several studies suggested that patients with cancer often experience problems in obtaining informational support and/or in sustaining the level of informational support desired (Arora, Gustafson, et al., 2001; Rose, 1990). Research has shown that some obstacles have to be considered. These include: the timing and quality of information given, inconsistent or contradictory information, a general lack of information (Berland et al., 2001; Echlin & Rees, 2002; Hall, Roter, & Katz, 1988; Rozmovits & Ziebland, 2004), and the need for help for interpreting this information (Gray et al., 1997a; Hamilton & Sandelowski, 2004; Kerr et al., 2003; Manning & Dickens, 2006; Wang, Cosby, Harris, & Lieu, 1999). In addition, limited access to oncologists and other health care professionals (Anderson, 2004; Hulka & Wheat, 1985; Turner et al., 2005), learning difficulties, cultural differences or language limitations, or failure by some professionals to listen and respond to patients' concerns (Edgar, Greenberg, & Remmer, 2002; Manning & Dickens, 2006; Say & Thomson, 2003) also can be pointed out. Recently, another potential obstacle in cancer care, patient-professional communication, has received much attention. The role of information and communication in effective patient involvement was also highlighted (Evans, et al., 2003). In Canada, an extensive review of the literature of research conducted during the last 35 years was realized by the Patient-Professional Communication Team of the Sociobehavioural Cancer Research Network (SCRN), and was supported by the Canadian Cancer Society. These critical reviews (Butler, Degner, Baile, & the SCRN Communication Team, 2005;

Carlson, Feldman-Stewart, Tishelma, Brundage, & the SCRN Communication Team, 2005; Feldman-Stewart, Brundage, Tishelma, & the SCRN Communication Team, 2005; Hack, Degner, Parker, & the SCRN Communication Team, 2005; Parker, Davison, Tishelma, Brundage, & the SCRN Communication Team, 2005; Thorne, Bultz, Baile, & the SCRN Communication Team, 2005) have documented the importance of understanding patient-professional communication and related issues, which revealed the need to take into account patient preferences at any time in the illness trajectory to help patients make informed choices about their own care. This research team plan to study and support the use of several methods of communication such as audio-taping oncologist consultations (Hack, 2007) to help patients understand their disease.

In terms of methods of communication, the format of information available can be identified as an obstacle for patients. It is well known that patients tend to forget between 30 to 50% of the verbal information they receive (Ley & Morris, 1984; Mossman, Boudioni, & Slevin, 1999) within minutes of their consultation. For men with prostate cancer, a qualitative study (Lavery & Clarke, 1999) revealed that verbal information given by health care professionals on side effects was completely forgotten. For women with breast cancer, who were found to prefer verbal forms of information from health care professionals around the time of diagnosis (Rees & Bath, 2000), a qualitative study (Wolf, 2004a) reported that women who had undergone surgery had difficulty retaining verbal and written information. Two other reviews of the literature supported these findings (Echlin & Rees, 2002; Mills & Sullivan, 1999). In our health care system, verbal information is one of the most common methods by which to provide information along with written and audiovisual methods (Mills & Sullivan, 1999; Wolf, 2004b). A meta-analysis (Zabora et al., 1998) suggested that no one type of intervention related to information is better. Information in a single format seems insufficient to achieve positive outcomes (Haby, Waters, Robertson, Gibson, & Ducharme, 2001). Using varied methods for providing information particularly at the early stages of cancer seems to be of benefit to patients (Echlin & Rees, 2002).

The use of technology as a new method for delivering education to patients has increased radically. Moreover, the Internet, labelled as an intervention medium in health promotion and for behavior change (Lintonen, Konu & Seedhouse, 2007), provides a new way to access health information and disease-relevant information easily. However, some barriers in relation to multimedia formats for patient education and health information could be issues of literacy (Hart, Henwood, & Wyatt, 2004; Manning & Dickens, 2006), sensory disabilities, access to information technology, language, and culture (Hardyman, Hardy, Brodie, & Stephens, 2004). Little empirical research has examined how the Internet is used by those who have been diagnosed with a serious illness (Ziebland, 2004) and, to date, mixed findings of the use of the Internet has been reported: the Internet, social isolation, and depression could be related. In addition, patients with cancer felt that Internet information can be overwhelming (31%), conflicting (76%), and confusing (27%; Eysenbach, 2003).

As noted, several barriers in relation to the information itself, the patient, or the health care professional have to be taken into account to develop and provide informational interventions for patients diagnosed with cancer.

Health Care Service Use

Health care services utilization refers to individuals' reliance on health facilities (e.g., hospital, clinics, home care) offered by professionals for prevention, treatment, and management of illness to meet their health care needs (Cleland, 1990; Evans, 1984). The use of health care services—studied as a behavior in the literature (Gortmaker, Eckenrode, & Gore, 1982; Hulka & Wheat, 1985; Muller, 1990), and related to health actions (Verbrugge, 1985)—is also identified as a complex process (Leaf et al., 1988; Muller, 1990). Interestingly, a broad range of theoretical frameworks has been used to study health care service use (see Table 1 for a review of frameworks used). Health care service use by patients has been the focus of several studies (including cancer) and also has been measured as an outcome (Andersen, 1995; Cox, 1982; Gortmaker et al., 1982; Hulka & Wheat, 1985; Kouzis & Eaton, 1998; Porter, 1995; Vasiliadis et al., 2007). However, as noted in a recent Cochrane review on the involvement of patients in their care (Wetzels, Harmsen, Van Weel, Grol, & Wensing, 2007), interventions that focus on the use of health care services are lacking.

There are many different services used in oncology (Carlson & Bultz, 2004). For the purpose of the present study, these include health facilities (e.g., emergency room, community health centre, and support groups), and resources (e.g., family practitioner, oncologist/urologist, nurse, radiotherapist/radiologist, pharmacist, surgeon, other health care providers [e.g., psychologist, nutritionist], and alternative care providers).

A review of the literature of papers published between 1966 and 1997 included 53 studies (de Boer et al., 1997) and suggested factors that predict health care use. These factors are best depicted by Andersen's and Newman's Behavioral Model of Health

Service Use (Andersen, 1995; Andersen & Newman, 1973), and as mentioned previously include: (1) Predisposing factors (e.g., demographics variables); (2) Enabling factors or impeding factors (e.g., support); and (3) Need factors (e.g., information) related to illness (Andersen et al., 1973; de Boer et al., 1997; Hulka et al., 1985; Leaf et al., 1988; Vasiliadis et al., 2007). Several researchers found that these factors all played a role in use of health care services and conclude that the need factors are the most significant in explaining variance in health care service use, predisposing, and enabling factors being found to be less important (Andersen et al., 1973; Blaum et al., 1994; de Boer et al., 1997; Tanner, Cockerham, & Spaeth, 1983; Vasiliadis et al., 2007; Wolinsky et al., 1994). Stressful life events, for instance, have been identified as significant predictors of utilization (Gortmaker et al., 1982; Pilisuk, Boylan, & Acredolo, 1987). Particularly, Padgett and Brodsky (1992) reported that predisposing factors (race, sex), enabling factors (i.e., having a usual source of support), and proximity of services affect the use of health care services, both alone and in interaction with race. Nonurgent use of the emergency room was also found to be linked to need factors arising from socioeconomic stress, psychiatric comorbidities, and a lack of support.

In relation to chronic diseases, a review of the literature performed several years ago (Hulka et al., 1985; all diseases included) on patterns of health care service use (defined as physician and hospital utilization from a patient's perspective) found significant variations in measures of utilization. Needs (individually perceived and professionally assessed) have been consistently found to be the primary factor in determining medical use as mentioned previously. Findings suggested that the availability of health care resources is an essential variable to predict utilization. Use of health services was influenced by age; it was higher at both extremes (infant and elderly) and was lower in youth and young adulthood. At this time, women were also identified as greater users of services.

For patients diagnosed with breast or prostate cancer, few studies on health care service use have been conducted. To date, the use of health services has been associated with several factors such as being a woman, younger, better educated and of a higher socioeconomic status (Gray, Goel et al., 2000; Steginga et al., 2008). Similar findings were documented elsewhere (Arora, Johnson, et al., 2002; Campbell et al., 2004; Gray et al., 2002). Higher levels of psychological distress was also found to be associated with the use of services (Edgar, Remmer, Rosberger, & Fournier, 2000; Grande, Meyer, Sutton, 2006; Steginga et al., 2008). Moreover, an increased use of services (e.g., in terms of number of visits to general practitioner, community or public health nurses, pharmacist, emergency room, and walk-in clinics) was observed for patients who reported mild to severe fatigue (Ashbury et al., 1998). In a study (Johansson, Holmberg, Berglund, Sjoden, & Glimelius, 2004) among 399 patients newly diagnosed with cancer (49% breast cancer, 21% prostate cancer, and 30% for gastrointestinal cancer), use of services was associated with their cancer, treatment, comorbidity, physical function, pain, higher age, and lower income. It was noted that age alone did not significantly determine higher utilization of health care services and patients living in rural areas and those with low income utilized hospital care more often.

Several studies have suggested that sex differences pertaining to illness behaviors are complex and vary during the life course (Helgeson, 2005; Macintyre, Hunt, & Sweeting, 1996; Mutran & Ferraro, 1988). Women have been found to use health care services more frequently than men (Briscoe, 1987; Clearly, Mechanic, & Greenley, 1982; Corney, 1990; Green & Pope, 1999; Kouzis & Eaton, 1998; Ladwing, Marten-Mittag, Erazo, & Gundel, 2001; Marcus & Siegel, 1982; Marshall, Gregorio, & Walsh, 1982; Muller, 1990; Pilisuk et al., 1987; Sindelar, 1982; Vasiliadis et al., 2007; Verbrugge, 1985; Wilensky & Cafferata, 1983), and this phenomenon persists even after controlling for care related to pregnancy (Green & Pope, 1999; Sindelar, 1982; Wilensky & Cafferata, 1983). Seeing a physician, number of visits, probability of using hospital services, and the use of prescribed medication are higher among women than men (Andersen, 1976; Verbrugge, 1985). However, according to Muller (1990), women used more preventive services than men, mostly for cancer-related issues (Gornick et al., 2004). Several explanations were suggested to account for this finding among women, including role obligations (Nathanson, 1975), more interest in health, more knowledge about health than men (Clearly et al., 1982; Green & Pope, 1999), and more time to seek medical care (Sindelar, 1982). Nevertheless, care-seeking behaviors do not necessarily result in better health outcomes (Muller, 1990); nonfatal chronic diseases are more prevalent among women (Verbrugge, 1985; Helgeson, 2005).

Sex was often associated with several factors related to the use of services, such as the tendency to adopt a sick role, attitudes, and psychological distress (Clearly et al., 1982; Marcus & Siegel, 1982). For important problems such as chronic diseases, women and men are similar in willingness and ability to take initial health actions; women are more willing to tell their symptoms to others and to seek help than men; women may elaborate more, giving more details on their illness, including both somatic and psychological effects; women take follow-up actions sooner and are more commonly proxy respondents for family members than are men (Addis & Mahalik, 2003; Green & Pope, 1999; Helgeson, 2005; Kessler, 1986; Ladwing et al., 2001; Muller, 1990; Verbrugge, 1985). Several factors have been suggested to explain sex behaviors related to health care service use. Particularly, affective disorders or psychological distress often prompt patients to use health care services (Barsky, Wyshak & Klerman, Campbell & Roland, 1996; 1986; Pope, 1979; Johnson, Weissman, & Klerman, 1992); however, this disorder seems to be more frequent for women than men (Gove, 1984; Jackson, Chamberlin, & Krewnke, 2003; Ladwing et al., 2001; Macintyre et al.,1996; Walters, McDonough & Strohschein, 2002). A recent mail survey (Koopmans & Lamers, 2007; N = 8698) showed that the use of health care services is associated with psychological distress, and because women reported higher levels of mental distress, this results in higher use of health care services. Although sex differences and use of health services is a complex area of study, it is interesting to investigate this link in oncology populations because of the clear empirical criteria for the diagnosis, the duration of the symptoms, and the progression of the disease and psychosocial factors related to cancer (Marshall et al., 1982).

In relation to health facilities, support groups, a general feature in hospitals and in many communities, constitute a health service that has been increasingly popular and accessible (Edelman, Craig, & Kidman, 2000; Gray, 1996). Volunteer cancer organizations (for example, Canadian Cancer Society and American Cancer Society) offer peer support programs that could link survivors with newly diagnosed individuals with cancer (Campbell et al., 2004). The emotional ambivalence to the diagnosis often experienced by family and friends of individual diagnosed with cancer may explain why support from other patients with cancer can be perceived as more beneficial (Ahlberg & Norder, 2006; Bauman, Gervey, & Siegel, 1992; Bottomley, 1997; Nelles, McCaffrey, Blanchard, & Ruckdeschel, 1991; Poole et al., 2001; Spiegel, 1992; Steginga, Pinnock, Gardner, Gardiner, & Dunn, 2005). Support groups can be professionally led (e.g., nurse) or peer led. However, to date, no difference has been noted between these two kinds of leaders, which suggest that the professional background of the leader is unimportant (Ussher, Kirsten, Butow, & Sandoval, 2006). Given such an important trend, there is growing interest in creating support groups in the form of *networks of information* (i.e., support groups available online) for individuals diagnosed with cancer (Gooden & Winefield, 2007; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Klemm et al., 2003; Seale, 2006; Seale, Ziebland, & Charteris-Black, 2006; Shaw et al., 2007; Winzelberg et al., 2003).

Access to health care services was also explored by several researchers. Defined as the availability and accessibility of health care services, access is significantly associated with utilization (Aday & Andersen, 1974; Andersen, 1995; Andersen & Davidson, 2001; Hulka & Wheat, 1985). Research on access to services was more important in the 1990s (Andersen, 1998) and was documented as an issue in psychosocial oncology (Stephen & Boyle, 2005; Turner et al., 2005). Several studies were conducted taking into account age, ethnicity, and social class (Andersen, Giachello, & Aday, 1986; Andersen, Yu et al., 2002; Haas et al., 2004; Kessler, Peters, Lee, & Parr, 2005; Leduc & Proulx, 2004) with a variety of diseases including cancer (Arora et al., 2002; Gray, Goel et al., 2000). As noted by several authors, more work is needed in this multifaceted area of research (Gysels & Higginson, 2007; Kessler, 1986).

In summary, several factors have been identified as influencing health care service use by individuals (e.g., age, education, socioeconomic status, psychological distress, fatigue). In particular, sex differences in health care service use suggest, so far, that women use more services than men. This can be explained, in part, by higher levels of psychological distress. However, as mentioned by several authors, research on utilization of health care services must to be interpreted cautiously because of various quantitative measures used, inconsistencies in theoretical underpinnings, and differing research methods used that produce disparate findings (Hulka & Wheat, 1985; Jewett et al., 1992; Pilisuk et al., 1987). For example, cross-sectional designs are often used (Lima & Kopec, 2005), as are self-report measures (de Boer et al., 1997), and instruments that have been established for only one gender have been generalized to both (Dibble, Padilla, Dodd, & Miaskowski, 1998). In addition, few studies have been conducted with the cancer population (Gray, Goel et al., 2000).

Relationships Between Informational Support and Health Care Service Use

Few studies have directly investigated the role of informational support in health care service use. A recent U.S. national survey (Baker et al., 2003) involving the general population (8,935 individuals, 47.2% male) found that health information provided on the Internet and email exchanges with health care professionals had little effect on decreasing health care utilization, as assessed by the number of physician visits and health care professional telephone contacts. Others found that booklets, mailed information or found on the Internet about the management of minor illnesses did not have a significant effect on the reduction of demand for health care services, particularly emergency departments (Heaney et al., 2001; Rector, Venus, & Laine,

1999) or to clinical visits (Dickerson et al., 2004). However, mailed information (N = 339,220) about vaccination during the influenza season reduced inpatient admissions by 9.67%, and emergency visits by 22.64% (Berg, Thomas, Silverstein, Neel, & Mireles, 2004). In the field of disease prevention, combining informational strategies such as the use of leaflets, posters, and information sessions for elderly patients resulted in an increase of 30% in the use of services (e.g., vaccination; Humair, Buchs, & Stalder, 2002). There is some evidence that mass media campaigns can be effective in disseminating information on prevention and may encourage the effective use of health care services (Grilli, Ramsay, & Minozzi, 2002). Examples of impact in prevention include smoking prevention among youth (Sowden, Arblaster, & Stead, 2003) and promotion of HIV testing (Vidanapathirana, Abramson, Forbes, & Fairley, 2005). However, as outlined by three systematic Cochrane reviews (Grilli et al., 2002; Sowden et al., 2003; Vidanapathirana et al., 2005), further research is needed to explore the characteristics of the information provided (e.g., scope, nature, and timing of the information) as well as the long-term effects of these messages on health care service use. In addition, little is known about how mass print media designed for sex groups differs or indeed whether they differ; what we know is that a variety of media are designed to target particular populations (Hoffman-Goetz & Friedman, 2005).

Several studies explored preventive areas relative to cancer. Informational support was found to lead to the use of cancer screening for breast (Michielutte et al., 2005), colorectal (Green & Kelly, 2004; Straus et al., 2005), and cervical cancer (Howe, Owen-Smith, & Richardson, 2002). In addition, providing information on the pros and cons of cervical screening showed no effect on the use of services between women at higher and lower risk of cervical cancer (Adab et al., 2003). For prostate cancer, the provision of information and participation in decision-making was related to more use of screening (Finney Rutten et al., 2005; Taylor et al., 2001).

In chronic disease, Gustafson et al. (1999) conducted a study to document the role of illness information on quality of life and use of heath care services among patients diagnosed with HIV. In this randomized control trial (RCT) with 204 patients (90% of the sample were men), information provided via computerized means led patients to report spending less time in ambulatory care visits, making more phone calls to health care professionals, and experiencing fewer and shorter hospitalizations. For this study, the researchers developed a service utilization scale, which was adapted for the Loiselle et al. (2002-2005) study. In addition, health information found on the Internet, mainly on treatment choices was shown to be related to the use of health care services (Khechine, Pascot, & Prémont, 2004; 2008).

For newly diagnosed individuals with cancer, few studies have examined the specific relationship between informational support and use of health care services. Simpson, Carlson, and Trew (2001), for instance, conducted a prospective RCT on the effect of group therapy for women diagnosed with breast cancer (N = 123) on health care utilization. Chart reviews recorded the number of visits to the cancer center. This study was the first to demonstrate that women who participated in a group psychosocial intervention (including informational and psychological support by health care professionals), reported less depression and mood disturbance, better quality of life, and a reduction in cost of medical expenses (23.5% less in terms of number of visits) than those in the usual care condition. However, although informational support was part of the intervention, its impact was assessed using a measure of general social support.

A RCT conducted by Wyatt, Donze, and Beckro (2004) with women diagnosed with breast cancer (N = 240) tested the efficacy of a home nursing intervention on health care service use following short-stay surgery. Two of the outcomes were self-care knowledge and the use of health care services. Results showed that information in the intervention group improved self-care knowledge, but no significant differences were reported in the subsequent use of health care services between the groups (i.e., visits or phone calls to the emergency room).

More recently, a matched-control design study (Chumbler et al., 2007) was conducted with veterans (predominantly men) diagnosed with cancer (N = 125; all cancer types), to compare a *telehome* health care program (i.e., use of Internet and computerized systems, including professional follow-up during chemotherapy treatment and symptoms-based education), with standard care relative to the use of health care services. Results showed fewer visits to clinics and fewer hospital stays in the experimental group. However, this study focused on coordination of care for symptom management that included informational support that was not separately measured. In addition, participants were older (i.e., veterans) and more than 75% had a late-stage disease. No data were collected on the influence of severity of symptoms on the use of health services (e.g., less use of services with older individuals or those who had less pain).

Women and men newly diagnosed with either breast or prostate cancer often join a support group, a health care service, to help satisfy their information needs particularly on diagnosis, treatment, and side effects of treatment or to share, for example, information on benefits and side effects for alternative medicine (Boehmer & Babayan, 2005; Breau & Norman, 2003; Crawford et al., 1997; Docherty et al., 2007; Edgar et al., 2000; Helft, 2004; Poole et al., 2001; Steginga et al., 2006; Stevens & Duttlinger, 1998). Support groups are also used to facilitate exchange with other patients on difficult issues related to their disease (Gray, Fitch, Davis, & Phillips, 1997b). Support groups provide informational support at low cost (Gray et al., 1997b; Steginga et al., 2006). To date, studies have revealed that women are more engaged in supportive responses than men who use this source of support primarily for information exchange with other members (Harrison, Maguire, & Pitceathly, 1995; Klemm et al., 2003; Seale, 2006; Seale et al., 2006). However, several studies have shown that support groups are appealing to those who lack support (Bauman et al., 1992; Helgeson et al., 2000; Voerman et al., 2007). Further research is needed to improve our understanding of which individuals (e.g., from other cultures) and why these individuals do not attend this low cost service (Ussher et al., 2006).

In summary, a few studies that focus on factors that influence the use of cancer care services (e.g., modalities of prevention or treatment, comorbidity, physical function, pain, sociodemographic variables) by individuals diagnosed with cancer have investigated how these factors may moderate service use mainly in terms of less or more intense use. With the importance of information as support in oncology care, studies examining the impact of informational support intervention have included health care service use as one of their outcomes (e.g., Davison, Goldenberg, Wiens, & Gleave, 2007). The use of a popular model of health service use (Andersen, 1995) to guide the study of informational support as an individual factor that may independently influence the subsequent use of health services will continue to improve our capacity to explain the use of health care services particularly relevant in this time of limited health care resources.

CHAPTER 3

METHODOLOGY

This chapter reports on the methods used in the present dissertation. It includes rationale, ethical considerations, and an overview of the procedures used for each portion of the sequential mixed design.

Based on a pragmatic approach (Morgan, 2007; Twinn, 2003), a sequential mixed methods research design (i.e., the use of more than one approach for the same project following a sequence) was used to obtain a more complete picture of the research topic of interest (Morse, 2003; Morse & Field, 1995; Sandelowski, 2000a; Tashakkori & Creswell, 2007; Wilkins & Woodgate, 2008). This approach allows the use of complementary strategies, adds richness and detail (Creswell & Plano Clark, 2007; Morse, Niehaus, & Wolfe, 2005; Tashakkori & Teddlie, 2003), and provides an increasingly important method for nursing research (Twinn, 2003). Moreover, using a sequential mixed methods design allowed the researcher to: (1) perform a secondary statistical analysis on an existing cancer education intervention trial database to determine relationships among variables of interest and to guide the next step of inquiry; (2) explore, in greater depth, participants' experiences with cancer information and health care services through a qualitative study; and (3) provide further insights into the interrelationships between cancer informational support and health care service use using a mixed methods data analysis. Although the nature of quantitative methods allowed inferences about the examined topic, qualitative methods expanded the inquiry to include key elements that were not revealed in the quantitative enquiry (Morse, 2003; Morse et al., 2005; Loiselle, Profetto-McGrath et al., 2007; Rossman & Wilson, 1994).

The combination of both quantitative and qualitative findings confirmed and clarified some findings and elaborated on others. This combination also allowed increased confidence in the findings (Tashakkori & Teddlie, 2003). In health care service research, only 18% of studies were classified as mixed methods research (O'Cathain, Murphy, & Nicholl, 2007). Methodological decisions and the rationale for these decisions are detailed in the third manuscript.

Insights were provided into research questions in several steps. First, a secondary quantitative analysis was undertaken and then a follow-up qualitative inquiry was conducted. Results that emerged from the quantitative analysis guided the qualitative investigation. Each study was conducted individually, and each data set remained analytically separate from the others (Creswell, Plano Clark, Guttmann, & Hanson, 2003; Sandelowski, 2000a). Third, both quantitative and qualitative findings were merged and reanalysis of qualitative data was completed.

The first step, the secondary analysis inquiry, described in the initial manuscript (Loiselle & Dubois, in press), was part of a large CIHR-funded study (Loiselle, Edgar & Batist, 2002-2005), *The Contribution of Interactive Health Communication (IHC) to the Health and Well-Being of Oncology Patients*. The purpose of the Loiselle et al. (2002-2005) study was to document the impact of interactive health communication on the well-being and health services utilization of oncology patients (diagnosed with breast or prostate cancer). The principal investigator was Dr. Carmen G. Loiselle and the coinvestigators were Dr. Linda Edgar and Dr. Gerald Batist. Using secondary analysis, the quantitative inquiry focused on the impact of an educational intervention on health care service use (e.g., face-to-face and telephone consultations), and perceived satisfaction with support from the perspective of women and men newly diagnosed with cancer.

Before starting secondary quantitative analyses, the researcher took into account the ethical considerations for both Loiselle et al. (2002-2005) and Loiselle and Dubois (2008). The large-scale study received approval from the McGill University Faculty of Medicine Institutional Review Board (Appendix B) and each of the four hospitals that were involved. Data from the larger study were kept in a locked filing cabinet at the Centre for Nursing Research of the SMBD-Jewish General Hospital. Approval for undertaking secondary analysis was obtained by the SMBD-Jewish General Hospital review board in September 29, 2005, and renewed in September 10, 2006, and September 9, 2007 (Appendix C). Study instruments used for this doctoral study consisted of five of the original questionnaires assembled by Loiselle et al. (2002-2005) mostly reported in the first manuscript (Loiselle & Dubois, 2008; Appendix D for copies of instruments).

Moreover, demographic data were collected with the sociodemographic information sheet developed by Dr. Loiselle (2002) and provided by the Loiselle et al. (2002-2005) study. This information sheet was used at baseline to obtain demographic data from the participants such as age, sex, education, income, religious background, work status, marital status, number of children and dependents. In addition, two variables were used as controls because they might confound the findings.

On the one hand, the State-Trait Anxiety Inventory (STAI; Spielberger, 1983) is a scale designed to measure current anxiety symptoms. Anxiety is a transitory emotional state or condition characterized by subjective, consciously perceived feelings of tension and apprehension. This scale consists of 20 items rated on a 4-point scale (1 = Not at all, to 4= Very much so). Possible scores range from a minimum of 20 to a maximum of 80 with high scores indicating higher levels of state anxiety. Participants are asked to "indicate how you feel right now, that is, at this moment. There are no right or wrong answers." Examples of questions include: "I feel calm; I feel frightened; I feel upset." Measures of internal consistency for the STAI are uniformly high (Ritterband & Spielberger, 2001). The alpha coefficients are .86 or higher for a large independent sample of students and working individuals with a median Cronbach alpha of .93 (Spielberger, 1983). In addition, the scale has high internal consistency and alpha reliability coefficients ranging from .83 to .92 have been reported in studies conducted with surgically treated patients with cancer (Oberst & Scott, 1988), and patients newly diagnosed with breast cancer (Scott, 1983).

On the other hand, the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977), is a short self-report scale with 20 items designed to measure depressive symptomatology in the general population (Markush & Favero, 1973). Various aspects of depressive symptomatology are evaluated such as depressive mood, guilt feelings, despair, psychomotor deceleration, anorexia and sleep disorders. Each item is scored on a four-point scale (0-3); 0 (rarely or none of the time/less than one day), 1 (some or a little of the time/1-2 days), 2 (occasionally or a moderate amount of time/3-4 days), 3 (most or all the time/5-7 days). Examples of items: "During the past week, (1) I did not feel like eating: my appetite was poor." (2) "I was bothered by things that usually don't bother me." (3) "I felt that I could not shake off the blues even with help from family and friends." Scores range from 0-60, with higher scores indicating greater depressive symptoms. Radloff (1977) recommended that scores greater than or equal to 16 should be considered positive. The CES-D has been used in numerous studies with general populations and populations with cancer since the 1980s with acceptable reliability and validity (e.g., internal consistency of .87; Hann, Winter, & Jacobsen, 1999).

Finally, for data analysis, a global index for oncologist informational support and nurse informational support was calculated as the average of scores obtained from each of the two subscales from the questionnaire. Not explained in the manuscript, the scores obtained for the nine items, rated on a four-point scale, related to the oncologist informational support were added up and divided by nine; the same method was used for the nurse informational support. A higher the global index indicates that more information was received from the patient by the oncologist or the nurse.

The second step, the qualitative inquiry, described in the next manuscript (Dubois & Loiselle, 2008a), was a follow-up qualitative study that explored in greater depth the potential role of informational support in guiding individuals in their use of health care services. A descriptive qualitative approach, a general and pragmatic approach toward clinical issues (Morse & Field, 1995; Sandelowski, 2000b), was used to capture knowledge from health care services and was guided by the nature of the research questions. This implies studying the target phenomenon in its natural state (i.e., naturalistic inquiry). To date, there is a growing trend toward using this generic and straightforward approach to inform the practice of health care mainly of how and why something worked (Meyrick, 2007). Thus, when little is known about a phenomenon, with few theoretical propositions, observations and recording of "facts" in everyday language are indicated.

For this qualitative inquiry, recruitment was done at the oncology clinic of a Montreal university teaching hospital (MUHC), the Montreal General Hospital. This site was chosen because it had follow-up services for patients with cancer and had a history of being receptive to research. Prior to data collection, the researcher sought ethics approval from appropriate Institutional Review Boards (IRB; i.e., the McGill Institutional Review Board, approval from specific MUHC ethics committee, and the committee from the Montreal General Hospital; Appendix E). Potential participants received both verbal and written descriptions of the study. The participants signed a consent form to participate in the study and to be audio taped (Appendixes F, G). Using a pool of questions to guide individual interviews and to collect data (see interview guide, Appendix H), participants were informed that the audio recording could be stopped at any time, but it never became necessary to do so. They were also informed about the confidentiality of information given, their voluntary participation, and their right to withdraw at any time without affecting their present or future care.

The third step, described in the last manuscript (Dubois & Loiselle, 2008b, in press), involved a combination (i.e., merging) of quantitative and qualitative data, and a reanalysis of qualitative data was completed. The purpose was to integrate results from these two different approaches using a quantitative hierarchical strategy. Most frequently used in health care services research, hierarchical strategy "treats one [research] approach as primary and the other as an adjunct to amplify the impression provided by the first approach" (McDowell & MacLean, 1998, p. 18). The analysis of quantitative data provides a broad understanding of the research problem, the analysis of qualitative data refines the findings by investigating participants' views in more depth (Tashakkori & Teddlie, 2003), and the merging of both quantitative and qualitative findings with the reanalysis of qualitative data offers insights that could not otherwise be obtained (Bryman, 2007). This manuscript also documented the research process and research findings.

CHAPTER 4

FINDINGS

This study developed three manuscripts on work preformed in describing informational support related to health care service use. The first manuscript is titled, "The Impact of a Multimedia Cancer Informational Intervention as Opposed to Usual Care on Health Care Service Use Among Individuals Newly Diagnosed with Breast or Prostate Cancer." The second manuscript is titled, "Understanding the Role of Informational Support in Relation to Health Care Service Use Among Newly Diagnosed Individuals." The third manuscript is titled, "Cancer Informational Support and Health Care Service Use Among Individuals Newly Diagnosed: A Mixed Methods Approach." The full papers are presented following a preface that documents the context with additional information that was not included in the submitted texts.

Manuscript 1: The Impact of a Multimedia Cancer Informational Intervention as Opposed to Usual Care on Health Care Service Use Among Individuals Newly Diagnosed with Breast or Prostate Cancer.

Authors: Carmen G. Loiselle, N., Ph.D., Sylvie Dubois, N., Ph.D. (c).

Cancer Nursing, in press (Appendix I).

Preface

In accordance with our literature review, the role of informational support in relation to health care service use is understudied. Several benefits of informational support have been reported in terms of knowledge, decision-making, self-care skills, treatment adherence, psychological distress (Lambert & Loiselle, 2007), and satisfaction with care (Andreassen et al., 2005; Chelf et al., 2001). It has also been identified as valuable when information needs are high (Chelf et al., 2001; Cunningham, 1995) but when these needs are unmet, oncology patients are more likely to rely on community health services and visit emergency facilities (Carlson & Bultz, 2004).

Whereas the link between illness informational support and optimal use of health care services makes intuitive sense, the fact is that few quantitative studies have directly investigated the role of informational support in health care service use. There is some evidence that information on prevention encourages effective use of health care services (Grilli, Ramsay, & Minozzi, 2002); however, systematic reviews (Grilli et al., 2002; Sowden, Arblaster, & Stead, 2003; Vidanapathirana, Abramson, Forbes, & Fairley, 2005) have underscored the need to explore further the information provided as well as the long-term effects of this communication on health care service use.

The purpose of the first manuscript is to use secondary quantitative analysis of data gathered as part of a larger study (funded by the Canadian Institutes of Health Research; Loiselle, Edgar, & Batist, 2002-2005) to explore the role of informational support in the use of health care services by women newly diagnosed with breast cancer and men newly diagnosed with prostate cancer who experience either traditional cancer-information delivery or information technology (IT) intervention. This intervention was being tested by the Loiselle et al. (2002-2005) study. Potential sex differences were also explored.

Abstract

This quasi-experimental longitudinal study documented the impact of a comprehensive cancer informational intervention using information technology (IT) on health care service use among individuals newly diagnosed with cancer. Women with breast cancer (n = 205) and men with prostate cancer (n = 45) were recruited within eight weeks of diagnosis at four university teaching hospitals in Montreal, Quebec, Canada. The intervention group (n = 148) received a one-hour training on IT use, a CD-ROM on cancer, and a list of reputable cancer-related websites. The intervention material was available for a period of 8 weeks. The control group (n = 102) received usual care. Self-reported questionnaires were completed at T1 (baseline), T2 (one week post intervention), and T3 (three months post intervention). Using multivariate statistics, the experimental group reported significantly more satisfaction with cancer information received than the control group. No significant differences were found between experimental and control groups in their reliance on health care services. However, women as opposed to men spent more time with nurses, were more satisfied

with cancer information received, and relied more heavily on health services. Future research would explore whether the latter observations reflect genuine sex differences or are more contingent on the specific cancer diagnosis.

Introduction

Computer-based interactive educational tools are perceived as engaging and convenient (Loiselle & Dubois, 2003; Gysels & Higginson, 2007) and have the potential to enhance psychosocial outcomes in cancer. Informational support, defined as access to or receipt of advice, suggestions, and additional knowledge about a situation, might not only increase knowledge, informed decision-making, self-care skills, and adherence to treatment but also may be instrumental in decreasing anxiety, fear, and distress, and in increasing hope and empowerment (Lambert & Loiselle, 2007). Informational support has been identified as therapeutic for individuals diagnosed with cancer particularly when information needs are high (Chelf et al., 2001). In addition, patients who are better informed tend to report greater satisfaction with their medical care and their interactions with health care providers (Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2005; Chelf et al., 2001).

As patients' cancer information needs are predicted to increase in complexity and demand for cancer-related services to intensify (de Boer et al., 1997; NCIC, 2007; 2008), the need for efficient and cost-effective psychosocial and timely informational support is acute. Moreover, when psychosocial care and information needs are unmet, significant psychological distress often follows (Boberg et al., 2003; NAO, 2005). The consequences of not identifying and effectively managing cancer-related distress include poorer health-related outcomes, decreased quality of life, and increased health care costs through higher reliance on services such as emergency rooms and community health services (Carlson & Bultz, 2004; Zabora, Brintsenhofeszoc, Curbow, Hooker, & Piantadosi, 2001).

Interactive Health Communication (IHC), defined as the interaction of an individual with or using an electronic device or communication technology to access or transmit health information and support (Robinson et al., 1998), has been identified as promising for meeting psychosocial needs of individuals diagnosed with cancer (Loiselle & Dubois, 2003). IHC can guide individuals' reliance on cancer care services as it offers readily available, complementary informational support to patients with cancer and their family (Wiljer & Catton, 2003). However, the contribution of IHC to psychosocial adjustment and health care service use remains understudied in cancer supportive care (Wiljer & Catton, 2003). Health care service use refers to individuals' reliance on health facilities (e.g., hospital, clinics, home care), offered by professionals for treatment and management of illness, to meet their health care needs (Cleland, 1990).

Purpose of the study. The larger study examined the impact of multimedia informational support or IHC/IT on psychosocial adjustment (Loiselle, Edgar, Batist & Lu, 2008) with a focus herein on health care service use by individuals newly diagnosed with either breast or prostate cancer. These two types of cancers were chosen as they involved different sexes and are the most frequently diagnosed cancers in both Canada and the United States (ACS, 2008; NCIC, 2008).

This paper presents findings that were part of a study funded by the Canadian Institutes of Health Research (Loiselle, Edgar, & Batist, 2002-2005). The analysis focused on three research questions:

(1) Does reliance on health care services vary between the intervention and control groups and are there potential sex differences?

(2) Are participants more satisfied with informational support provided by the intervention as opposed to support received in the usual care condition?

(3) Do the aforementioned factors vary across time (e.g., between T1 and T3)?

Theoretical model. The Andersen and Newman's behavioral model of health service use (Andersen, 1995) was used as guide to organize and to interpret relevant findings. In brief, the model identifies key factors (e.g., personal/background and needs, enabling resources, contextual characteristics) that may determine subsequent reliance on health care services and health-related outcomes (Kouzis & Eaton, 1998; Vasiliadis et al., 2007). In this study, we assessed how personal characteristics (e.g., sex, cancer type) and contextual factors such as cancer informational support that may predict reliance on health care services.

Method

Sample and setting. A convenience sample of individuals newly diagnosed with cancer was recruited from four cancer clinics within large teaching hospitals in Montreal, Quebec between April 2003 and January 2006. Eligibility criteria included: (1) Primary diagnosis with early stages of either breast or prostate cancer, (2) newly diagnosed (i.e., three to eight weeks), (3) planning to undergo cancer treatment at the study sites (i.e., treated with surgery and/or adjuvant therapy), (4) proficient in either

English or French, and (5) cognitively and physically capable of completing the self-report measures. Individuals with a major comorbidity were excluded from the study. Of the 490 individuals approached (358 women, 132 men) those matching the eligibility criteria and agreeing to participate were enrolled (*N* = 250; Figure 4). The most common reasons reported by potential participants for declining to be enrolled in the study included: not interested, not having enough time, and reluctance to talk about their illness. A total of 205 women enrolled in the study divided between the intervention (n = 120) and the control group (n = 85). Fourty five men completed the study with 28 in the intervention and 17 in the control group. Ninety two percent completed all three measurement points (i.e., T1, T2, and T3).

Instruments. A series of fourteen self-report questionnaires (available in French or English) were completed by participants. The present analysis includes tools pertaining to perceived cancer informational support and patients' reliance on health care services. The Oncologist Informational Support questionnaire (Helgeson et al., 1999) was used along with a modified version to reflect nurse informational support. This tool includes nine items rated on a four-point scale (from 1 = he or she would *not* do this to 4 = he or she would *certainly* do this); scores range from 9 to 36 with higher scores indicating higher informational support. Patients were introduced to the scale as follows: "People help each other out in a lot of ways. Given the following options, indicate how likely your cancer specialist would be to help you." Cronbach alphas for this study ranged from .77 to .85. In addition, we also asked the following question: Who, among all health care professionals seen, provided the most cancer informational support? Participants indicated their first, second, and third choice in terms of the most significant source of cancer information among health professionals encountered.

The Health Service Utilization and Satisfaction with Services scale (Gustafson et al., 1998) was used to assess health care service use and satisfaction with visits to health care professionals. A few questionnaire items were slightly modified to reflect the nature of Quebec's health care services available such as community health centers. The scale consists of a list of 17 different types of health care providers (e.g., oncologist/urologist, nurse, radiotherapist/radiologist, family practitioner) or services (e.g. the emergency room). For each one, participants are asked to identify the number of visits made, time spent for each visit (in minutes and hours), and their overall satisfaction (on a 5-point scale) with the visits. In a separate study conducted by the authors of the scale, it was found to only be 2.8% inaccurate in terms of the correspondence between patients' self-report and chart reviews pertaining to health care services use (Gustafson et al., 1999). Because we were also interested in participants' reliance on complementary and alternative medicine, we presented them with a list of different approaches (e.g., acupuncture, special diet, exercise, herbs, medication from other countries, relaxation, visualization, and vitamins) and asked whether they had relied on them.

Overall satisfaction with cancer information received from health care professionals was also measured with a one-item 9 point scale from 1 "Not at all" to 9 "Very Much" which asked "Overall, how satisfied are you with the information on cancer that you have received so far?".

Procedure. As part of the large study, participants were recruited during regular visits to the cancer clinics at four hospitals in Montreal, associated either with McGill University or Université de Montréal. The sites were comparable in both the demographics of patient populations, their diagnostic and the follow-up services for oncology patients. The control and experimental sites were geographically near (within less than one mile). The experimental group was recruited through three hospitals and a fourth hospital made up the control group. Notably, the assignment of hospital settings to treatment and nontreatment conditions was not random as 2 of the 3 experimental hospitals were already in the process of implementing IHC in the form of web and CD-ROM training for oncology patients. The hospital that served as control was retained as their patients had no ready access to the study materials. The study received approval from the McGill University Faculty of Medicine Institutional Review Board and from each of the participating hospital ethics committees.

Potential participants were identified by the research assistant from lists of clinics' appointment records and via chart review. Those meeting the inclusion criteria were approached by the research assistant during their regularly scheduled medical appointments. At this time, the study was described in more detail and a participant's suitability was further determined. If he/she agreed to participate, a consent form was provided and signed either at the time of recruitment or prior to completing the questionnaire at a later date. Two professional interviewers contacted the participants to schedule a meeting where all the questionnaires were completed by these interviewers (i.e., they read the questions to the participants and recorded their answers). Interviews took place at the hospital, in participants' homes or in a public place according to participants' preferences. Two graduate students also assisted a few participants in the completion of questionnaires as part of their doctoral research training. At baseline (T1), participants completed a first series of questionnaires (that included personality variables, anxiety, depression and use of health care services). A second meeting (T2) took place approximately one week after completion of the 8-week intervention (questionnaires included factors related to the impact of the intervention such as perceived informational support and use of health care services). The third interview (T3) took place at 6 months following the initial meeting (i.e., 3 months post-intervention and again, assessed perceived informational support and health care service use). Participants received $20 for each questionnaire completed at T1, T2, and T3.

Participants in the *control group* received care as usual (i.e., provision of cancer information in the form of face-to-face discussions and pamphlets/booklets) and completed the same questionnaires as those in the experimental group with the same two professional interviewers at T1, T2, and T3 also. In addition to the study questionnaires, control group participants were asked to use a log to document any Internet use pertaining to cancer information. However, there were too few log sheets completed to allow analysis of this information. Anecdotally, however, we found out that a subset of participants in the control group relied on Internet but found the information overwhelming. Participants in the experimental group appreciated the guidance provided by the intervention (see below) in terms of having a pre-identified list of reputable websites on their particular cancer diagnosis.

Intervention. Participants in the experimental group underwent a one-hour training session conducted by a trained volunteer or the study medical librarian on

Internet use and use of the CD-ROM from the Oncology Interactive™ Educational Series (OIES™). This CD-ROM contains information on cancer-related topics including anatomy, physiology, treatment modalities, and psychosocial oncology information such as how to inform loved ones about one's cancer diagnosis. Participants also received a list of reputable Websites on either breast or prostate cancer prepared by the medical librarian. All participants left with the study materials following their training. Those without access to a home computer could borrow a portable computer, and Internet access was installed by a technician who was hired as part of the study. Similar to the control group, these participants also recorded their use of IT on a log sheet provided by the research team. The intervention materials were provided to participants for a period of eight weeks and a research assistant was available by phone or e-mail to answer questions.

Data Analysis

In this analysis, we report on T1 and T3 data to address potential long term impacts of the intervention on health care service use. The Statistical Analysis System 9.1.3® (SAS; SAS Institute Inc., 2003) was used to conduct all analyses. Sample characteristics, and independent and outcome variables were examined using descriptive statistics (mean, standard deviation, range, and frequency distributions). Global indexes (average scores) were created for oncologist informational support and nurse informational support. The higher the global index was, the more information was received from the patient by the oncologist or the nurse.

Analysis of covariance (ANCOVA) with repeated measures was undertaken using SAS procedure mixed (PROC MIXED; Neter, Kutner, Nachtsheim, & Wasserman, 1996;

Searle, 2006) as variables were normally distributed with all means adjusted. For significance testing of all fixed effects (i.e., predictors), Type III Sum of Square (Fox, 1997) was utilized; this type is generally used with unequal cell size to test the effect of a given independent variable while controlling for all other potential effects in the statistical model. The initial statistical model included sex, age, years of schooling, income, anxiety, and depressive symptoms as predictors (independent variables), and only the significant predictors were retained in the final model. Post-hoc contrast tests assessed the extent to which the experimental group differed from controls, and potential group and sex differences.

Findings

Participant characteristics. Table 2 depicts background characteristics of participants for the total sample and for men and women separately. Women in the experimental and control groups were comparable with regards to marital status but significant differences were noted on employment status, language, religion, and income. In addition, women in the experimental group were slightly younger (mean [SD] = 53.5 [10.7] years) and more education (mean [SD] = 14.56 [3.7]) than in the control group (age, mean [SD] = 57.25 [12.6] years; education, mean [SD] = 12.07 [3.3]).

The two groups of men were comparable with regards to marital status, employment status, and religion but differed in terms of language and income. Similarly, men in the experimental group were slightly younger (mean [SD] = 62.3 [7.72] years) and more education (mean [SD] = 16.33 [4.18]) than those in the control group (age, mean [SD] = 67.8 [9.55] years; education, mean [SD] = 13.39 [4.58]).

There are pragmatic as well as sex- and illness-specific reasons for the resulting small sample size for men with prostate cancer. We initiated recruitment with women first and had underestimated costs (time and financial) for accrual. By the time we began recruiting men, we further found that more men as opposed to women declined participation. As the study's grant moneys were fast being depleted, we decided to revise our targeted sample size to include a total of 50 men. Prior analysis pertaining to one of our key variable suggested that this sample size was adequate to capture potential effects of the intervention.

Professional sources of informational support. Among important sources of informational support at T1 (e.g., health care professionals, family members, friends, support groups), 58.8% of participants (n = 147 of 250) reported physicians/ oncologists as their first choice for the most important source of cancer informational support. This was endorsed more strongly by the intervention group participants than the control group (68.9% versus 44.1%; χ^2 [2, $N = 250$] = 45.17, $p < .001$). In addition, more men than women (75.6% versus 55.1%) identified physicians as their most important source of information (χ^2 [2, $N = 250$] = 12.03, $p = .002$). The most prominent second choice was nurses. However, nurses were reported by only 12.2% of the participants in the experimental group and 50% of those in the control group. This difference was significant (χ^2 [2, $N = 250$] = 45.17, $p < .001$). Interestingly, more women (32.2%) than men (6.7%) reported nurses as an important source of information (χ^2 [2, $N = 250$] = 12.03, $p = .002$).

Three months following the completion of the intervention (T3), 49.6% of the total sample reported that physicians were the most important source of cancer information: 54.1% of the experimental group and 43.1% of the control group; χ^2 (2, N = 230) = 28.64, $p < .001$. This source preference was fairly equally reported by women and men (47.8% versus 57.8%; χ^2 [2, $N = 230$] = 4.73, $p = .09$). Nurses were participants' next choice particularly for the control group: 46.1% as opposed to 16.9% for the experimental group; χ^2 (2, $N = 230$) = 28.64, $p < .001$. More women than men endorsed this second choice (31.7% of women as opposed to 15.6% of men; χ^2 [2, N = 230] = 4.73, $p = .09$).

Oncologist informational support variable. Using multivariate analysis, the impact of the intervention on perceived oncologist informational support was explored. Interestingly, A significant SEX*GROUP (experimental or control) interaction was found ($F = 6.37$, $p = .01$): men in the experimental group were more likely to report better oncologist informational support than men in the control group ($F = 11.47$, p = .0008). No significant differences were found between groups for women ($F = 1.81$, p = .18).

For perceived nurse informational support, a SEX*GROUP*TIME interaction ($F = 5.39$, $p < .02$) and a SEX*GROUP interaction ($F = 3.74$, $p = .05$) were found. That is, overall, women were more likely than men to report higher informational support from nurses ($F = 11.24$, $p = .0009$; $X = 3.21$ [0.069] vs $X = 2.69$ [0.15]). In the control group, men were significantly less likely than women to report higher informational support from nurses ($F = 12.22$, $p < .0001$; $X = 2.53$ [0.22] vs $X = 3.33$ [0.1]). The SEX*GROUP interaction for perceived informational support was significant only at T1 ($F = 13.12$, $p < .0004$).

Differences in health care service use- number of visits, and time spent. For the number of visits to oncologists, a SEX*TIME interaction was found ($F = 60.47, p < .0001$). Whereas women's visits increased over time ($p < .0001$) they decreased for the men ($p = .03$). Being in the experimental group had no significant main effect on the number of visits to the oncologist ($p = .51$).

For the number of visits to nurses, a SEX*TIME interaction was also found ($F = 4.35, p = .04$). Whereas the number of nurse visits increased among women ($p = .002$), these did not significantly change over time for the men ($p = .38$). Higher anxiety was related to more visits to nurses among women but not among men ($F = 6.12, p = .01$). Being in the experimental group had no significant main effect on number of visits to nurses ($p = .59$) nor on the number of telephone consultations ($p = .54$).

For time spent with oncologists, a significant SEX*TIME interaction was found ($F =36.96, p < .001$) with decreasing time spent from T1 to T3 among women ($p < .0001$) but not among men ($p = .17$). Being in the experimental group had no significant main effect on time spent with oncologists ($p = .10$).

For time spent with nurses in face-to-face consultations, again, a significant SEX*GROUP*TIME interaction was found ($F = 3.24, p = .02$) with a GROUP*TIME interaction ($F = 8.86, p = .003$). Overall, participants in the experimental group spent more time with nurses ($F = 4.73, p = .03$). More specifically, time spent with nurses increased from T1 to T3 among women with breast cancer that were in the experimental group ($F = 8.86, p = .003$), but not in the control group ($F = 2.24, p = .14$). Not taking time into account, men were found to spend less time with nurses in the experimental group only ($F = 4.29, p = .04$). Interestingly, for participants in the experimental group, depressive symptomatology as measured by the CESD (*Center for Epidemiologic Studies-Depression Scale*; Radloff, 1977) was significantly associated with more time spent with nurses $F = 4.35, p = .04$).

For time spent in telephone consultations, no significant interactions among sex, experiment, or time were found. Nevertheless, exploratory analyses were conducted with women's groups and men's groups separately. Neither men nor women in the experimental and control groups differed significantly with respect to amount of time spent in telephone consultations ($F = .28, p = .59$ and $F = .34, p = .56$), respectively. However, men in the experimental group spent marginally less time in telephone consultations at T3 than at T1 ($F = 3.50, p = .06$).

Satisfaction with cancer information received. At T1, 63.6% of the total sample reported being very satisfied (7 to 9 on a nine-point scale) with the information they received from their health care professionals. Surprisingly, at T1, more participants in the control group (78.4%) reported being satisfied with cancer information than those in the experimental group (53.4%; χ^2 [2, $N = 250$] = 17.31, $p < .001$). This was reported more by women (65.4%) than by men (55.6%; χ^2 [2, $N = 250$] = 6.33, $p = .04$). Further analyses suggested a significant main effect, however, between T1 and T2 with more satisfaction with cancer information reported by the experimental group than the control group, $F = 9.10, p < .01$)

Health care services use: Complementary and alternative medicine. Participants were also asked about their reliance on complementary and alternative medicine (CAM). At T1, 14% of the total sample reported using at least one type of CAM with more reliance in the experimental (17.2%) than in the control group (7.8%; χ^2 [1, $N =$

250] = 5.42, $p = .02$). Women and men did not differ on their use of CAM χ^2 (1, N = 250) = 11, $p = .74$).

At T3 however, more individuals relied on CAM than at T1 (24.4%), with more participants in the experimental group (28.4%) reporting using CAM in comparison to those in the control group (17.6%; χ^2 [1, N = 230] = 3.11, $p = .07$). Again there were no significant differences between men and women.

Discussion

Findings revealed that overall the intervention had a positive impact on participants' satisfaction with the cancer information received from the intervention but subsequent analyses showed the effect to be most striking between T1 and T2. Such findings add to descriptive studies which point to higher cancer information needs at the time of cancer diagnosis and shows that the intervention had a beneficial impact by satisfying these informational needs (Chelf et al., 2001; Hack & Degner, 1999). A recent study also found that men with prostate cancer were more satisfied with the cancer information provided via computers when compared to usual care (Davison, et al., 2007). Findings from this study also revealed that, overall, women reported being more satisfied with cancer information received than men. These findings might be explained, in part, by the fact that women with breast cancer might find it particularly helpful to discuss their cancer experience with others (Chen, Diamant, Thind, & Maly, 2008; Loiselle, Lambert, & Cooke, 2006) whereas men tend to seek only "necessary" (factual information) and are not as interested in engaging in discussions about their cancer (Hoffman-Goetz & Friedman, 2005; Kiss & Meryn, 2001). A separate qualitative study found that men preferred written cancer information from health care professionals during regular visits to the oncology clinic and information found on the Internet (Dubois & Loiselle, 2008a).

Interestingly, a separate study suggests that satisfaction with information might vary according to type of cancer diagnosis (Davidson & Mills, 2005). In this study, more satisfaction with cancer information was found among individuals with either colorectal or breast cancer when compared to those with gynecological or prostate cancer. In the present study, the nature of participants' cancer diagnosis might explain, in part, this observation as the prostate cancer illness trajectory is often more ambiguous than that of breast cancer (e.g., in terms of treatment modalities, intensity, timeline etc.). Anecdotally, researchers' observations at the time of training for the intervention also pointed to sex differences in terms of acceptability of the training, with men more frequently refusing training. They often stated that they would take the intervention materials home (i.e., CD ROM and recommended websites) and figure it out on their own. The findings that women and men showed different patterns of service use make intuitive sense in relation to particular types of cancer diagnosis (beyond genuine sex differences). Obviously, differences in treatment regimens according to breast or prostate cancer often dictates patterns of use and number of required visits to physicians and nurses – an issue further developed in a related paper relying on a mixed design approach (Dubois & Loiselle, 2008b). The observation that women as opposed to men spent more time with nurses but only in the experimental group is in line with previous work indicating that women are more willing to seek help and rely on face-to-face professional assistance when made readily available (Moody, 2003; Steginga et al., 2008). Interestingly, findings revealed a rather low reliance on

CAM (between 36%-43%) for Canada, the United States, and Europe (Adams & Jewell, 2007; Verhoef, Balneaves, Soon, & Vroegindewey, 2005). Future studies should elucidate key factors that may contribute to differential reliance on CAM.

More participants in the experimental group reported the oncologist as their first choice as cancer informational resource. This observation might be related to their need to further discuss the wide range of cancer information provided by the multimedia intervention. As subsequently found in our in-depth interviews (Dubois & Loiselle, 2008a), participants often reported their need to further clarify or confirm with their physician, cancer information found on the Internet.

Of note, several limitations are linked to the present study. The generalization of findings is limited to patients with breast or prostate cancer with similar background and illness characteristics. In addition, reliance on a convenience sample and a quasi-experimental as opposed to a randomized clinical trial design reduces the robustness of findings. The small sample size for men may also not provide an accurate account of the larger group and challenges in recruitment and budget consideration precluded the researchers from reaching the targeted sample for men. Therefore, findings related to this restricted sample must be interpreted with caution. Last, the possibility that controls may have significantly sought cancer information through IT on their own while not reporting it limits inferences that can be drawn from this study.

Future research is obviously needed to disentangle the differential contribution of sex and particular types of cancer diagnosis in relation to patterns of health care service use. In addition, reliance on more robust designs such as randomized control trials would elucidate further the nature of the findings contributed by this study.

Conclusions

This study is innovative in that it builds on a relevant theoretical model to assess the impact of a cancer educational intervention using multimedia technology on health care service use. The findings suggest that the intervention provides added-value for individuals newly diagnosed with cancer which includes ready access to timely cancer information, tailored informational support, and possibly a more informed utilization of health care services. Considering potential sex/gender differences and related cancer informational needs, the targeting or tailoring of supportive health information interventions is likely to more adequately meet these differential needs which in turn will ease psychological suffering, increase quality of life and guide individuals in their reliance on the most appropriate supportive care services. Ideally, future studies would include larger, hard-to-reach samples of individuals with cancer with lower-socioeconomic-status and whose informational needs remain all too often unmet.

Manuscript 2: Understanding the Role of Informational Support in Relation to Health Care Service Use Among Newly Diagnosed Individuals

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Preface

In accordance with our literature review, few studies have explored the role of informational support in relation to health care service use. Even though an educational intervention was reported to lead to fewer visits to health care professionals in oncology care (Simpson et al, 2001), qualitative data to obtain a better understanding of the topic have been rare. Studies on health care services have mostly focused on factors that predict the use of services (e.g., demographic variables; Baker, Wagner, Singer, & Bundorf, 2003; Gray, Goel et al., 2000; Heaney, Wyke, Wilson, Elton, & Rutledge, 2001). However, the use of health services was identified as a complex process (Leaf et al., 1988; Muller, 1990).

The purpose of the second manuscript is to explore in more depth, using a qualitative approach and semistructured interviews, informational support received, health care service used, and links between informational support and health care service use from the point of view of women newly diagnosed with breast cancer and men newly diagnosed with prostate cancer. Questions asked were developed based on data from the previous quantitative study.

Abstract

A qualitative study was undertaken to explore the role of informational support in relation to health care service use among individuals with cancer. In-depth interviews were conducted with participants (N = 20) newly diagnosed with either breast or prostate cancer receiving radiotherapy from an oncology clinic in Montreal, Quebec. Content analysis revealed that participants' perceptions about their experience with cancer informational support in relation to health care services varied along the following dimensions: (1) Cancer informational support as tangible, which enabled, confirmed, normalized, and directed their decisions about reliance on health services; (2) Cancer informational support as somewhat paralysing, which lead to distress, conflict, reduced confidence in the health care system and, at times, misuse of health care services; and (3) Cancer informational support as limiting, with perceptions of having received both helpful and unhelpful cancer information which, in turn, although tolerated offered little guidance in terms of reliance on the most appropriate services. Knowledge about how and when informational support may be most timely may optimize individuals' well being and further guide their use of cancer-related services.

Abrégé[1]

Cette étude qualitative a été réalisée dans le but d'explorer le rôle du soutien informationnel dans l'utilisation des services de santé par des individus diagnostiqués d'un cancer. Des entrevues individuelles en profondeur ont été faites avec des participants (N = 20) nouvellement diagnostiqués soit avec un cancer du sein ou de la prostate et recevant des traitements de radiothérapie en clinique d'oncologie à Montréal,

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[1] A French abstract is required for this journal

Québec. Par une analyse de contenu, l'expérience vécue par les participants varie selon les dimensions suivantes: (1) le soutien informationnel tangible, lequel facilite, confirme, normalise, et dirige les décisions des participants dans l'utilisation des services de santé; (2) le soutien informationnel paralysant, lequel amène de la détresse psychologique, de l'opposition, de la méfiance, et de la confusion dans l'utilisation des services; et (3) le soutien informationnel mixte lié aux perceptions d'avoir reçu à la fois de l'information aidante et non aidante (et tolérée) qui optimise peu l'utilisation des services. Les connaissances sur le comment et le moment où le soutien informationnel est plus pertinent peuvent optimiser le bien-être et l'utilisation mieux informée des services en oncologie

Background

With advances in treatment, individuals with cancer now live longer, increasing the need for various services such as psychosocial support and cancer control (Rosenbaum & Rosenbaum, 2005; Rutgers, 2004). Part of psychosocial support, informational support is now known to contribute to knowledge acquisition, decision-making, self-care abilities, and adherence to treatment recommendations; it may also decrease fear and anxiety, and increase hope and empowerment (Gornick, Eggers, & Riley, 2004; Lambert & Loiselle, 2007). When information needs are not fulfilled, individuals with cancer may be more likely to over use health services such as community and emergency facilities (Carlson & Bultz, 2004).

Even though a literature review suggests that informational support may lead to more reliance on cancer screening services (Finney Rutten, Arora, Bakos, Aziz, & Rowland, 2005) and that overall, women are more likely to use health services than men

(Green & Pope, 1999; Vasiliadis, Lesage, Adair, Wang, & Kessler, 2007), few studies have explored the role of informational support in relation to health care service use. Studies on health care services have mostly focused on factors that predict the use of services (e.g., treatment modalities, comorbidity, physical function, pain, sociodemographic variables) often with one main goal of reducing costs (Andersen, 1995). For instance, one study conducted among women diagnosed with breast cancer (N=123) reported fewer visits to the cancer center after receiving an educational intervention (Simpson, Carlson, & Trew, 2001). This study was the first to demonstrate that women who participated in an intervention group reported a reduction of visits to clinics and a better quality of life than those in the usual care condition. More recently, a study was conducted with veterans (predominantly men) diagnosed with cancer (N = 125; all cancer types), to compare a telehome health care program (i.e., using technology for informational support, including professional follow-up during chemotherapy treatment), with usual care relative to the use of health care services (Chumbler et al., 2007). Results showed fewer visits to clinics and fewer hospital stays in the experimental group. However, this study focused on coordination of care for symptom management that included informational support which was not separately measured. Moreover, the role of cancer informational support in guiding their use of services from the participants' point of view has not been reported.

The present study was conducted to further explore the perceived role of informational support in relation to the use of health care services among women and men newly diagnosed with cancer. Several questions guided the inquiry such as: What is it like, for individuals newly diagnosed with cancer, to be provided with or to have to seek cancer-related information? What is it like to negotiate health care services when one has just learned that they have cancer? To what extent is cancer-related informational support (both formal and informal) helpful or unhelpful in guiding reliance on cancer-related services? We also explored whether sex differences were emerging from the data. Breast and prostate cancers were chosen as they involved different sexes and are the most frequently diagnosed cancers in both Canada and the United States (American Cancer Society, 2008; National Cancer Institute of Canada, 2008).

Method

This descriptive qualitative study used a purposive sampling strategy to recruit participants who showed an interest in communicating their experience with cancer information in relation to health care service use. Inclusion criteria also included a primary diagnosis of breast or prostate cancer (within a year of diagnosis), reliance so far on at least two distinct cancer services (e.g., outpatient clinics, emergency rooms, group support, community health centres) to allow enough richness in accounts. In addition, individuals had to have a good understanding of English or French, and be cognitively and physically capable of participating in a two-hour face-to-face interview. Individuals with major comorbidity were excluded as this would have confounded reports of health care services utilization. Following ethical review and approval by the relevant ethics' committees (hospital and University), data were collected over a four-month period (between the months May and September in 2006) in a large urban teaching hospital in Montreal, Quebec.

Initially, potential participants were identified by staff nurses or radio-technologists and initial agreement to be approached by the researcher was obtained. The researcher then met interested patients in a private clinic room; the study was described, eligibility criteria were assessed, and ethical considerations were discussed. Written consent was obtained from patients who agreed to participate, and they completed the sociodemographic sheet. Next, an appointment was scheduled to conduct the individual interview. Participants were interviewed in a location of their choice (either at the participant's home or in a private room in the hospital). The interview was either conducted in French or English according to the wish of participants.

All individual interviews, conducted by the first author, lasted between 55 to 150 minutes and were digitally recorded. The open-ended interview questions asked the participants to describe sources of information used since they received their cancer diagnosis, types of services used and issues related to information and services such as accessibility of services, barriers or frustrations, potential links between the cancer information received and subsequent use of health care services, and satisfaction with these services. Specific probes were used to develop further the recounting of events surrounding their experience with cancer (e.g., diagnosis, treatment). The interviews ended with a summary of the discussion, and verification of the accuracy of the main points made by participants. Detailed field notes with comments, and personal impressions were compiled during and immediately after each interview. A compensation ($20) was offered before the interview to participants to acknowledge their time spent with the interviewer.

An initial sample size of 20 participants was planned with an overarching goal of continued recruitment until the research questions were sufficiently documented and additional data became redundant. Sample characteristics of participants (women with breast cancer, *n* = 10; men with prostate cancer, *n* = 10) are described in Table 3.

Data analysis. Field notes and digital interviews were transcribed verbatim and a content analysis was undertaken (Miles & Huberman, 1994). Transcriptions were checked by the first author for accuracy. They were then transferred into NVivo 7.0 (QSR International). To easily search, retrieve, code and analyse the data collected, a unique marker was attributed to each participant (i.e., W1 to W10 for women, and M11 to M20 for men). The lead author (SD) undertook coding of the content.

The analysis began concurrently with data collection starting with the first interview. As data collection progressed, categories were identified through content analysis which involves three stages of analysis (Miles & Huberman, 1994). First, data that appeared in field notes and transcriptions for each participant were sorted and organized with respect to the questions being addressed. Second, information was organized with narrative text; then a matrix presentation was developed to classify data into categories. This allowed the identification of preliminary themes and potential connections between informational support and health care service use. Third, data were explicitly connected to themes, and revised several times with the second author to cross-check and verify emerging recurrent, converging and contradictory findings. Pertinent literature was also used to identify and describe the emerging themes. All categories and themes were reviewed by the second author through discussing and reexamining discrepancies to ensure that they reflected the content. In addition, decisions and events related to the study were documented in an audit trail. In terms of methodological rigor (Loiselle, Profetto-McGrath, Polit, & Beck, 2007), credibility was enhanced by feedback from participants in terms of the adequacy of the summary of findings and detailed field notes were kept. Direct quotes and summary of findings were also reviewed and discussed among our research team and additional nurse researchers involved in qualitative research.

Findings

Following in-depth content analysis, three main experiences emerged with respect to cancer informational support and health care service use. These included: (1) a positive experience with informational support to guide service use — *i.e., Cancer informational support as tangible in guiding participants' use of health care services*, (2) an unsupportive experience with informational support to guide service use— *i.e., Cancer informational support perceived as paralysing, precluding participants from using certain health care services,* and (3) a mixed experience with informational support although tolerated, was less than optimal in guiding service use— *i.e., Cancer informational support experienced as limited in terms of guiding participants to the most appropriate services*. In addition, gender or sex differences emerged according to both concepts of interests. These findings are reviewed in turn with relevant quotes from participants.

Cancer information as tangible support in guiding health care service use. The first category of informational support refers to its positive role as a tangible support in guiding participants' use of services through several distinct processes that were either *enabling*, *confirming*, *normalizing*, or *directing* services use.

The process of *enabling* refers to cancer informational support as assisting individuals in self-care and facilitating informed use on relevant health services (e.g., using phone calls as opposed to visits to health care providers). With enabling support, participants felt better prepared for appointments with health care professionals such as their oncologist; they reported taking part in decision making and progressing more smoothly through the illness trajectory. Participants also reported that the services sought seemed appropriate and helpful and that they gained confidence in these services in terms of having additional information related to their cancer experience. For a few, satisfaction with information meant that they used these services on several occasions. One woman recalled:

> I called Info-cancer [Société québécoise du cancer] to have information before my surgery [breast cancer]. A nurse returned my call. He answered clearly my questions and I knew what to do [mainly with wound and persistent pain]. I called the service at least 7 times. That really helped me. (W_P9)

The Internet was also reported as enabling particularly at the time of diagnosis as such information was readily accessible, presented in simple language, and often used to guide subsequent exchanges with health professionals. This was particularly salient for four participants (2 women and 2 men). For instance, one man explained:

> After being told of my diagnosis [prostate cancer].....the Internet was the way to have easy information about my disease... And the more I learn the more I know what I have to do...and what to ask the doctors [about treatment, side effects and fatigue]... (M_P14)

A second process that of *confirming* captures the process of validation of cancer information accessed through subsequent formal or informal means (e.g., through consultations with oncologists, radio-oncologists, nurses, support groups or lay individuals). Cancer information, particularly pertaining to types of treatments or side effects was sought to be confirmed before choosing to act on such information. One man recounted:

> I told the doctor [the urologist] who advised me… I wasn't sure I wanted this treatment. … my wife and I [went] to a support group, and by listening to the others… we were sure about our decision to go further [in searching for other treatment choices]…We went to a conference and had a discussion with the keynote speaker, a radio-oncologist…he confirmed the treatment option…(M_P16)

The third process, *normalizing*, refers to informational support that serves to reassure or place into context various pieces of cancer information that can then be used to decide which health care services to rely on (i.e., agreement with their own perceptions about cancer information received). In this study, we observed that men particularly tended to normalize their cancer situation through reliance on literature provided routinely by staff. They decision to subsequently consult health care professionals or not was based on what they learned. One man explains:

> I refer to the information that the nurses gave me [brochures and booklets]. For example, if I have cramps, I will see the side effects and I see that it is normal, and then fine, everything is normal… I do not need to call the hospital for that. I do not ask for more…
> (M_P19)

Interestingly, women tended to report that they preferred personal contact (e.g., phone calls or visits) as opposed to written materials as they felt that the information was more personalized. For instance, one said:

> Even though I had read the booklet, I called the nurse three times and asked questions about side effects I experienced… (W_P7)

The fourth process, information as *directing* use of health care services, refers to informational support that guide participants' decision to rely on particular services. Informational support from health care providers, particularly from oncology nurses, was reported by most of participants as an important source of information often helping them in deciding which service to use and when (e.g., when to rely on emergency services as opposed to the walk-in clinic). One woman recalled:

> When I had chemotherapy, the nurses informed me that if I had a fever or difficulty breathing, to come immediately to the emergency. So, when I felt so badly and that I did not know what to do, I came automatically to the emergency. When I need to ask questions but it was outside business hours or working days, I phoned them [nurses at the oncology clinic]. (W_P1)

One participant reported using informal channels to obtain information and services that he felt he needed:

> I spoke with my sister-in-law about my cancer [prostate], her brother had the same cancer as I did… I really didn't like the oncologist I had consulted… My sister-in-law … found me another oncologist. (M_P20)

When using cancer services, tangible informational support was experienced positively by participants. This support was perceived as helpful and satisfying for their search and use of services. In addition, most participants reported experiencing a blend of processes. As indicated in Table 4, *enabling* and *directing* were experienced more frequently by participants (women and men) whereas *normalizing* was least frequent. Participants' capacity for involvement in decisions pertaining to service use may have been enhanced by the type of informational support provided.

Cancer information as paralyzing participants' potential reliance on health care services. The second category of informational support refers to its perceived unsupportive role in guiding participants' use of services. Four distinct processes were found within this category. Informational support perceived as *distressing*, *conflicting*, or *misguiding* service use. Last, unsupportive information also could lead to a process of not longer trusting the health care system.

Informational support construed as *distressing,* refers to information provided by health care professionals that participants experienced as stressful, especially pertaining to wait times. Participants often felt that they had waited more than they should have to obtain the services they needed (e.g., test results, follow-up appointments, consultations with health care professionals). They also often felt that they had to persevere to get the needed services (e.g., making repeated phone calls to get through). As expressed by this woman:

> After the surgery [breast cancer], it had been several days since I had any information [about the next step in treatment]. I called [in radiotherapy] and the nurse told me, "We will call you, don't you worry". And I waited. I called twice a week and she [the secretary] told me, "I'm overbooked; there are people from January who are still on standby". We were in March. Then I came that close to not wanting treatment [radiotherapy] anymore. (W_P4)

In addition, when participants received information that they had not expected or did not understand, they experienced anxiety and felt unsure about further service utilization. For one man, such ambivalence was related to treatment options and his wish to consult more than one oncologist. He reported "I did not see more options than surgery with this oncologist" (M_P17).

For one participant (W_P7), the physician minimization of her pain at her first visit lead her to question whether she should consult again. She recounted him stating that: "All women above 60 (years) have some physical problems." She waited several weeks before deciding to see the physician again.

The second process, *conflicting*, refers to informational support that places participants in a quandary as to what to do or what services to use next. Some participants reported that they had received contradictory information from health care professionals at different stages of their experience with cancer (e.g., at their first consultation with the oncologist, post surgery, etc.) or from informal sources (e.g., lay individuals), that left them confused as to what to do. One participant recounted:

> The oncologist was not happy to learn I was taking a drug, Paxil (to decrease dysphoria prior to menses). My gynaecologist had prescribed it to me ...because of my pre-menopause ... Then one of them says, "I want you to stop taking this drug," and the other one, "I want you to stick to it... Do I have to see my family doctor to talk about it?... [She did not know] (W_P1)

The third process, *misguiding*, refers to informational support that lead to erroneous or incorrect perceptions of the health situation based on the information (or lack of) received. This particularly seemed to happen at the time of diagnosis. As reported by this participant:

> Then I never had news from them [professionals at the private clinic for the results of the breast biopsy]. The doctor told me, 'Within 15 days you will have the results.' I did not worry too much. But I did not have news.... I phoned them to have the results. I was told that if they did not call back it meant that the results were good... However...later, the doctor told me: 'We found malignant cells ..." (W_P9)

Mistrust of the health care system refers to how unsupportive or inadequate informational support lead to reduce participants' confidence in relying on health care services. One participant explained that receiving "generic" information from health professionals that did not apply to her made her reluctant to seek further assistance (e.g., through phone calls or visits). She recalled:

> The nurse gave me all the training on the drain [before my breast surgery]..... I tried to remember it all but I [ended up] not having a drain... I didn't want to receive any more information ... because when I receive information I don't need, I don't want to ask questions or use [of subsequent] services like the emergency or the oncology clinic ... they [professionals] gave me information that was not for me... I would like to be more confident but ...(W_P1)

In this study, more than half of the participants (both women and men) experienced at least one episode that was reported to be found unsupportive in terms of directing them to cancer services (Table 4). Of those, most related to the experience as *distressing* rather than *conflicting, misguiding* or leading to *mistrust*. This highlights that distressing experience with informational support perceived as unhelpful could stimulate overutilization of health care resources (Roy-Byrne & Katon, 1997; Saares & Suominen, 2005). In this study, only one participant (W_P3) reported all four unsupportive processes to have been present at some point of her illness trajectory which ended up undermining her overall confidence in the health system.

Cancer information as limiting support in guiding health care service use. The third category refers to a mixed experience with informational support leading to both positive and negative feelings pertaining to participants' use of health care services. Within this category, the process of *tolerating* less than optimal informational support often led participants to limit their subsequent use of cancer-related services.

Within this category, even though cancer information provided by health care professionals was perceived by participants as minimal or insufficient, they provided excuses to account for such limitation while acknowledging that this impacted on their use of relevant care services. Participants often reported that they felt they had to accept the situation; they did not wish to complain or to be more proactive in searching or using services. One woman and three men referred to this situation (Table 4). As one woman recalled:

> The surgeon removed the mass [breast cancer]… yes I had three surgeries within the last five months to remove all of the malignant cells; I knew I had cancer but I did not know more about it…What can I do?... It took a long time to get the first appointment, to have surgery, to get results… I did not want to complain and lose my turn, searched for another specialist and not find one, or had other kinds of problems…(W_P9)

The types of excuses made by participants included rushed consultations because of limited professional time and overbooking of appointments (particularly among physicians). However, participants seemed resigned to accept the situation. One man reported:

> The doctor's waiting room [family practitioner or oncologist] is always filled and as time goes by, the more I see that time he takes with patients decreases; instead of 15 minutes, it is 10 minutes and even 5 minutes. He is so overflowed and in a rush…with each visit, it is always the same thing. (M_P16)

In addition, one man said that it was the patients' own fault if they did not get sufficient information from health care professionals because "the nurse and the doctor gave information; each of them is set out to help us. We only have to ask". (M_P15).

Discussion

To date, little is known about how and when the receipt of cancer information from health care professionals may impact on their subsequent use of health care services. The present qualitative study provide new insights about the role of the informational support (formal and informal) among women and men newly diagnosed with cancer differentially guiding their use of health care services.

Findings revealed various experiences with cancer informational support provided and several related processes that subsequently guided (or misguided) health care service use. Participants either perceived informational support as positive, unsupportive or have a mixed impact on their subsequent search and use of health care services. To our knowledge, these processes have not been reported elsewhere.

In the present inquiry, participants experienced at least one type of informational support (e.g., positive, unsupportive, or mixed) as well as several processes (e.g., enabling, distressing, conflicting) underlying health service use. Moreover, the relationship between informational support and use of health care services was found to be more complex than initially thought. Participants who experienced positive informational support (e.g., that met their needs for cancer information) also reported being satisfied with the services sought. Whereas the "need factor" is reported to be the most significant predictor of actual health care service use (de Boer, Wijker, & de Haes, 1997; Vasiliadis et al., 2007), the relationship between enhanced informational support and more or less health care service use still remains unclear.

For participants who reported negative experiences, the findings were in line to those described by individuals with cancer (Bowes, 1993; Kearney, Miller, Paul, Smith, & Rice, 2003). Individuals were less likely to ask questions, come back to the health care system or seek appropriate services when they received what they considered inadequate cancer information or when they experienced ineffective communication with health care providers. These observations suggest that several challenges and issues still exist with our health care system across the illness continuum.

Although anecdotal and in need of further study, some gender/sex differences particularly pertaining to modes of communication about cancer emerged (e.g., preferences for verbal as opposed to written advice). More men relied on written information and more women relied on personalized exchanges with professionals. Similarly, Seale, Ziebland & Charteris-Black (2006) found that men with cancer tended to prefer written information and the Internet whereas women generally preferred direct communication.

Several limitations are linked to the present study. All interviews were conducted with participants receiving active radiotherapy treatments for their cancer which often dictate reliance on particular health care services. Interview questions relied on participants' memory of events and bias in recall may have been introduced. In addition, men in this sample were more educated than the women (5 held University degrees as opposed to one woman) may have also qualified the findings in terms of eagerness to seek cancer information and accessing more services – a finding reported elsewhere (Gray et al., 2000; Steginga et al., 2008).

Implications for Practice and Research

The present findings highlight the need for health care professionals to more explicitly address how patients' perceptions of informational support may affect their subsequent use of health care services and possibly their health outcomes.

To our knowledge, this is the first study to document the nature of the relationship between informational support and health care service use among women with breast cancer and men with prostate cancer. Future studies would document this phenomenon among more diverse samples (in terms of cultural background, socioeconomic status, health literacy and according to differing cancer diagnoses) and at different points on the cancer trajectory.

Manuscript 3: Cancer Informational Support and Health Care Service Use Among Individuals Newly Diagnosed: A Mixed Methods Approach

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Preface

Historically, researchers have used mostly quantitative methods to document the use of health care services (O'Cathain et al., 2007). However, in the last decade, interest in the combination of quantitative and qualitative methods has been developed to explore discrepancies between findings (Barbour, 1999; Moffatt, White, Mackintosh, & Howe, 2006). Given this, quantitative and qualitative data from the current study were combined and reanalyzed taking into account that women tended to use more health care services than men (Green & Pope, 1999; Vasiliadis et al., 2007), and knowledge of the interrelationships among informational support, a new cancer diagnosis, and potential sex differences relative to health care service use.

The purpose of the third manuscript is to explore in greater depth the quantitative data by refining them with qualitative data collected using a hierarchical model.

Abstract

Aim: To report on the integration of quantitative and qualitative findings to further understand the role of cancer informational support and use of health care services among individuals newly diagnosed with either breast or prostate cancer.

Methods: A mixed methods sequential design was used. First, a secondary quantitative analysis was undertaken of self-report data from a large number of individuals newly diagnosed with cancer (N = 250); next, a follow-up, in-depth qualitative inquiry with distinct individuals also newly diagnosed was conducted (N = 20); last, using a quantitative-hierarchical strategy, quantitative and qualitative findings were merged and reanalyzed.

Results: Quantitative analyses showed significant relationships between informational support and health care services. For instance, individuals who received more intense cancer informational support (face-to-face and information technology/IT/IHC) spent more time with nurses. Women with breast cancer as opposed to men with prostate cancer also were found to rely primarily on nurses for cancer information and information on health services available, whereas men relied mostly on their oncologists. In-depth interviews revealed that informational support could be construed as positive, unsupportive, or mixed depending on context. The mixed design analysis documented positive experiences for individuals who reported to be better prepared for consultations and treatments with information provided by more than one source. Negative experiences with physicians were reported by both women and men but the former was about quality of cancer information provided and the latter in terms of quantity.

Conclusions: A mixed methods approach allowed a deeper understanding of the role of informational support on subsequent use of health care services by individuals with cancer. Further studies may include other types of cancer and diverse background

characteristics to clarify how informational support and subsequent use of health services may be jointly determined by these factors.

Introduction

To date, breast and prostate cancers remain the most frequently diagnosed cancers in both Canada and the U.S. (ACS, 2008; NCIC, 2008). However, these individuals newly diagnosed with cancer have significant psychosocial and information needs which often are unmet (Chelf et al., 2001; Sanson-Fisher et al., 2000; Steginga et al., 2001; Vivar & McQueen, 2005; Zabora et al., 1998). Evidence suggests that these unmet needs are mainly related to difficulties in accessing cancer related health services and lack of continuity in cancer care (Stephen & Boyle, 2005). In addition, individuals diagnosed with cancer often report dissatisfaction with the information they receive and demand more cancer information (Chelf et al., 2001; Loiselle & Dubois, 2003). This is concerning as appropriate informational support[2] is known to improve informed decision-making, self-care skills, and adherence to treatment recommendations and also is instrumental in decreasing fear and anxiety, increasing hope and empowerment, and reducing cancer morbidity (Broeders et al., 2002; Gornick et al., 2004; Lambert & Loiselle, 2007). Also, it has been suggested that informational support may also influence use and access to health care services (Berg et al., 2004). For instance, lack of illness information has been suggested to contribute to anxiety, which in turn may stimulate overutilization of health care resources (McCaul et al., 1999; Roy-Byrne & Katon, 1997; Saares & Suominen, 2005). Despite the implications of informational

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[2] For the purpose of this study, *usual care* refers to cancer informational support received in the form of verbal and written information and *enhanced informational support* refers to usual cancer informational support complemented by additional information obtained through IHC, information technology (IT; i.e., computer, and the Internet).

support in the use of health care services (e.g., less or more use) by individuals newly diagnosed with cancer, this relationship remains poorly documented (Blaum et al., 1994; de Boer et al., 1997). This study therefore clarifies the role of informational support in relation to health care service use to guide future development of innovative informational interventions and seeks to optimize health care service use by individuals newly diagnosed with cancer, and to provide new insights for integrating informational support into routine care.

Background: Informational Support and Health Care Service Use in Oncology Care

A few studies that focus on factors that predict the use of health care services (e.g., treatment modalities, comorbidity, physical function, pain, sociodemographic variables) by individuals diagnosed with cancer have investigated how these factors may moderate service use mainly in terms of more intense use (Arora, Johnson, et al., 2002; Ashbury et al., 1998; Gray, Goel, Fitch, Franssen, & Labrecque, 2002; Johansson et al., 2004). Additional factors such as sex and informational support received from health care providers have also been suggested to influence which service individuals diagnosed with cancer used and how often these are accessed. Evidence suggests that overall women are more likely to use health services than men (Green & Pope, 1999; Vasiliadis et al., 2007) particularly when it comes to preventive cancer-related services (Gornick et al., 2004). This may be explained, in part, by the higher number of cancer-related services available to women than to men and differential media overage of particular types of cancer diagnosis. For instance, there is 2.6 times more information available about breast cancer in the media than prostate cancer (ACS, 2007; National Prostate Cancer Coalition [NPCC], 2007). Note that breast and prostate cancer vary in terms of diagnostic procedures, treatment options available, associated side effects, and illness trajectories (ACS, 2007; NPCC, 2007), which may also account for differences in health care service use.

Previous research has shown that individuals who are better informed tend to report more satisfaction with their medical care and their interactions with health care providers (Andreassen et al., 2005; Chelf et al., 2001). This prompts the question of whether better informed individuals diagnosed with cancer use health services differently than less informed ones. A variety of studies have explored preventive areas (e.g., primary care in terms of physical exam, blood testing) related to cancer and showed that informational support prompted individuals to use cancer screening services (Finney Rutten et al., 2005; Michielutte et al., 2005; Taylor et al., 2001). Two randomized controlled trials (Simpson et al., 2001; Wyatt et al., 2004) conducted among women with breast cancer revealed divergent findings in terms of service use following an educational intervention. Simpson et al. (2001) reported that for those receiving the educational intervention, a reduction was noted in the number of visits to health care professionals by women (N = 123) and overall better psychological outcomes (i.e., in terms of depressive symptoms and mood disturbances). Wyatt et al. (2004) reported improvement in women's knowledge of self-care (N = 240) but no significant differences in the use of health care services compared to the control group. However, Simpson et al. (2001) assessed informational support using a measure of general social support (i.e., with a focus on emotional support) which may have influenced the obtained results in terms of health care service used. More recently, a matched-control design (Chumbler et al., 2007) was conducted with veterans (predominantly men) diagnosed with cancer (N = 125; all cancer types), to compare a telehome health care program (i.e., use of Internet and computerized systems, including professional follow-up during chemotherapy treatment and symptoms-based education), with standard care relative to the use of health care services. Results showed fewer visits to clinics and fewer hospital stays in the experimental group. However, this study focused on coordination of care for symptom management that included informational support that was not separately measured. In addition, participants were older (i.e., veterans) and more than 75% had a late-stage disease. No data were collected on the influence of severity of symptoms on the use of health services (e.g., less use of services with older individuals or those who had less pain). Unfortunately, studies examining the impact of informational support intervention do include health care service use as one of their outcomes (e.g., Davison et al., 2007). Despite the potential influence of informational support in health care service use for individuals newly diagnosed with cancer, there are still very few empirical studies that have investigated the role of informational support in health care services use.

Purpose of the Study

The purpose of the present study is to document relationships among informational support and a new cancer diagnosis relative to health care service use with regard to sources of support and patterns of service use among women diagnosed with breast cancer and men diagnosed with prostate cancer. The study further explores potential sex differences. When ambulatory oncology services are estimated to intensify (Erikson et al., 2007), it is important at this point to better understand whether individuals who have access to more cancer information show differing patterns of health care service use compared to those who have less access to such information. In addition, clarifying the potential role of background variables such sex and disease type may contribute to our understanding.

The general research question for this inquiry was: To what extent is informational support related to health care service use among individuals newly diagnosed with either breast or prostate cancer? This question could arguably have been addressed using a single method. However, we considered a mixed methods design useful as it employs inductive as well deductive reasoning to account for participants' experiences with cancer informational support and health care services. The intent of using of a sequential, mixed methods design was threefold: (1) to perform a secondary statistical analysis on an existing cancer education intervention trial database in order to determine relationships among variables of interest and to guide the next step of inquiry; (2) to explore in greater depth participants' experiences with cancer information and health care services through a qualitative study; and (3) to provide further insights into the interrelationships between cancer informational support and health care service use through the reliance on a mixed methods analysis.

The first step relied on secondary analyses to measure relationships between the independent variable (i.e., informational support), control variables (e.g., anxiety, demographic variables), and health care service use. The second step used in-depth interviews to collect similar information with additional samples of women diagnosed with breast cancer (n = 10) and men diagnosed with prostate cancer (n = 10). The third step, a mixed methods analysis, compared similarities and differences between quantitative and qualitative findings and reanalyzed some of the qualitative data to add further knowledge.

Method

Mixed methods are defined as the process of collecting, analyzing, or integrating quantitative and qualitative data to draw inferences (Sandelowski, 2000a; Tashakkori & Creswell, 2007). As per Creswell and Plano Clark (2007), Wilkins and Woodgate (2008), and McDowell and MacLean (1998), four methodological decisions were made before conducting this mixed design study: (1) the reliance on a sequential approach, (2) the quantitative inquiry leading the qualitative and mixed inquiries, (3) the integration of both quantitative and qualitative findings at the interpretation step of the research process, and (4) the use of a theoretical model as a guide. The rationale for these decisions is provided next.

First, this study followed a mixed quantitative-qualitative sequential approach where one research approach is treated as the primary and the other as an adjunct to further examined the findings obtained by the first approach (McDowell & MacLean, 1998). Second, the quantitative data was given priority (i.e., hierarchical strategy) in that they were used initially to identify statistically significant relationships between informational support and health care service use which were then further explored in the qualitative inquiry. The qualitative study afforded more flexibility in exploring how and why cancer information may influence individuals' use of health care services as their responses were not constrained by the pre-determined responses of the survey used in the quantitative study. Third, findings from the quantitative and qualitative inquiries were integrated at the interpretation stage of this study; this is in line with mixed sequential studies, in which integration can occur in data analysis and data interpretation, rather than in data collection (Creswell & Plano Clark, 2007). Finally, although a sequential approach does not specifically require a theoretical perspective (Creswell, 2003), we used Andersen and Newman's Behavioral Model of Health Service Use (Andersen, 1995; Andersen & Newman, 1973) as it is a useful guide for organizing and interpreting relevant findings.

Developed more than 30 years ago with the aim of delineating factors or conditions that facilitate or impede the use of health services, this popular model allows the identification of potential relationships among the studied variables with the goal of understanding how and why people use health care services (Davidson, 2004). The model suggests several factors that predict use of health care services. These factors include individual and predisposing characteristics (i.e., demographic characteristics), enabling resources (i.e., support), and needs (Figure 3). Further, research using the Andersen model shows that enabling resources are associated with less reliance on healthcare services (e.g., source of support, including informational support; Andersen & Newman, 1973; Kouzis & Eaton, 1998; Manning et al., 1987; Vasiliadis et al., 2007).

Procedures

Data were collected in several steps (Figure 1). A sequential mixed approach is used in which findings from the secondary analysis (Loiselle & Dubois, 2008) of an existing database (Loiselle, Edgar, & Batist, 2002-2005) guided the qualitative inquiry (Dubois & Loiselle, 2008a). Each study was conducted individually, and each data set remained analytically separate from the others (Creswell et al., 2003; Sandelowski, 2000a). The final step was to combine quantitative and qualitative findings and reanalyze the qualitative data.

Quantitative inquiry: Secondary analysis. First, a secondary quantitative analysis of a larger study by Loiselle, Edgar, and Batist (2002-2005) was conducted focusing on the sources of informational support used, the patterns of health care service use (number of visits, amount of time per visit, and satisfaction), the relationships between informational support and health care service use, and differences (including anxiety, depressive symptoms, and sex). The specific research questions were: (1) What health care professional informational support did participants use (e.g., medical, nursing)? (2) What are the patterns of health care service use among these individuals (e.g., number of visits, amount of time per visit, satisfaction)? (3) What are the relationships between informational support (and control variables) and health care service use? (4) Do women with breast cancer and men with prostate cancer with enhanced informational support use health care services differently?

The purpose of the Loiselle et al. (2002-2005) study was to document the impact of interactive health communication as a complement to more traditional means of informational support on the well-being and health services utilization of oncology patients and examined 18 variables. Thus, data for this secondary analysis focused on a subset of variables (6 of the 18 variables) to answer the research questions of interest. In the original study (i.e., a quasi-experimental longitudinal controlled trial), a convenience sample of women (n = 205) and men (n = 45) were recruited from four cancer clinics at large university teaching hospitals in Montreal, Quebec, between April 2003 and January 2006. Eligibility criteria were: (1) primary diagnosis of breast or prostate cancer, (2) within eight weeks of diagnosis, (3) early stages of cancer, (4) planning or undergoing cancer treatment, (5) good understanding of English or French, and (6) cognitively and physically capable of participating and completing self-report measures. Individuals with a major concurrent illness were excluded. Participants in the control group received care as usual (i.e., provision of cancer information in the form of face-to-face discussions and pamphlets/booklets); the intervention group (i.e., enhanced informational support using IT) experienced the same care as well as a one-hour training, then access for eight weeks to an educational CD-ROM and the Internet.

A series of self-report questionnaires (available in French and English) were administered by two trained professional interviewers at three points: T1-baseline, 3-8 weeks after the diagnosis; T2, one week after the 8-week intervention; and T3, three months postintervention. The secondary analysis focused on data collected at T1 and T3. Valid and reliable tools were used to measure the variables included in the secondary analysis: the State-Trait Anxiety Inventory (STAI; Spielberger, 1983), the Center for Epidemiologic Studies Depression scale (CESD; Radloff, 1977), the Oncologist Informational Support questionnaire (Helgeson et al., 1999), an adapted version to assess nurses' informational support, and the Health Service Utilization and Satisfaction with services scale (Gustafson, Wise et al., 1993; Gustafson, McTavish et al., 1998).

After obtaining ethical approval for the secondary analysis, descriptive statistics (mean, standard deviation, range, frequency distributions) were recalculated for sample characteristics, and analyses of covariance (ANCOVA) with repeated measures for relationships and patterns of change over time. *Post hoc* contrast tests were conducted using the Statistical Analysis System 9.1.3® (SAS Institute Inc., 2003) to assess how the experimental group differed from controls, and also to assess the effect of sex and group. The initial statistical model included age, years of schooling, income, sex, anxiety, and depressive symptoms as predictors (independent variables); only the significant predictors were retained in the final model.

Qualitative inquiry. Once the secondary analysis completed, a descriptive qualitative study (Morse & Field, 1995; Sandelowski, 2000b) was undertaken to further explore the relationships among informational support received and health care service used. There is a growing trend toward clinical issues using this generic and pragmatic approach to inform the practice of health care mainly of how and why something worked (Meyrick, 2007). Specific research questions were: What is it like, for individuals newly diagnosed with cancer, to be provided with or to have to seek cancer-related information? What is it like to negotiate health care services just after learning that one has cancer? To what extent is cancer-related informational support (both formal and informal) helpful or unhelpful in guiding the reliance on cancer-related services?

Following ethical review and approval by the relevant ethics' committees, 10 women and 10 men newly diagnosed with either breast or prostate cancer were recruited between May and September 2006 from an outpatient radiotherapy clinic of a university teaching hospital by the first author (SD). A purposive sampling strategy was used to select participants with the same eligibility criteria as for the secondary quantitative analysis with the exception that they had relied on at least two health care services (e.g., outpatient clinics, emergency rooms, group support, community health centre) to ensure that participants shared similar experiences and to allow enough richness in accounts (Patton, 2002).

Participants were subsequently interviewed one-on-one by the first author at a place and time most convenient to them. Interviews were conducted by the first author, either at the participants' homes, in a private room in the radio-oncology department, or in a hospital conference room. Interviews lasted from 55 to 150 minutes and were tape-recorded. An open-ended interview guide was used to keep discussions focused on the study topic. Samples of questions included: "What does the expression 'cancer-related information' mean to you? In what ways have you sought cancer-related information? Since your diagnosis, what kind of health care services have you used? How did you obtain the services that you needed? Issues explored were accessibility of cancer services, barriers or frustrations related to accessing information about cancer, potential links between cancer information received and use of health care services, and satisfaction with these services.

Audiotapes were transcribed verbatim. A content analysis (Hsieh & Shannon, 2005), assisted by NVivo 7.0, was conducted using Miles and Huberman's (1994) data analysis method. This method involves three stages of analysis: data reduction, data display, and data interpretation. Three final categories and their themes (for a total of nine) were identified. The criteria used to evaluate the rigor of the qualitative inquiry were credibility (i.e., truth in the data), confirmability (i.e., objectivity), and transferability (i.e., can be transposed to other individuals, groups or settings; Loiselle, Profetto-McGrath et al., 2007; Sandelowski, 1986). Credibility was enhanced by the use of participants' point of view (to guide the study) and field notes (to recognize and document biases). In addition, strategies used to enhance confirmability were audit trail and personal notes (to document details of data analysis and decisions made) and feedback from participants, research team, and oncology nurses (to discuss and compare findings). Transferability was also enhanced by the use of sample, and setting already delineated and the presentation of direct quotes.

Mixed design analysis. Last, the mixed design analysis took place after both the secondary and qualitative data analysis were completed. Following the quantitative-hierarchical strategy, significant quantitative findings were first merged with qualitative findings (themes). They were sorted and organized in a matrix (Creswell & Plano Clark, 2007; Onwuegbuzie & Teddlie, 2003). This pragmatic approach used for the complexities of data analysis included development of a matrix, transcription of data into a matrix, coding data and noting reflections and comments of the researchers (Miles & Huberman, 1994). Similar to the qualitative study, the matrix included: three quantitative categories (rows) as informational support, health care services, and links between both and nine qualitative themes (columns) as cancer informational support found to differentially guide service use (i.e., enabling, confirming, normalizing, directing, distressing, conflicting, misguiding, mistrust, and tolerating). Quantitative findings were sorted in their respective categories creating the subcategories. Qualitative information (text) was then reported in corresponding cells of the matrix. The matrix allowed to compare and to contrast the findings and to draw inferences across categories.

Then, a subsequent content analysis using Miles and Huberman's (1994) method was performed to explore quantitative findings, including convergent findings, and discrepancies to find further qualitative explanations. Qualitative data for each participant were reviewed to search for meaningful comments and sorted under corresponding quantitative results through the matrix; condensed information was organized and potential connections between variables of interest identified and revised several times with the second author to cross-check emerging recurrent, converging, and contradictory findings. In addition to following the usual steps of qualitative data analysis, pertinent literature and professional experience were used to identify and clarify findings.

Findings

The present paper focuses on the mixed methods of our study; an overview of quantitative and qualitative findings also is reported here. To summarize, the quantitative secondary analysis suggest that women with breast cancer who receive enhanced informational support by using IT are less anxious over time and more satisfied with the cancer information received, particularly around the time of diagnosis. They also spend more time in face-to-face consultations with nurses than those who receive usual care. Participants with prostate cancer who receive the IT intervention are less satisfied with cancer information and reported shorter face-to-face consultations and telephone consultations than those in the usual care condition. Regardless of conditions, women with breast cancer were more satisfied with information received than men; they spent more time with health care providers, and were more satisfied with health professionals' interactions. In addition, women had a tendency to use nurse informational support more whereas men relied mostly on the oncologist.

Qualitative findings highlighted three overall perceptions of cancer informational support in relation to subsequent use of health care services. These included: (1) positive perceptions of cancer informational support provided by professionals, which enabled, confirmed, normalized, and directed participants' decisions about health service use; (2) unsupportive perceptions of support, which led to distress, conflict, distrust, and misuse of health services; and (3) *mixed* perceptions, with feelings of ambivalence pertaining to cancer informational support received in guiding their use of health services.

The mixed methods analysis relied mostly on findings pertaining to anxiety, satisfaction, and use of health care services. The findings report first on the merging and then the reanalysis of results. They are described in the following paragraphs (also see Table 5 for a summary).

Cancer information and anxiety. Women with breast cancer who received the IT intervention reported significantly less anxiety over time (F [1, 216] = 7.72, p = .006), whereas changes in anxiety were not significant for the usual care condition (F [1, 216] = 1.46, p = .23). When merging findings it became clear that women felt more anxious when they did not know what to expect in terms of the unfolding of events pertaining to cancer. They also reported that waiting times to get cancer information and services produced significant distress. The qualitative reanalysis supported the observation that women were less anxious after receiving cancer information; this anxiety decreased particularly when women knew what to expect and how to prepare for each step of the illness trajectory. With enhanced informational support, participants were also in a better position to address their questions to health care professionals. One participant noted,

> I wanted to know what to expect, what was happening to me, what to do, what is my disease [breast cancer], why is it happening to me. . . . I wanted to be prepared to ask questions. . . . I just wanted to know. . . . I was not very anxious. . . but in fact . . . I think I was, because I felt better after [less anxious]. (W_P9)[3]

Anxiety-related quantitative findings for men with prostate cancer were in the opposite direction. Men who received the IT intervention reported no significant changes in anxiety (*F* [1, 216] = 1.92, *p* = .17), whereas changes in anxiety over time were significant for those who received usual care (*F* [1, 216] = 6.74, *p* = .01). As indicated in Table 5, the qualitative reanalysis supported the quantitative findings: men were not as anxious with usual cancer information provision and felt they needed no additional information about what was occurring. Men explained:

> I used to read the information that the [oncology] nurse gave me. . . . I wasn't anxious about this information. . . . I wasn't really interested unless I got it [prostate cancer], then I'd get it fixed, but it wasn't something that was on my mind all the time. . . . It's like business. I want to have enough information about it, particularly at the beginning, about treatments, because I think it's going to help me, if I can do something about it. . . . No, I didn't ask [health care professionals] for more information. (M_P11)

> I met with the oncologist and she explained everything to me . . . the procedure and the side effects, just general information, which was enough and thorough. No, I was not anxious with that information. . . . I can manage it. (M_13)

The qualitative reanalysis also added information on the role of cancer information provided by health care professionals for men with prostate cancer. They often referred to their experience as a type of "business"; they asked "just enough"

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[3] Participants are identified by a unique number; i.e., W1 to W10 for women, and M11 to M20 for men.

information, particularly at the time of diagnosis, to manage and do something about their condition.

Cancer information and satisfaction. Women with breast cancer who received the IT intervention expressed significantly more satisfaction over time (F [1, 246] = 27.46, $p < .001$) and over those who received usual care (F [1, 246] = 1.19, $p = .28$). Merged findings confirmed more use of the Internet (and written cancer information) by women. These participants also reported being most satisfied with the Internet, adding that it is readily accessible and easy to understand. The qualitative reanalysis supported these findings. The following illustrates:

> I hear a lot from them [from nurses, oncologists, family doctor] . . . and read a lot too [use of booklets and the Internet]; this enables me to know more about my disease [breast cancer], my treatments, and particularly, about this drug, Tamoxifen. . . . I am very satisfied with this information. (W_P10)
>
> I read a lot on my cancer [breast cancer] . . . the Internet, pamphlets, booklet. . . . For me, it was satisfying to have all this information. (W_P4)

Moreover, the reanalysis also added insights into the previous findings. For instance, as indicated in Table 5, the gradual combination and integration of verbal and written cancer information from health care professionals during regular visits to the oncology clinics and information found on the Internet allowed them to grasp the different facets of cancer treatment.

> First, the oncologist had explained everything about my surgery [breast cancer]. . . . I wanted only a partial, the micro surgery. . . . I got back several times to the pamphlet and asked the nurse about the drain and what's going to happen when they'll take the drain out . . . but you don't know what's going to happen until you have it. . . . Anyway at home I looked on the Internet with my daughter to better understand. . . . I do not want to come back and to do it again [the surgery]. (W_P2)

> I talked to the oncologist and the nurse . . . mainly the nurse who answered my questions. . . . I read the information she gave me [pamphlets, booklet]. I talked to a nurse at the Canadian Cancer Society. . . . She [the nurse] guided me to the information available on their Web site. . . . I wanted to be sure to understand what was happening to me. (W_P4)

Interestingly, men with prostate cancer who received usual care expressed significantly more satisfaction over time (*F* [1, 246] = 13.58, *p* = .0003) than those who received enhanced informational support (*F* [1, 246] = 0.81, *p* = .37). As indicated in Table 5, the qualitative reanalysis added insights to this observation as most men reported satisfaction with usual care provided by health care professionals to manage their disease, but they still continued to seek additional information from other sources (e.g., the Internet, magazines, and friends):

> I am satisfied with the information provided by health care professionals here in radio oncology. . . . If I don't get the information [from professionals] I'll find it. . . . There are Web sites on prostate cancer. [They] help to fill in the gaps. (M_P13)

> At the first hospital, the treatment they [oncologists] preferred was surgery. I was satisfied with the information provided . . . but I searched on my own, through the Internet, for more information about treatments offered in several hospitals. . . . I wanted to be able to explore other avenues. . . . I could explain to the doctors why I didn't want surgery. (M_P17)

Although men who received usual care reported more satisfaction with the cancer information provided by health care professionals than men who received the IT intervention, overall, they were significantly less satisfied than women (*F* [1, 246] = 11.32, *p* = .0009). The very nature of their cancer (a more ambiguous illness course than that of breast cancer) may explain, in part, this finding. Moreover, the qualitative reanalysis revealed that, as opposed to women, men were willing to incur costs for medical tests to obtain a faster diagnosis. For instance,

> Dr. X [urologist] recommended that I go to a private clinic for a blood test [for prostate cancer]. . . . It will be faster. . . . Then he said, or why don't you just go to your local CLSC [community health centre]? They'll do it. I went to the CLSC, said I'd like to have a blood test, and showed my requisition. She [the receptionist] said, "I can give you an appointment one month from now.". . . No I was not satisfied. . . I didn't want to wait. . . . I went to a private clinic. (M_P14)

Interestingly, only 2 of the 10 men interviewed reported using community health center services (covered by the national health coverage plan) for blood tests and waited 2 to 4 months for their appointment.

Informational support and health care service use: Face-to-face consultations with nurses. Women with breast cancer who received enhanced informational support reported spending significantly more time in face-to-face consultations with nurses over time (F [1, 224] = 8.86, p = .003) than those who received usual care (F [1, 224] = 2.24, p = .14). With the merged analysis, women explained that they preferred direct contact, such as talking to nurses, for more personalized information. As indicated in Table 5, the qualitative reanalysis suggested that women spent considerable more time with nurses after their surgery in face-to-face consultations, seeking additional information, mainly about chemotherapy, side effects, and what to expect next. Topics of exercise, diet, and treatments were also discussed. For example,

> After my surgery, the nurse gave me a document explaining which exercises to do every day, and she reviewed each one with me, and discussed what I needed to eat. Also, she showed me on the computer what the surgeon had done to my breast and gave me more information. She took the time to explain [information in the booklet] and to talk to me. She gave me a lot of information and answered all of my questions. (W_P4)

> I already had a lot of information. . . . When I had chemotherapy, the nurse told me that if I had a fever or difficulty breathing, to come immediately to the emergency. . . . We took the time to answer my questions, mostly about side effects. . . . In fact, I had a lot of questions. (W_P1)

A reanalysis emphasized that further information on breast cancer found on the Internet prompted women to increase their subsequent use of health care services. To illustrate,

> When the doctor [oncologist] told me the type and stage of my cancer, I went on the Internet to understand exactly what that meant. I then discussed with my gynecologist to be certain I understood it correctly. . . . I also went on the Internet to get information about the effects of medication, then, after that, I discussed my findings with my pharmacist. (W_P1)
>
> When I got home, I started looking the topic of cancer on the Internet, and the food and the exercises. . . . I read all the pamphlets [provided by the oncology nurse]. . . . They're very nice to read, but then you expect to get sick, to be nauseous. . . . I read about side effects on the Internet because I needed to know more about all of this . . . but, of course, I called the nurse to verify this information. (W_P2)

These women primarily relied on the Internet to obtain additional information about their disease and to attain a better understanding of either their oncologist's explanations or the written information provided. Although women tended to increase the time spent with nurses to enhance their understanding of cancer, the additional information found in sources such as the Internet led them to return to health care professionals to discuss and verify this information.

Interestingly, a marginally significant interaction was found between sex and IT intervention in the quantitative inquiry F [1, 216] = 2.98, p = .08. Men who received the intervention reported spending significantly less time in face-to-face consultations with nurses than men who received usual care (F [1, 224] = 4.29, p = .04), the opposite of the finding for women. The merged analysis suggested that men seemed to prefer literature provided by staff during routine consultations and when they return, later on, they clarify this information. The qualitative reanalysis shed some light on these findings:

> As I said earlier, if I had questions about my back pain, for example, I checked in the booklet and then I went to the Internet. . . . So, when I saw the nurse, my

> questions were ready and I got answers right away. . . . No, my questions were not general. (M_P11)

> The Internet was helpful. . . . So when I came back to the hospital for my treatment, I talked to the nurse at the oncology department. . . . I had specific questions about side effects related to what the doctor told me during the first visit. . . . It only took a few minutes. (M_P13)

These statements reveal that men who sought further information from sources such as the Internet seemed better prepared for face-to-face consultations and radiotherapy treatments.

Informational support and health care service use: Telephone consultations with health care professionals. Men with prostate cancer who received the IT intervention reported spending less time in telephone consultations with health care professionals (F [1, 92] = 3.50, p = .06) than those who received usual information (F [1, 224] = 2.24, p = .14) over time. As indicated in Table 5, the qualitative reanalysis clarified that those who sought or received cancer information but did not find answers to their specific questions tended to use the telephone to obtain answers. For example,

> I wanted to know if I could go with my friends on this trip. . . . It was before my treatment started. I was supposed to receive an injection. . . . I looked in the booklet [provided by the nurse], and went on the Internet but it wasn't clear. . . . I wanted to ask the nurse if it was okay for me to go with my friends [the last weekend before my treatment] and drink alcohol. I didn't want to delay my treatment. . . . I called [the oncology clinic] and she [the nurse] said no problem. . . . No, I didn't have to go to the hospital for that. . . . You know you can call and talk to nurses more easily than to doctors, to ask questions. . . . It takes only a few minutes and you get an answer. (M_P14)

> I phoned the nurse for information about alternative medicines. I did not find anything in the pamphlet she gave me but I found a lot of information on the Internet. . . . If I can use them, I want to know it right away. (M_P17)

Men seeking further cancer information could phone the oncology nurse for a quick answer. Men often stated that they did not want to wait, delay their treatments, or go to the hospital to ask a question.

Informational support and health care service use : Informational support from oncologists or nurses. Women with breast cancer, regardless of group (IT or usual care), were more likely to receive informational support from nurses (F [1, 215] = 3.74, p = .05), whereas men with prostate cancer were more likely to receive informational support from oncologists (F [1, 215] = 6.37, p = .01). With merged findings, some women reported negative experiences with physicians (e.g., pain minimization). A reanalysis emphasized that they found it easier to talk to nurses than to physicians. The following comments underscore the role played by nurses according to women with breast cancer:

> Some health care professionals are not very communicative but nurses rectify this problem by providing the information. . . . They have an oncology nurse at the hospital, her name is X. Without her, I really don't know what would have happened. . . . They introduced me to her just before my surgery. . . . The doctors were wonderful, they explained things, but . . . she was the one who talked to me, gave me all these pamphlets, told me how I was going to feel, and what floor to go to. . . . She'd call up after the surgery to find out how I was doing . . . feeling, asked about my blood test, and then I said, well, I'm coming on Thursday to get the drain out, she goes . . . I'll see you then. (W_P2)
>
> I met with the oncologist [and the nurse] in a room, with his resident. . . . The oncologist said to me: "Take off your clothes." . . . I used to be shy. . . . After a while the nurse said, "Doctor, I don't think she [the patient] understands everything you just told her." She [the nurse] looked at me and said, "So what questions do you have? Don't leave that room until you get the information you require." . . . He's [the oncologist] too fast sometimes and does not ask if I have questions. . . . After this, I would ask the nurse questions. . . . She was my resource. (W_P5)

> When I saw the nurse [in oncology], she said, "Well then if you have any problems, here's my card. I'm your nurse. . . . My name and phone number are on this card. . . . You can see me or call me if you have any questions." (W_P7)

Women talked about wanting to talk to nurses during their illness, especially before and after surgery and during treatment. Nurses provided the participants with emotional and instrumental support by explaining what was going on when they met with the oncologist or by taking action when women reported health problems or specific issues.

The qualitative reanalysis revealed additional information on certain negative experiences with physicians (e.g., wrong information provided by a physician after surgery) in terms for instance of wound care after surgery. One woman who was provided with inadequate information by her physician later declined support from that physician. Another woman, after receiving the wrong advice, did not feel compelled to turn to him for additional information. Quantitative results and the interviews suggest that women are more inclined to receive informational support from nurses and are less likely to seek cancer information from physicians. For example,

> Like I said, there was one little rotten apple . . . and unfortunately, a bad one [doctor]. He was very rude. . . . In addition, that man could have caused me a lot of pain. Because if I had listened to what he had told me to do, I don't know what I would have done. . . . [After] the surgery, you have bandages, you've got tape from here to here . . . go home and take it off he said. I'll call the nurse and she said: No! No! No! We're going to do that on Thursday! . . . I said to the nurse that I didn't want to see him anymore . . . and I didn't. (W_P2)

> After the surgery [breast cancer] my hand and my fingers were swollen. . . . Dr X [radio oncologist] got the results [blood tests] and said he will speak to the secretary because I told him about my hand. Two and a half weeks later and I hear nothing.. . . . Three weeks later, I told him [radio oncologist] I was mad. I said, look at my hand. Anyhow, you don't get answers right away with doctors. I always felt that. . . . But I saw the nurse [for my arm], and the head nurse said, "I'm going to send you for an ultrasound." Well, I had one Monday. (W_P3)

Merged findings confirmed that men were more likely to seek informational support from their oncologists. As indicated in Table 5, the qualitative reanalysis revealed that men perceived oncologists as specialists, although they could have asked nurses some questions, they preferred their oncologists as they were perceived to have the appropriate expertise. The following comments support this observation:

> The way I see it, I have an oncologist; he is a specialist and he is supposed to know his business while I do not know that. . . . I asked him information when needed. (M_P19)

> You know, the information that I got from the oncologist was good. . . . I wrote down questions, and yes, I discussed them with him and got the answers. . . . He makes the diagnosis; he knows what has to be done. . . . You can call and talk to the nurses easier than the doctors to ask questions particularly about side effects. . . however, he is the specialist. (M_P11)

In addition, the diagnosis seemed to be the starting point and the participants' health was managed as a matter-of-fact issue to be resolved in a business-like manner (expertise led to solutions). The reanalysis also revealed negative experiences for men particularly pertaining to limited information provided by physicians (e.g., their oncologist) at the time of diagnosis and when treatments were offered to them. They often felt that communication with the oncologist was restricted particularly because of limited time spent with them.

> At a certain point, when I was with the oncologist, it was at this specific time that I got anxious . . . because I did not see any more options, other than the surgery that he proposed and that I did not want. . . . No, I was not satisfied. (M_P17)

> I didn't really like the way he [the oncologist] answered me. In fact, when I asked him what the test result had to be to go on to the biopsy; he answered that he would decide himself when he gets the result of the blood test. (M_P15)

However, some men did not hesitate to find another oncologist if they were not satisfied with the information received. For example,

> I did not like the treatment [watchful waiting] he [the oncologist] suggested. . . . We [my wife and I] went to the CLSC [to ask another doctor on treatment options for prostate cancer]. However, the CLSC, I do not know how they work. . . . We were not able to have an appointment. We did not go back. . . . Later we talked to another oncologist but not at the CLSC. (M_P16)

> I really didn't like the oncologist I had consulted. . . . He told me that he absolutely had to do the surgery. . . . Yes, I found another oncologist. (M_P20)

Satisfaction with health care services: Telephone consultations. In the quantitative study, women with breast cancer reported significantly less satisfaction with telephone consultations (F [1, 212] = 3.89, $p = .05$) than men with prostate cancer. Merged findings also revealed negative experiences for women with telephone consultations in cancer services and difficulties accessing services (e.g., biopsy, chemotherapy). The qualitative reanalysis revealed that these experiences often resulted in inadequate use or nonuse of health care services.

> I had pain [breast cancer]. . . . I went to the clinic. . . . I had a mammography and the doctor saw something. . . . So they said I need a biopsy. . . . They phoned me for an appointment and told me it was for a biopsy. . . . I get there and I sit for about 2-1/2 hours or more. . . . It was an ultrasound. . . . They called me back for another appointment. . . . I went there but they told me it was $200, which I did not know at the time and I did not have the money. . . . I waited few more weeks but I had pain. . . . I went back to the clinic. (W_P3)

> [Chemotherapy nurses at the hospital] gave me a telephone number in the event of an emergency. I called once. They told me, "At night, if ever you have a problem, you call the hospital with this number: it is in oncology." I called but there someone told me, "You have to call the emergency." I called the emergency, and was told "Call the oncology." I call the oncology and was told again "Call the emergency." I called back the emergency, but then I was told, "You have to call back". I was transferred back and forth from one department to another. . . . I did not have an answer but I told myself that perhaps I overrated my pain and symptoms . . . . But I was so sick. . . . I was not satisfied; I really needed to talk to someone about these side effects but I did not talk to anyone. . . . I did not go to the emergency; I waited.(W_P9)

Discussion

The purpose of this sequential mixed approach followed by a mixed methods analysis was to document the relationships between informational support in the context of a recent diagnosis of breast or prostate cancer and health care service use, taking into account sources of support and patterns of service use among individuals newly diagnosed with either breast or prostate cancer. The key steps of the research process for the quantitative and qualitative inquiries were presented. Each analysis first was conducted separately and results were merged following a quantitative-hierarchical procedure. A reanalysis of qualitative data produced further insights in our phenomenon of interest. Similar to the findings of Ziebland, Chapple, Dumelow, Evans, Prinjal, and Rozmovits (2004), women with breast cancer used the Internet mainly to better understand the oncologist's explanations or written documentation. Men with prostate cancer also sought additional information from several sources (e.g., the Internet, magazines, friends) even though they were satisfied with informational support provided by health care professionals. Lack of quality of cancer information from physicians, particularly following surgery, led some women to get support from nurses whereas men did not hesitate to find another oncologist to get better information (i.e., on treatment options).

Although the nature of the particular cancers studied (i.e., breast cancer and prostate cancer) may have confounded sex-based trends in the findings, both quantitative and qualitative studies and the mixed methods analysis provided insights into the crucial role of informational support in terms of subsequent use of health care services by these individuals. Regarding sex differences, women in this mixed study mainly preferred nurses as their informational source whereas men seemed to prefer their oncologist. Other studies have found that women with breast cancer tended to prefer a more humanistic approach to care, to talk about and share their feelings with others and may have an opportunity to do so with nurses (Helgeson, 2005; Kiss & Meryn, 2001). Men with prostate cancer do not have the same need to share their feelings and rely mainly on their urologists for support (McGregor, 2003) because they are perceived as the expert (Goodwin, 1980; West, 1990). In the present study, women identified the oncology nurse as a source of satisfaction and as the facilitating agent providing them with informational support, a finding also reported by others (e.g., Marshall, 2006; Pepler et al., 2006).

Informational support provided by health care professionals at the time of diagnosis and during the cancer trajectory is often instrumental in decreasing anxiety (Lambert & Loiselle, 2007). In this study, women with breast cancer who received the IT intervention reported being less anxious than those who received usual information. These participants may have felt better prepared to ask questions and to manage the ramifications of their illness. These findings were later supported by the in-depth interviews.

Men with prostate cancer who received the IT intervention spent less time with nurses in face-to-face and telephone consultations, preferring to seek the cancer information themselves. This was also documented in a randomized controlled trial (Gustafson et al., 1999) conducted with 204 patients diagnosed with a chronic disease. Information accessed on the Internet resulted in patients spending less time in ambulatory care visits. Our qualitative findings also revealed that men tended to be proactive in managing their care: they consulted the documentation provided and subsequently asked pointed questions about their disease and made judicious use of health care services (e.g., phone calls versus face-to-face visits).

Interestingly, findings show that men in the usual care condition were less anxious than those in the IT intervention. Similarly qualitative findings revealed that men receiving usual information reported being less anxious and handling their illness in a business-like manner. An extensive literature review on information needs among men with prostate cancer suggests that men may overestimate their level of knowledge about their disease (Echlin & Rees, 2002).

Previous studies have shown that the reliance on health care services is related to patient-professional communication (O'Connor et al., 2003; Shumay, Maskarinec, Kakai, & Gotay, 2001). Moreover, poor communication by health care professionals has been reported to produce negative experiences, dissatisfaction with care, and poor patient outcomes (Butler et al., 2005). In the present study, poor communication between physicians and women with breast cancer was reported as significantly distressing, resulting in decreased use of oncologists for informational support. Conversely, men seemed more inclined to receive their information from a specialist even if they had to seek another oncologist.

Study Strengths and Limitations

Several benefits and challenges accrued from the reliance on a mixed methods approach, which was found to be a productive way to document the phenomenon of interest in its entirety (see also Dunning, Williams, Abonyi, & Crooks, 2007). The sequential design allowed for the findings from the quantitative study to guide the development of the questions included in the interview guide of the qualitative study. However, several challenges were also encountered. The undertaking of two substantial studies with the resulting high volume of quantitative and qualitative data mean that time, financial costs, and the complexity of analyses were high. Potential threats to validity of this sequential mixed design were also addressed. Separate samples were used; participants were selected with identical inclusion and exclusion criteria of the population of interest (i.e., women and men with either breast or prostate cancer) for the follow-up qualitative study; quantitative data from the database were collected using reliable and valid tools; development of the interview guide used for the qualitative study was based on findings from secondary quantitative analysis; themes from the qualitative study were merged with the quantitative results in the interpretation phase (Creswell & Plano Clark, 2007; Johnson & Turner, 2003).

In conclusion, to the best of our knowledge, this is the first published inquiry to rely on a mixed methods approach to examine the role of informational support in relation to the reliance on health care services among individuals newly diagnosed with cancer. Future research is needed using a similar approach to identify whether these findings can be reproduced among individuals with more diverse socioeconomic backgrounds, differing cancer types, and of varying cultures.

CHAPTER 5

OVERALL DISCUSSION

The main purpose of the present dissertation was to examine the role of informational support in relation to health care service use among individuals newly diagnosed with cancer. The specific goals were to: (1) use an existing quantitative database to determine further how differential provision of cancer information may have an impact on health care service used by this group; (2) document, using an in-depth exploration, how patients' experience with cancer information may alter (or not) subsequent use of health care services and; (3) combine quantitative and qualitative results to further understand quantitative data by refining them with qualitative data collected. This chapter discusses key findings in terms of the quantitative analysis (first inquiry), the qualitative analysis (second inquiry), the merged analysis and the qualitative reanalysis (third inquiry) and reports limitations and the overall conclusion.

The use of health care services is multifaceted as suggested in the literature (Andersen, 1995; Andersen & Newman, 1973; see Figure 5). The studies reviewed helped to clarify certain characteristics (personal/contextual) included in the relationship between informational support and health care service use. Figure 6 highlights some of the factors elucidated in more depth by this dissertation. For instance, personal variables (e.g., sex) and contextual variables that included informational support from different sources (e.g., oncologists and nurses, family, friends, support groups, and the Internet), types/experiences of informational support (i.e., positive, unsupportive, and mixed), and several distinct, related processes (e.g., confirming, directing, conflicting), types of cancer diagnosis and related treatments served to elucidate further the relationship between informational support and health care service use. For the first quantitative inquiry, significant sociodemographic differences between experimental (enhanced informational support, face-to-face and IT) and control (traditional cancer informational delivery) groups were controlled for. The latter was less well-educated, slightly older with less income and more employment than the former. No significant differences in overall reliance on health care services related to informational support were noted. However, it makes intuitive sense that cancer type (i.e., breast versus prostate) was key in determining patterns of service use with less weight given to the type of informational support received.

The review of key findings take into account each inquiry (analysis) included in this dissertation and their links with the extant literature. As illustrated by Figure 6, the use of health care services involves other factors. These factors served to highlight the complexity of the relationship between informational support and health care service use.

First, pertaining to specific types of cancer diagnosis, findings from the quantitative analysis revealed a trend toward greater reliance for women diagnosed with breast cancer on health care service use compared with men diagnosed with prostate cancer. Women and men have different experiences of illness and treatment mainly related to cancer types of cancer diagnosis (i.e., breast vs. prostate). Compared to prostate cancer, a slow-growing disease, women with breast cancer had a more extensive illness trajectory (i.e., in terms of treatment), which exposed them to a greater number of health services. For instance, findings from both, the merged analysis and the qualitative reanalysis, suggested that after being diagnosed, women spent more time with health care professionals (e.g., nurses) even though they received enhanced informational support in discussions about chemotherapy (i.e., side effects and what to expect next, exercises, diet, and treatment options) whereas men spent less time; men sought additional cancer information on treatment options mainly on their own. Compared to women, most of men continued to work during treatment; men were physically able to maintain their lifestyle as documented elsewhere (Schulman, 2007) and to return to a normal life as soon as possible (McCaughan & McKenna, 2007). Ashbury et al. (1998) also reported increased use of health services (e.g., in terms of number of visits to general practitioner, community or public health nurses, pharmacist, emergency room, and walk-in clinics) for patients with cancer who reported mild to severe symptoms related to treatment. Previous research also confirmed more reluctance among men to use health care services including informational preventive services (Kiss & Meryn, 2001; Znajda, Wunder, Bell, & Davis, 1999). Thus greater reliance on health care services (i.e., in terms of time spent, number of visits, number of phone calls, etc.) by women diagnosed with breast cancer can be viewed as an expected health-related outcome in clinical settings.

Furthermore, pertaining to sex differences, first, the quantitative analysis also showed that women with breast cancer tend to report higher informational support from nurses, whereas men with prostate cancer tend to report higher informational support from oncologists. In addition, women were more likely to use nurse informational support than men. The merged analysis emphasized that women with breast cancer tended to use more personal contact, such as nurses, to normalize their health situation.

Interestingly, the qualitative reanalysis added that women found it easier to talk to nurses and desired to talk to them particularly before and after surgery and during treatment (radiotherapy and chemotherapy). Women are known to be more expressive, talk and elaborate more, and give more details than men about their health condition. According to several authors, women are more willing to and confident about sharing their feelings with others, such as nurses (Helgeson, 2005; Helgeson & Cohen, 1996; Kiss & Meryn, 2001). In contrast, the qualitative reanalysis revealed that men considered the diagnosis the starting point from which to manage their health situation and to treat their health problem with oncologists in a business-like manner, taking into account time for treatment. Men were also more willing to incur costs for medical tests to get a faster diagnosis. This can be explained in part by the fact that work experience seemed to shape actively how men deal with prostate cancer by using a similar approach as in the workplace (Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002). Men talked mostly about time, comparative strategies, and how they made decisions. In addition, previous research reported that men tend to use a narrower circle of human support and are more reluctant to seek professional help or other types of support than women (McCaughan & McKenna, 2007; Moody, 2003; Roesch et al., 2005). These results suggest that a degree of sex difference may exist in the use of cancer support services.

Next, the quantitative analysis showed that men were less satisfied with information provided by health care professionals than women. The qualitative reanalysis revealed negative experiences for men with oncologists at the time of diagnosis related to insufficient information provided mainly on treatment options, poor communication, and limited time spent for consultations. Informational needs for women with breast cancer and men with prostate cancer are well documented (Davison et al., 2002; Degner et al., 1997). Topics particularly important to both groups are related to physical, psychological, and social aspects of cancer care and treatment and include information on the spread of disease, likelihood of cure, risk to the family of getting the same disease, treatment options, treatment side effects, impact on social life, effect on family and friends, self-care, and sexual attractiveness. Men's dissatisfaction can be explained in part by the fact that men considered oncologists to be experts for support and related-services (Goodwin, 1980; West, 1990) and men's needs are more oriented toward health care delivery (e.g., prompt diagnosis and treatment) than on information needs (Boberg et al., 2003). However, the qualitative reanalysis also revealed that men do not hesitate to find another oncologist for more treatment options. This area may merit further investigation to optimize the use of health care services and satisfaction with care.

Last, the quantitative analysis showed that women were less satisfied than men with telephone consultations. The qualitative reanalysis revealed negative experiences for women with telephone consultations on cancer services and negative experiences in accessing a service (e.g., biopsy, chemotherapy), resulting in more phone calls to several health care professionals to obtain information, followed by subsequent nonuse of telephone consultations for health problems (e.g., side effects). As reported in previous research, satisfaction with health care services related mainly to the way individuals were treated, ease of access to needed health services, the treatment setting, and the continuity and coordination of care (Murray & Evans, 2003; Ouwens, Bruinooge, Hermens, Hulsher & Grol, 2005), and types of cancer diagnosis (Davidson & Mills, 2005).

For sources of informational support, first, the quantitative analysis reported physicians as participants' first choice as the most important source of cancer informational support. Nurses were the second most important source. In other studies, nurses were particularly found to be an important source of informational support that assisted patients in their use of services (Marshall, 2006; Pepler et al., 2006)

Interestingly, the merged analysis also revealed that support groups were used as subsequent health care services to confirm information provided by oncologists on treatment choices. Previous research suggested that support groups were subsequently used to facilitate communication with other patients on issues related to their disease (Gray et al., 1997b) or to satisfy their information needs (e.g., diagnosis, treatment options, and side effects of treatment; Boehmer & Babayan, 2005; Edgar et al., 2000; Steginga et al., 2006).

Next, the merged analysis revealed that family members (e.g., sister-in-law) and friends (particularly ones who had the same health problem) considered as informal support (i.e., not professional sources) were used by individuals with cancer as positive informational support to direct subsequent use of health care services (e.g., to find another oncologist). The qualitative reanalysis also added that men diagnosed with prostate cancer continued to seek information from other informal sources (e.g., friends) on other types of treatment, pain, medication, or support groups. The present study reported these sources of information as useful. In contrast, previous research reported significant others as unhelpful in terms of the information they provided (Neuling & Winefield, 1988; Smith et al., 1985).

Last, the merged analysis revealed that individuals diagnosed with cancer used the Internet at the time of diagnosis for easy access to information presented in simple language to guide subsequent consultations with health care professionals. The qualitative reanalysis confirmed these findings and added that the Internet allowed women a better understanding of their disease, oncologists' explanations, or written documentation and contributed to the use of additional health care services (e.g., visits to health care professionals) to discuss and verify cancer information sought. Men reported using the Internet to prepare for consultations with oncologists and treatments. These findings were in line with those of previous research that highlighted the role of informational support provided by the Internet in increasing patients' participation in their cancer care (Eysenbach, 2003; McMullan, 2006; Shaw, McTavish et al., 2000) and meeting information needs that were unlikely to be provided by health care professionals (Ziebland et al., 2004). The Internet may also contribute primarily to the continuation of an already chosen treatment or to the starting of further treatment (Kirschning, von Kardoff, & Merai, 2007). Moreover, the Internet is also considered a tool with which to reduce isolation for individuals diagnosed with cancer (Ziebland et al., 2004). However, research suggests a socioeconomic gap in access and use of the Internet (Digital Divide Network, 2004; DiMaggio, Hargittai, Russell Neuman, & Robinson, 2001). This source of informational support merits further exploration to determine its impact on subsequent use of cancer services.

Pertaining to types/experiences of informational support and processes through which health care service are used, the qualitative analysis highlighted that individuals diagnosed with cancer experienced one or more types of informational support (e.g., combination of supportive and paralyzing) as well as related processes (e.g., confirming, enabling, misguiding) to guide their use of health care services. Tangible informational support underlined helpful processes for women and men with cancer to guide their use of services. For instance, tangible support confirmed cancer information provided to individuals from the use of subsequent formal or informal services (e.g., consultations with oncologists, nurses, support groups, lay individuals). The qualitative reanalysis supported these findings and added the Internet as an informal service used. In addition, tangible informational support normalized men's health situations with reliance on literature provided with usual care, although women, preferring more personalized information, used literature provided and additional health services (i.e., visits to oncology nurses). The qualitative reanalysis also addressed helpful management of illness situations mainly for men. Benefits (e.g., empowerment, knowledge) of positive informational support have been documented elsewhere (Lambert & Loiselle, 2007).

The qualitative analysis showed that when services were difficult to obtain, had lengthy waiting times, and lacked in continuity, the unsupportive role of information (e.g., that did not meet individual information needs in terms of accuracy, for instance) increased participants' distress with health care services and led to inadequate use health care services (e.g., visits to more than one health care provider for the same problem, more phone calls, nonuse of needed services). Previous research documented the impact of a suboptimal health care service system on further individual psychological distress related to the use of health care services (Stephen & Boyle, 2005). In addition, the merged analysis revealed that contradictory information contributed to confusion in individuals diagnosed with cancer such that they did not know what to do next. In-depth interviews revealed more use of health services (e.g., additional visits to health care professionals) if the problem persisted. The qualitative reanalysis added that some women preferred to decline support from physicians or did not return, whereas some men consulted another oncologist for additional information. In addition, findings also revealed a misuse of health care services (i.e., nonuse) by individuals at the time of diagnosis related to problematic communication or lack of confidence (i.e., distrust) in using subsequent health care services related, for instance, to generic information provided by health care professionals. These findings were in line with those of previous research that highlighted the role of information and communication in effective patient involvement (e.g., efficient use of health care services) that was unclear to many cancer service users (Evans et al., 2003; Hack, 2007). Furthermore, the qualitative analysis also revealed that individuals who tolerated less-than-optimal informational support limited their use of health care services. Background experiences with the health care system could change the way patients perceive and use services. As reported elsewhere (Bowes, 1993; Kearney, Miller, Paul, Smith, & Rice, 2003), individuals who had a negative experience (e.g., ineffective communication with health care providers, inadequate information) and who felt unwanted by health care professionals are less likely to ask questions, come back to the health care system, or seek appropriate services. Conversely, positive experiences (e.g., attitudes) were found to help individuals with cancer to seek support services (Steginga et al., 2008). Harmful processes through which individuals with cancer obtain health services confirmed that several challenges and issues still exist with our health care system across the illness continuum to address continuity of and easy access to services answering to individuals' information needs (Harrison, 2004).

Finally, regarding delivery of enhanced informational support versus usual informational support, findings highlighted some differences in terms of quantity and multimedia used to provide cancer information. The quantitative analysis showed more satisfaction, less anxiety, and more time spent with health care professionals in face-to-face consultations for women with enhanced informational support compared to women in usual care. The quantitative findings also showed greater satisfaction and less anxiety for men with usual care compared to men with enhanced informational support but shorter face-to-face and telephone consultations for men with enhanced informational support than for men in usual care. The qualitative reanalysis revealed that women felt less anxious with the mass of information, knew what to expect and how to prepare for each step of their illness trajectory and subsequent consultations with health care professionals, and reported that written (including Internet) and verbal information allowed a better understanding of the disease. For men, though they compared their experience to business, they reported not being anxious about information and did not need a great deal of it; they preferred to seek additional information themselves from different sources (i.e., formal and informal) as they were satisfied with usual information provided by health care professionals. Although previous research reported that men may overestimate their knowledge (Echlin & Rees, 2002), a meta-analysis

(Tamres, Janicki, & Helgeson, 2002) suggested that men are relatively more likely to use problem-focused strategies, whereas women are more likely to use emotion-focused strategies. These findings may reflect the fact that even though the majority of patients want as much information as possible about their diagnosis and treatment (Jenkins, Fallowfield, & Saul, 2001), perhaps more use should be made of the multimedia support in addition to usual informational support delivered in oncology care.

Conclusion

In conclusion, this dissertation shows the usefulness of a various methodological approaches to study the relationship between informational support and the use of health care services by women and men newly diagnosed with breast or prostate cancer. The quantitative study highlighted relationships between informational support and health care service used; the qualitative study underlined processes through which individuals with cancer used health care services; and the mixed design analysis, with the combination of findings (merged and reanalyzed), confirmed quantitative findings, developed qualitative findings, and allowed documentation of a broader perspective of the complexity of the relationship between informational support, health care service use, and other factors that have to be taken into account. For instance, issues of paternalistic health professional practices, which were not directly documented in this dissertation, may be also significant barriers to patients' involvement in their care and decision.making about health care service use (Beauchamp & Childress, 1994; Coulter, 2002). Broader contextual factors such as the clinical situation and professionals' characteristics (Shepherd, Tattersall, & Butow, 2007) may have affected the way individuals relied on health services. In addition, not all individuals with cancer are necessarily comfortable with proactive in their own care and in searching for particular health care services (Beaver, Bogg, & Luker, 1999; Beaver et al., 1996; Davison et al., 1995), an observation in need of further clarification.

Further, some issues and concerns pertaining to the findings remain. For instance, how social interactions between family members and patients for instance, may have impacted on perceptions of cancer informational support which, in turn may have influenced their subsequent use of health care services. Levels of literacy, and more specifically health literacy may also have impacted on the observed relationships between perceived informational support and decision making about reliance on health services. In their interactions with one another, whether health professionals and patients were male or female also could have had an impact on their communication patterns and ensuing behaviors pertaining to the variables under study. These issues require further research attention.

Limitations

This dissertation has several limitations related to each inquiry. First, the smaller sample size of men compared to women and the use of self-report questionnaires must be taken into account when drawing inferences in the quantitative inquiry. Second, the interview guide in the qualitative study with its predetermined topics may have unduly restricted the range of topics relevant to the research questions The use of different participants for the follow-up qualitative inquiry (but with the same eligibility criteria than for the quantitative inquiry) to explain significant results may be considered a limitation if we seek explanation of the quantitative findings (as opposed to solely exploration). The unbalanced sample characteristics as education in the qualitative study may have confounded the results. Consequently, findings from the mixed methods analysis must be interpreted with caution.

Implications for Practice and Future Research

Optimal informational support offered in clinical settings is key for individuals newly diagnosed with cancer to ensure both adjustment to the illness experience and informed use of health services. To achieve optimal support, health care professionals must identify systematically patients' needs for cancer information and for particular health services at time of diagnosis and follow up. Innovative informational interventions that rely on technology coupled with usual care can add value for individuals dealing with cancer. Future studies on cancer informational support provided in various forms and formats could provide valuable data for health care providers, organizations and policies makers to guide their decisions on individuals' access to cancer services and standards of care.

Further research is needed on patterns of health care service use in the context of cancer as Canadian data are still scant. In addition, we must document potential shifts in informational needs and cancer service use as the cancer experience unfolds. Also, how patients' perceptions of cancer informational support evolve may affect their subsequent use of health care services and possibly their health outcomes. The potential confounding effect of sex with type of cancer diagnosis needs to be disentangled using cancer diagnoses that include both sexes (e.g., lung, colorectal). Obviously, more research is needed among diverse samples such as hard-to-reach, lower socioeconomic status individuals diagnosed with cancer.

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APPENDIX A

CO-AUTHORSHIP AGREEMENT

-------- Original Message --------
Subject: Permission - co-author manuscripts included in thesis
Date: Wed, 9 Apr 2008 18:47:56 -0400
From: Carmen Loiselle, Dr. <carmen.g.loiselle@mcgill.ca>
To: Sylvie Dubois <sylvie.dubois@mail.mcgill.ca>
References:<47FD44BD.6030207@mail.mcgill.ca>

To the Thesis Office at McGill University

This is to confirm that I have agreed to be co-author on the following manuscripts:

Loiselle, C. G., & Dubois, S. (2008). The impact of a multimedia informational intervention on health care service use among women and men newly diagnosed with cancer. Submitted for publication to *Cancer Nursing.*

Dubois, S., & Loiselle, C., G., (2008a). The role of informational support in guiding health care service use: A qualitative study among individuals newly diagnosed with cancer. Submitted for publication to *Canadian Oncology Nursing Journal (CONJ).*

Dubois, S., & Loiselle, C.G. (2008b, in press). Cancer informational support and health care service use among individuals newly diagnosed: A mixed methods approach. *Journal of Evaluation in Clinical Practice.*

Thank you,

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CIHR/NCIC PORT Program Leader www.port.mcgill.ca
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APPENDIX B

ETHICS' APPROVAL FOR LOISELLE, EDGAR & BATIST (2002-2005) STUDY

The Sir Mortimer B. Davis
Jewish General Hospital
A McGill University Teaching Hospital

"The Contribution of Interactive Health Communication (IHC) to the Health and Well-being of Oncology Patients"

Information and Consent form

Principal Investigator:
Dr. Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill School of Nursing
Nurse Scientist
Centre for Nursing Research
SMBD-Jewish General Hospital

Co-Investigators:
Dr. Linda Edgar, N., Ph.D.
Nursing Research Consultant- McGill University Health Centre
Assistant Professor Nursing and Oncology- McGill University
Research Associate - Hope and Cope - Division of Psychology, Department of Psychiatry, SMBD-Jewish General Hospital

Dr. Gerald Batist, M.D.
Chair of Oncology-McGill University Health Centre
Director of the Centre for Translational Research in Cancer

Study Objectives

We invite you to participate in a study that explores patients' adjustment to illness, in particular, the experience of patients who have been recently diagnosed with breast, colorectal or prostate cancer. Before accepting to participate in this study, please take the time to read and understand the information that follows. This document may contain terms that are unfamiliar to you. We invite you to ask the researcher and assistants to clarify anything that is unclear to you.

The aim of the research is to better understand the role of information in the illness experience. We expect to recruit 300 patients for this study, 50 of whom will come from the SMBD-Jewish General Hospital. This study is funded, in part, by the Canadian Institutes of Health Research.

What will happen if you take part in this study

If you agree to take part in this study, you will be asked: 1) to provide answers to three separate questionnaires with the help of an interviewer, and 2) to participate in a training session on how to use a CD-ROM about cancer and how to access reputable cancer-related Web sites.

First, a research assistant will phone you within a few days following your diagnosis to answer any questions you may have about your involvement in this study. A research assistant will then call you to schedule the first interview at a time and place that is most convenient to you. The 2nd and 3rd interviews will be completed at the 3-month and 6-month mark following your diagnosis. The research assistant will call you to schedule both of these interviews.

At the first interview, you will be asked to sign and return this consent form. You will be provided with a copy. During the interview, the research assistant will complete a questionnaire with you that inquires about your needs for information, quality of life and well being, as well as your use of health services and experience with health care providers. The questions will also include some background information about yourself such as your education, your work status, and medical treatment. Each interview for the questionnaire takes approximately one hour. You will receive a payment of $20 for your time for each set of questionnaires completed (up to three sets).

This study also involves participating in a brief training session on how to access reputable cancer-related Web sites and how to use an informative CD-ROM. This training session can take place either on the same day as your first interview, or at a time that is more convenient to you. This training will take approximately one hour, however it may vary depending on your needs. Should you also wish to view the CD-ROM and use the Internet at home, we will do our best to provide you with the necessary equipment and hook-ups. Technical support will be provided, if needed, throughout the period of use of the CD-ROM (8 weeks).

We will also need to review your medical record to get information on your medical history.

Risks and Benefits

Although this study has no direct benefit to you, the computer training, Internet access and the CD-ROM will provide you with the opportunity to learn more about cancer. Answering the questionnaires may help you to reflect on your experience. The feedback you provide will give us valuable information on ways the health care team can best support people facing a diagnosis of cancer.

You may find that some of the questions touch on sensitive issues; the investigators are available to discuss your concerns and help you find appropriate resources if needed.

Confidentiality

All the information you provide remains strictly confidential. Your name will not appear on the questionnaires. Each questionnaire will be identified with a code that will be used to protect your anonymity. All measures will be taken to ensure that the confidentiality of your medical file, if consulted, and all information collected pertaining to yourself will remain confidential. We will keep all collected information in a locked filing cabinet in the Centre for Nursing Research at the SMBD-Jewish General Hospital. Your name or personal information will not be identifiable in any resulting publications.

Voluntary Participation

Your participation in this study is voluntary. You have the right to refuse to participate, or to withdraw at any time, without affecting your present or future care at the SMBD-Jewish General Hospital.

Contact People for the study

Principal Investigator

Dr. Carmen Loiselle, N., PhD.
Assistant Professor
McGill School of Nursing
Nurse Scientist
Centre for Nursing Research
SMBD-Jewish General Hospital
(514) 398-4163 or (514) 340-8222 ext. 5784

Co-Investigator

Dr. Linda Edgar, N., Ph.D.
Nursing Research Consultant, McGill University Health Centre
Assistant Professor Nursing and Oncology, McGill University
Research Associate - Hope and Cope - Division of Psychology, Department of Psychiatry, SMBD-Jewish General Hospital
(514) 842-1231 ext. 35918

Contact Person about your rights as a research participant

For questions pertaining to your rights as a research participant, contact the SMBD-Jewish General Hospital Patient Representative:
Ms. Laurie Berlin (514) 340-8222 x 5833

You do not give up any of your legal rights by signing this form.

"L'impact des Communications Interactives sur le Cancer (CIC) et ses effets sur la santé et le bien-être des patients en oncologie"

Formulaire d'information et de consentement

Chercheuse principale
Dre Carmen Loiselle, Inf., Ph. D.
Professeure adjointe-École des sciences
Infirmières - Université McGill
Chercheuse - Centre de recherche en soins
Infirmiers - Hôpital Général Juif S.M.B.D.
(514) 398-4163 ou
(514) 340-8222, poste 5784

Co-Chercheurs
Dre Linda Edgar, Inf., Ph. D.
Experte-conseil en recherche infirmière
Centre universitaire de santé McGill
Professeure adjointe en sciences infirmières et oncologie - Université McGill
Associée de recherche pour « L'espoir c'est la vie » - Division de la psychologie du département de psychiatrie, Hôpital Général Juif S.M.B.D
(514) 842-1231, poste 35918

Dr Gerald Batist, M.D.
Chef du Département d'oncologie, Centre universitaire de santé McGill
Directeur du Centre de recherches appliquées sur le cancer

Objectifs de l'étude

Nous vous invitons à participer à une étude qui explore le processus d'adaptation à la maladie, et plus particulièrement, qui étudie l'expérience des patients ayant reçu récemment un diagnostic de cancer du sein, du colon, du rectum ou de la prostate. Avant d'accepter de participer à ce projet, veuillez prendre le temps de lire et de comprendre les renseignements qui suivent. Le présent document peut contenir des termes que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugez utiles au chercheur et à ses adjoints et à leur demander de vous expliquer les éléments qui ne sont pas clairs.

Le but de cette recherche est de mieux comprendre le rôle de l'information dans la manière dont se vit la maladie. Nous prévoyons recruter 300 patients pour l'étude dont 50 provenant de l'Hôpital Général Juif - SMBD. Cette étude a reçu un soutien financier des Instituts de recherche en santé du Canada.

Implications d'une participation à l'étude

Si vous acceptez de participer à cette étude, nous vous demanderons : 1) de répondre à trois questionnaires différents avec l'aide d'une intervieweuse et 2) de participer à une formation sur l'utilisation d'un CD-ROM ayant pour sujet le cancer et sur l'accès à des sites Internet reconnus.

Dans un premier temps, une agente de recherche vous téléphonera quelques jours après votre diagnostic afin de répondre à toute question au sujet de votre éventuelle implication dans l'étude. Par la suite, une autre agente de recherche vous téléphonera afin de fixer un premier rendez-vous à un temps et à un lieu de votre convenance. Les 2ième et 3ième entrevues se feront trois mois et six mois après votre diagnostic. Vous recevrez un téléphone de l'agente de recherche afin d'organiser ces rencontres.

Lors de la première entrevue, on vous demandera de signer ce consentement et une copie vous sera remise. Durant cette entrevue, l'agente de recherche remplira le questionnaire. Les questions porteront autant sur vos besoins en information que sur votre état de santé, votre bien-être, votre qualité de vie ainsi que sur votre utilisation des services de santé et vos expériences avec les professionnels de la santé. D'autres questions comme, votre degré de scolarité, votre occupation principale et votre traitement médical, vous seront également posées. La durée d'une entrevue est d'environ une heure. Vous recevrez une compensation de 20.00 $ après chaque questionnaire complété (pour un maximum de 3).

Cette étude implique également que vous participiez à une brève formation sur l'accès à des sites reconnus dans Internet ainsi que sur l'utilisation d'un CD-ROM interactif. Cette formation pourra avoir lieu le même jour que l'entrevue ou à un autre moment qui vous convient le mieux. Cette formation d'une durée d'environ une heure pourra toutefois varier en fonction de vos besoins. Si vous souhaitez avoir le CD-ROM à la maison ainsi que la possibilité de naviguer dans Internet, nous ferons le nécessaire pour vous fournir l'équipement requis. Un soutien technique sera également offert, en cas de besoin, durant la période d'utilisation du CD-ROM (8 semaines).

L'étude nécessite également que nous consultions votre dossier médical afin d'accéder à votre histoire médicale.

Risques et bénéfices

Bien que cette étude ne vous offre aucun bénéfice apparent, la formation à l'ordinateur et l'accès à Internet et au CD-ROM vous permettront d'en apprendre davantage sur le cancer. Répondre aux questionnaires pourrait également vous aider dans votre réflexion sur votre expérience. Par ailleurs, vos réponses nous apporteront une information précieuse sur la manière dont une équipe de soins de santé doit agir afin d'aider davantage les patients faisant face à un diagnostic de cancer.

Vous trouverez peut-être certaines questions personnelles. Si tel est le cas, les chercheuses de l'étude sont disponibles pour en discuter avec vous et vous référer à une ressource appropriée, au besoin.

Confidentialité

Toutes les informations que vous nous fournirez demeureront strictement confidentielles. Afin de protéger l'anonymat, nous attribuerons un code à vos questionnaires de sorte que votre nom n'y apparaîtra pas. Toutes les mesures appropriées seront prises, en cours d'étude, afin que soit préservée la confidentialité des données recueillies à votre sujet ainsi que les renseignements de votre dossier médical, s'il doit être consulté. Toutes les informations seront conservées sous clé au Centre de recherche en soins infirmiers de l'Hôpital Général Juif. En cas de publication des résultats de l'étude, les mesures prises feront en sorte qu'il sera impossible de vous identifier.

Participation volontaire

Votre participation est volontaire et vous êtes totalement libre d'accepter ou non de participer à ce projet de recherche. De plus, vous demeurez libre de vous retirer du projet en tout temps sans que cela affecte vos relations avec votre médecin ni la qualité des soins que vous recevez dans un des hôpitaux suivants, soit: l'Hôpital Général de Montréal, l'Hôpital Royal Victoria, l'Hôpital Général Juif S.M.B.D., le Centre Hospitalier de St. Mary, l'Hôpital Notre-Dame, l'Hôpital Maisonneuve-Rosemont et l'Hôpital Sacré-Coeur.

Personnes à contacter au sujet de l'étude :

Chercheuse principale de l'étude
Dre Carmen Loiselle, Inf., Ph. D.
Professeure adjointe - École des sciences infirmières, Université McGill
Chercheuse - Centre de recherche en soins infirmiers,
Hôpital Général Juif S.M.B.D.
(514) 398-4163 ou (514) 340-8222, poste 5784

Cochercheurs
Dre Linda Edgar, Inf., Ph. D.
Experte-conseil en recherche infirmière
Centre universitaire de santé McGill
Professeure adjointe en sciences infirmières et oncologie - Université McGill
Associée de recherche pour « L'espoir c'est la vie » - Division de la psychologie du département de psychiatrie, Hôpital Général Juif S.M.B.D
(514) 842-1231, poste 35918

À propos de vos droits en tant que participant(e) à une recherche

Une représentante des patients pourra répondre à toute question concernant vos droits:

Représentant des patients de l'Hôpital Général Juif-SMBD
Ms. Laurie Berlin (514) 340-8222 x 5833

Vous n'abandonnez aucun de vos droits en signant ce formulaire.

APPENDIX C

ETHICS' APPROVAL FOR SECONDARY ANALYSIS

HÔPITAL GÉNÉRAL JUIF
SIR MORTIMER B. DAVIS
JEWISH GENERAL HOSPITAL
HÔPITAL D'ENSEIGNEMENT DE L'UNIVERSITÉ MCGILL
A MCGILL UNIVERSITY TEACHING HOSPITAL

BUREAU D'ÉTHIQUE DE LA RECHERCHE
RESEARCH ETHICS OFFICE

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CHIEF, RESEARCH ETHICS OFFICE
BUREAU/ROOM A-925
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BUREAU/ROOM A-925
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E-MAIL: carolyn.ells@mcgill.ca

September 10, 2006

Dr. Carmen Loiselle
School of Nursing
McGill University

SUBJECT: **Protocol #02-076 entitled** "The Contribution of Interactive Health Communication (IHC) to the Health and Well-Being of Oncology Patients"

Dear Dr. Loiselle:

Thank you for submitting your Continuing Review Application pertaining to the above-mentioned protocol to the Research Ethics Office for review.

The Research Ethics Committee of the SMBD-Jewish General Hospital (Federalwide Assurance Number: 0796) is designated by the province (MSSS) and follows the published guidelines of the Tri-Council Policy Statement, 1998 (with 2000, 2002 updates), in compliance with the "Plan d'action ministeriel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998), the membership requirements for Research Ethics Boards defined in Part C Division 5 of the Food and Drugs Regulations; acts in conformity with standards set forth in the United States Code of Federal Regulations governing human subjects research, and functions in a manner consistent with internationally accepted principles of good clinical practice.

Given the fact that recruitment is complete and that protocol (03/2002) is active for secondary analysis purposes only we are pleased to inform you that expedited re-approval is granted for a period of **one year**. Please be informed that this study proposal will be presented for corroborative approval at the next meeting of the Committee on October 20, 2006.

Expedited Re-Approval Date: **September 10, 2006**
Expiration date of Expedited Re-Approval: **September 9, 2007**

…2

HÔPITAL GÉNÉRAL JUIF
SIR MORTIMER B. DAVIS
JEWISH GENERAL HOSPITAL
HÔPITAL D'ENSEIGNEMENT DE L'UNIVERSITÉ MCGILL
A MCGILL UNIVERSITY TEACHING HOSPITAL

BUREAU D'ÉTHIQUE DE LA RECHERCHE
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September 1, 2007

Dr. Carmen Loiselle
School of Nursing
McGill University

SUBJECT: **Protocol #02-076 entitled** "The Contribution of Interactive Health Communication (IHC) to the Health and Well-Being of Oncology Patients"

Dear Dr. Loiselle:

Thank you for submitting your Continuing Review Application pertaining to the above-mentioned protocol to the Research Ethics Office for review.

The Research Ethics Committee of the SMBD-Jewish General Hospital (Federalwide Assurance Number: 0796) is designated by the province (MSSS) and follows the published guidelines of the Tri-Council Policy Statement, 1998 (with 2000, 2002 updates), in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998), the membership requirements for Research Ethics Boards defined in Part C Division 5 of the Food and Drugs Regulations; acts in conformity with standards set forth in the United States Code of Federal Regulations governing human subjects research, and functions in a manner consistent with internationally accepted principles of good clinical practice.

Given the fact that recruitment is complete and that protocol (03/2002) is active for secondary analysis purposes only we are pleased to inform you that expedited re-approval is granted for a period of **one year**. Please be informed that this study proposal will be presented for corroborative approval at the next meeting of the Committee on September 7, 2007.

Expedited Re-Approval Date: **September 1, 2007**
Expiration date of Expedited Re-Approval: **August 30, 2008**

...2

APPENDIX D

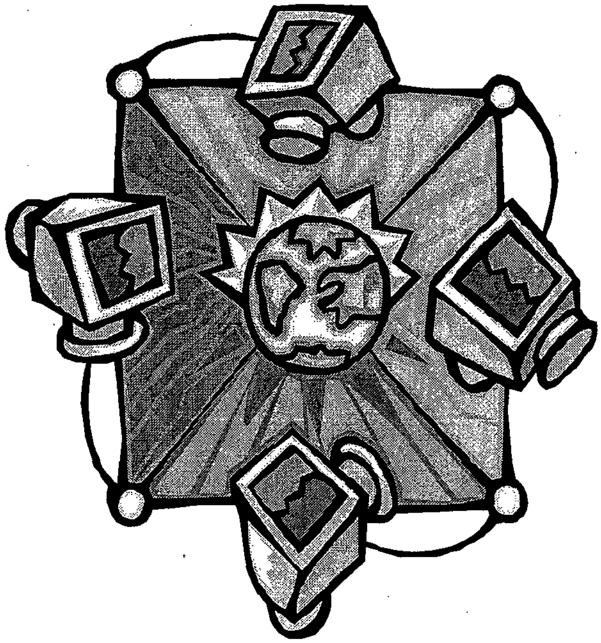
STUDY QUESTIONNAIRES AND SCALES USED

Patient Initials and Hospital Name: ____________________

☐ ☐ ☐ ☐ ☐ ☐

Connecting Patients to Cancer Information

A Study of Patient's Information Needs and Resources



Thank you for participating in the *"Connecting Patients to Cancer Information"* study.

This questionnaire assesses personal characteristics and health information needs. Your answers are crucial to the success of the study.

Please answer every question by following the instructions that are given. If you are unsure how to answer a question, give the best answer you can.

All information you provide remains **strictly confidential.**

McGill

Principal investigator:

Dr. Carmen G. Loiselle, N. PhD.,
Assistant Professor, School of Nursing
McGill University, 3506 University Avenue
Nurse Scientist SMBD – Jewish General Hospital &
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Dr. Linda Edgar, N. PhD.,
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Email: linda.edgar@muhc.mcgill.ca

Name of interviewer: ______________________________ ☐ ☐ ☐ ☐ ☐ ☐

[illegible]t time of interview: _____ :_____

Socio-demographic Information

	Code
1. Today's date: ____/____/____ day / month / year	
2. Your date of birth: ____/____/____ day / month / year	
3. Age: ________	
4. (a) Marital status: (1) Single (2) Married / common law (3) Separated / divorced (4) Widowed (b) Do you live alone? (1) Yes___ (2) No ___	
5. Work status: (1) Full time in the paid work force (2) Part time in the paid work force (3) Unemployed (4) Disability / Sick leave (5) Homemaker (6) Retired (7) Other (specify)____________________	
6. How many children do you have? ____	
7. How many dependants do you have living with you (including your partner's children)? ____	
8. In which country were you born? ______________________	
9. What language(s) do you speak most at home? _________________	

`Medical Information *see sheet at the end of the questionnaire *`

☐ ☐ ☐ ☐ ☐ ☐

CES-D Scale

Using your response card, choose a statement which best describes how often you felt or behaved this way **during the past week**

During the past week:	Code	**Rarely or none of the time** (less then 1 Day)	**Some or a little of the time** (1-2 Days)	**Occasionally or a moderate amount of time** (3-4 Days)	**Most or all of the time** (5-7 Days)
1. I was bothered by things that usually don't bother me.		0	1	2	3
2. I did not feel like eating; my appetite was poor.		0	1	2	3
3. I felt that I could not shake off the blues even with help from my family and friends.		0	1	2	3
4. I felt that I was just as good as other people.		0	1	2	3
5. I had trouble keeping my mind on what I was doing.		0	1	2	3
6. I felt depressed.		0	1	2	3
7. I felt that everything I did was an effort.		0	1	2	3
8. I felt hopeful about the future.		0	1	2	3

Source : Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.

☐ ☐ ☐ ☐ ☐ ☐

During the past week:	Code	Rarely or none of the time (less then 1 Day)	Some or a little of the time (1-2 Days)	Occasionally or a moderate amount of time (3-4 Days)	Most or all of the time (5-7 Days)
9. I thought my life had been a failure.		0	1	2	3
10. I felt fearful.		0	1	2	3
11. My sleep was restless.		0	1	2	3
12. I was happy.		0	1	2	3
13. I talked less than usual.		0	1	2	3
14. I felt lonely.		0	1	2	3
15. People were unfriendly.		0	1	2	3
16. I enjoyed life.		0	1	2	3
17. I had crying spells.		0	1	2	3
18. I felt sad.		0	1	2	3
19. I felt that people disliked me.		0	1	2	3
20. I felt like I could not get going		0	1	2	3

☐☐☐ ☐☐☐

STAI-Y

I will read out a number of statements which people have used to describe themselves. Using your response card, indicate **how you feel right now**, that is, at this moment. There are no right or wrong answers.

Right now…	Code	**Not at all**	**Somewhat**	**Moderately So**	**Very much So**
1. I feel calm		1	2	3	4
2. I feel secure		1	2	3	4
3. I am tense		1	2	3	4
4. I feel strained		1	2	3	4
5. I feel at ease		1	2	3	4
6. I feel upset		1	2	3	4
7. I am presently worrying over possible misfortunes		1	2	3	4
8. I feel satisfied		1	2	3	4
9. I feel frightened		1	2	3	4
10. I feel comfortable		1	2	3	4
11. I feel self-confident		1	2	3	4
12. I feel nervous		1	2	3	4

Source : Spielberger, C. D. (1983). *Strait-Trait Anxiety Inventory (STAI) for Adults: Sampler set manual, test, scoring key*. Redwood, CA: Mind Garden.

Right now…	Code	**Not at all**	**Somewhat**	**Moderately So**	**Very much So**
13. I am jittery		1	2	3	4
14. I feel indecisive		1	2	3	4
15. I am relaxed		1	2	3	4
16. I feel content		1	2	3	4
17. I am worried		1	2	3	4
18. I feel confused		1	2	3	4
19. I feel steady		1	2	3	4
20. I feel pleasant		1	2	3	4

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Oncologist Information Support

People help each other out in a lot of different ways. Given the options on your response card indicate how likely your **cancer specialist** would be to help you. Try to base your answers on your experience with this person up to now.

A) Have you already seen a cancer specialist?

(1) Yes ____
(2) No (Please indicate the titles of the health professionals who you have already seen, such as a G.P. or a nurse):
____
(Please don't write actual names)
(3) I don't know ____

B) How likely would your <u>cancer specialist</u> be to :	Coding	He/She would **not** do this	He/She **might** do this	He/She would **probably** do this	He/She would **certainly** do this
1. help you decide what to do		1	2	3	4
2. tell you about the available choices and options		1	2	3	4
3. suggest how you could find out more about a situation		1	2	3	4
4. give advice about what to do		1	2	3	4
5. give you reasons why you should or should not do something		1	2	3	4
6. respond to your concerns when you think that something is wrong with your health		1	2	3	4
7. communicate and explain your test results with you		1	2	3	4
8. explain the different treatment options		1	2	3	4
9. provide information on different organizations and support groups that you could contact		1	2	3	4

Source : Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry, 56,* 340-347.

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C) How likely would your <u>nurse</u> be to…	Coding	He/She would **not** do this	He/She **might** do this	He/She would **probably** do this	He/She would **certainly** do this
10. help you decide what to do		1	2	3	4
11. tell you about the available choices and options		1	2	3	4
12. suggest how you could find out more about a situation		1	2	3	4
13. give advice about what to do		1	2	3	4
14. give you reasons why you should or should not do something		1	2	3	4
15. respond to your concerns when you think that something is wrong with your health		1	2	3	4
16. communicate and explain your test results with you		1	2	3	4
17. explain the different treatment options		1	2	3	4
18. provide information on different organizations and support groups that you could contact		1	2	3	4

D) Considering all of the people, (health care professionals such as cancer specialist, G.P. or nurse) or someone close to you who gave you information about your illness, who was useful? Please indicate your first, second and third choice.

(Please don't give actual names)

(a) First choice: ______________________________

(b) Second choice: ____________________________

(c) Third choice: ______________________________

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Health-Care Use and Satisfaction

Use the table on your response card to describe your **out-patient visits over the last two months** to various health care providers. If you haven't used a certain kind of health care provider in the last two months please mention this. We've filled in a sample in the first row to show you how someone might answer. **Do not include the time you may have spent overnight in the hospital or for day surgeries in this table**. Hospitalizations and surgeries will be covered in the next section.

OUT-PATIENT VISITS TO HEALTH CARE PROVIDERS:

During the last two months:	**(A)** How many times in the last two months have you visited your …	**(B)** What is the average amount of time (excluding waiting time) you have spent with your… (specify minutes or hours)*		**(C)** Overall, how satisfied were you with visits to this provider? Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied
Example	e.g. 2 visits or 0 if haven't seen	**Hours**	**Minutes**	e.g. 4 (Circle)
		1	15	
1. Oncologist				1 2 3 4 5
2. Nurse				1 2 3 4 5
3. Radiotherapist				1 2 3 4 5
4. Family Practitioner (G.P.)				1 2 3 4 5
5. Pharmacist				1 2 3 4 5

Source: Gustafson, D. H., McTavish, F., Hawkins, R., Pingree, S., Arora, N., Mendenhall, J., et al. (1998). Computer support for elderly women with breast cancer. *Journal of the American Medical Association, 280,* 1305.

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Health-Care Use and Satisfaction (cont.)

During the last two months:	(A) How many times in the last two months have you visited your …	(B) What is the average amount of time (excluding waiting time) you have spent with your… (Hours	/ Minutes	(C) Overall, how satisfied were you with visits to this provider? Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied
6. Surgeon				1 2 3 4 5
7. Plastic Surgeon				1 2 3 4 5
8. Other health care provider (e.g. social worker, psychologist, counselor, therapist)				1 2 3 4 5
9. Alternative Care Provider (e.g. massage, acupuncture, osteopath, chiropractor)				1 2 3 4 5
10. Other Specialty Clinic (dermatologist, etc.)				1 2 3 4 5

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Health-Care Use and Satisfaction (cont.)

During the last two months:	(A) How many times in the last two months have you visited your …	(B) What is the average amount of time you have spent (excluding waiting time) with your health care providers at the… (specify minutes or hours)*		(C) Overall, how satisfied were you with visits to this provider? Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied
		Hours	/ Minutes	
11. Outpatient Lab Visit (e.g. blood test, x-ray, mammogram, etc.)				1 2 3 4 5
12. Emergency Room				1 2 3 4 5
13. Dental Clinic (dentist, oral surgeon, etc.)				1 2 3 4 5
14. **Telephone** consultations (e.g. Info-Santé) or other health professional				1 2 3 4 5

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Health-Care Use and Satisfaction (cont.)

15. Have you had day surgery or surgery that required you to stay for more than 24 hours in the hospital over the last two months?

(1) Yes___ (2) No ___ (Please go to question #18)

Use the table below to describe your **hospital visits (either overnight stays or day surgeries) over the last two months**. Indicate the length of your visit and your overall satisfaction with the care you received.

OVERNIGHT HOSPITAL VISITS AND DAY SURGERIES:

During the last two months:	**(A)** Reason for day surgery or overnight hospitalization (e.g. removal of a tumor)	**(B)** Number of hours (if day surgery) or number of days (for stays longer than 24 hours)		**(C)** Overall, how satisfied were you with your care? Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied
		Hours /	Days	
16. Day surgery (no overnight stays)			NIL	1 2 3 4 5
17. Overnight hospital stays		NIL		1 2 3 4 5

Level of Satisfaction with Information Received

18. Overall, how satisfied are you with the information on cancer that you have received so far ?

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

Medical Information – Part 1

	Code
1. When were you diagnosed with cancer? ______/______/______ day / month / year 2. Have you had a biopsy? (1) Yes___ (2) No ___ (3) I don't know ___ 3. a) Have you already had surgery for this cancer? (1) Yes___ (2) No ___ ▼ b) If no, has surgery been planned? (1) Yes___ (2) No ___ (3) I don't know ____	

Medical Information – Part 2

	Code
1. Have you used other types of treatments or approaches for your cancer ? (1) Yes ____ (2) No ____	
2. If yes, check all that apply: (1) Acupuncture ____ (2) Special diet____ (3) Exercise ____ (4) Herbs ____ (5) Medication from other countries____ (6) Relaxation ____ (7) Visualisation ____ (8) Vitamins ____ (9) Other : ______________________________	
3. Have you been in touch with other people who have cancer? (1) Yes ____ (2) No ____	
4. If yes, specify who: (1) Family member(s) ___________________________ (2) Friend(s) (3) Other(s) ___________________________________	
5. Are you participating in any other study related to cancer? (1) Yes (Please indicate the name of the study): ____ (2) No ________ (3) I don't know _____	

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Socio-Demographic Information (continued):

	Code
10.What is your religious background? (1) Buddhist (2) Christian (3) Greek or Eastern Orthodox (4) Hindu (5) Jewish (6) Muslim (7) Not applicable (8) Other ____________________	
11.What is your total household income before taxes? (1) Less than $10,000 (2) 10-$29,999 (3) 30-$49,999 (4) 50-$79,999 (5) 80-$99,999 (6) $100,000-$119,999 (7) more than $120,999 (8) I don't know	
12. What is the highest level of education that you have completed? (1) Elementary school (2) High school (3) CEGEP : technical (4) CEGEP: general (5) Bachelors (6) Masters (7) Doctorate	
13. How many years of education does this represent? ________	

APPENDIX E

ETHICS' APPROVAL FOR QUALITATIVE STUDY

APPENDIX F

CONSENT FORM FOR PARTICIPANTS IN QUALITATIVE STUDY

"The Role of Informational Support in Relation to Health Care Services Use among Individuals Newly Diagnosed with Cancer."

Information and Consent Form

Investigators
Sylvie Dubois, N., Doctoral Candidate
McGill University School of Nursing
sylvie.dubois@mail.mcgill.ca

Dr Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill University School of Nursing
Nurse Scientist
Center for Nursing Research
SMBD-Jewish General Hospital
carmen.loiselle1@mcgill.ca

If you have any difficulty reading this form, please let the nurse-researcher or research assistant know.

Introduction

I am a nurse completing my doctoral studies at the School of Nursing, McGill University. As part of my research training, I am conducting a research project under the direction of Dr. Carmen Loiselle. We are interested in exploring how individuals diagnosed with either breast or prostate cancers make use of cancer information and health care services. You are being asked to participate in this study because you have been diagnosed with cancer and you are receiving medical care at one of the following hospitals: the McGill University Health Centre, the SMBD-Jewish General Hospital or the Hôpital du Sacré-Cœur de Montréal.

This consent form should provide you with the basic idea of what this research is about and what your participation will involve. Before accepting to participate in this study, please take the time to read the information that follows. If you would like more details about this study, please feel free to ask the nurse-researcher or research assistant. You may take this form with you and take the time necessary before making your decision to take part in this study. This document may contain terms that are unfamiliar to you. We invite you to ask the nurse-researcher or research assistant to clarify anything that is unclear to you. If you decide to participate, you will be asked to sign this form and a copy will be given to you.

Study Objectives

We invite you to participate in a study that explores the roles of cancer information and use of health care services in individuals' adjustment to cancer. The aim of this study is to better understand how the cancer information you received and health care services you use assist you in coping with illness.

We anticipate to interview approximatively 20 patients for this study from the Royal Victoria Hospital, the Montreal General Hospital, the SMBD-Jewish General Hospital, and the Hôpital du Sacré-Cœur de Montréal.

What will happen to you if you take part in this study

Information will be gathered through interviews with individuals with cancer. We will asked questions about how you seek information related to your cancer and how this may affect your use of health care services. The interview is anticipated to last approximately 1.5 to 2 hours and will take place in a private room, most likely, within the hospital. Alternate space could be identified according to participant's preference (e.g., participant's home, workplace). Interviews will be audiotaped. The audiotaped will only be listened to by the researchers to help recall details of the interview.

You also will be asked to complete a brief questionnaire on background information about yourself, such as your educational level, your work status, and medical treatment. This will take approximately 10 minutes to complete. We may also need to review your medical record to get information on your medical history.

Risks and Discomforts

There are no expected risks for participating in this study. Some individuals may find that discussions raise unpleasant thoughts or memories for them. If at any time you wish to stop the interview, this will be accommodated. The investigators are available to discuss any concerns, and if needed, assist you in finding appropriate resources.

Potential Benefits

There are no direct benefits for participating in this study. However, some individuals may find it helpful to have the opportunity to share their experience with the researcher. Findings may inform health care providers on how to best assist individuals, in the future, with their information needs related to their illness and support them with the most relevant health care services.

Compensation

To participate in this study, 20$ will be given to you as a recognition for your participation.

Confidentiality

All the information you provide will remain strictly confidential within the limits set by law with the exception of members of the McGill University (Faculty of Medicine), McGill University Health Centre, SMBD- Jewish General Hospital Ethics Committee, or Hôpital du Sacré-Cœur de Montréal Ethics Committee. Authorized hospital personnel may have direct access to certain records for verification/auditing purposes. The group interview transcript, demographic sheet, and audiotape will be identified with a code that will be used to protect confidentiality. Your name and the names of anyone you mention will not appear anywhere to ensure anonymity. All measures will be taken to ensure that the confidentiality of your medical file, if consulted, and all information collected pertaining to yourself will remain confidential. We will keep all collected information and audiotapes in a locked filling cabinet at the Centre for Nursing Research of the SMBD-Jewish General Hospital. The researchers and research assistants are the only ones who have access to these materials. All documents and materials related to this study will be destroyed after 5 years. Names or personal information will not be identifiable in any resulting publications. The findings of this study may be available to you upon request.

Voluntary Participation and/or Withdrawal

Your participation in this study is entirely voluntary. Therefore, you have the right to refuse to participate, or to withdraw at any time, without explanation, by informing the researcher or the research assistant. Your decision to not participate in the study or to withdraw from the study will have no consequence on the present or future care you will receive at the Royal Victoria Hospital, the Montreal General Hospital, the SMBD-Jewish General Hospital or the Hôpital du Sacré-Cœur de Montréal.

Contact People for the Study

Investigators:
Sylvie Dubois, N., Doctoral Candidate
McGill University School of Nursing
(514)-398-2478 or 514-340-8222 ext. 5237

Dr. Carmen Loiselle, N., Ph.D.
Assistant Professor
McGill University School of Nursing
Nurse Scientist
Centre for Nursing Research
SMBD-Jewish General Hospital
(514)-398-4163

For questions about your rights as a research participant and/or research related injuries please contact:

The Patient Representatives of the participating hospitals are listed below:

Royal Victoria Hospital
Ms. Pat O'Rourke (514) 934-1934 #35655

Montreal General Hospital
Ms. Line-Marie Casgrain (514) 934-8306

SMBD- Jewish General Hospital
Ms. Laurie Berlin (514) 340-8222 #5833

Hôpital du Sacré-Cœur de Montréal
Ms. Lena Rodrigue (514) 338-2222 #2259

You do not give up any of your legal rights by signing this form.

Consent

I have read this consent form and accept to be involved in the present study. I have been given sufficient time to decide whether or not to participate.

This study has been explained to me and questions that I might have were answered to my satisfaction. I know that at any time I may ask questions I have about the study or the research procedures.

I have been assured that information relating to me will be kept confidential and that no information will be released or printed that would disclose my personal identity.

By signing this consent form, I have in no way waived my legal rights, nor do I free the researchers or the hospital of their civil and professional responsibilities. I know that I am free to withdraw from this study at any time without jeopardizing the health care that I am entitled to receive. I know that my continued participation should be as informed as my initial consent, and I feel confident that I may ask at any time for clarification about the study or new information about my participation. I will be given a signed copy of this consent form.

I agree to participate in this study

Name of participant: ______________________ (*please print*)
Signature ______________________ Date ______________

Name of witness: _________________________ (*please print*)
Signature __________________________ Date ________________

I have explained the nature of this study as well as the contents of this consent form to the participant. I have answered all of his/her questions and have informed the participant of his/her right to withdraw at any time. I will give a signed copy of this consent form to the participant.
Name of the researcher or the person representing her: __________________ (*please print*)

Signature __________________________ Date ________________

Formulaire de consentement- Étude qualitative

"Le Rôle de l'Information et son Impact sur l'utilisation des Services de Santé chez les Individus Nouvellement Diagnostiqués avec un Cancer."

Information et formulaire de consentement

Chercheuses
Sylvie Dubois, inf., Candidate au doctorat
Université McGill- École des sciences infirmières
sylvie.dubois@mail.mcgill.ca

Dre Carmen Loiselle, inf., Ph.D.
Professeure adjointe
Université McGill- École des sciences infirmières
Chercheuse en sciences infirmières
Centre de recherche en soins infirmiers
Hôpital Général Juif SMBD
carmen.loiselle1@mcgill.ca

Si vous avez des difficultés à lire ce document, SVP en informer l'une des chercheuses ou agents de recherche.

Introduction

Je suis infirmière et étudiante au doctorat à l'École des sciences infirmières de l'Université McGill. Dans le cadre de ma formation en recherche, je fais une étude sous la direction du Docteure Carmen Loiselle. Nous voulons explorer comment les individus nouvellement diagnostiqués avec un cancer du sein ou de la prostate utilisent l'information liée au cancer et son impact sur l'utilisation des services de santé. Vous avez été invités à participer à cette étude parce que vous avez un diagnostic de cancer et que vous recevez des soins médicaux à un des hôpitaux suivants: l'Hôpital Général de Montréal, l'Hôpital Royal Victoria, l'Hôpital Général Juif SMBD ou l'Hôpital du Sacré-Coeur de Montréal.

Ce formulaire de consentement fournit des informations sur l'étude et explique ce que votre participation impliquera. Avant d'accepter de participer, veuillez prendre le temps de lire attentivement l'information qui suit. Si vous voulez plus d'informations au sujet de cette étude, n'hésitez pas à poser vos questions aux chercheuses ou aux agents de recherche. Vous pouvez prendre une copie de ce formulaire avec vous et prendre le temps nécessaire avant de décider de participer à cette étude. Ce formulaire peut contenir des termes qui ne vous sont pas familiers. Nous vous invitons à demander à l'infirmière-chercheuse ou à l'assistante de recherche de clarifier les éléments qui ne sont pas clairs pour vous. Si vous décidez de participer, nous vous demandons de signer ce formulaire et une copie vous sera remise.

Objectifs de l'étude

Nous vous invitons à participer à cette étude qui vise à explorer le rôle de l'information liée au cancer et l'utilisation des services de santé dans l'adaptation des individus au cancer. Le but de cette étude est de mieux comprendre comment l'information que vous avez reçue sur le cancer et les services de santé que vous utilisez vous aident à faire face à la maladie.

Nous anticipons interviewer, pour cette étude, approximativement 20 patients provenant de l'Hôpital Général de Montréal, l'Hôpital Royal Victoria, l'Hôpital Général Juif SMBD et à l'Hôpital du Sacré-Coeur de Montréal.

Participation à l'étude

L'information sera recueillie par le biais d'entrevues individuelles avec des personnes ayant le cancer. Nous vous questionnerons sur la façon dont vous cherchez l'information liée à votre cancer et comment celle-ci peut affecter votre utilisation des services de santé. L'entrevue devrait durer approximativement 1,5 à 2 heures et elle se déroulera dans un endroit privé, probablement, à l'hôpital. Selon les préférences du patient, un autre endroit peut être identifié (par exemple, maison, bureau). Les entrevues seront enregistrées. Les cassettes seront écoutées seulement par les chercheuses afin de les aider à se rappeler les détails de l'entrevue.

Vous serez également invité à remplir un bref questionnaire concernant de l'information sur vous-même, comme votre degré de formation, votre statut d'emploi, etc. Ceci prendra approximativement 10 minutes à compléter. Nous pouvons également devoir réviser votre dossier médical pour obtenir de l'information sur vos antécédents médicaux.

Risques et malaises

Il n'y a aucun risque prévu à participer à cette étude. Quelques personnes peuvent constater que les questions soulèvent des pensées ou des souvenirs désagréables pour elles-mêmes. Si à tout moment vous souhaitez arrêter la discussion, nous en aviser. Les chercheuses de l'étude sont disponibles pour discuter avec vous et vous référer à une ressource appropriée, au besoin.

Bénéfices potentiels

Bien que cette étude ne vous offre aucun bénéfice apparent, quelques personnes peuvent trouver utile d'avoir l'occasion de parler de leur expérience. Les résultats de cette étude peuvent informer les professionnels de la santé sur la manière dont ils doivent agir dans l'avenir afin d'aider davantage les patients, avec leurs besoins d'information liés à leur maladie et les soutenir avec les services de santé les plus appropriés.

Compensation

Une compensation de 20$ vous sera remise à titre de reconnaissance pour votre participation à l'étude.

Confidentialité

Toutes les informations que vous fournirez demeureront strictement confidentielles selon les limites indiquées par la loi à l'exception des membres de l'Université McGill (faculté de médecine), du centre de santé universitaire McGill, le comité d'éthique de l'Hôpital Général Juif SMBD ou le comité d'éthique de l'Hôpital du Sacré-Coeur de Montréal. Le personnel autorisé de l'hôpital peut avoir accès à votre dossier dans un but de vérification. La transcription de l'entrevue, la feuille de données démographiques et la cassette d'enregistrement du magnétophone seront identifiées avec un code pour assurer la confidentialité. Votre nom et les noms des personnes que vous mentionnerez n'apparaîtront à aucun endroit afin d'assurer l'anonymat. Toutes les mesures seront prises pour s'assurer que la confidentialité de votre dossier médical, s'il est consulté, et toute l'information collectée demeurera confidentielle. Toutes les informations obtenues ainsi que les cassettes d'enregistrement seront conservés sous clés au Centre de recherche de soins infirmiers de l'Hôpital Général Juif SMBD. Les chercheuses et les assistantes de recherche sont les seules personnes qui auront accès à ce matériel. Tous les documents et matériel reliés à cette étude seront détruits après 5 ans. Les noms et l'information personnelle ne seront pas identifiables dans aucune publication produite. Les résultats de cette étude pourront être à votre disposition sur demande.

Participation et/ou retrait volontaire

Votre participation à cette étude est entièrement volontaire. Par conséquent, vous avez le droit de refuser de participer ou de vous retirer à tout moment, sans explication, en informant la chercheuse ou l'assistante de recherche. Votre décision à ne pas participer à l'étude ou de vous retirer de l'étude n'aura aucune conséquence sur les soins actuels ou futurs que vous recevrez à l'Hôpital Général de Montréal, l'Hôpital Royal Victoria, l'Hôpital Général Juif SMBD ou à l'Hôpital du Sacré-Coeur de Montréal.

Personnes à contacter au sujet de l'étude:

Chercheuses
Sylvie Dubois, inf., candidate au doctorat
Université McGill- École des sciences infirmières
(514)-398-2478 or 514-340-8222 ext. 5237
sylvie.dubois@mail.mcgill.ca

Dre Carmen Loiselle, inf., Ph.D.
Professeure adjointe
Université McGill- École des sciences infirmières
Chercheuse en sciences infirmières
Centre de recherche en soins infirmiers
Hôpital Général Juif SMBD
(514)-398-4163
carmen.loiselle1@mcgill.ca

Pour vous renseigner sur vos droits en tant que participant(e) à une recherche :

La personne qui représente les patients dans chacun des hôpitaux est indiquée ci-dessous:

Hôpital Royal Victoria
Royal Victoria Hospital
Mme Pat O'Rourke (514) 934-1934 #35655

Hôpital Général de Montréal
Mme Line-Marie Casgrain (514) 934-8306

Hôpital Général Juif SMBD
Mme Laurie Berlin (514) 340-8222 #5833

Hôpital du Sacré-Cœur de Montréal
Mme Lena Rodrigue (514) 338-2222 #2259

Vous n'abandonnez aucun de vos droits en signant ce formulaire.

Consentement

J'ai lu ce formulaire de consentement et j'accepte de participer dans la présente étude. J'ai eu suffisamment de temps pour décider si je participais ou non.

Cette étude m'a été expliquée et les questions que je pouvais avoir ont été répondues de façon satisfaisante. Je sais qu'à tout moment je peux poser des questions tant sur l'étude que sur les procédures de recherche.

J'ai été assuré que l'information me concernant sera maintenue confidentielle et qu'aucune information ne sera divulguée ou imprimée qui pourrait révéler mon identité personnelle.

En signant ce formulaire de consentement, j'ai n'ai aucunement écarté mes droits légaux, ni libérer les chercheuses ou l'hôpital de leurs responsabilités civiles et professionnelles. Je sais que je suis libre de me retirer de cette étude à tout moment sans compromettre les soins que je suis sensé recevoir. Je sais que ma participation devrait être aussi éclairée que mon consentement initial et je me sens confiant(e) de demander à tout moment des clarifications sur l'étude ou de nouvelles informations sur ma participation. Une copie signée de ce formulaire de consentement me sera remise.

J'accepte de participer à cette étude,

Nom du participant: ________________________ (*Lettres moulés svp*)
Signature ________________________ Date _______________

Nom du témoin: ________________________ (*Lettres moulés svp*)
Signature ________________________ Date _______________

J'ai expliqué la nature de cette étude et le contenu de ce formulaire de consentement au participant. J'ai répondu à toutes ses questions et ai informé le/la participant(e) de son droit de se retirer en tout temps. Je donnerai une copie signée de ce formulaire de consentement au participant. Nom de la chercheuse ou de la personne la représentant :
________________ (*Lettres moulés svp*)

Signature ________________________ Date _______________

APPENDIX G

CONSENT FORM FOR PARTICIPANTS TO BE AUDIOTAPED

"The Role of Informational Support in Relation to Health Care Services Use among Individuals Newly Diagnosed with Cancer."

Audio taping consent form

Investigators
Sylvie Dubois, N., Doctoral Candidate
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If you have any difficulty reading this form, please let the nurse-researcher or research assistant know.

Purpose

You have agreed to participate in a research study that explore how individuals diagnosed with either breast or prostate cancers make use of cancer information and health care services. You will be participating in an interview, conducted by the investigator or the research assistant (RA). These interviews will be audio taped. The purpose of audio taping is to help the researchers recall the details of the interviews.

Confidentiality

All information collected during this interview will be kept confidential. Although results of this study may be published, individuals will not be identified. Your name and the names of anyone you mention will not appear anywhere. Participants will be identified in the study by numeric codes. Data and audiotapes will be kept in a locked filling cabinet at the Centre for Nursing Research of the SMBD-Jewish General Hospital. Only the researchers and research assistants will have access to these materials. All audiotapes will be destroyed in 5 years.

Agreement

By signing this consent, you agree for the interviews to be audio taped.

I hereby agree to have interviews audio taped.

Name of participant: ________________________ *(please print)*
Signature ________________________ Date ______________

Name of Investigator/RA: ________________________ *(please print)*
Signature ________________________ Date ______________

"Le Rôle de l'Information et son Impact sur l'utilisation des Services de Santé chez les Individus Nouvellement Diagnostiqués avec un Cancer."

Formulaire de consentement pour enregistrement audio

Chercheuses
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Dre Carmen Loiselle, inf., Ph.D.
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Chercheuse en sciences infirmières
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Si vous avez des difficultés à lire ce document, SVP en informer l'une des chercheuses ou agents de recherche.

But

Vous avez accepté de participer à une étude qui a pour but de mieux comprendre comment l'information que vous avez reçue sur le cancer et les services de santé que vous utilisez vous aident à faire face à la maladie. Vous participerez à une entrevue qui sera réalisée par une infirmière-chercheuse ou une assistante de recherche. Les entrevues seront enregistrées. Les cassettes seront écoutées seulement par les chercheuses afin de les aider à se rappeler les détails de l'entrevue.

Nous anticipons recruter approximativement 20 patients pour cette étude provenant de l'Hôpital Général de Montréal, l'Hôpital Royal Victoria, l'Hôpital Général Juif SMBD et à l'Hôpital du Sacré-Cœur de Montréal.

Confidentialité

Toute l'information obtenue pendant cette entrevue sera maintenue confidentielle. Bien que les résultats de cette étude puissent être publiés, les noms et l'information obtenue ne pourront être identifiés. Votre nom ainsi que les noms de personnes que vous mentionnerez n'apparaîtront nulle part. Les participants à cette étude seront identifiés par des codes numériques. Les données et les cassettes d'enregistrement seront gardées sous clés au Centre pour la recherche en soins infirmiers de l'hôpital général juif SMBD. Les chercheuses et les assistantes de recherche sont les seules personnes qui auront accès à ce matériel. Toutes les bandes sonores seront détruites après 5 ans.

Consentement

En signant ce formulaire de consentement, j'accepte à ce que l'entrevue soit enregistrée sur bande sonore.

Nom du participant: ___________________________ (*Lettres moulés svp*)

Signature _________________________________ Date ________________

Nom de la chercheuse ou de la personne désignée: __________________________

Signature ________________________________ Date ________________

APPENDIX H

INTERVIEW GUIDE FOR PARTICIPANTS

"The Role of Informational Support in Relation to Health Care Services Use
among Individuals Newly Diagnosed with Cancer."

Introduction

Thank you to agree to take part in this interview on "cancer-related information" and "health care service use".

You are invited to read and sign the consent form, if you have not already done so, and to complete the demographic sheet for general questions such as your age, education, etc.

Everything discussed in this interview is kept confidential. A tape-recorder will be used if there is no objection to ensure that I do not loose track of important topics being discussed. The tape recorder can be stopped at any time; just signal to me and I will stop it.

The purpose of the interview today is to learn more about the role of cancer information in your lives and the sources of informational support you use; how such information guides you in your use of health care services; is there a link between the information you receive and your subsequent use of health care services. All questions relate to your experience with cancer.

Do you have any questions or issues before we start our discussion?

Introductory questions

1) Tell me, what does the expression "cancer-related information" mean to you?
   In what ways have you sought cancer-related information?
   What has been most helpful in this process?
   What has been less helpful? Or frustrating?

2) What does "health care service use" mean to you?
   What health care services have you accessed for your current medical condition?
How?
   What has been most helpful in this process?
   What has been less helpful? Or unhelpful?

Interviewing questions

1. Informational sources and content of support

Describe *sources* of informational support.
Thinking back. Let's first talk about all possible *sources* you used to obtain information about cancer (e.g. books, newspaper, magazines, TV, radio, Internet, CD-Rom, E-mail, family, friends, someone else with cancer, religious institution, professionals- oncologist, nurse, radiotherapist, radiologist, family practitioner, pharmacist, surgeon, alternative health care provider, other).

- Since your diagnosis, when you needed information related to your condition, where did you turn to?
    - Describe a situation that stands out the most for you where you found something or someone that acted as a important *source* of information
- Probe – What other *sources* of information were recommended and by whom?
- What have been the best sources of information? Why?

Describe the *content* of informational support.
Please think about the *content* or cancer-related topics you have been needing (e.g., effect of cancer on your body, on family members, on work, on one's leisure activities, on treatment options, on the effects related to cancer treatment, on cancer support groups, on lifespan, on percentage of people with cancer, on institutions or other specialists that provide treatment).

- What types of information did you search for?
- What types of information were most meaningful to you?
    - Probe - Why was it most meaningful?
    - Probe - What types of information were least meaningful? Why?

2. Health care service use

Identifying and describing *health care service use.*
We would like you to focus on all possible health care and oncology services you used (e.g., oncology clinic, emergency room, CLSC, Info-santé, other specialty clinic, dental clinic, outpatient laboratory, alternative health care clinic).

- Since your diagnosis, what kind of health care services did you turn to?
    - Describe a situation that stands out the most for you where you sought a health care service that you needed.
- How did you obtain the health care services that you needed?
    - Explain and discuss various situations were you sough services (e.g., referral from a friend, a patient, a health care provider).
- Tell me about the health care services in terms of accessibility.

    - Probe - Which services were easy to access? Why?
    - Probe - Which services were difficult to access? Why?
    - Probe –How quickly were you able to use them?
- With which health care services were you most satisfied?
    - Explain why it was the best health care service received.
    - Probe - How many attempts did you make to get the services needed?
- Which health care services have been less satisfactory to you?
    - Probe - Why?
- Did you experience any psychological distress related to your use of cancer services?
    - Describe and explain your distress.

3. Links between informational support and use of health care services

- Since your diagnosis, when you needed information related to your cancer, what to health care services did you access?
    - If so, describe a situation that stand out the most for you and specify the health care service used to get information.
- How were your information needs met or not met by these services?
- What role did your significant other play in assisting you with cancer related information?
- What were the barriers or frustrations related to accessing information from health care services?
    - Probe - Can you provide specific examples?
    - Probe – Did anything facilitate access to these services?
- How closely did the information provided match your needs?
    - Probe - Describe a situation where the provision of information by health care professionals exceeded your expectations.
    - Probe - Describe a situation where you were disappointed by information provided by health care professionals.
- What would you consider the best informational support to be provided to people that are newly diagnosed with cancer?

This ends our interview. Do you have comments or additional questions?

Guide pour l'entrevue

"Le Rôle de l'Information et son Impact sur l'utilisation des Services de Santé chez les Individus Nouvellement Diagnostiqués avec un Cancer."

Introduction

Merci d'avoir accepter de participer à cette entrevue sur "l'information liée au cancer" et "l'utilisation des services de santé".

Vous êtes invité(e) à lire et à signer le formulaire de consentement, si ce n'est déjà fait, et à compléter la feuille de données sociodémographiques pour des questions générales comme votre âge, votre degré de scolarité, etc.

Toutes les informations que vous nous fournirez durant l'entrevue demeureront confidentielles. L'entrevue sera enregistrée sur magnétophone, si vous acceptez, afin d'aider les chercheures à se rappeler des détails de l'entrevue. Le magnétophone peut être arrêté à tout moment; simplement me le dire et je l'arrêterai.

Le but de l'entrevue est d'en apprendre davantage sur le rôle de l'information liée au cancer et son lien avec les services de santé. Par exemple, comment cette information vous guide-t-elle dans votre utilisation des services de santé? Existe-t-il un lien entre l'information que vous recevez et l'utilisation subséquente des services de santé? Toutes les questions sont liées à votre expérience avec le cancer.

Avez-vous des questions ou des préoccupations que vous voudriez aborder avant que nous commencions?

Questions d'introduction

1) Dites-moi ce que l'expression "L'information liée au cancer" représente pour vous?
   De quelle façon avez-vous cherché cette information liée cancer?
   Qu'est-ce qui a été le plus utile dans ce processus?
   Qu'est-ce qui a été le moins utile? Ou frustrant?
2) Qu'est-ce que l'expression "L'utilisation des services de santé" représente pour vous?
   A quels services de santé avez-vous accédés pour votre condition médicale? Comment?
   Qu'est-ce qui a été le plus utile dans ce processus?
   Qu'est-ce qui a été le moins utile? Ou frustrant?

Questions d'entrevue

1. Sources et contenu de l'information comme soutien informationnel

Décrivez les *sources* d'information.
Revenons en arrière. Parlons tout d'abord de toutes les sources possibles que vous avez utilisées pour obtenir des informations sur le cancer (par exemple livres, journaux, revues, télévision, radio, Internet, CD, courrier électronique, famille, amis, quelqu'un d'autre avec le cancer, établissement religieux, professionnels de la santé comme oncologiste, infirmière, radiothérapeute, radiologiste, médecin de famille, pharmacien, chirurgien, médecine alternative, autre).

- Depuis votre diagnostic, vers qui ou quoi vous êtes-vous tourné quand vous avez eu besoin d'information liée à votre état de santé?
    - Décrivez une situation pour laquelle la plupart du temps vous avez trouvé quelque chose ou quelqu'un qui a agi en tant que source importante d'information.
- Sonde – Quelles autres sources d'information vous ont été recommandées et par qui?
- Quelles ont été les meilleures sources d'information? Pourquoi?

Décrivez le *contenu* de cette information.
Pensez svp à l'information ou aux autres sujets liés au cancer que vous avez eus besoin (par exemple, effets du cancer sur votre corps, sur les membres de votre famille, sur le travail, sur les activités de loisir, sur des options de traitement, sur les effets liés au traitement du cancer, sur des groupes de soutien, sur la durée de vie, sur le pourcentage des personnes atteintes de cancer, sur des établissements ou d'autres spécialistes qui donnent des traitements).

- Quel type d'information avez-vous recherché?
- Quel type d'information a été le plus significatif?
    - Sonde - Pourquoi était-il le plus significatif?
    - Sonde - Quel type d'information était le moins significatif? Pourquoi?

2. Utilisation des services de santé

Identifiez et décrivez *l'utilisation de service de santé*.
Nous voudrions que vous pensiez à tous les services de santé possibles, incluant les services en oncologie, que vous avez utilisés (par exemple, clinique d'oncologie, salle d'urgence, CLSC, Info-santé, toute autre clinique spécialisée, clinique dentaire, laboratoire externe, clinique de soins alternatifs).

- Depuis votre diagnostic, vers quel type de services de santé vous êtes-vous dirigé?

  - Décrivez une situation pour laquelle, la plupart du temps, vous avez trouvé le service de santé dont vous aviez besoin.
- Comment avez-vous obtenu les services de santé que vous aviez besoin?
  - Expliquez et discutez des différentes situations où vous avez cherché des services de santé (par exemple, par le biais d'un ami, d'un patient, d'un professionnel de la santé).
- Parlez-nous des services de santé en termes d'accessibilité.
  - Sonde - Quels services ont été les plus faciles à accéder? Pourquoi?
  - Sonde - Quels services ont été les plus difficiles à accéder? Pourquoi?
  - Sonde - Pouviez-vous les utiliser rapidement?
- Quel service de santé vous a le plus satisfait?
  - Expliquez pourquoi ce service a été le meilleur service de santé que vous avez reçu.
  - Sonde - Combien de tentatives avez-vous faites pour obtenir les services dont vous aviez besoin?
- Quel service de santé vous a le moins satisfait?
  - Sonde - Pourquoi?
- Avez-vous éprouvé une détresse psychologique liée à l'utilisation des services de santé?
  - Décrivez et expliquez votre détresse.

3. Liens entre le soutien informationnel et l'utilisation des services de santé

Depuis votre diagnostic, quand vous avez eu besoin d'information liée à votre cancer, à quels services de santé avez-vous accédé?

  - Si oui, décrivez une situation pour laquelle la plupart du temps vous avez trouvé le service de santé dont vous aviez besoin pour obtenir l'information.
- Comment vos besoins d'information ont-ils été satisfaits ou non satisfaits par ces services?
- Quel rôle votre partenaire a- t-il joué dans ce contexte d'information liée au cancer?
- Quelles ont été les barrières ou les frustrations liées à l'accès pour l'information par les services de santé?
  - Sonde - Pouvez-vous donner des exemples concrets?
  - Sonde – Est-ce que quelque chose a facilité l'accès à ces services?
- Est-ce que l'information fournie était étroitement liée à vos besoins?
  - Sonde - Décrivez une situation où l'information fournie par les professionnels de la santé a dépassé vos attentes.
  - Sonde - Décrivez une situation où vous avez été déçu par l'information fournie par les professionnels de la santé.

- Que considéreriez-vous comme le meilleur soutien informationnel à être fourni aux individus nouvellement diagnostiqués avec le cancer?

Ceci termine notre entrevue. Avez-vous des commentaires ou des questions additionnelles?

APPENDIX I

CANCER NURSING JOURNAL ACCEPTANCE

-------- Original Message --------
Subject:FW: CN Decision
Date: June 30, 2008 18:14
From: Carmen Loiselle, Dr. <carmen.g.loiselle@mcgill.ca>
To: Sylvie Dubois <sylvie.dubois@mail.mcgill.ca>

From: em.cn.0.c006d.98dede28@editorialmanager.com
[mailto:em.cn.0.c006d.98dede28@editorialmanager.com] **On Behalf Of** Cancer Nursing
Sent: Monday, June 30, 2008 2:31 PM
To: Carmen Loiselle, Dr.
Subject: CN Decision

Jun 30 2008 2:30PM

RE: CN-D-08-00039R2, entitled "The impact of a multimedia cancer informational intervention as opposed to usual care on health care service use among individuals newly diagnosed with breast or prostate cancer"

Dear Dr. Loiselle,

I am absolutely thrilled to share with you that your work has now been accepted for publication in CANCER NURSING: An International Journal for Cancer Care. All manuscript materials will be forwarded immediately to the production staff for placement in an upcoming issue. I do not yet know which issue your good work will be a part of but we shall certainly share that information with you as soon as we are certain. I am excited to see your work in print!

Thank you for submitting your interesting and important work to the journal.

With Kind Regards,

Dr. Pamela Hinds
Editor-in-Chief
CANCER NURSING: An International Journal for Cancer Care

Sylvie Dubois
Doctoral Candidate
School of nursing - Mc Gill University
3506 University Ave.
Montreal, Qc , H3A 2A7

APPENDIX J

CANADIAN ONCOLOGY NURSING JOURNAL ACCEPTANCE

-------- Original Message --------
From: Heather B. Porter [mailto:hbporter@rogers.com]
Sent: July 18, 2008 12:37
To: 'Sylvie Dubois'
Subject: RE: Your manuscript]

Dear Sylvie Dubois: I am pleased to tell you that the manuscript submitted to the Canadian Oncology Nursing Journal (CONJ) by you and your colleague titled: *Understanding the role of cancer informational support in relation to health care service use among newly diagnosed individuals* has been accepted for publication. I will contact you later when the journal issue in which it will appear is decided.

For your interest, I am enclosing the edited article so you can see that I made some adjustments to the English syntax related only to the word "tolerate" . Otherwise the article is fine. I hope this acceptance comes in time for your dissertation defense.

Heather B. Porter, BScN, PhD
Editor, Canadian Oncology Nursing Journal
and
Health Services Consultant
14-54 Blue Springs Drive, Waterloo ON, N2J 4M4
tel: 1-519-886-8590
fax: 1-519-886-9329
cell: 1-519-807-9329
email: hbporter@rogers.com

APPENDIX K

JOURNAL OF EVALUATION IN CLINICAL PRACTICE ACCEPTANCE

11 March 2008

Ms Sylvie Dubois
School of Nursing, McGill University
3506 University Street
Montreal, Quebec
CANADA

Dear Ms Dubois,

"Cancer Informational Support and Health Care Service Use Among Individuals Newly Diagnosed: A mixed Methods Approach "

Thank you for your letter with submission to the *Journal of Evaluation in Clinical Practice.*

Very fortuitously, your paper arrived just in time to be considered this morning by the Commissions Review Group which normally exercises the peer review function for invited works but which we also employ, where time allows, in the fast-tracking of unsolicited manuscripts as a journal efficiency measure.

I am pleased to tell you that the Group had no criticism of your paper and on the basis of its advice I am happy to confirm acceptance of your article for publication in the *Journal of Evaluation in Clinical Practice.*

In order to proceed I should be grateful if you would:

(1) complete the enclosed copyright Licence and fax it back to me to: ++44 20 3242 0042.

I look forward to hearing from you and send kind regards.

Yours sincerely

Professor Andrew Miles
Professor of Public Health Sciences/
Editor-in-Chief, Journal of Evaluation in Clinical Practice

APPENDIX L

PERMISSION TO ADAPT THE BEHAVIORAL MODEL OF HEALTH SERVICES USE

-------- Original Message --------
Subject: Fwd: Permission please for my doctoral dissertation
Date: Tue, 22 Apr 2008 13:48:39 -0700
From: Ron Andersen <randerse@ucla.edu>
To: Sylvie Dubois <sylvie.dubois@mail.mcgill.ca>

Dear Sylvie,

You have my permission to use the attached figures in your dissertation. Best wishes for completing your dissertation and an exciting career to follow.

Ron Andersen

>X-Sieve: CMU Sieve 2.2
>Date: Tue, 15 Apr 2008 09:40:44 -0400
>From: Sylvie Dubois <sylvie.dubois@mail.mcgill.ca>
>User-Agent: Thunderbird 1.5.0.14 (Windows/20071210)
>To: Randerse@ucla.edu
>Subject: Permission please for my doctoral dissertation
>X-Probable-Spam: no
>X-Scanned-By: smtp.ucla.edu on 169.232.46.249
>
>Dear Dr Andersen,
>I am a PhD student working on health care services with patients
>diagnosed with cancer.
>I used your Behavioral Model of Health Services Use including some
>modifications to guide my research . I have to include a statement
>reflecting your written permission to used it in the thesis.
>Enclosed figures that will be included with your permission in my dissertation.
>Thank you very much
>Sylvie Dubois
>
>Sylvie Dubois
>Doctoral Candidate
>School of nursing - Mc Gill University
>3506 University Ave.
>Montreal, Qc , H3A 2A7
>e-mail : sylvie.dubois@mail.mcgill.ca

Table 1

Theoretical Frameworks Used To Study Health Care Service Use

Frameworks	Authors
Behavioral Model of Health Service	Aday & Andersen, 1974
	Andersen et al., 1968, 1973, 1995
Economic Model	Gale, 1960
Health Belief Model	Rosenstock, 1974, 1990
Interaction Model of Client Health Behavior	Cox, 1982
Theory of Reasoned Action	Ajzen & Fishbein, 1980
	Fishbein, 1980
Triandis' Theory of Behavior	Triandis, 1977,1980, 1982
Self-Regulation Model	Leventhal, 1980
Sex-role Model	Broverman et al., 1970
Stress and Coping Model	Lazarus & Folkman, 1984
Suchman Inquiry Training Model	Suchman, 1965, 1967

Table 2

Principal Background Characteristics of Participants

	Women ($n = 205$)		**Men ($n = 45$)**		**Total ($N = 250$)**	
Variable	Exp (n = 120)	Control (n = 85)	Exp (n = 28)	Control (n = 17)	Exp (n = 148)	Control (n = 102)
Age						
M (SD)	53.5 (10.7)	57.25 (12.6)	62.3 (7.72)	67.78 (9.55)	55.08 (10.76)	59.11 (12.75)
Ethnic background						
Asian	7 (5.8)	—	—	—	7 (4.7)	—
Black	4 (3.3)	4 (4.7)	2 (7.1)	1 (5.9)	6 (4.1)	5 (4.9)
Caucasian	101 (84.3)	79 (92.9)	22 (78.6)	14 (82.3)	123 (83.1)	93 (91.2)
Hispanic	4 (3.3)	—	—	1 (5.9)	4 (2.7)	1 (1.0)
Middle Eastern	4 (3.3)	—	4 (14.3)	1 (5.9)	8 (5.4)	1 (1.0)
Other	—	2 (2.4)	—	—	—	2 (1.9)
Marital status						
Single	12 (10)	16 (18.8)	1 (3.6)	1 (5.8)	13 (8.8)	17 (16.7)
Married/ living with a partner	83 (69.2)	46 (54.1)	22 (78.5)	14 (82.4)	105 (70.9)	60 (58.8)
Separated/ divorced/ widowed	25 (20.8)	23 (27.1)	5 (17.9)	2 (11.8)	30 (20.3)	25 (24.5)
Employment status						
Full-time	52 (43.3)	26 (30.6)	8 (28.6)	3 (17.6)	60 (40.5)	29 (28.4)
Part-time	6 (5)	9 (10.6)	3 (10.7)	—	9 (6.1)	9 (8.9)
Unemployed	6 (5)	1 (1.2)	1 (3.6)	—	7 (4.7)	1 (0.1)
Retired	17 (14.2)	27 (31.8)	11 (39.3)	14 (82.4)	28 (18.9)	41 (40.2)
Other	39 (32.5)	22(25.8)	5 (17.8)	—	44 (29.8)	22 (21.5)
Language most spoken at home						
French	33 (27.5)	76 (89.4)	12 (42.9)	15 (88.2)	45 (30.4)	91 (89.2)
English	60 (50)	7 (8.2)	10 (35.7)	—	70 (47.3)	7 (6.8)
Other	27 (22.5)	2 (2.4)	6 (21.4)	2 (11.8)	33 (22.3)	4 (3.9)
Country of birth						
Canada	93 (77.5)	76 (89.4)	15 (53.6)	11 (64.7)	108 (72.9)	87 (85.3)
Other	27 (22.5)	9 (10.6)	13 (46.4)	6 (35.3)	40 (27.1)	15 (14.7)

countries						
Religion						
Christian	90 (74.4)	85 (100)	22 (77.8)	17 (100)	112 (75.6)	102 (100)
Jewish	15 (12.4)	—	3 (11.1)	—	18 (12.2)	—
Other	15 (13.2)	—	3 (11.1)	—	18 (12.2)	—
Household income						
< $10,000	4 (3.3)	5 (6)	—	—	4 (2.7)	5 (4.9)
$10,000-$29,999	15 (12.5)	23 (28.2)	4 (14.3)	1 (6)	19 (13)	25 (24.5)
$30,000-$49,999	26 (21.7)	20 (23.5)	6 (21.4)	7 (41.2)	32 (21.6)	27 (26.5)
$50,000-$79,999	24 (20)	16 (18.8)	7 (25)	3 (17.6)	31 (20.9)	19 (18.6)
≥ $80,000	40 (33.3)	12 (14.1)	8 (28.6)	3 (17.6)	48 (32.4)	15 (14.7)
No answer	11 (9.2)	8 (9.4)	3 (10.7)	3 (17.6)	14 (9.4)	11 (10.8)

Note. Data are presented as *n* (%).

Table 3

Sample Characteristics of Newly Diagnosed (< 1 Year) Individuals (N = 20)

	Age	Ethnic Background	Marital Status	Live Alone	Work Status	Income	Level of Education
W_P1	47	French Canadian	Married	No	Full-time	>$30,000	High school
W_P2	58	English Canadian	Married	No	Unemployed	>$30,000	High school
W_P3	59	English Canadian	Single	No	Full-time	<$29,999	High school
W_P4	68	French Canadian	Married	No	Retired	>$30,000	High school
W_P5	68	Haitian	Divorced	Yes	Retired	<$29,999	High school
W_P6	79	French Canadian	Widowed	Yes	Retired	>$30,000	High school
W_P7	63	Italian	Married	No	Full-time	<$29,999	Elementary
W_P8	36	English Canadian	Married	No	Full-time	>$30,000	Elementary
W_P9	29	Tunisian	Married	No	Full-time	>$30,000	University
W_P10	40	Libyan	Married	No	Unemployed	<$29,999	Cegep
M_P11	78	English Canadian	Married	No	Retired	>$30,000	High school
M_P12	75	French Canadian	Married	No	Retired	<$29,999	Elementary
M_P13	65	British	Married	No	Full-time	>$30,000	University
M_P14	59	English Canadian	Married	No	Full-time	>$30,000	University
M_P15	70	Belgian	Widowed	Yes	Retired	<$29,999	High school
M_P16	69	Asian	Married	No	Retired	>$30,000	University
M_P17	69	French Canadian	Married	No	Part time	>$30,000	University
M_P18	74	French Canadian	Married	No	Retired	<$29,999	Elementary
M_P19	64	French Canadian	Married	No	Full-time	>$30,000	University
M_P20	58	French Canadian	Married	No	Full-time	>$30,000	Elementary

Note. *N* (20) = Women with breast cancer (*n* = 10) and men with prostate cancer (*n* = 10)

Table 4

Summary of Experiences with Informational Support and Related Processes Used by Participants (N =20)

Participants	Informational Support and Related Processes								
	Tangible Type				Paralysing Type				Mixed Type
	Enabling	Confirming	Normalizing	Directing	Distressing	Conflicting	Misguiding	Mistrust	Tolerating
W_P1		X		X		X		X	
W_P2			X						
W_P3				X	X	X	X	X	
W_P4					X				
W_P5				X					
W_P6	X								
W_P7			X		X				
W_P8	X			X	X				
W_P9	X	X					X		X
W_P10	X	X							
M_P11		X	X	X					
M_P12					X				X
M_P13	X	X							
M_P14	X				X				
M_P15							X		
M_P16		X				X			X
M_P17					X				
M_P18									X
M_P19	X		X	X					
M_P20				X				X	

Note. *N* (20) = Women with breast cancer (*n* = 10) and men with prostate cancer (*n* = 10)

Table 5

Summary of findings (quantitative, qualitative and mixed)

Type of Analysis	Type of Data	Data Category	Exemplars of Findings
Quantitative	Quantitative	Cancer information and anxiety	Breast cancer ↓ anxiety in experimental condition Prostate cancer ↓ anxiety with usual care (i.e., usual information)
Merging of quantitative and qualitative	Qualitative		Breast cancer and Prostate cancer -anxiety increased with information not expected or not understood -information provided by health care professionals experienced as stressful (waiting times, getting services)
Subsequent qualitative data analysis	Qualitative		Breast cancer -felt less anxious after receiving the mass of information -knew what to expect and how to prepare for each step of the illness -addressed their questions to health care professionals Prostate cancer -compared their experience to business; required just enough information, particularly at the time of diagnosis, to manage the situation -reported not being anxious with usual cancer information

Type of Analysis	Type of Data	Data Category	Exemplars of Findings
Quantitative	Quantitative	Cancer information and satisfaction	Breast cancer ↑ satisfaction in experimental condition Prostate cancer ↑ satisfaction with usual care
Merging of quantitative and qualitative	Qualitative		Breast cancer and Prostate cancer -satisfaction with information provided on several occasions with the use of services -satisfaction with the use of the Internet (i.e., readily accessible, simple language)
Subsequent qualitative data analysis	Qualitative		Breast cancer -sought information about their disease and treatment from various sources, including IT -verbal and written information from health care professionals and information on the Internet allowed a better understanding of their disease Prostate cancer -satisfied with usual information to manage their disease -continued to seek additional information from other sources (e.g., the Internet, magazines, and friends) about other types of treatment, pain, medication, or support groups -willing to incur costs for medical tests to get a faster diagnosis
Quantitative	Quantitative	Informational support and health care service use/face-	Breast cancer ↑ time spent with health care professionals in experimental condition Prostate cancer ↓ time spent with health care professionals in experimental condition

Type of Analysis	Type of Data	Data Category	Exemplars of Findings
		to-face consultations	
Merging of quantitative and qualitative	Qualitative		Breast cancer -women preferred personal contact (e.g., phone calls or visits) for more personalized information Prostate cancer -men preferred literature provided routinely by staff
Subsequent qualitative data analysis	Qualitative		Breast cancer -talked about chemotherapy, side effects and what to expect next, exercise, diet, and treatment options -used the Internet to better understand their oncologist's explanations or the written documentation provided -additional information found on the Internet brought women to increase their use of health care services Prostate cancer -used the Internet for additional information to be better prepared for consultations and treatment -asked more specific questions about their health condition -tended to manage their health and address their care delivered as quickly as possible -considered the delay for delivery of care a more important problem than unmet information needs
Quantitative	Quantitative	Informational support and health care	Prostate cancer ↓ time with nurses in experimental condition

Type of Analysis	Type of Data	Data Category	Exemplars of Findings
		service use/telephone consultations	
Merging of quantitative and qualitative	Qualitative		Breast cancer -had negative experiences with telephone consultations (repeated phone calls for information)
Subsequent qualitative data analysis	Qualitative		Prostate cancer -used telephone consultations for quick answers -did not want to wait, delay their treatment, or go to the hospital to ask questions
Quantitative	Quantitative	Informational support from oncologists or nurses	Breast cancer -were more likely to receive nurse informational support Prostate cancer -were more likely to receive oncologist informational support
Merging of quantitative and qualitative	Qualitative		Breast cancer -had negative experiences with physician (i.e., pain minimization) Breast cancer and Prostate cancer -received contradictory information from health care professionals that left them confused -had erroneous or incorrect perceptions of their health situation -received unsupportive or inadequate information which reduced confidence for subsequent use of services

Type of Analysis	Type of Data	Data Category	Exemplars of Findings
			-felt they had to accept limited information from oncologists and limited services -made excuses for oncologists
Subsequent qualitative data analysis	Qualitative		<u>Breast cancer</u> -found easier to talk to the nurse than to the physician -desired to talk to nurses, especially before and after surgery, and during treatment -reported that nurses provided them with emotional and instrumental support -reported negative experiences (e.g., inadequate or erroneous information) with physicians, particularly after the surgery <u>Prostate cancer</u> -reported perceived oncologists as specialists having the expertise to treat their health problems -diagnosis seemed to be the starting point to manage their situation -health problem treated as business-like manner (expertise leads to solutions) -reported negative experiences with physicians (e.g., oncologist) at the time of diagnosis and related to treatment offered by oncologists -reported negative experiences: limited information provided by oncologists, problematic communication with oncologists, and limited time spent with them -did not hesitate to find another oncologist to get better information (i.e., treatment options)
Quantitative	Quantitative	Satisfaction with telephone consultations	<u>Breast cancer</u> -were less satisfied with telephone consultations than men
Merging of quantitative and	Qualitative		<u>Breast cancer</u> -reported negative experiences with telephone consultations in oncology services and in accessing a service (e.g., biopsy, chemotherapy) or obtaining information for

Type of Analysis	Type of Data	Data Category	Exemplars of Findings
qualitative			a specific problem <u>Prostate cancer</u> -did not report dissatisfaction
Subsequent qualitative data analysis	Qualitative		<u>Breast cancer</u> -resulted in inadequate or nonuse of services

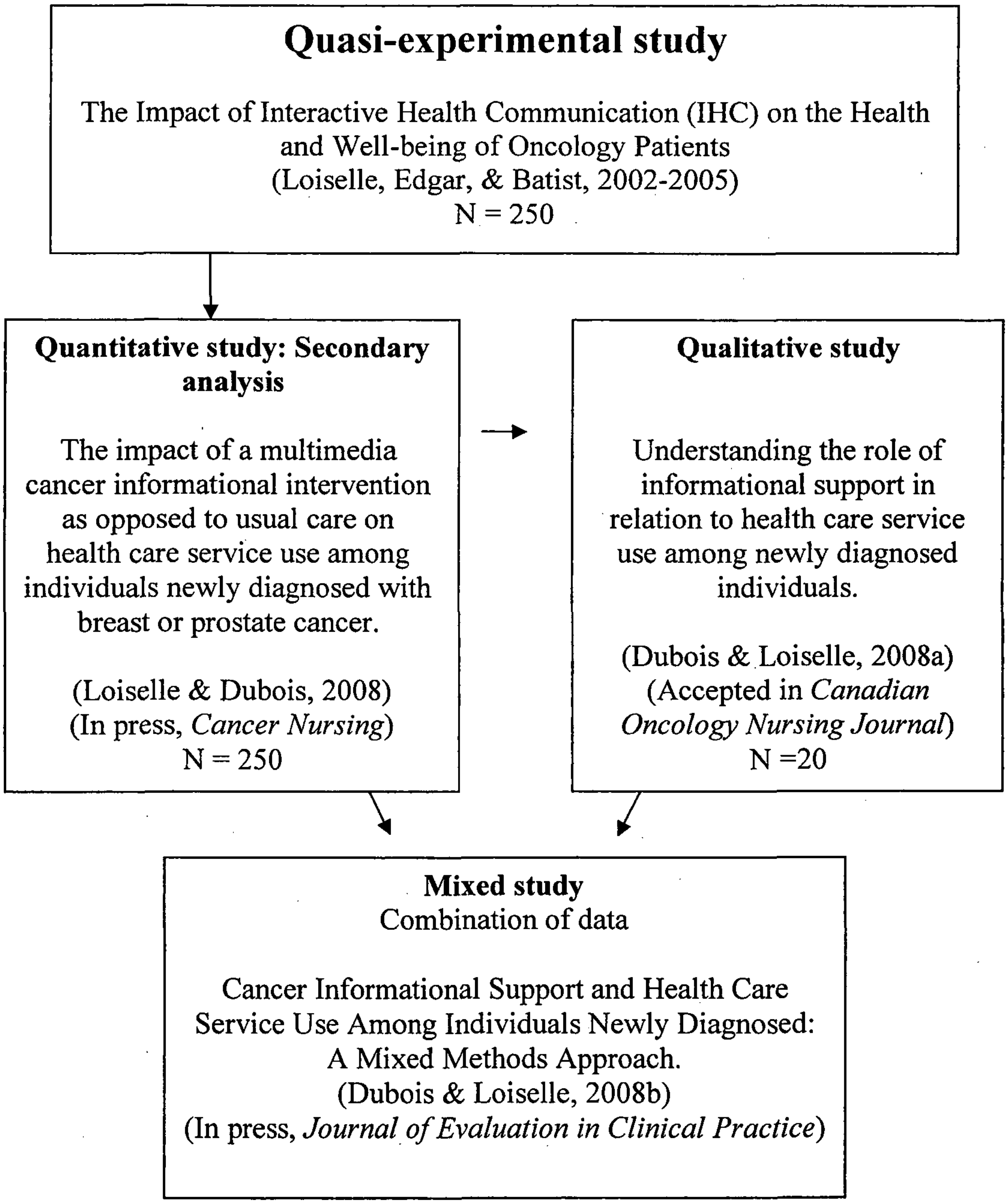

Figure 1. Graphic Presentation of the Series of Studies.

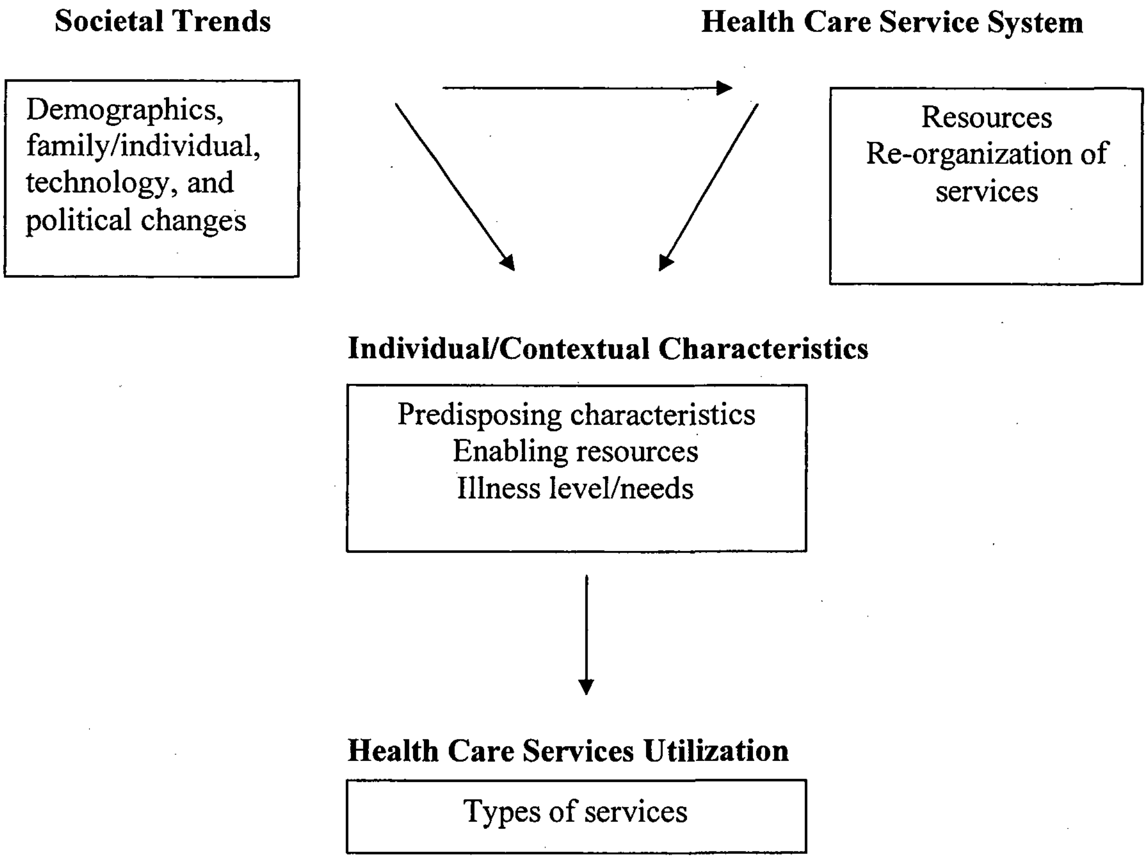

Figure 2. General view of Andersen and Newman (1973) model.
Note. From R. M. Andersen & J. F. Newman (1973). "Societal and Individual Determinants of Medical Care Utilization in the United States." *Milbank Memorial Fund Quarterly, 51*, 98. Copyright 1973 by *Milbank Memorial Fund Quarterly* Adapted with permission (Annexe L).

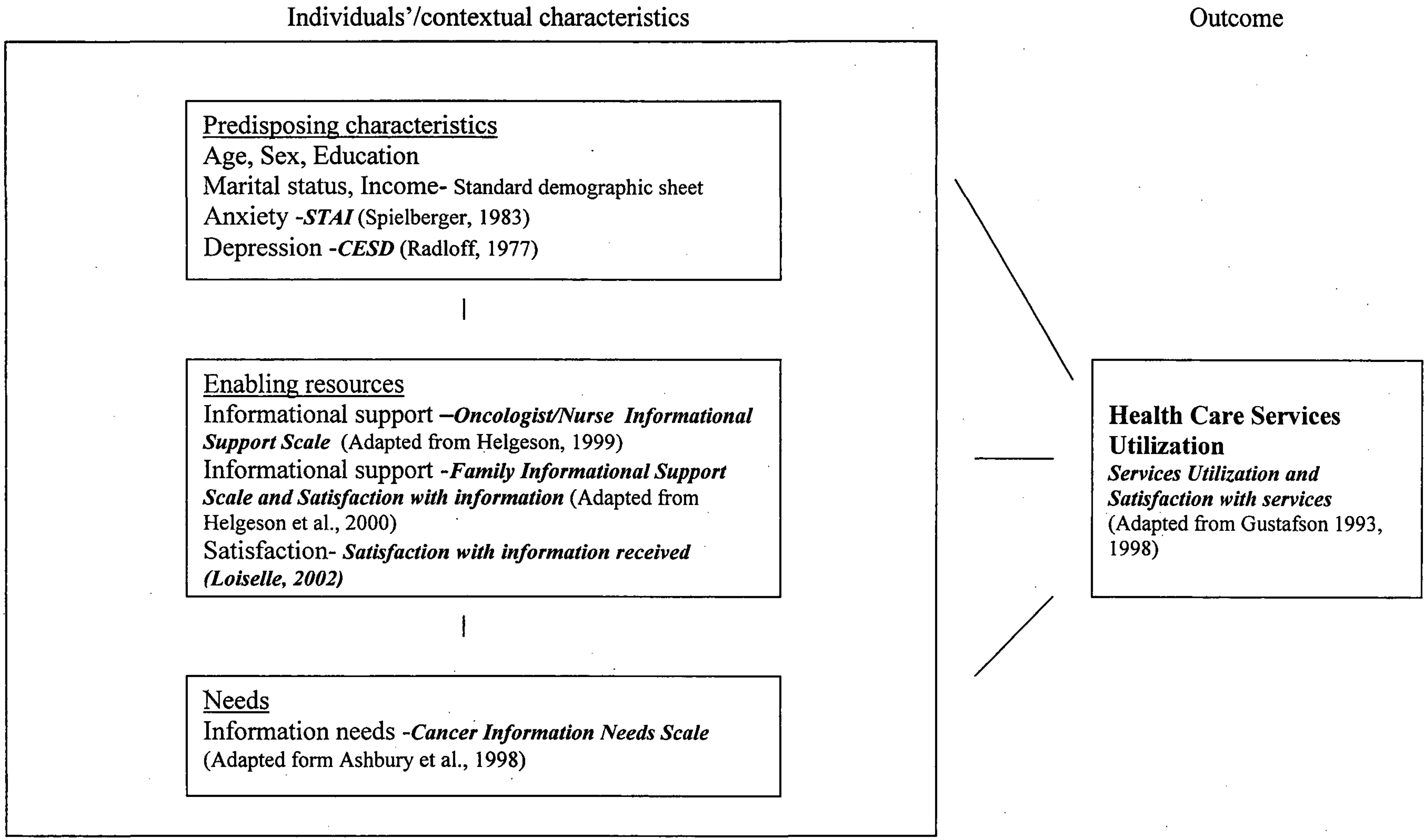

Figure 3. Operationalization of the Behavioral Model to Predict Use of Health Care Services.
Note. From R. M. Andersen & J. F. Newman (1973). "Societal and Individual Determinants of Medical Care Utilization in the United States." *Milbank Memorial Fund Quarterly, 51*, 98. Copyright 1973 by *Milbank Memorial Fund Quarterly*
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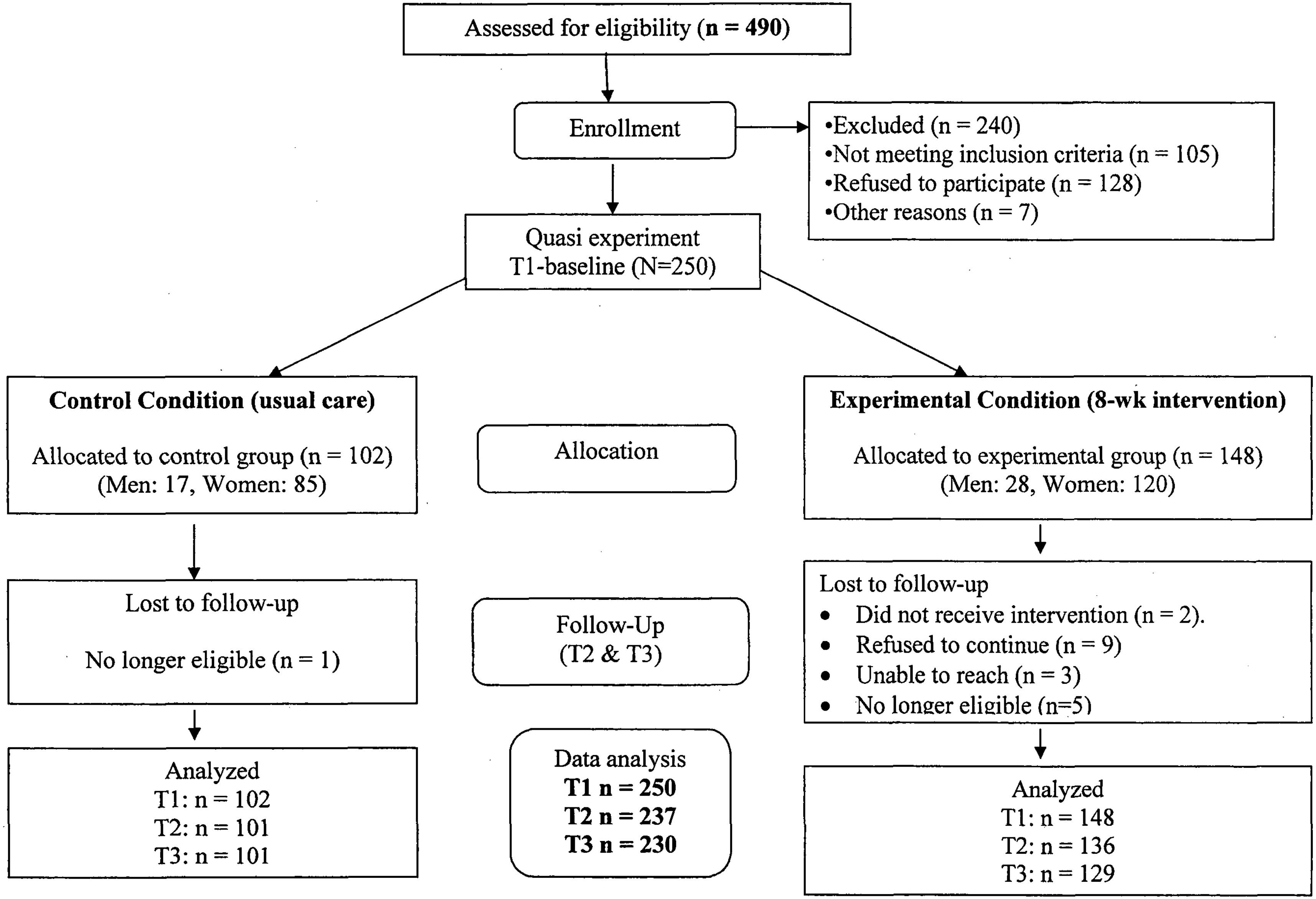
Figure 4. Flow Chart for Participants' Enrollment into Either the Control or Experimental Group



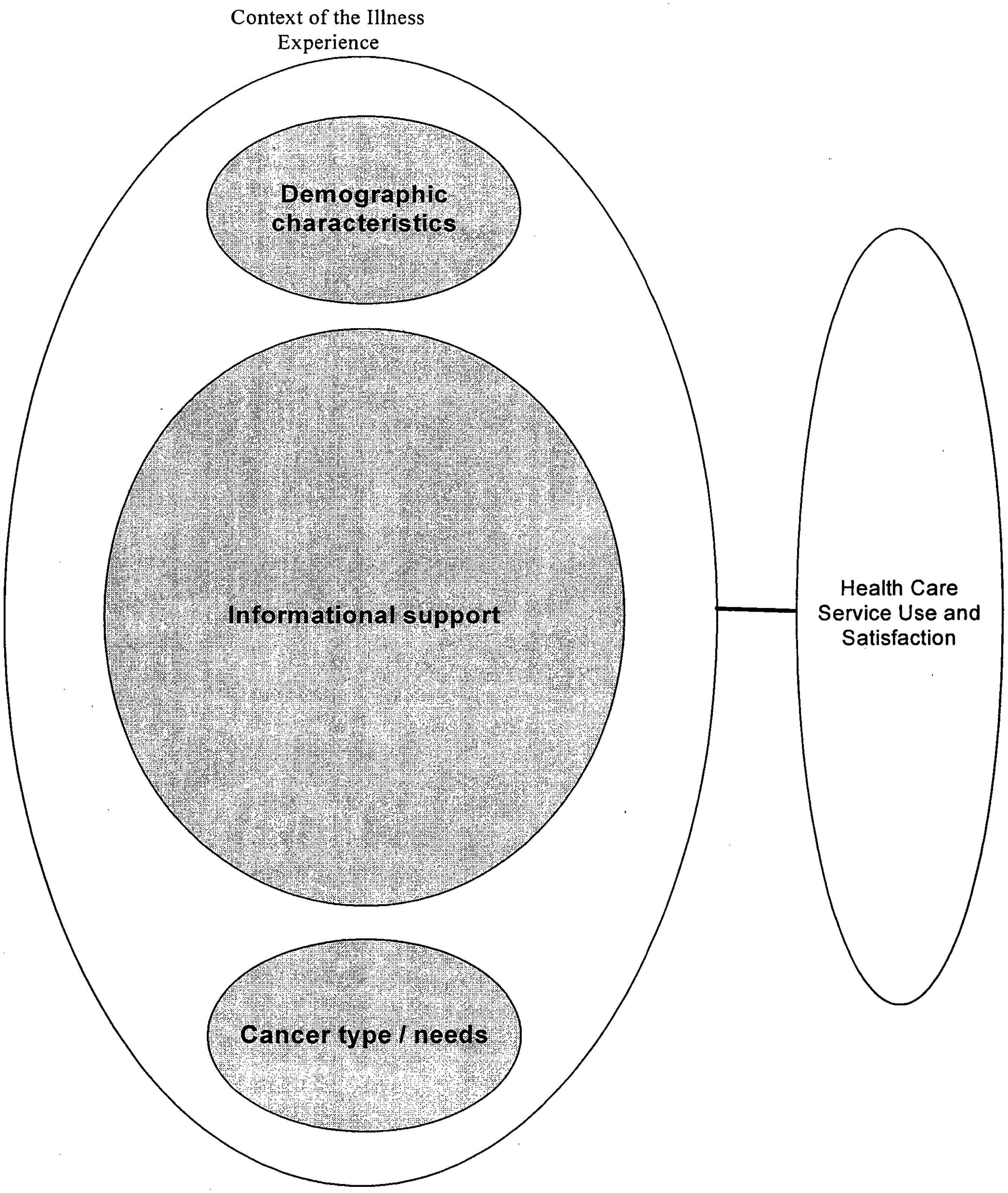


Figure 5. The Interrelationship Between Informational Support and Healthcare Service Use

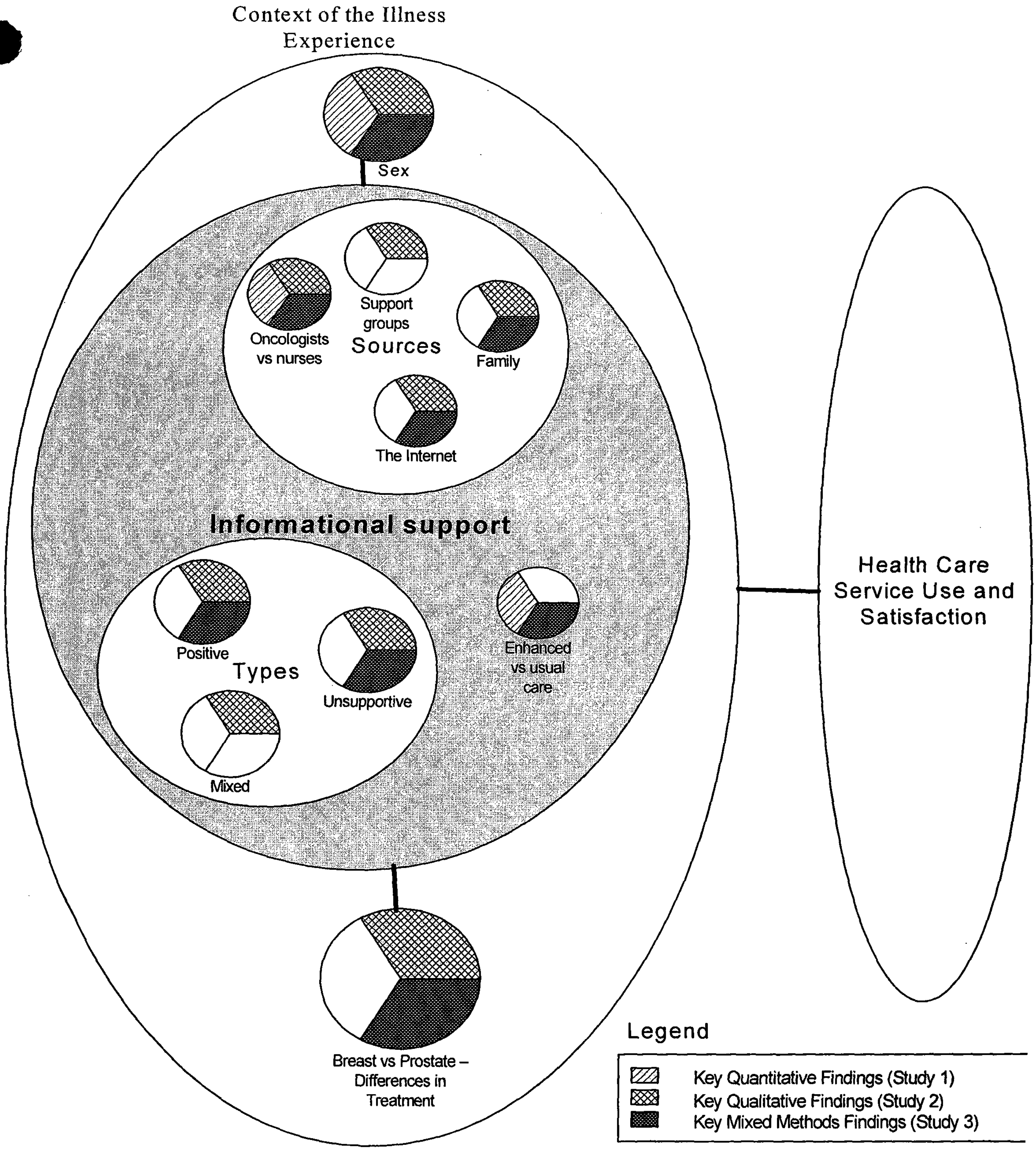


Figure 6. The Interrelationship Between Several Factors, Informational Support and Healthcare Service Use.